

**Exploring the Feasibility of Implementing  
Self-Management and Patient Empowerment through  
a Structured Diabetes Education Programme  
in Yogyakarta City Indonesia:  
A Pilot Cluster Randomised Controlled Trial**

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# Table of Contents

Table of Contents .....	i
Thesis Summary .....	vii
Declaration.....	x
Conference Presentations Resulting from This Thesis.....	xi
Acknowledgements.....	xii
List of Tables .....	xiv
List of Figures .....	xvi
List of Boxes.....	xviii
List of Terms.....	xix
The PhD Project Context .....	xxii
<b>1 CHAPTER 1 – Introduction .....</b>	<b>1</b>
1.1 BACKGROUND .....	2
1.2 RESEARCH QUESTIONS AND HYPOTHESES.....	8
1.3 RESEARCH AIMS AND OBJECTIVES .....	9
1.4 RESEARCH SIGNIFICANCE .....	9
1.5 SUMMARY.....	10
<b>2 CHAPTER 2 – Literature Review.....</b>	<b>12</b>
2.1 INTRODUCTION.....	13
2.2 TYPE 2 DIABETES .....	13
2.2.1 <i>Definition, Classification and Diagnosis of Diabetes Mellitus</i> .....	13
2.2.2 <i>Symptoms and Complications of Diabetes Mellitus</i> .....	14
2.2.3 <i>Management of Type 2 Diabetes</i> .....	15
2.3 DIABETES CARE AND NATIONAL PROGRAMMES.....	19
2.3.1 <i>Evolution in Diabetes Care</i> .....	19
2.3.2 <i>Shifting Diabetes Care: Secondary to Primary Care</i> .....	21
2.3.3 <i>Diabetes Care in Indonesia</i> .....	23
2.3.4 <i>National Diabetes Programmes (NDPs)</i> .....	26
2.4 CHRONIC DISEASE SELF-MANAGEMENT .....	27
2.4.1 <i>Chronic Disease Care</i> .....	27

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2.4.2	<i>Collaborative Care and Self-Management Education</i> .....	28
2.4.3	<i>The Chronic Care Model</i> .....	30
2.4.4	<i>Self-Management Support of the Chronic Care Model</i> .....	31
2.4.5	<i>Chronic Disease Self-management Education</i> .....	33
2.5	<b>THE ROLE OF CHRONIC DISEASE SELF-MANAGEMENT IN DIABETES EDUCATION</b> .....	36
2.5.1	<i>Patient Education in Type 2 Diabetes</i> .....	36
2.5.2	<i>Diabetes Self-Management Education (DSME)</i> .....	38
2.5.3	<i>Diabetes Self-Care Behaviours</i> .....	40
2.5.4	<i>Underlying Philosophy and Theories for DSME</i> .....	41
2.5.5	<i>Patient Empowerment in the Self-Management of Diabetes</i> .....	44
2.5.6	<i>Diabetes Self-Management Support for Patient Empowerment</i> .....	47
2.6	<b>MODELS OF STRUCTURED PATIENT EDUCATION IN TYPE 2 DIABETES</b> .....	49
2.6.1	<i>The Diabetes X-PERT Programme</i> .....	49
2.6.2	<i>The DESMOND Structured Group Education Programme</i> .....	50
2.7	<b>SUMMARY</b> .....	51
	<b>CHAPTER 3 – Country Setting: Geography, Population, Government, and Health Care System of Indonesia</b> .....	<b>53</b>
3.1.	<b>INTRODUCTION</b> .....	54
3.2.	<b>GEOGRAPHY AND POPULATION OF INDONESIA</b> .....	54
3.3.	<i>STATISTICS OF INDONESIA</i> .....	55
3.4.	<i>INDONESIAN GOVERNMENT AND DECENTRALISATION POLICY</i> .....	58
3.5.	<i>HEALTH CARE SYSTEM OF INDONESIA</i> .....	59
3.6.	<b>SUMMARY</b> .....	64
	<b>CHAPTER 4 – Research Methods</b> .....	<b>65</b>
4.1.	<b>INTRODUCTION</b> .....	66
4.2.	<b>RESEARCH OVERVIEW AND CONCEPTUAL FRAMEWORK</b> .....	66
4.2.1.	<i>Research Overview</i> .....	66
4.2.2.	<i>Research Conceptual Framework</i> .....	69
4.3.	<b>RESEARCH SETTING</b> .....	70
4.4.	<b>OPERATIONAL TERMS AND OUTCOME MEASUREMENTS</b> .....	71
4.4.1.	<i>Definitions of Operational Terms</i> .....	71
4.4.2.	<i>Description of Outcome Measurements</i> .....	83
4.5.	<b>RESEARCH ETHICS</b> .....	85

---

4.6. SUMMARY.....	85
<b>CHAPTER 5 – Cross-Cultural Adaptation of Diabetes-Related Instruments .....</b>	<b>86</b>
5.1. INTRODUCTION.....	87
5.2. BACKGROUND .....	87
5.3. AIMS .....	89
5.4. METHODS .....	89
5.4.1. <i>Procedure of Cross-Cultural Adaptation</i> .....	89
5.4.2. <i>Research Design</i> .....	95
5.4.3. <i>Sample Size</i> .....	95
5.4.4. <i>Preparation</i> .....	96
5.5. Participants .....	96
5.6. <i>Instruments and Data Analysis</i> .....	98
5.7. RESULTS .....	102
5.7.1. <i>Sociodemographic Characteristics and Medical History</i> .....	102
5.7.2. <i>The 24-item Diabetes Knowledge Questionnaire (DKQ-24)</i> .....	104
5.7.3. <i>The Diabetes Health Belief Measure (DHBM)</i> .....	106
5.7.4. <i>The Summary of Diabetes Self-Care Activities (SDSCA)</i> .....	108
5.7.5. <i>The Diabetes Empowerment Scale – Short Form (DES-SF)</i> .....	110
5.8. DISCUSSION.....	111
5.9. LIMITATIONS .....	118
5.10. CONCLUSIONS AND RECOMMENDATIONS.....	119
5.10.1. <i>Conclusions</i> .....	119
5.10.2. <i>Recommendations</i> .....	120
5.11. SUMMARY.....	120
<b>CHAPTER 6 – Development of Diabetes Education Materials .....</b>	<b>121</b>
6.1. INTRODUCTION.....	122
6.2. EXISTING DIABETES EDUCATION MATERIALS .....	122
6.3. DEVELOPMENT OF NEW DIABETES EDUCATION MATERIALS.....	124
6.3.1. <i>Leaflet 1: “Recognise Diabetes Mellitus and Act on it”</i> .....	130
6.3.2. <i>Leaflet 2, 3 and 4: “Meal Planning for Diabetics 1, 2, 3”</i> .....	130
6.3.3. <i>Leaflet 5 and 6: “Physical Activity for Diabetics 1, 2”</i> .....	131
6.3.4. <i>Leaflet 7: “Foot Care and Foot Exercise for Diabetics”</i> .....	132
6.3.5. <i>Leaflet 8: “Target for Management of Diabetes Mellitus”</i> .....	132

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6.3.6.	<i>Leaflet 9: “Seven Successful Steps for Diabetes Self-Care”</i> .....	132
6.3.7.	<i>Booklet 1: “Food Exchanges and Menu”</i> .....	132
6.4.	DISTRIBUTION AND USE OF NEW DIABETES EDUCATION MATERIALS .....	133
6.4.1.	<i>Distribution of Diabetes Leaflets</i> .....	133
6.4.2.	<i>Use of Diabetes Posters and Banners</i> .....	133
6.5.	EVALUATION METHOD OF THE NEW DIABETES LEAFLETS .....	134
6.6.	RESULTS OF THE EVALUATION OF DIABETES LEAFLETS .....	135
6.6.1.	<i>Evaluation of Diabetes Leaflets in the Control Group</i> .....	135
6.6.2.	<i>Evaluation of Diabetes Leaflets in the Intervention Group</i> .....	137
6.7.	DISCUSSION.....	141
6.8.	CONCLUSIONS AND RECOMMENDATIONS .....	146
6.8.1.	<i>Conclusions</i> .....	146
6.8.2.	<i>Recommendations</i> .....	147
6.9.	SUMMARY .....	147
	<b>CHAPTER 7 – The Feasibility of a Structured Diabetes Education Programme: A Pilot Cluster Randomised Controlled Trial</b> .....	<b>149</b>
7.1.	INTRODUCTION.....	150
7.2.	BACKGROUND.....	150
7.3.	RESEARCH METHODS.....	152
7.3.1.	<i>Research Design</i> .....	152
7.3.2.	<i>Sample Size</i> .....	153
7.3.3.	<i>Preparation</i> .....	154
7.3.4.	<i>Research Participants</i> .....	154
7.3.5.	<i>Randomization</i> .....	156
7.3.6.	<i>Blinding</i> .....	156
7.3.7.	<i>Hypothesis</i> .....	157
7.3.8.	<i>Research Interventions</i> .....	157
7.3.9.	<i>Research Outcomes</i> .....	159
7.3.10.	<i>Data Analysis</i> .....	162
7.4.	RESULTS.....	163
7.4.1.	<i>Sociodemographic Characteristics and Medical History</i> .....	163
7.4.2.	<i>Reassessment of the Internal Consistency Reliability of the Indonesian Version of Four Diabetes-Related Instruments</i> .....	167
7.4.3.	<i>Assessment of Key Outcome Variables of the Main Study</i> .....	172

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7.4.4. Summary of Key Findings of Scoping discussions .....	190
7.5. DISCUSSION.....	201
7.5.1. Sociodemographic Characteristics and Medical History.....	201
7.5.2. Reassessment of the Internal Consistency Reliability of the Indonesian Versions of Four Diabetes-Related Instruments .....	202
7.5.3. The Cluster Randomised Controlled Trial and Scoping Discussions .....	204
7.6. STRENGTHS AND LIMITATIONS OF THE STUDY.....	218
7.6.1. Strengths .....	218
7.6.2. Limitations .....	218
7.7. CONCLUSIONS AND RECOMMENDATIONS.....	219
7.7.1. Conclusions .....	219
7.7.2. Recommendations.....	221
7.8. SUMMARY.....	223
<b>CHAPTER 8 – Overall Conclusions and Recommendations .....</b>	<b>224</b>
8.1. INTRODUCTION.....	225
8.2. OVERALL CONCLUSIONS AND RECOMMENDATIONS.....	226
<b>REFERENCE LIST .....</b>	<b>230</b>
<b>APPENDIX A – Research Ethics Approval.....</b>	<b>250</b>
<b>APPENDIX B – Participant Consent Form .....</b>	<b>258</b>
<b>APPENDIX C – Participant Complaint Sheet .....</b>	<b>261</b>
<b>APPENDIX D – Participant Information Sheet .....</b>	<b>264</b>
<b>APPENDIX E – Research Questionnaire in English .....</b>	<b>275</b>
<b>APPENDIX F – Research Questionnaire in Indonesian Language.....</b>	<b>283</b>
<b>APPENDIX G – List of Open-Ended Questions for Scoping discussions .....</b>	<b>292</b>
<b>APPENDIX H – Full Key Findings of Scoping discussions .....</b>	<b>295</b>
<b>APPENDIX I – Frameworks of Management of Type-2 Diabetes .....</b>	<b>313</b>
<b>APPENDIX J – Frameworks of Diabetes Self-Management Education.....</b>	<b>316</b>
<b>APPENDIX K – Frameworks of Patient Empowerment .....</b>	<b>323</b>
<b>APPENDIX L – Conference Presentation Abstracts.....</b>	<b>329</b>
<b>APPENDIX M – Diabetes Leaflets.....</b>	<b>334</b>

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<b>APPENDIX N – Diabetes Posters.....</b>	<b>361</b>
<b>APPENDIX O – Pictures of Research Activities .....</b>	<b>376</b>



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# Thesis Summary

## **BACKGROUND**

Diabetes is a global public health problem which can cause serious disabling complications. Indonesia is among the top four countries with the highest numbers of diabetes. Diabetes self-management education (DSME) is widely recognized as an essential element of diabetes care. Patient empowerment has long served as the philosophical foundation for DSME. However, self-management and patient empowerment are largely unknown in diabetes education and care in Indonesia. The current traditional diabetes education found in hospitals and publicly funded community health centres (CHCs) does not incorporate these two concepts. Therefore, there is a particular need for research on DSME and patient empowerment for people with type 2 diabetes (T2D) in Indonesia.

## **AIMS**

The main aims of this research project were to develop a pilot model of a structured diabetes education programme promoting diabetes self-management and patient empowerment for people with T2D in the primary care setting in Indonesia, and to evaluate its effectiveness on clinical outcomes and diabetes-related scores of knowledge, health beliefs, self-care behaviours, and self-efficacy. The research project also aimed to cross-culturally adapt the 24-item Diabetes Knowledge Questionnaire (DKQ-24), the Diabetes Health Belief Measure (DHBM), the Summary of Diabetes Self-Care Activities revised scale (SDSCA), and the Diabetes Empowerment Scale - Short Form (DES-SF); and to identify the perceptions of people with T2D and their family members, and health care providers (HCPs) towards the current diabetes education and/ or diabetes education intervention administered.

## **METHODS**

This research project was undertaken in two studies. A convenience sample survey ( $n = 83$ ) was used to test the internal consistency reliability of the final Indonesian versions of the DKQ-24, the DHBM, the SDSCA, and the DES-SF in an Indonesian population (Study 1). The internal consistency reliability of the adapted instruments were then reassessed among the participants of the main study ( $n = 101$ ). A pilot cluster randomised controlled trial comparing a four-weekly structured diabetes education programme (intervention group = 51) and a three-hour diabetes seminar trial (control group = 50) in improving clinical outcomes and diabetes related scores of knowledge, health beliefs, self-care behaviours, and self-efficacy for patients with T2D was conducted at four community health centres (CHCs) in Yogyakarta City, Indonesia (Study 2, the main study). Both groups received a set of

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comprehensive diabetes leaflets. Outcome assessment was performed at baseline and 3 months after the research interventions were completed. Six scoping discussions were also conducted with four groups of patients with T2D and their family members ( $n=43$ ), and two groups of health care providers working at the participating CHCs ( $n=18$ ).

Quantitative data were double-entered for verification, analysed and digitally stored using SPSS statistical software version 18. Descriptive statistics were used to examine sociodemographic characteristics and medical history outcome variables. Cronbach's alpha coefficients were performed to assess the internal consistency reliability of the Indonesian version of the DKQ-24, the DHBM, the SDSCA, and the DES-SF. *T*-tests were used to analyse differences on continuous data between mean scores for the intervention and control groups. Categorical data were analysed using Chi-square statistics to test the significance of different proportions. Repeated measures ANOVA were used to assess the group differences on clinical outcomes and diabetes-related scores of diabetes knowledge, health beliefs, self-care behaviours and self-efficacy.

Scoping discussions were audiotaped and notes of important issues were taken during the discussions. Loose transcription of discussions and interview notes were combined to generate a summary of key findings.

## **RESULTS**

### ***Study 1***

Using the main study population, the Indonesian versions of DKQ-24 ( $\alpha = 0.723$ ) and the DHBM ( $\alpha = 0.718$ ) demonstrated satisfactory internal consistency reliabilities. The Indonesian versions of 10-item SDSCA ( $\alpha = 0.605$ ) and the DES-SF ( $\alpha = 0.595$ ) showed adequate internal consistency reliabilities to be used as research instruments for a preliminary study.

### ***Study 2 (the main study)***

Participation in the structured diabetes education programme led to significant improvements only in diabetes knowledge (95% CI = 1.43 to 14.75;  $p = 0.004$ ); 2-hour postprandial plasma glucose level (95% CI = -2.82 to 1.58;  $p = 0.02$ ) and waist circumference (95% CI = -6.15 to 5.14;  $p = 0.04$ ) at 3-month follow-up. The intervention group demonstrated improvements in HbA1c (primary outcome), fasting blood glucose, systolic and diastolic blood pressure, body weight, BMI, the SDSCA scores on general diet, specific diet, exercise, blood sugar testing and foot care, and the DES-SF score. However, these changes did not significantly differ to the changes in the control group. Findings from scoping discussions suggested that there was inadequate provision of traditional diabetes education due to constrained resources and the characteristics of patients attending CHCs.

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Patients with T2D attending CHCs were ready and enthusiastic to engage with diabetes self-management and patient empowerment concepts. In contrast, the scoping discussions raised questions about the readiness of HCPs working at CHCs to embrace diabetes self-management education, particularly when they were reluctant to engage adequately in traditional diabetes education, let alone accommodate the patient empowerment concept.

## **CONCLUSION**

A structured diabetes education programme for patients with T2D resulted in significant improvements in diabetes knowledge, 2-hour postprandial plasma glucose level and waist circumference at 3-month follow-up, but no significant difference in the primary outcome (HbA1c). The findings of this preliminary study can contribute to the development of DSME programmes based on patient empowerment approach in the primary care settings with limited resources, and will provide building blocks for an improved programme of diabetes education and care in Indonesia.

## **Key Words:**

Type 2 diabetes, cluster randomised controlled trial, structured diabetes education programme, diabetes self-management education, and patient empowerment

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# Declaration

I certify that this work contains no material which has been accepted for the award of any other degree or diploma in any university or other tertiary institution and, to the best of my knowledge and belief, contains no material previously published or written by another person, except where due reference has been made in the text. In addition, I certify that no part of this work will, in the future, be used in a submission for any other degree or diploma in any university or other tertiary institution without the prior approval of the University of Adelaide.

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Signed: \_\_\_\_\_

Date: \_\_\_\_\_

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# Conference Presentations Resulting from This Thesis

1. Hilman-Agrimon O, Beilby J, Street J. Patient Empowerment Programme Promoting Self-Management for Adult Patients with Type 2 Diabetes in Primary Care Setting in Indonesia. *2009 State Population Health Conference, Adelaide, Australia, 31 October 2009,*
2. Hilman-Agrimon O, Beilby J, Street J, Prabandari YS. Cross Cultural Adaptation Of Diabetes-Related Health Belief Instrument For Patients With Type 2 Diabetes in Indonesia. *The 18<sup>th</sup> WONCA Asia Pacific Regional Conference 2011, Cebu, Philippines, 21-24 February 2011.*
3. Hilman-Agrimon O, Beilby J, Street J, Prabandari YS. Patient Empowerment Program Promoting Diabetes Self-Management in Community Health Centres (*Puskesmas*) in Yogyakarta City, Indonesia. *The 2<sup>nd</sup> ASEAN Regional Primary Care Conference 2011, Jakarta, Indonesia, 24-26 November 2011.*
4. Hilman-Agrimon O, Beilby J, Street J, Prabandari YS. Patient Empowerment Programme Promoting Diabetes Self-Management in Primary Care Setting in Yogyakarta City, Indonesia. *The 19<sup>th</sup> WONCA Asia Pacific Regional Conference 2012, Jeju, Korea, 24-27 May 2012.*

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# List of Tables

Table 2-1	The Stanford Chronic Disease Self-Management Program <sup>114</sup> and the Flinders Program <sup>115</sup> .....	35
Table 3-1	Regional comparison of health performance indicators among Asian countries. <sup>158</sup> .....	57
Table 3-0-2	The trends of Indonesia's HDI in 1980, 1990, 2000, 2010 and 2011. <sup>163</sup> .....	58
Table 3-0-3	The comparison of HDI ranks and values among ASEAN countries in 2011. <sup>164</sup> .....	58
Table 4-0-1	AADE 7 <sup>TM</sup> Self-Care Behaviors <sup>124</sup> and the Principles of Self-Management of the Flinders Program <sup>TM115</sup> .....	73
Table 4-0-2	Existing validated instruments on diabetes knowledge .....	75
Table 4-0-3	Existing validated instruments on diabetes health beliefs .....	78
Table 4-0-4	Existing validated instruments on diabetes self-care behaviours .....	80
Table 4-0-5	Existing validated instruments on diabetes self-efficacy and empowerment.....	82
Table 5-0-1	Additional notes for the DHBM, the SDSCA and the DES-SF instruments .....	93
Table 5-0-2	Additional items and several original items of the SDSCA .....	95
Table 5-0-3	Sociodemographic characteristics of the participants ( <i>n</i> = 83) .....	102
Table 5-0-4	Medical history of the participants ( <i>n</i> = 83) .....	103
Table 5-0-5	Psychometric properties of the Indonesian version of DKQ-24 instrument.....	105
Table 5-0-6	Psychometric properties of the Indonesian version of DHBM instrument.....	107
Table 5-0-7	Psychometric properties of the Indonesian version of SDCSA instrument.....	108
Table 5-0-8	Additional items of the Indonesian version of SDCSA instrument...	109
Table 5-0-9	Psychometric properties of the Indonesian version of DES-SF instrument.....	110



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Table 6-0-1	Summary of the Guidelines for Developing Effective Print Materials for Low-Literate Readers <sup>268</sup> .....	124
Table 6-0-2	Quick tips for writing low literacy materials <sup>271</sup> .....	127
Table 6-0-3	The most helpful written materials for all users, especially poor readers <sup>270</sup> .....	127
Table 6-0-4	Evaluation of the diabetes leaflets .....	134
Table 6-0-5	Results of the evaluation of diabetes leaflets in the control group ( <i>n</i> = 42) .....	136
Table 6-0-6	Results of the evaluation of diabetes leaflets in the intervention group ( <i>n</i> = 46) .....	139
Table 6-0-7	Comparison of the results of diabetes leaflet evaluation in both groups .....	140
Table 7-0-1	Comparison of sociodemographic characteristics of the intervention and control group participants at baseline ( <i>n</i> = 101) .....	164
Table 7-0-2a	Comparison of medical history of the intervention and control group participants at baseline ( <i>n</i> = 101) .....	165
Table 7-3	Psychometric properties of the Indonesian version of the DKQ-24 instrument ( <i>n</i> =101) .....	168
Table 7-4	Psychometric properties of the Indonesian version of the DHBM instrument ( <i>n</i> =101) .....	169
Table 7-5	Psychometric properties of the Indonesian version of the SDCSA instrument ( <i>n</i> =101) .....	170
Table 7-6	Psychometric properties of the Indonesian version of the DES-SF instrument ( <i>n</i> =101) .....	171
Table 7-7	Summary of the internal consistency reliability of the four adapted Indonesian diabetes-related instruments .....	172
Table 7-8	Comparison of key outcome variables of the intervention and control groups at baseline ( <i>n</i> =101) .....	174
Table 7-9	Comparison of clinical outcomes and diabetes-related scores between intervention and control groups at baseline and 3-month follow-up ..	176

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# List of Figures

Figure 3-1	Map of Indonesia.....	54
Figure 4-1	Overview of research procedures and objectives .....	68
Figure 4-2	Conceptual framework of the research.....	69
Figure 7-1	Flow of participants through study.....	173
Figure 7-2	The interaction between group and time for HbA1c (%) .....	177
Figure 7-3	The interaction between group and time for fasting blood glucose (mmol/L).....	178
Figure 7-4	The interaction between group and time for two-hour postprandial plasma glucose (mmol/L) .....	179
Figure 7-5	The interaction between group and time for systolic blood pressure (mmHg).....	179
Figure 7-6	The interaction between group and time for diastolic blood pressure (mmHg).....	180
Figure 7-7	The interaction between group and time for body weight (kg).....	181
Figure 7-8	The interaction between group and time for body mass index (kg/m <sup>2</sup> )....	181
Figure 7-9	The interaction between group and time for waist circumference (cm) .....	182
Figure 7-10	The interaction between group and time for the Diabetes Knowledge Questionnaire (DKQ-24) score.....	183
Figure 7-11	The interaction between group and time for the Diabetes Health Beliefs Measure (DHBM) score .....	184
Figure 7-12	The interaction between group and time for the SDSCA score on general diet.....	185
Figure 7-13	The interaction between group and time for the SDSCA score on specific diet.....	185
Figure 7-14	The interaction between group and time for the SDSCA score on exercise .....	186

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Figure 7-15	The interaction between group and time for the SDSCA score on blood sugar testing.....	187
Figure 7-16	The interaction between group and time for the SDSCA score on foot care.....	187
Figure 7-17	The interaction between group and time for the Diabetes Empowerment Scale –Short Form (DES-SF) score.....	188

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# List of Boxes

Box 2-1	Preventing complications of type 2 diabetes <sup>38</sup> .....	16
Box 2-2	Goals for optimum diabetes management from guidelines of type 2 diabetes <sup>46</sup> .....	18

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# List of Terms

AADE	American Association of Diabetes Educators
ADA	American Diabetes Association
ASEAN	Association of South East Asian Nations
<i>Askes</i>	<i>Asuransi Kesehatan</i> (Government mandatory health insurance for civil servants)
<i>Askeskin</i>	<i>Asuransi Kesehatan Keluarga Miskin</i> (Government subsidised social health insurance programme for poor families)
BMI	Body Mass Index
CBIA-DM	Community-Based Interactive Approach - Diabetes Mellitus
CDSME	Chronic Disease Self-Management Education
CDSMP	Chronic Disease Self-Management Programme
CHCs	Community Health Centres ( <i>Puskesmas</i> )
CVI	Content Validity Index
DAWN	The Diabetes Attitudes Wishes and Needs study
DCCT	Diabetes Control and Complications Trial
DES-SF	The Diabetes Empowerment Scale – Short Form
DHBM	The Diabetes Health Belief Measure
DKQ-24	The 24-item Diabetes Knowledge Questionnaire
DSME	Diabetes Self-Management Education
DSMS	Diabetes Self-Management Support
DSMT	Diabetes Self-Management Training
FBG	Fasting Blood Glucose
FPG	Fasting Plasma Glucose
GDM	Gestational Diabetes Mellitus
GLP-1	Glucagon-Like Peptide
GMS	General Medical Services

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GNI	Gross National Income
GPs	General Practitioners
GSM	Grams per Square Metre
HCPs	Health Care Providers
HDI	Human Development Index
IDI	<i>Ikatan Dokter Indonesia</i> (Indonesian Medical Association)
IDF	International Diabetes Federation
IDR	Indonesian Rupiah (AUD 1 = IDR 9,600-10,600)
IMR	Infant Mortality Rate
<i>Jamkesmas</i>	<i>Jaminan Kesehatan Masyarakat</i> (Government subsidised public health security programme for poor people)
<i>Jamkesmas</i>	<i>Jaminan Kesehatan Sosial</i> (Government social security programme)
<i>Jamsostek</i>	<i>Jaminan Sosial Tenaga Kerja</i> (Social security insurance for work forces)
LM	The Lifelong Management programme
MKDT	Michigan Diabetes Knowledge Test
MMR	Maternal Mortality Rate
NCDs	Non-Communicable Diseases
NCI	National Cancer Institute
NDPs	National Diabetes Programmes
NGSP	National Glycohemoglobin Standardization Program
NHS	National Health Service
NICE	National Institute for Clinical Excellence
NSF	National Service Framework
OGTT	Oral Glucose Tolerance Test
PCO	Primary Care Organisation
<i>PEDI</i>	<i>Perhimpunan Diabetes Edukator Indonesia</i> (Indonesian Diabetes Educator Association)
<i>PERKENI</i>	<i>Perhimpunan Endokrinologi Indonesia</i> (Indonesian Society of Endocrinology)

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<i>PERSADIA</i>	<i>Persatuan Diabetes Indonesia</i> (Indonesian Diabetes Association)
<i>Prolanis</i>	<i>Program Pengelolaan Penyakit Kronis</i> (Integrated chronic disease management programme based on self-management initiatives developed by <i>Askes Inc.</i> )
QOF	Quality and Outcome Framework
RCT	Randomised Controlled Trial
SDSCA	The Summary of Diabetes Self-Care Activities
SEEIP	The Self-Efficacy Enhancing Intervention Programme
SMART	Specific – Measurable – Achievable – Realistic – Time line
SMBG	Self-Monitoring of Blood Glucose
STR	<i>Surat Tanda Registrasi</i> (Certificate of registration for new medical doctors, one of prerequisites to practice)
TPB	The Theory of Planned Behaviour
T2ARDIS	The Type 2 Diabetes Accounting for a Major Resource Demand in Society study
2-h PBG	Two-hour Postprandial Blood Glucose
2-h PPG	Two-hour Postprandial Plasma Glucose
T1D	Type 1 Diabetes
T2D	Type 2 Diabetes
UKDI	<i>Uji Kompetensi Dokter Indonesia</i> (National competency examination for newly graduated medical doctors)
UKPDS	The United Kingdom Prospective Diabetes Study
WHO SEARO	World Health Organisation South-East Asia Regional Office

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# The PhD Project Context

## Researcher's background, training and experience working in the area

The researcher obtained a medical doctor degree in 1997 from University of Gadjah Mada Faculty of Medicine, in Yogyakarta, Indonesia. The university is one of the oldest and leading state universities in Indonesia. After graduating, she worked as a general practitioner in several private clinics in Jakarta (the capital city of Indonesia) prior to embarking on three-years of government service in a community health centre in Gondomanan Subdistrict, Yogyakarta City in 1998. While conducting the government service, she also opened her private practice as a general practitioner at her home in Sleman Regency serving the local communities; and worked as an attending physician at an emergency unit in a private hospital in Yogyakarta City.

Approaching the end of her government service in Yogyakarta City, she was involved in a joint voluntary team of medical graduates from Gadjah Mada University and Universitas Muhammadiyah Yogyakarta to serve East Timorese refugees in Belu Subdistrict, at the border of Indonesia and East Timor. She joined the voluntary work for three months from November 1999 to January 2000. She was appointed as the coordinator of the team and assigned at Belu Community Health Centre providing health care services to thousands of refugees.

After completing the government service, she worked as a lecturer at Universitas Muhammadiyah Yogyakarta Faculty of Medicine, a private medical school. She was assigned to the Department of Public Health to direct the teaching Family Medicine – a newly introduced subject in Indonesian medical schools at the time – for medical students and clerks. She was also involved in the development of problem based curriculum commenced in 2004 at the medical school. During this period, she maintained her private practice at home and her work at the private hospital. She was then sent to take a master's study programme in Family Medicine at the University of the Philippines Manila, Philippines, funded by the Universitas Muhammadiyah Yogyakarta Faculty of Medicine. Two of the important core competencies taught were communication and counseling skills for family doctors. The topic of her master's research project was the development of Family Medicine Practice in Indonesia. She obtained the Master of Science in Clinical Medicine – Family Medicine in 2007.

After returning to her home university, she continued teaching Family Medicine and began to teach communication and counseling skills at the medical school. She was also involved in the national initiatives for the development of Family Medicine/ Primary Care in



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Indonesia. Additionally, she was involved in the Joint Committee for Competence Exam of Indonesian Doctors (KBUKDI) to set up a national competence exam for medical doctors which has been administered in Indonesia since February 2007. In August 2008, she obtained a scholarship from the Republic of Indonesia Ministry of Education and Culture Directorate of Higher Education to undertake a doctoral study at the University of Adelaide, Australia. She commenced the doctoral study in the Discipline of General Practice and Public Health in mid October of 2008. While conducting the PhD research project in Yogyakarta City in 2009-2011, she continued to be involved in national meetings for developing Family Medicine/ Primary Care in Indonesia.

### **Selection of the PhD Research Project Topic**

The researcher chose this topic for her PhD research project based on several factors. This research project was initiated out of the researcher's concern for the alarming increasing prevalence of chronic diseases in Indonesia, particularly in type 2 diabetes. During her practice at the private clinics, community health centres, at home and at the hospital, she observed that many patients with chronic diseases were not well-informed about their chronic conditions. This might be related to the approach of many Indonesian health care providers who offer prescriptions during patient-provider encounters without providing adequate information to the patients about their health problems. The situation where patients were being instructed to take the medicines prescribed without being informed about their underlying condition was very common. This observation was supported in discussions with the researcher's colleagues. In particular, it was clear that the idea of self-management and patient empowerment in the area of chronic disease management was very poorly understood in Indonesia.

The lack of sufficient provision of education and empowerment in health care delivery to patients with chronic diseases became the researcher's main concern. Additionally, both the researcher's parents also suffered from chronic diseases with her father suffering from type 2 diabetes and chronic heart disease, and mother from hypertension and chronic heart disease. Both parents were hospitalised several times while the researcher was conducting field work in Yogyakarta City. Both parents then died during the time the researcher was waiting for the outcome of the thesis examination. These circumstances inspired the researcher to provide solutions for addressing the needs of patient self-management and empowerment in Indonesian health care delivery management by conducting a research topic in the area.



# **CHAPTER 1 – Introduction**

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**A Structured Diabetes Education Programme  
in Indonesia**

## 1.1 BACKGROUND

Projections suggest that chronic conditions will be the leading causes of death and disability globally by the year 2020, causing immense health care costs for societies and governments. These chronic conditions include non-communicable diseases such as diabetes, cardiovascular diseases, cancers, mental health disorders, and certain non-communicable diseases such as HIV/AIDS.<sup>1</sup> According to World Health Report 2001, non-communicable diseases (NCDs) accounted for almost 60% of total deaths and 46% of the burden of disease in the world in 2000. By the year 2020, this disease burden is predicted to increase to 60% globally, with 78% of it in developing countries. While chronic conditions presently make up the main disease burden in developed countries, 75% of the total deaths due to NCDs in fact occur in developing countries, indicating that these conditions affect both high and low income countries at an alarming rate. NCDs pose a threat in health, economic and social aspects throughout the world.<sup>2,3</sup> Developing countries, including Indonesia, are thus facing a double burden of disease in which NCDs are rising rapidly while communicable diseases, although in decline, remain high.<sup>3,4</sup> This inevitably poses an enormous challenge for Indonesia, as a developing nation with the fourth largest population in the world.<sup>5</sup>

Diabetes, as one of the prevalent NCDs, has become a growing public health problem as estimates and projections continue to indicate a 'diabetes epidemic' worldwide. This is due to population growth, aging, urbanization, and particularly increasing prevalence of obesity, decreasing levels of physical activity and adoption of other unhealthy lifestyles. Diabetes is a life-threatening condition; it can cause devastating complications silently developed, sometimes even without being realized by the sufferers and eventually lead to deaths, thus largely known as a "silent killer" disease. Globally, more than 170 million people suffered from diabetes in 2000, a number projected to double to 366 million by the year 2030.<sup>3,6,7</sup> Diabetes Atlas 2006 indicates that estimates show approximately 5.9% of global population in the age group 20-79 or 246 million people have diabetes in 2007, with 80% of them living in developing countries. By the year 2025, this global estimate is predicted to rise to 7.1% of adult population or 380 million people, mostly in developing countries.<sup>7</sup> The World Health Organization (WHO) suggests that the escalation in diabetes in developing nations is particularly alarming since developing nations contribute approximately 75% of the global diabetes burden.<sup>2</sup> This includes Indonesia.

In a 2004 study on Global Prevalence of Diabetes, Indonesia is listed the fourth amongst the top ten countries with the highest numbers of estimated diabetes cases after India, China, and USA. Diabetes cases in Indonesia are projected to increase from 8.4 million in 2000 to 21.3 million in 2030.<sup>6</sup> Similarly, the Diabetes Atlas 2006 indicates that

Indonesia is in the fourth place amongst the top ten countries with the highest number of people with impaired glucose tolerance. In 2007, this is estimated to affect 14.1 million people, while the estimate for 2025 puts Indonesia in the third place with 20.6 million people.<sup>7</sup> Meanwhile, Indonesia's Health Profile 2008 indicates that diabetes is one of the most rapidly increasing chronic diseases in Indonesia, and it is listed amongst the top ten causes of morbidity and mortality.<sup>8</sup> This double burden of disease puts additional pressures on Indonesia's health system which is currently entering a period of transitions due to demographic, epidemiological and nutritional shifts.<sup>4</sup> Therefore, evidence based and cost-effective public health strategies should be implemented in Indonesia in order to not only prevent diabetes and reduce diabetic complications, but many other NCDs as well.

According to WHO (2002), chronic conditions in developing nations present mainly at primary health care level, and yet most primary health care is acute-problem oriented. Many developing countries continue to face the issues of acute infectious diseases, malnutrition and maternal health which have been the focus of health care delivery in the past. With the increasing prevalence of chronic conditions, primary health care must be strengthened to effectively prevent and manage chronic conditions. Therefore, despite limited resources, a paradigm shift is required to focus primary health care to incorporate quality care for chronic conditions.<sup>2</sup>

In response to the rise of chronic conditions, WHO suggests that health care systems that are presently based on the acute care model must evolve. Identified problems of health care systems related to this issue are classified into different levels, i.e.: patient interaction level, health care organization and community level, and policy level. At patient interaction level, two common problems are "the failure to empower patients to improve health outcomes" and "the lack of emphasis on quality interactions with the health care personnel". Meanwhile, problems at health care organization and community level include: (1) Failure to organize care for chronic conditions, (2) Health care workers lack tools and expertise, (3) Practice is not informed by scientific evidence, (4) Failure to address prevention, (5) Information systems are not in place, and (6) Failure to connect with community resources. Problems at policy level include: (1) A legislative framework is lacking, (2) Health policies and plans are outmoded, (3) Governments are not investing wisely, (4) Financing systems are fragmented, (5) Provider incentives are misaligned, (6) Standards and monitoring are insufficient, (7) Continuing education is lacking, and (8) Inter-sectoral links are overlooked.<sup>2</sup> Due to the enormous magnitude of the identified problems within the health care system in addressing chronic conditions, this research project attempts to only focus on the problem at patient interaction level i.e. "the failure to empower patients to

improve health outcomes” and “the lack of emphasis on quality interactions with the health care personnel”, particularly in primary care setting in Indonesia.

Chronic health problems, including diabetes, are enduring and inevitably pose considerable health and economic burdens on the patients and their families, as well as for the communities and the health care systems. Patients with chronic diseases need to live with their illness and manage it on a daily basis, such as taking medication as prescribed, eating and exercising properly, sleeping regularly, and dealing with stress appropriately. Therefore, they have to take a more active role in their health care and can no longer be considered as, nor view themselves as, passive recipients of health care services, and thus must be supported by health care personnel in their efforts. There is considerable evidence in the literature showing that interventions designed to promote the patient’s role in chronic disease management are associated with improved health outcomes.<sup>2,9</sup> According to Holman and Lorig, patients must become partners in managing chronic disease, contributing at almost every decision or action level, because a partnership between patients and physicians is a prerequisite for effective and efficient health care.<sup>10</sup> Furthermore, Bodenheimer et al. suggest that a new chronic disease paradigm requires a patient-professional partnership, involving collaborative care and self-management education that teaches problem-solving skills. ‘Self-efficacy’, a pivotal concept in self-management education and defined as confidence to perform a behaviour necessary to reach a desired goal, is thus enhanced when patients are successful in solving their own identified problems.<sup>11</sup>

There is a growing interest in self-management programmes that highlight the patients’ vital role in managing their chronic illness, as well as in controlling and preventing chronic disease complications. The goal of self-management programmes is to provide patients with skills and resources to cope with numerous social and environmental challenges to healthy living. Increasing evidence from controlled clinical trials suggests that programmes teaching self-management skills are more effective in improving clinical outcomes as compared to information-only patient education. The benefits of chronic disease self-management education interventions reported in developed countries include maintaining and improving patients’ health behaviour and health status, lowering health care utilization through self-management skills, ‘self-efficacy’, and better communication between patients and health providers. Chronic disease self-management education (CDSME) is thus expected to become an integral part of high-quality primary care.<sup>9,11-15</sup>

As a complex and progressive chronic condition, diabetes requires both high quality clinical care and effective self-management. Diabetes self-management education (DSME) is increasingly recognized as a central component of diabetes care. According to Tang et al.,

the focus of DSME is to help patients acquire the knowledge, information, self-care practices, coping skills, and attitudes required to self-manage their diabetes effectively. Furthermore, several reviews and meta-analyses suggest that DSME interventions have a positive impact on diabetes-related health and psychosocial outcomes, specifically increasing diabetes-related knowledge, and improving blood glucose monitoring, dietary and exercise habits, foot care, medication taking, coping and glycaemic control.<sup>16,17</sup> The International Diabetes Federation (IDF) views the critical importance of DSME and diabetes self-management support (DSMS) as integral components of diabetes prevention and care, and recommends that DSME and DSMS should be made available and accessible to everyone. This is because efforts to promote DSME and DSMS are crucial in decreasing the human and economic burden of diabetes. A collaborative effort is thus required among all health stakeholders, namely people with diabetes and those who are at risk of diabetes, governments and health care services, health care providers and the general public. According to the IDF, the focus of DSME and DSMS is to prepare those affected by diabetes to: (1) make informed decisions; (2) cope with the demands of living daily with a complex chronic disease; and (3) make changes in their behaviour that support their self-management effort and improve outcomes”.<sup>17</sup>

The recommendations in Australian National Evidence Based Guideline for Patient Education in Type 2 Diabetes 2009 indicate that diabetes structured patient education, delivered in groups or individually, should be provided to all people with type 2 diabetes (T2D).<sup>18</sup> According to Loveman et al., the purpose of patient education for people with T2D is to empower patients by improving knowledge, skills and confidence, enabling them to take increasing control of their condition. Furthermore, they suggest that the nature of structured educational programmes for diabetes self-management are frequently multifaceted interventions providing information and management skills on diet, exercise, self-monitoring and medication use.<sup>19</sup>

A large body of literature in developed and Western countries has shown the effectiveness of empowerment-based CDSME and DSME interventions in improving health outcomes. These interventions have increasingly been introduced in Asian countries. Studies on CDSME and DSME programmes in several Asian countries showed promising results. A randomised controlled trial (RCT) by Fu et al. to evaluate a CDSME programme found that the programme was culturally acceptable to Chinese patients and could improve the participants' health behaviour, self-efficacy and health status and reduce hospitalisation rate.<sup>14</sup> Wu conducted an RCT on self-efficacy enhancing intervention programme (SEEIP) based on self-efficacy theory for T2D and found that the programme was culturally acceptable to Taiwanese patients and effective in the self-management of people with T2D.

The 3- and 6-month benefits of the programme were significant increases in self-efficacy, outcome expectation, self-care activities and social support over usual care.<sup>20</sup> An RCT by Shi et al. to evaluate a one-month hospital clinic intervention on group-based diabetes education in Chinese patients with T2D demonstrated that the intervention improved glycaemic control self-efficacy and glycaemic control behaviour.<sup>21</sup> An RCT of the chronic care model in diabetic care in Hong Kong by Lee et al. showed significant improvements in HbA1c level, DM self-efficacy scale, BMI and dietary behaviours.<sup>22</sup>

A study by Tan & Magarey investigating Malaysian adults with T2D on their self-care practices showed that there were diabetes-related knowledge deficits and inadequate self-care practices among the majority of the participants with sub-optimal glycaemic control. Consequently, it implied the need for effective education strategies to encourage diabetes self-management.<sup>23</sup> Tan et al. conducted an RCT assessing the effectiveness of a brief structured diabetes education programme based on self-efficacy concept on self-care and glycaemic control in Malaysians with poorly controlled T2D. They found that the programme significantly improved diabetes knowledge, self-monitoring of blood glucose, HbA1c, physical activity, and medication adherence over usual care.<sup>24</sup>

In Indonesia, structured patient education in T2D is hardly available. Generally, traditional diabetes education can be found in hospitals and publicly funded community health centres (CHCs). This patient education is mostly a didactic teaching, neither structured nor comprehensive, and usually conducted by a nutritionist focusing primarily on diabetes meal planning to an individual patient with T2D. Other common forms of traditional diabetes education are carried out in groups, including: diabetes public education conducted in the communities within the working areas of CHCs, and diabetes seminars conducted in hospitals.

Funnel et al. suggests that the traditional model of diabetes education has been ineffective in bringing about the desired outcomes.<sup>25</sup> According to Goldstein, self-management education approaches signify involving patient judgement and values within the context of daily living to inform how a comprehensive treatment plan can be best agreed and implemented. Therefore, the American and British Diabetes Associations have referred to diabetes education as diabetes self-management education.<sup>26</sup> However, more than 50% of patients with diabetes receive limited diabetes self-management education, or none.<sup>27,28</sup> Meanwhile, the diabetes self-management concept is barely known in diabetes education and care in Indonesia. Participation of the researcher in an annual national training for diabetes educators organised by *PEDI* (the Indonesian Association of Diabetes Educator) in Jakarta (the capital city of Indonesia) indicated that diabetes self-management was neither discussed with nor taught to the participants.



According to Anderson et al., increases in diabetes self-efficacy are related to empowerment and improved outcomes.<sup>29</sup> Self-efficacy is a major concept in the patient empowerment approach to diabetes education and plays an important role in successful behaviour change. Therefore, enhancing the perceived self-efficacy of patients to self-manage their diabetes is an important goal of diabetes education and care.<sup>30</sup> Empowerment has served as the philosophical foundation for diabetes self-management education for more than two decades.<sup>31</sup> However, the patient empowerment concept for diabetes education is also almost unknown in Indonesia.

Furthermore, besides the author, there are no researchers in Indonesia engaged in DSME intervention studies. A study by Primanda *et al.* on dietary behaviours among patients with T2D in a hospital in Yogyakarta, Indonesia, showed “a moderate level of the total score of dietary behaviours”, and “there was a positive significant relationship between the knowledge regarding diabetes diet and total dietary behaviour score” (p.211). They suggested that further study regarding intervention in increasing patients’ knowledge is needed to achieve better dietary behaviours.<sup>32</sup> Hartayu et al. investigated the effectiveness of a community-based interactive approach-diabetes mellitus (CBIA-DM) strategy for patients with T2D in Yogyakarta. They found that the intervention was effective in improving knowledge, attitude and practice on diabetes self-care for people with T2D.<sup>33</sup> However, these studies were based on traditional diabetes education commonly found in health care facilities. There is very limited awareness and availability of structured diabetes education based on diabetes self-management and patient empowerment concepts in the health care service in Indonesia.

Additionally, there are no validated instruments that measure diabetes self-management or diabetes-related knowledge, health beliefs, self-care behaviours and self-efficacy written in Indonesian language or *Bahasa Indonesia*. Instruments to appropriately measure the effectiveness of DSME interventions in *Bahasa Indonesia* have yet to be made available. Since there is no available literature on DSME in Indonesia, studies on this topic are crucial at the moment and into the future.

Diabetes self-management and patient empowerment are entirely new concepts in Indonesia, and yet to be introduced into the health care service, particularly in primary health care. Considering the continuously growing prevalence of diabetes in Indonesia and the increasing evidence supporting the effectiveness of diabetes self-management programmes, it is essential to pilot a programme for structured diabetes education which promotes diabetes self-management and patient empowerment for patients with T2D in primary care setting in Indonesia. While these concepts are primarily tailored to the Western people’s socio-culture and their thinking paradigm, its implementation in Indonesia – that has largely

different social, economic and cultural characteristics as compared to those in the developed countries – will impose extensive planning and evaluation. Therefore, it should be carefully designed, taking into account the complexity of social and cultural aspects of the local setting and target communities. One of the essential characteristics is that Indonesian people are generally family-oriented with the support of extended family. Therefore, family involvement as an important social support was incorporated into such research intervention.

## 1.2 RESEARCH QUESTIONS AND HYPOTHESES

This research project was divided into two studies, namely:

- 1) Study 1: A cross-cultural adaptation of existing validated diabetes-related instruments.
- 2) Study 2: A cluster randomised controlled trial of a structured diabetes education programme (the main study); which was enriched by scoping discussions on perceptions towards the current diabetes education and the diabetes education interventions among people with T2D and their family members, and health care providers.

The research project sought to answer the following questions:

- Study 1: “Are the existing validated diabetes-related instruments valid and reliable for an Indonesian population?”
- Study 2: “Is a structured diabetes education programme promoting self-management and patient empowerment effective in improving clinical outcomes and diabetes related scores of knowledge, health beliefs, self-care behaviours, and self-efficacy in adult patients with T2D in primary care setting in Indonesia?”; and  
“What are the perceptions of patients with T2D and their family members regarding the current diabetes education they receive?”; “What are the perceptions of health care providers regarding the current diabetes education they provide to patients with T2D?”; “What are the perceptions of patients with T2D and their family members regarding the diabetes education intervention?”

The following research hypotheses were tested during the main study, Study 2: “Patients with T2D who receive a primary care delivery of structured diabetes education programme promoting diabetes self-management and patient empowerment would have greater improvement in clinical outcomes and diabetes-related scores of knowledge, health beliefs, self-care skills, and self-efficacy than those who do not.”

### 1.3 RESEARCH AIMS AND OBJECTIVES

This research project aimed to develop a pilot model of structured diabetes education programme which promotes diabetes self-management and patient empowerment, and evaluate the effectiveness of the programme on clinical outcomes and diabetes-related scores of knowledge, health beliefs, self-care behaviours, and self-efficacy in people with T2D in primary care setting in Indonesia.

The objectives of the research were:

- 1) To cross-culturally adapt existing validated diabetes-related instruments.
- 2) To develop diabetes education materials for research interventions, i.e. diabetes leaflets, posters, and banners.
- 3) To assess clinical outcomes and diabetes-related scores of knowledge, health beliefs, self-care skills and self-efficacy of patients with T2D at baseline.
- 4) To identify the perceptions of patients with T2D and their family members towards diabetes education they previously received.
- 5) To identify the perceptions of health care providers towards diabetes education they provided to patients with T2D.
- 6) To develop and provide diabetes education interventions to patients with T2D.
- 7) To assess clinical outcomes and diabetes-related scores of knowledge, health beliefs, self-care skills and self-efficacy of patients with T2D at 3-month follow-up.
- 8) To identify the perceptions of patients with T2D and their family members towards the diabetes education interventions they had received and their experiences in implementing what they had learned from the interventions.

### 1.4 RESEARCH SIGNIFICANCE

This research project sought to pilot a health care model in primary care setting for integrating a structured diabetes education programme promoting diabetes self-management and patient empowerment into diabetes education and care in Indonesia. Various benefits were expected to be achieved when this project was carried out in Indonesia.

Results of this research not only provided benefits for patients with T2D and the health care providers, but also for the broader community, health policy makers, and medical discipline as follows:

- 1) Benefits for patients with T2D: Empowering patients with T2D to do self-management enabled them to achieve better health outcomes and live well with their chronic condition.
- 2) Benefits for health care providers: Health care providers could adopt the model for the education and management of T2D and other chronic conditions in their health care facilities in order to provide high-quality care and obtain high level of patient satisfaction from their health care provision.
- 3) Benefits for broader community: With the increasing prevalence of diabetes in the society, community members affected were equipped with sufficient knowledge and self-management skills to live well with the chronic condition of diabetes; and in turn, this would raise awareness of the family members, friends, work colleagues and other broader community about how to manage this devastating disease.
- 4) Benefits for health policy makers in Indonesia: This project produced noteworthy data for advocacy to policy makers with regards to the development of appropriate health policies and initiatives for T2D and other chronic conditions, to be adopted at provincial and national level.
- 5) Benefits for medical discipline: Finally, this project contributed significant evidence for health care services regarding the education and management of T2D and other chronic conditions in primary care.

## 1.5 SUMMARY

In summary, the motivation to conduct this research project was based on the alarming increasing prevalence of T2D in the world and Indonesia, the increasing implementation of diabetes self-management education as an integral component of diabetes care in developed countries and other Asian countries, and the limited awareness and availability of diabetes structured education based on diabetes self-management and patient empowerment concepts in health care service in Indonesia. This research project proposed that providing a structured diabetes education programme promoting diabetes self-management and patient empowerment to patients with T2D and their family members would improve their clinical outcomes and diabetes-related scores of knowledge, health beliefs, self-care skills, and self-efficacy.

This chapter has outlined the background and significance of this study, including its aims and objectives, research questions and hypotheses. Chapter 2 will describe important issues raised in this chapter in more detailed through a critical review of the literature on

diabetes self-management and patient empowerment. Chapter 3 will illustrate the country setting of the research, which is an overview of the geography, population and government and health care system of Indonesia. Chapter 4 will discuss various methods utilised in this research project. Chapter 5 will describe the cross-cultural adaptation of existing validated diabetes-related instruments. Chapter 6 will discuss the development of diabetes education materials. Chapter 7 will describe the cluster-randomized controlled trial and scoping discussions. And finally, the last chapter, Chapter 8 will present overall conclusions and recommendations emerging from this research project.

# **CHAPTER 2 – Literature Review**

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## **A Structured Diabetes Education Programme in Indonesia**

## 2.1 INTRODUCTION

This thesis is about the current understanding of patient education in type 2 diabetes highlighting diabetes self-management and patient empowerment concepts. In designing the research intervention, the researcher has created a chronic disease self-management concept with a specific focus on structured diabetes education programme conducted in community health centres, the predominantly model for primary health care facilities in Indonesia. The literature review begins with a description of type 2 diabetes and its management. It is followed with discussions on diabetes care and national programmes, chronic disease self-management, and the role of chronic disease self-management in diabetes education. The literature review is completed with a description of models of structured patient education in type 2 diabetes; one of which was adapted to provide the intervention in this research project.

A literature search was conducted in PubMed, Scopus, Google Scholar and the Cochrane Library to include publications in any language available in these databases. The key words used for search strategy included: type 2 diabetes, chronic diseases, chronic disease self-management, diabetes self-management, chronic disease self-management education, diabetes self-management education, and patient empowerment.

## 2.2 TYPE 2 DIABETES

### 2.2.1 Definition, Classification and Diagnosis of Diabetes Mellitus

Diabetes mellitus (diabetes) encompasses a group of metabolic diseases characterised by hyperglycaemia resulting from defects in insulin secretion, insulin action or both. The effects of diabetes include long-term damage, dysfunction and failure of various organs, particularly the eyes, kidneys, nerves, heart and blood vessels.<sup>34</sup>

There are two main types of diabetes. Type 1 diabetes (T1D) results from  $\beta$ -cell destruction, usually leading to absolute insulin deficiency. T1D usually develops in childhood and adolescents, and patients require lifelong insulin injections for survival. Type 2 diabetes (T2D) results from a progressive insulin secretory defect on the background of insulin resistance. T2D usually develops in adulthood and is related to obesity, lack of physical activity and unhealthy diets. T2D accounts for 85 to 95% of all diabetes in developed countries, and an even higher percentage in developing countries.<sup>7,34,35</sup> Other categories of diabetes include: (1) gestational diabetes mellitus (GDM), i.e. diabetes diagnosed during

pregnancy, and (2) other specific types of diabetes which are rare, e.g. genetic defects in  $\beta$ -cell function, genetic defects in insulin action, diseases of the exocrine pancreas (such as cystic fibrosis), and drug or chemical-induced diabetes.<sup>34,35</sup> This research project focuses on the self-management of T2D.

American Diabetes Association (ADA) suggests the following four criteria for the diagnosis of diabetes:

- 1) HbA1c  $\geq$  6.5%. The test should be performed in a laboratory using a method that is certified by National Glycohemoglobin Standardization Program (NGSP) and standardised to the Diabetes Control and Complications Trial (DCCT) assay; OR
- 2) Fasting plasma glucose  $\geq$  126 mg/dL (7.0 mmol/L). Fasting is defined as no caloric intake for at least 8 hours; OR
- 3) Two-hour plasma glucose  $\geq$  200 mg/dL (11.1 mmol/L) during an oral glucose tolerance test (OGTT). The test should be performed as described by the World Health Organization, using a glucose load containing the equivalent of 75 grams of anhydrous glucose dissolved in water; OR
- 4) In a patient with classic symptoms of hyperglycaemia or hyperglycaemic crisis, a random plasma glucose  $\geq$  200 mg/dL (11.1 mmol/L).

In the absence of unequivocal hyperglycaemia, criteria 1-3 should be confirmed by repeat testing.<sup>34</sup>

## 2.2.2 Symptoms and Complications of Diabetes Mellitus

In the short term, hyperglycaemia causes symptoms of increased thirst (polydipsia), increased urination (polyuria), increased hunger (polyphagia) and unexplained weight loss – known as the four classic symptoms of diabetes. Common symptoms include: fatigue, blurred vision, frequent infections, poor wound healing, dry, itchy skin, numbness and tingling in hands, legs and feet.<sup>35,36</sup>

In the long term, hyperglycaemia causes diabetes complications, categorised as macrovascular (affecting large arteries), and microvascular (affecting capillaries and small blood vessels). Macrovascular complications include: transient ischaemic attack, stroke, angina, myocardial infarction, cardiac failure, and peripheral vascular disease. Microvascular complications include: diabetic retinopathy, microalbuminuria, macroalbuminuria, end-stage renal disease, erectile dysfunction, autonomic neuropathy, peripheral neuropathy, osteomyelitis, and amputation.<sup>37-39</sup>

These wide-ranging complications with multiple vascular risk factors result in complex and challenging nature of diabetes care and draw on many areas of health care



management.<sup>40</sup> Diabetes complications are common and cause enormous cost to the individuals, families, societies, health systems and national economies.<sup>7,37,38</sup> Therefore, the major goal of diabetes management is to prevent complications.<sup>37</sup>

The United Kingdom Prospective Diabetes Study (UKPDS) provided evidence that hyperglycaemia is the major contributor to diabetes complications. The study showed that lowering blood glucose levels was significantly beneficial in decreasing microvascular complications. A 25% decrease of the overall microvascular complication rate was observed. Epidemiological analysis of the UKPDS data demonstrated a continuous relationship between glycaemia and the risks of microvascular complications i.e. for every percentage point decrease in HbA1c (e.g. 8 to 7%) there was a 35% reduction in the risk of complications. However, no significant effect of lowering blood glucose on macrovascular complications was observed, although there was a 16% reduction in the risk of combined fatal or non-fatal myocardial infarction and sudden death. Epidemiological analysis showed a continuous association between glycaemia and the risk of macrovascular complications i.e. for every percentage point decrease in HbA1c (e.g. 8 to 7%) there was a 25% reduction in diabetes-related deaths, a 7% reduction in all-cause mortality and an 18% reduction in combined fatal and non-fatal myocardial infarction. Lowering blood pressure to a mean of 144/82 mmHg was also demonstrated to significantly reduce strokes, diabetes-related deaths, heart failure, microvascular complications, and visual loss.<sup>41,42</sup>

Type 2 diabetes can be asymptomatic for many years and is frequently diagnosed from associated complications or unexpectedly through abnormal blood or urine tests. Several possible factors in the development of T2D include: ethnicity; obesity, diet and inactivity; insulin resistance; family history; and intrauterine environment.<sup>7</sup> Type 2 diabetes is associated with reduced life expectancy and diminished quality of life.<sup>43</sup> Complications are the major cause of associated morbidity and mortality in T2D.<sup>37,38</sup>

### 2.2.3 Management of Type 2 Diabetes

Monitoring metabolic control is paramount to the care of people with T2D, while glycaemic control is only part of the holistic care of T2D.<sup>44</sup> Good metabolic control has been shown to be associated with significant risk reduction of complications.<sup>19,37,38</sup> The prevention of macrovascular complications is a major goal in the care of people with T2D. The key to this prevention is multifactorial intervention.<sup>45</sup> The basic targets in the management of T2D thus include: glycaemic control, blood pressure control, lipid control, lifestyle measures, and aspirin therapy. The measures for preventing complications of T2D are presented in **Box 2-1**.<sup>38</sup>

The complexity of diabetes care requires systematic and integrated care from the practice team involving several health professionals, including: general practitioner/ family doctor, specialist physicians such as endocrinologist/ diabetologist/ paediatrician, diabetes educator, dietician, practice nurse, ophthalmologist/ optometrist, dentist, exercise professional, podiatrist, and pharmacist. However, primary care physicians – general practitioners or family doctors – continue to provide most of the medical care to people with T2D.<sup>46</sup>

**Box 2-1 Preventing complications of type 2 diabetes<sup>38</sup>**

**Preventing diabetes complications:**

**1. Blood glucose control**

Glycated haemoglobin (HbA1C) should be as low as possible (but avoid undue hypoglycaemia) – i.e. aim for < 7.0% if the patient is on insulin or < 6.5% if not on insulin.

**2. Blood pressure control**

Blood pressure should be as low as possible (avoiding symptoms of postural hypotension) – aim for <130/80 mm Hg or < 125/75 mm Hg if proteinuria is present, if the glomerulus filtration is < 60 ml/min/1.73 m<sup>2</sup>, or if the patient has cardiovascular disease.

**3. Lipid control**

- Statins should be prescribed for patients over 40
- Statins should be prescribed for patients under 40 who have microvascular or macrovascular complications, hypertension, metabolic syndrome, or a strong family history of cardiovascular disease.
- Total cholesterol should be < 4.5 mmol/litre
- LDL-cholesterol should be < 2.5 mmol/litre
- Fibrates should be prescribed if triglycerides are > 2.3 mmol/litre LDL-cholesterol values are < 2.5 mmol/litre

**4. Lifestyle measures**

Lifestyle measures are recommended to help prevent cardiovascular diseases:

- Dietary modification i.e. healthy eating
- Regular exercises,
- Smoking cessation
- Weight reduction in overweight individuals.

**5. Aspirin therapy**

Low-dose of aspirin should be prescribed for all patients over 40, even in the absence of overt cardiovascular disease

Diabetes Australia and the Royal Australian College of General Practitioners developed a practice guide for T2D addressing various issues, including: diagnosis, assessment, the team approach, initial management, health care for diabetes, medication, sick days, hyperglycaemic emergencies, factors complicating management, diabetes and reproductive health, driving, and travel. The guide also describes goals for optimum diabetes management.<sup>46</sup> The initial management of T2D<sup>46</sup> is summarised and presented in **Appendix I – The Frameworks of Management of Type 2 Diabetes**. The management of type 2 diabetes based on the clinical guideline developed by National Institute for Health and Clinical Excellence<sup>40</sup> is also summarised and presented in **Appendix I**. The current management of T2D in primary care includes: self-monitoring of blood glucose, nutrition

therapy, physical activity, medication, medical monitoring, and diabetes self-management education (DSME).<sup>34,44,46</sup>

Self-monitoring of blood glucose (SMBG) is an essential part of diabetes self-care for evaluating treatment efficiency and adjusting therapy. SMBG is recommended for diabetic patients taking agents that can cause hypoglycaemia, such as sulphonylureas and insulin. When prescribed SMBG, patients should receive initial instruction in, and routine follow-up evaluation, SMBG technique and their ability to use data to adjust therapy. SMBG should be carried out 3-4 times daily (early morning, plus other tests before and after meals).<sup>34,46</sup> Studies have shown that up to 50% of patient-generated SMBG results are inaccurate.<sup>47</sup>

The initial management of T2D emphasises nutrition therapy and physical activity. In more than 50% of people presenting with T2D, a combination of energy intake restriction, increased activity and weight reduction will initially normalise blood glucose levels. Medication is likely to be prescribed when needed later. Nutrition management involves healthy eating and weight control.<sup>46</sup> While physicians should give advice on the importance of nutrition management, detailed instructions need to be provided by a dietician familiar with diabetes nutrition therapy.<sup>34,46</sup> Healthy eating, weight control and regular physical activity are important objectives for people with T2D. Weight loss will often result in near normal glycaemic, blood pressure and lipid profiles. A weight loss of 5 to 20% has been shown to improve glycaemic control. Regular physical activity improves metabolic control and reduces other cardiovascular risks.<sup>46</sup> People with T2D should be advised to perform at least 150 min/week of moderate-intensity aerobic physical activity (50-70% of maximum heart rate), and when there are no contraindications, should be encouraged to perform resistance training three times per week.<sup>34</sup>

Multiple medications are needed to control multiple risk factors associated with T2D, such as hyperglycaemia, hypertension, dyslipidaemia, and increased thrombogenesis. If a trial of healthy lifestyle for 6 weeks or more is unsuccessful in controlling blood glucose, oral hypoglycaemic agents can be used. Medication can be used early for patients with symptoms at initial diagnosis or very high blood glucose level (> 20 mmol/L) in order to decrease glucose levels and relieve symptoms. The first line medication is metformin which reduces hepatic glucose output and insulin resistance. Sulphonylureas increase insulin secretion, and can be used after a trial of health lifestyle and metformin, comprising the second line medication. The third line medication include: acarbose, repaglinide, glucagon-like peptide (GLP-1) agents, glitazones, and insulin. Acarbose is useful when blood glucose values remain high after meals despite dietary modification. Acarbose inhibits the digestion of carbohydrate and thus slows the glucose delivery rate into the circulation. Repaglinide causes a rapid, transient increase in pancreatic insulin secretion, and can be used as

monotherapy or with metformin to control postprandial hyperglycaemia. Glitazone is effective in lowering blood glucose by reducing insulin resistance, and can be used as dual therapy with metformin or sulphonylureas. GLP-1 enhances insulin secretion, inhibits glucagon secretion in a glucose dependent manner, increases satiety and decreases gastro-emptying, reducing both fasting and postprandial glucose.<sup>46,48</sup>

Regular follow-up visits provide opportunities for both health care providers (HCPs) and patients to explore the patients' understanding, fears and concerns about T2D.<sup>46</sup> Medical monitoring by HCPs should include the following assessment: nutrition, physical activity, smoking, alcohol intake, patient's record of SMBG, weight and waist circumference, blood pressure, foot examination, eye examination, HbA1c (at least six monthly), lipid profile, thyroid function, liver function, renal function, and proteinuria and microalbuminuria.<sup>34,46</sup> Goals for optimum diabetes management are presented in **Box 2-2**.<sup>46</sup>

**Box 2-2 Goals for optimum diabetes management from guidelines of type 2 diabetes<sup>46</sup>**

<b>Goals for Management of Type 2 Diabetes</b>	
• Blood sugar level	ideal 4.0-6.0 mmol/L (fasting) NHMRC 6.1-8.0 mmol/L (fasting)
• HbA1c	≤ 7%
• LDL-cholesterol	< 2.5 mmol/L*
• Total cholesterol	< 4.0 mmol/L*
• HDL-cholesterol	> 1.0 mmol/L*
• Triglyceride	< 1.5 mmol/L*
• Blood pressure	≤ 130/80 mm Hg**
• BMI	< 25 kg/m <sup>2</sup> where appropriate
• Urinary albumin excretion	< 20 µg/min (timed overnight collection) < 20 mg/L (spot collection) < 3.5 mg/mmol: women < 2.5 mg/mmol: men (albumin creatinine ratio)
• Cigarette consumption	Zero
• Alcohol intake	≤ 2 standard drinks (20 g) per day for men and women***
• Physical activity	at least 30 minutes walking (or equivalent)
Doctors should consider:	
<ul style="list-style-type: none"> <li>• Prophylactic aspirin (75-325 mg) daily unless there are contraindications</li> <li>• Immunisation against influenza and pneumococcal disease</li> </ul>	
* National Heart Foundation Guidelines	
** National Health and Medical Research Council Evidence Guidelines for the Management of Type 2 Diabetes 2005	
*** National Health and Medical Research Council Australian Guidelines to Reduce Health Risks from Drinking Alcohol 2009	

American Diabetes Education recommends that people with T2D should receive diabetes self-management education (DSME) according to national standards at initial diagnosis and as needed thereafter. The key outcomes of DSME are effective self-management and quality of life, and should be measured and monitored. DSME should address psychosocial issues because emotional well-being is associated with positive diabetes outcomes.<sup>34</sup>

## **2.3 DIABETES CARE AND NATIONAL PROGRAMMES**

### **2.3.1 Evolution in Diabetes Care**

Over the past six decades, diabetes care has evolved with the application of new concepts. This is due to several reasons. The sharp rise in the prevalence of T2D has prompted the shift of diabetes care from secondary to primary care. Consequently, shared care for diabetes between primary and secondary HCPs has gained increasing importance in the past years.<sup>49</sup>

Advances in diabetes treatments and equipment have enabled more effective and flexible management strategies. These include advances in oral hypoglycaemic agents and insulin therapy offering more useful choices. Insulin delivery systems have also significantly improved over the past six decades. Blood glucose monitoring has been greatly facilitated with the application of glycated haemoglobin (HbA1c) testing in clinical settings and self-monitoring of blood glucose (SMBG) using improved glucometer devices by diabetics. SMBG has an empowering effect in enabling diabetics to take a more active role in their care.<sup>49</sup> Evidences from randomised controlled trials suggest beneficial measures in preventing diabetes complications. The United Kingdom Prospective Diabetes Study (UKPDS) showed that intensive glycaemic control can decrease microvascular complications.<sup>41,42,49,50</sup> The Steno Type 2 Trial showed that a stepwise intensive treatment consisting of behaviour modification and pharmacological therapy is effective in reducing progression of microvascular complications in patients with T2D and microalbuminuria.<sup>50,51</sup> Other randomised trials support the use of aspirin<sup>50,52</sup> and statins for middle-aged and older patients with T2D to prevent cardiovascular disease.<sup>50,53</sup>

Type 2 diabetes is presently recognised as a major risk factor for cardiovascular disease. Therefore, programmes to prevent T2D and minimise the complications are essential. This requires a holistic approach including patient education and support for lifestyle modification (such as improved diet, increased physical activity and weight reduction), thereby improving patients' outcomes and well-being.<sup>49</sup>

The association of obesity, dietary fat intake and low levels of physical activity with increased risk of diabetes incidence was demonstrated in several observational studies.<sup>54</sup> There is substantial evidence from studies that lifestyle modification – such as weight reduction, improving dietary intake and increasing physical activity – can help prevent the development of T2D in high-risk people. These include four major controlled trials of lifestyle intervention, namely Malmö study conducted in Sweden, Da Qing study in China, the Finnish Diabetes Prevention Study, and Diabetes Prevention Program in the United States. These studies consistently found a clear benefit for diet and exercise intervention as compared with the usual care.<sup>54,55</sup>

A more recent study, the Indian Diabetes Prevention Programme, also demonstrated similar results. This was a prospective community based study that examined whether the progression to diabetes could be influenced by interventions in native Asian Indians with impaired glucose tolerance (IGT) who were younger, leaner and more insulin-resistant than the population studied in the four previous trials. The results showed that progression of IGT to diabetes is high in native Asian Indians. Both lifestyle modification and metformin significantly reduced diabetes incidence of diabetes in Asian Indians with impaired glucose tolerance; there was no added benefit from combining them. The relative risk reduction was 28.5% with lifestyle modification, 26.4% with metformin and 28.5% with lifestyle modification combined with metformin.<sup>55,56</sup>

Diabetes complications have enormous economic consequences and cause major impact on the lives of people with T2D. The findings of Type 2 Diabetes Accounting for a Major Resource Demand in Society (T2ARDIS) study demonstrated that: (1) hospitalisation of patients with diabetes-associated complications accounts for around 41% of overall expenditure as opposed to only 2% on oral antidiabetic therapy, and (2) early intervention with intensive therapy could reduce diabetes cost by decreasing the risk of diabetes vascular complications and consequently, hospitalisation.<sup>49,57</sup>

The growing incidence and burden of T2D has prompted the progression in health service strategies and national diabetes programme initiatives around the world.<sup>49</sup> In May 1989, World Health Assembly issued Resolution WHA42.36 for a global call to action on the prevention and control of diabetes. It was followed with four regional diabetes declarations in Europe, the Americas, the Western Pacific, and Africa which prepared the way for national diabetes programmes in many countries.<sup>58</sup>

The importance of patients' quality of life is increasingly realised by HCPs, thus more attention is given on disease management that is suitable to patients' lifestyles. In addition, patients today expect to be actively involved in their care, are often more health

literate, and are more active in asking questions about the advice given by the HCPs. Hence, these changes call for the close involvement of HCPs in the patients' care.<sup>49</sup>

Finally, the past two decades have witnessed the emergence of a new chronic disease paradigm and the introduction of the Chronic Care Model for improving primary care for patients with chronic conditions. For chronic conditions, including diabetes, patients themselves become the principal caregivers.<sup>10</sup> Patients have to make daily decisions about their illness, such as healthy eating, regular exercise, and taking medications as prescribed, thus self-management is inevitable. The fact that patient self-management is inevitable has introduced a new chronic disease paradigm highlighting 'the patient-physician partnership' which involves 'collaborative care' and 'self-management education'.<sup>11</sup>

The Chronic Care Model is a major rethinking of primary care practice. This is particularly because most of chronic disease care is carried out within primary care settings and primary care physicians spend most of their time treating chronic illness. However, the model does not offer a quick and easy fix, but rather 'a multidimensional solution to a complex problem'. The ultimate goal of the model is "informed, activated patients interact with prepared, proactive practice teams", creating high-quality, satisfying encounters and improved health outcomes. Many practice organisations in the United States have implemented the model at primary care level, attempting to transform primary care practice from untenable situations to more idealised worlds. Although none of the organisations has achieved full implementation of the model, many have made important strides towards the goal.<sup>59</sup>

### **2.3.2 Shifting Diabetes Care: Secondary to Primary Care**

Five to six decades ago patients with T2D were mostly treated in secondary care by hospital specialists. However, the sharp rise in the prevalence of T2D has made this secondary care not realistic anymore<sup>49</sup>. This fact was overtly expressed by Saudek (2002), as the president of the American Diabetes Association, in the following statement: "*...most diabetes care is done by primary care providers. No more than 20% of people with diabetes ever see an endocrinologist, and there are not nearly enough endocrinologists to handle the ever-increasing number of people with diabetes*" (p.65)<sup>60</sup>.

It has been argued for the past decades that diabetes is a typical disease that needs primary care providers as the coordinator of care due to its long-standing and complex nature.<sup>61,62</sup> Growing numbers of primary and community HCPs have assumed responsibility for the routine management of patients with T2D.<sup>49</sup> The shift of care from secondary to primary care in chronic disease management is in line with the trends that primary care has

become increasingly more relevant within many health care systems.<sup>63</sup> However, this shifting diabetes care seems to particularly apply in countries with established universal health coverage, such as the United Kingdom (UK) with its National Health Service (NHS).<sup>64-66</sup>

In the UK, general practitioners (GPs) have been encouraged to establish diabetes services since 1993. Changes in national policy have included specific payments for GPs offering structured diabetes care. Consequently, there has been an increase in the proportion of diabetics reviewed annually in primary care.<sup>61,67</sup> Yet, this change appears to be appreciated by the patients.<sup>61,68</sup> This shift in diabetes care can potentially create enormous demands on primary health care teams. However, there is evidence in short-term studies that structured diabetes care in primary care can be of high standard,<sup>61,69</sup> provided that primary care teams are enthusiastic and well organised.<sup>70</sup>

Diabetes has become a national health priority in the UK with the launch of National Service Framework (NSF) for diabetes standards and delivery strategy in 2001 and 2003.<sup>71</sup> Primary care thus has been increasingly recognised to provide the majority of diabetes care by the inclusion for clinical indicators for diabetes in the Quality and Outcomes Framework (QOF),<sup>72</sup> the annual reward and incentive programme detailing general practitioner practice achievement results.<sup>73</sup> Another key policy initiative which also explicitly acknowledges the provision of diabetes services in primary care is the new General Medical Services (GMS) contract.<sup>74</sup> Accordingly, recommendations for the provision of services in primary care for people with diabetes have been developed by a multidisciplinary group of experts recognised as advocates for improved care for diabetics. This document of recommendations serves as a guide for primary care teams and primary care organisations (PCO) in the UK on providing high quality care for diabetics, including meeting the quality criteria in the new GMS contract.<sup>74</sup>

Despite the evidence that primary care can be as good as hospital care, there are still many problems faced by primary care in delivering diabetes care. In a review of shifting diabetes care from secondary care to primary care, Goyder et al. found that with the increase transfer of diabetic patients, adequate resourcing in primary care should be ensured in order to provide high quality care.<sup>61,67</sup> A survey by Kunti and Ganguli disclosed large variations in delivery of diabetes services in primary care that require to be addressed by better organisation and funding.<sup>61</sup> Agarwal et al. conducted a study on the GP perspective on the problems experienced in providing good quality diabetes care. The main problems experienced included difficulty in effecting lifestyle alterations and lack of time with individual patients. The main barriers experienced by the practices included lack of time or under-funding and keeping up to date with new information or protocols.<sup>70</sup> Another survey by Buckley et al. showed that many general practices lack the essential infrastructure to deliver



comprehensive diabetes care. Without additional resources, these practices would struggle to follow the required diabetes NSF standards of care.<sup>75</sup>

Primary care in the UK therefore plays an essential role in ensuring that all people with T2D receive effective diabetes care. Presently, the majority of people with T2D are taken care solely or mainly in primary care. Meanwhile, some groups of patients are usually better managed by specialists, including diabetics with complications or complex psychological problems.<sup>72</sup> Having substantial supports of relevant national policy initiatives in the era of primary care led NHS, the provision of diabetes service in primary care in the UK – despite some remaining challenges – is undergoing its supremacy.

### 2.3.3 Diabetes Care in Indonesia

In contrast, in Indonesia, a developing country whose health service system is not primary-care oriented with no universal health coverage, the provision of diabetes care may present with very different problems. According to Starfield, countries with more highly developed primary care systems tend to have lower health care costs.<sup>76</sup> Therefore, health service reforms in many countries attempt to shift the balance from secondary to primary care.<sup>77</sup>

Currently, Indonesia does not have an integrated health care system with a referral system, thus health care services are very expensive and commercial. The government does not regulate the health care system, allowing extensive freedom for people in utilising the health care system. This results in considerable commercialisation of health care in Indonesia. Business players take advantage of this ignorance by projecting tertiary health care services as ‘primary needs’.<sup>78</sup> People who come from middle to upper socioeconomic groups are not willing to see general practitioners or go to publicly funded community health centres (CHCs); instead, they prefer seeing medical specialists or directly attending large hospitals. For many people, seeing medical specialists or sub-specialists seems as receiving ‘a prestige service’, while seeing general practitioners and attending CHCs is considered as receiving ‘a second class service’. CHCs manned by general practitioners are generally considered as health care facilities especially for people from lower socioeconomic groups or ‘second class’.<sup>79</sup> In contrast, evidence shows that health care systems dominated by secondary, tertiary and emergency care tend to be fragmented, discontinuous, uncoordinated and costly.<sup>76,77</sup>

In Indonesia, newly graduated medical doctors can directly practice as general practitioners (GPs) after passing a national competency examination for graduate medical doctors, called UKDI (*Uji Kompetensi Dokter Indonesia*) to obtain a certificate of registration

called STR (*Surat Tanda Registrasi*) from IDI (*Ikatan Dokter Indonesia*), the Indonesian Medical Association. This STR is thus used to acquire a certificate of practice permit.<sup>80,81</sup> To date, there is no requirement for postgraduate training for medical doctors who intend to practice in the community as GPs or '*dokter praktik umum*'; and there are no medical organisations providing this postgraduate primary care training. In contrast, medical specialist training through residency programmes in major government medical schools and tertiary hospitals is expensive.<sup>82</sup> The lack of additional vocational training for GPs in Indonesia and the expensive residency training for medical specialists reinforce the low public opinion of GPs and the high public regard for medical specialists and sub-specialists.

Presently, there is a complicated mixture of health insurance systems in Indonesia that vary in effectiveness and leave millions without any form of social security. The Social Security Law was enacted in 2004 in order to establish a single national health insurance system. However, the law's implementation was delayed for years due to prolonged debates on how to organise the social security system.<sup>83,84</sup>

Meanwhile, for the desperately poor in the informal sector, the government developed '*Askeskin*' (*Asuransi Kesehatan Keluarga Miskin*) programme in 2005 – a government subsidised social health insurance programme for poor families run by *Askes Inc.*, a state-owned health insurance company. The poor received a card which ensured the person who held it get free treatment at publicly funded CHCs and hospitals. These cards were issued by local government office at subdistrict level. The resulting medical claims were then covered by a combination of local taxes and central government revenues. After some protests from a number of stake holders, the *Askeskin* programme was changed into '*Jamkesmas*' (*Jaminan Kesehatan Masyarakat*) in 2008 – a government subsidised public health security programme run collaboratively by the Ministry of Health and *Askes Inc.* However, there have been problems related to the implementation of this programme, particularly in the distribution of the cards among the poor, the provision of medical treatment, and the payment of medical claims.<sup>83-85</sup>

Given the existing condition of health care services in Indonesia, the shifting diabetes care from secondary to primary care remains a challenging task. One of six 'shifting diabetes care' related myths as described by Munro et al. – "*The majority of people with diabetes are mainly supervised by secondary care*" (p.153)<sup>86</sup> – may thus still be the general fact commonly practiced in Indonesia. In its recent report on the consensus of management and prevention of T2D, *PERKENI* (*Perhimpunan Endokrinologi Indonesia*) or the Indonesian Society of Endocrinology acknowledged that the increasingly large number of people with T2D in Indonesia will place a considerable burden on secondary and tertiary care if the patients continue to be managed only by internal medicine specialists or endocrinologists.

The endocrinologists recognised the importance of GPs at the front line in primary care to manage patients with T2D with no complications. Thus, they conducted a range of training programmes and workshops for general practitioners on the management of patients with T2D in primary care.<sup>87</sup> However, the lack of regulations in the health care system potentially allow people's current health seeking behaviour in seeing health care providers of their choice to prevail. People with T2D from middle to upper socioeconomic groups prefer to see internal medicine specialists or endocrinologists directly at large hospitals or the specialists' private practices. Meanwhile, people with T2D from lower socioeconomic groups, confined by financial constraints, see GPs at publicly funded CHCs or the GPs' private practices.

Recently, *Askes Inc.* developed a programme for chronic disease management that supports the shifting balance from secondary to primary care. To date, the coverage of *Askes*, a government mandatory health insurance for civil servants, throughout the country is nearly 95 million people or 40% of the whole population. In 2010, *Askes Inc.* launched '*Prolanis*', an integrated chronic disease management programme based on self-management initiatives for its members. The *Prolanis* programme requires the active roles of both HCPs and patients. The programme places family doctors as the gate keepers in the managed care at the primary care level. The family doctor plays the role of care coordinator for the patient, including organising a referral to higher levels of care when needed. The family doctor provides comprehensive care with a particular focus on health promotion and preventive care, playing a role as a health educator promoting self-management. The family doctor monitors patients' compliance to treatment and gives attention to the patients' lifestyles. This programme is yet to be followed up with a national evaluation to assess its success, particularly on the satisfaction level of the patients and HCPs towards *Askes Inc.*<sup>88</sup> However, the *Prolanis* programme does not include the provision of structured education in chronic diseases. Additionally, although this pioneering primary care based chronic disease management programme promises to yield beneficial results in the future, its coverage is limited to government employees only.

Besides PERKENI, the other leading diabetes organisations in Indonesia include: *PERSADIA* (*Persatuan Diabetes Indonesia*) or the Indonesian Diabetes Association, and *PEDI* (*Perhimpunan Diabetes Edukator Indonesia*) or the Indonesian Diabetes Educator Association. Of these three organisations, only *PERKENI* and *PERSADIA* have organisation websites. However, these websites only highlight the organisations' activities, have limited information on T2D, and do not provide any downloadable diabetes educational materials for public use. Meanwhile, although *PEDI* has been conducting national diabetes educator training annually since 2002, it does not have any website for public access containing information and education of T2D. In 2011, *PERKENI* developed a national guideline for the

management and prevention of T2D which was a revision of the previous guidelines developed in 2006.<sup>87</sup> However, this clinical guideline is consensus-based rather than evidence-based clinical guideline.

### 2.3.4 National Diabetes Programmes (NDPs)

An overview of national diabetes programmes (NDPs) worldwide can be seen from a baseline survey conducted by the International Diabetes Federation (IDF) in 2008. This survey aimed to obtain information on the existence of, scope and status of NDPs among IDF member associations (n=202) in 190 countries. The survey achieved a 47% response rate (89 countries) with 61% of members (54 countries) reporting an NDP in their country. Europe had the highest percentage of respondents (38%), while South East Asia had the lowest (2%).<sup>58</sup> Unfortunately, Indonesia was one of the countries which did not respond to the survey. The neighbouring countries, i.e. Malaysia and Thailand, both reported having NDPs in their countries.<sup>89</sup>

Among the 54 countries with an NDP, 50 (93%) reported an official documentation of the NDP, but only 48 (89%) had government endorsement. Of the 35 countries (39%) that reported not having a NDP, 26 (74%) reported their plans for implementing and developing NDP components, while seven countries (27%) did not provide an outline of the development plans. The reported development plans include: formal diabetes training workshops for all health workers; development of a national diabetes registry; funding for diabetes research; planned improvements to access to care, self-care education, therapeutics and devices for people with diabetes and their carriers; development of national diabetes standards/ clinical guidelines; and implementation of an active screening plan for diabetes, prevention and co-morbidities.<sup>58,89</sup>

The IDF survey on NDP sought information about the NDP implementation including the involvement of stake holders, the key topics addressed and main activities conducted. The implementation of NDP was reported by 76% countries, ranging from 100% in some countries in South and Central America to no countries in South East Asia. The reported key figures actively involved in implementing the NDP included: health care workers (85%); government officials (78%); non-government/ private organisations (65%); and people with diabetes. Key topics addressed by NDPs were as follows: community awareness (85%); primary prevention (83%); screening/ early diagnosis (85%); routine clinical care and services; essential medications and supplies; secondary prevention of complications; vascular disease complications; and vascular and behavioural issues (59%). The leading NDP activities included: health worker training programmes (87%); clinical guideline

development and implementation (83%); strengthening health services/ resources, use of information systems (80%); and national diabetes registry (52%).<sup>58,89</sup>

The IDF survey also included components of patient-centred approach, national monitoring and surveillance, and evaluation of NDP. The incorporation of patient-centred approach in the NDPs included: patients were consulted about their needs (80%); focus on ensuring equal access to health care (76%); taking account of individual differences; preferences and cultural diversity (65%); and people with diabetes were represented on the committee responsible for implementing the NDP in the country (57%). Forty-five countries (83%) reported national monitoring and surveillance of the diabetes burden. Only 35% of all countries with an NDP reported NDP evaluation with main evaluation processes as follows: (1) prevalence of diabetes; (2) biochemical indicators and physical assessment (HbA1c levels and BMI); (3) diabetes patient education (knowledge of diabetes, success of self-management techniques and behaviour modification); (4) complications (referrals and treatment); (5) collaborations between health care services and diabetes associations, and (6) working national diabetes registry.<sup>58,89</sup> Despite the alarming prevalence of T2D in Indonesia, to date there is no national diabetes programme in Indonesia covering comprehensive components as described in this NDP survey.

## 2.4 CHRONIC DISEASE SELF-MANAGEMENT

### 2.4.1 Chronic Disease Care

There are key differences between acute disease and chronic disease as described by Lorig et al. in the book entitled “Living a Healthy Life with Chronic Conditions”, presented in **Appendix J**. For example, the role of health care provider (HCP), instead of ‘selecting and conducting therapy’, has become ‘teacher and partner’ for patients. Meanwhile, the role of patient, instead of ‘following orders’, has become ‘partner of HCPs and responsible for daily management’.<sup>90</sup> Understanding the inherent features of chronic disease as opposed to acute disease will help both HCPs and patients in embracing the new paradigm emerging in chronic illness care.

Unlike acute disease where the aim of treatment is to return to normal, the life of patients with chronic disease is irrevocably changed. Both the disease and its consequences are not static; in fact they progressively change and interact, creating illness patterns which demand endless and complex management. Moreover, variations in illness patterns and treatments with uncertain outcomes generate prognosis uncertainty. Understanding the different trends of illness patterns and their pace is vital to effective management. The goal is

not cure but achieving the most possible physical capability and pleasure from life, overcoming physical and emotional problems caused by the illness. In most circumstances, the patients know these trends better. Their task is to provide individual information and preferences as complements to the physicians' professional knowledge.<sup>10,90</sup> Therefore, while the physicians or other HCPs are experts about diseases, patients are indeed experts about their own lives.<sup>11</sup>

Traditional views in acute disease consider physicians or other HCPs as experts who select and conduct treatments, while patients follow orders from the physicians. In contrast, a new paradigm emerging in chronic disease views people with chronic conditions as principal caregivers and physicians should be consultants supporting the patients' caregiving role.<sup>11,90</sup> The new paradigm thus transforms the traditional patient-physician relationship into 'the patient-physician partnership' which comprises two key elements: 'collaborative care' and 'self-management education'. Collaborative care illustrates the patient-physician relationship in which both parties make health care decisions together. Self-management education emphasises patient education that incorporates a plan providing patients with problem solving skills for enhancing the patients' lives.<sup>11</sup>

## 2.4.2 Collaborative Care and Self-Management Education

An important feature of collaborative care is both physicians and patients are experts: the physicians are experts about diseases, while the patients are experts about their own lives.<sup>11</sup> Collaborative care is sometimes also called 'patient empowerment', which refers to patients accepting responsibility to manage their own conditions and are encouraged to solve their own problems with information, but not orders, from HCPs.<sup>11,91,92</sup> There are key differences between traditional and collaborative care, as described by Bodenheimer et al.<sup>11</sup> and presented in **Appendix J**.

In traditional care, compliance and adherence with instructions are the goal. These concepts are based on physician identification of problems which are mainly biomedical; and physicians may blame patients for their shortcomings. In contrast, in collaborative care, physicians accept the strength of patient-defined problems. Allowing patients to define their own problems, which are often biopsychosocial, can be eye-opening. Thus, the concepts of compliance and adherence no longer apply. While 'non-compliance' appears irrational to the physician, the patient may view it as a rational choice.<sup>11,90,93,94</sup>

The majority of physicians, predominantly trained in the acute care of hospitalised patients, may have unreasonable expectations of the extent to which patients with chronic illness can change behaviour. Patients with chronic illness have to change their behaviours

for the rest of their lives due to the progressive changes of the disease, its consequences and the trends of illness patterns. Through education about the disease, patients are expected to come to agree with their physician's description of the problem as unhealthy behaviours and set goals together regarding those behaviours, creating a true partnership. This will involve 'participatory decision making', an essential element of collaborative care.<sup>11</sup>

There are major differences between self-management education and traditional patient education, as described by Bodenheimer et al., presented in **Appendix J**. The former complements the latter in supporting patients to live with their chronic conditions with the best possible quality of life, rather than substitutes for it. While traditional patient education provides information and technical skill, self-management education teaches problem-solving skills. Self-management education is defined by two principal elements: (1) patients learn problem-solving skills, useful for identifying problems from their own perspectives and using action plans to find solutions; (2) these skills are applied to the biopsychosocial aspects of chronic illness. The goal of traditional patient education is compliance with the behaviour changes taught to the patient to improve clinical outcomes. Meanwhile, in self-management education, improving clinical outcomes is achieved through increased self-efficacy.<sup>11</sup>

According to Corbin and Strauss, people with chronic illness are faced with three tasks as follows: (1) taking care of the illness (such as changing diet, exercising, taking medication, self-monitoring of blood sugar or blood pressure, going to the doctor, and communicating the symptoms accurately); (2) continuing normal life activities (such as chores, employment, relationships with family and friends, and other social life); and (3) managing emotional changes brought about by the illness (such as anger, fear, frustration, sadness, uncertainty about the future, changed expectations and goals, and sometimes depression).<sup>11,95</sup> Therefore, people with chronic illness need to learn the following three self-management skills to become good self-managers, including: skills needed to deal with the illness, skills needed to continue the normal life, and skills needed to deal with emotions.<sup>90</sup>

The patient generated short-term action plan is another principal feature of self-management education.<sup>11</sup> The action plan should follow the SMART goal setting including: specific, measurable, achievable, realistic and having time line.<sup>96</sup> Action plans propose behaviours that patients are confident to accomplish; they should be developed by patients themselves as something they really desire to do and are not provided by physicians nor chosen from a list of options. The purpose of action plans is thus to provide confidence for fuelling internal motivation to the patients in managing their chronic illness.<sup>11</sup>

A central concept of self-management is 'self-efficacy', the confidence that a person can perform a behaviour needed to reach a desired goal.<sup>97-99</sup> In self-management training,

patients are thus asked to estimate their confidence in achieving their action plan.<sup>11</sup> Confidence is measured by asking the patients using a scale of 1 to 10, with 1 showing not at all confident and 10 totally confident.<sup>100</sup> The theory behind self-efficacy includes the view that the successful achievement of the action plan is more important than the plan itself. For example, if a physician advises a patient to do brisk walking for 20 minutes three times a week and the patient fails to do so, this will only create a sense of failure. In contrast, if a physician and a patient collaboratively agree that brisk walking is desirable and the short-term plan succeeds, the patient may propose a revised action plan to walk more.<sup>11</sup>

Collaborative care and self-management education are therefore two essential elements of the partnership paradigm that are conceptually similar but clinically separable. Both elements view patients and physicians as principal caregivers, each bringing expertise to the table. Although the emphasis has shifted towards patients as principal caregivers and experts in their own lives, physicians continue to have responsibility and must use their expertise to inform, motivate and assist patients to self-manage their illness. Application of the collaborative model across primary care is a considerable challenge because collaborative care aims to change the essence of the patient-physician relationship. On the other hand, providing self-management education is less difficult since self-management skills can be successfully taught in a 6-session course. Primary care physicians are expected to understand and support the process of self-management education. Incorporating chronic disease self-management education into primary care practice has been initiated in many Western countries. It is expected to become an integral part of high-quality primary care.<sup>11</sup>

### **2.4.3 The Chronic Care Model**

Within systems principally designed for acute care, both patients and health care professionals are not prepared in dealing with chronic care. Patients are not sufficiently taught to care for their own illness. Physicians, due to their acute care training of hospitalised patients, may have irrelevant expectations regarding the patients' behaviour changes required. Thus, caring for chronic illness frequently features uninformed passive patients interacting with unprepared health care professionals, creating frustrating, defective encounters.<sup>59</sup>

According to Bodenheimer et al. (2002), the chronic care takes place within three overlapping worlds which include: (1) the entire community, with its myriad resources and numerous public and private policies; (2) the health care system, including its payment structures; and (3) the provider organisation, whether an integrated delivery system, a small clinic, or a loose network of physician practices. Within these three worlds, the workings of



which may help or hinder optimal care, the Chronic Care Model developed by Wagner identifies six key elements required to achieve a high-quality chronic disease care within primary care: (1) community resources and policies; (2) health care organisation; (3) self-management support; (4) delivery system design; (5) decision support; and (6) clinical information systems. Improvement in its six interrelated elements is expected to result in a health care system reform providing optimal chronic care in which “informed, activated patients interact with prepared, proactive practice teams”.<sup>11,59,101,102</sup> The Chronic Care Model is presented in **Appendix J**.<sup>101</sup>

#### **2.4.4 Self-Management Support of the Chronic Care Model**

Self-management support – one element of the Chronic care Model – refers to the facilities provided by health care and social care services for enabling patients to enhance the management of their health by themselves. Various initiatives of self-management support have been conducted in many Western countries targeting both patients (most notably, chronic disease self-management education programmes) and HCPs (such as financial incentives, education and training, professional body endorsement). Chronic disease self-management education (CDSM) programmes, through formal and informal models, aim to provide patients with information and skills for enhancing their ability to participate in their health care, such as communicating with HCPs, identifying relevant information on diet, exercise, and treatment.<sup>103</sup> Therefore, self-management is increasingly recognised, not only as an essential component of chronic disease management, but also as part of secondary prevention and a way of reducing the burden of chronic illness on individuals and the community.<sup>103,104</sup>

However, self-management support initiatives at policy and programme levels, despite advancements, have tended to stay disconnected from mainstream health care system and have had inadequate coordination for effective and sustainable impact. Self-management support thus needs to be incorporated as an integral aspect of health service redesign for ensuring appropriate uptake and utilisation by key stakeholders that will improve integration. Otherwise, self-management support will only remain on the periphery of health care system.<sup>103</sup>

Patient-centred approach, with its two key elements, communication with patient and partnership, is particularly important in chronic disease care.<sup>105</sup> Enhancing patient engagement is thus paramount in chronic disease self-management support. The capacity of patients to participate highly influences the sustainability of self-management programmes and services. Patient participation is likely related to patient-specific issues, including: ability

to identify and understand health messages, access to information and services, and skills to decide what useful information is. The components necessary for patients to effectively engage with and participate in self-management include: access, knowledge, health education and empowerment, self-management, and command of health care system. A crucial element for the acquisition of self-management skills and active participation in health care is a patient's health literacy.<sup>103</sup> Health literacy refers to an individual's capacity to seek, understand and utilise basic health information and services needed to make appropriate health decisions.<sup>106</sup>

Despite encouraging developments, self-management support initiatives for patients and HCPs have greatly been separated, with no coordination and no recognition of their potential mutual reinforcement.<sup>103,107</sup> This fact is problematic, considering the important role of patient-physician relationship in enabling and supporting self-care, providing a critical juncture for information exchange, and collaborative decision making.<sup>103,104,107</sup> A study by Thorne et al. revealed that the ability of HCPs to engage in effective communication during consultations can reinforce or discourage health actions that influence the patients' capacity to live positively with chronic conditions.<sup>103,108</sup> A systematic approach is thus required to integrate components of self-management support. Initiatives focusing simultaneously on supporting patients to engage in self-management and equipping HCPs with the necessary resources to assist patients are needed. This will ensure self-management support to be effective and sustainable at the community level.<sup>103</sup>

In the uptake of self-management initiatives, there is a need for both affected parties, namely patients with chronic conditions and HCPs, to change the way they think and act in embracing the new paradigm. Patients may struggle with the behavioural changes required to successfully manage their conditions; while at the same time, they strive to deal with life uncertainties brought about by the chronic conditions and the desire to live as normal as possible. Many of them may not expect to be treated as partners by their professionals in decision making. On the other hand, HCPs may also struggle with the required role changes for helping their patients to have ability and confidence in self-managing their conditions. Providers have to deal with their patients using the biopsychosocial approach for providing self-management support including: (1) working as partners; (2) understanding the patients' coping methods and needs; (3) finding ways to help patients change their behaviours; and (4) considering the patients' family and social problems brought about by the illnesses. Generally, HCPs are reluctant to challenge their patients in ways that might upset the relationships built over many years. Thus, it is often easier for HCPs to slip into the paternalistic role of traditional advice-giving.<sup>109</sup>

Another identified crucial issue in self-management support is the socioeconomic imbalance among people accessing these services. Self-management programmes are more appealing to wealthier and better educated patients who tend to be prepared and able to find out about them. Meanwhile, patients from disadvantaged groups, who would most probably benefit from such programmes more than their wealthier peers, miss out the programmes, due to passivity, access problems, and lack of confidence and understanding about the programmes.<sup>109</sup> A lesson from the initial version of the UK Diabetes X-PERT Programme was that the programme did not reach marginalised sectors of the community, such as culturally and linguistically diverse groups.<sup>110</sup>

The setting of this research project was publicly funded community health centres (CHCs) which are the predominantly primary health care facilities in Indonesia. These centres are mostly accessed by patients from lower socioeconomic groups, and generally considered as 'second class' health centres. By conducting the programme in CHCs, rather than in hospitals, it was expected to reach people from disadvantaged groups who are likely to benefit from such programme more than their wealthier peers who usually attend hospitals.

### **2.4.5 Chronic Disease Self-management Education**

The definition of 'self-management' developed by the Centre of Advancement of Health is as follows: *"involves (the person with the chronic disease) engaging in activities that protect and promote health, monitoring and managing the symptoms and signs of illness, managing the impact of illness on functioning, emotions, and interpersonal relationship and adhering to treatment regimens."* (p.1).<sup>111</sup>

Lorig, one of the leading researchers in the area of chronic disease self-management defines 'self-management' as *"learning and practicing the skills necessary to carry on an active and emotionally satisfying life in the face of a chronic condition"* (p.11). Lorig further describes 'self-management programmes' i.e. *"allow participants to make informed choices, to adapt new perspectives and generic skills that can be applied to new problems as they arise, to practice new health behaviours, and to maintain or regain emotional stability"* (p.11). Self-management education assists participants in taking responsibility for their daily care of their illness and in learning that they can take control of their illness. The main goal of self-management education is to improve health status and lessen health care utilisation. Therefore, changes in knowledge, behaviours, or attitudes are not considered positive outcomes if they occur without concomitant changes in health status or health care utilisation.<sup>112</sup>

Self-management education comprises five core self-management skills including: problem solving, decision making, resource utilisation, helping people to form partnership with their HCPs, and taking action, such as changing behaviours with confidence. Self-management education is focused on patient concerns and problems, thus a detailed needs assessment must be carried out for each new topic and group of patients.<sup>113</sup> In self-management programmes, compliance is not generally an objective, because self-management are not prescriptive. Instead, self-management attempts to help participants to make informed choices and then carry out these choices with confidence.<sup>112</sup> Another distinguishing characteristic of self-management programmes is 'self-tailoring' or *"using self-management skills and knowledge and applying these to oneself as appropriate"* (p.3).<sup>113</sup>

There are two extensively accepted models for generic chronic disease self-management support, namely Stanford Chronic Disease Self-Management Program (CDSMP) developed by Patient Education Research Centre at Stanford University,<sup>114</sup> and The Flinders Program developed by the Flinders Human Behaviour and Health Research Unit at Flinders University.<sup>115</sup> Each model has specific strengths and weaknesses, however, both models are entirely complementary.<sup>116</sup>

The Stanford CDSMP is founded on Self-Efficacy Theory that is based on the following premises: (1) belief in one's ability to take actions is a good predictor of motivation and behaviour; (2) self-efficacy can be enhanced through mastery of skills, vicarious experiences provided by social modelling, social persuasion and goal attainment; and (3) improved self-efficacy leads to improved motivation, thinking patterns, emotional well-being and behaviour.<sup>99,102</sup> The Flinders Program is based on The Transtheoretical Model to guide the interventions of HCPs that should be characterised by: collaborative goal definition, targeting, goal setting and planning, training and support for individuals to change, and active, sustained follow up. The Transtheoretical Model identifies the following key concepts: (1) stages of behaviour change (i.e. pre-contemplation, contemplation, preparation, action and maintenance); (2) decisional balance (i.e. the benefits versus the cost of changing); and (3) self-efficacy or temptations (i.e. confidence that one can engage in health behaviours across a range of challenging situations versus temptation to engage in unhealthy behaviours).<sup>102,117</sup>

The Stanford CDSMP focuses on peer leadership and generic skill development. The Stanford CDSMP course is very structured in content and carried out in six weekly sessions in small groups (10-15 participants). Each course involves two leaders, i.e. one health professional and one peer leader. The course leaders are required to undertake a three-day training programme to deliver the course. There are several benefits of the course. Group environment reduces sense of isolation and facilitates self-efficacy and empowerment

of participants through peer learning and sharing. The course teaches strong goal-setting and problem solving focus. However, there are several limitations to the course. Not every one is suited to or responds well in a group environment. There is limited capacity in a group environment for addressing individual barriers. The course's very structured content limits flexibility for different learning needs, styles and speeds among the participants.<sup>118</sup>

Both programmes identify common tasks required to be achieved by people with chronic conditions in order to successfully manage their conditions,<sup>102</sup> as presented in **Table 2-1**.

**Table 2-1 The Stanford Chronic Disease Self-Management Program<sup>114</sup> and the Flinders Program<sup>115</sup>**

The Stanford Chronic Disease Self-Management Program	The Flinders Program
	<b>'Good self-managers' are individuals who:</b>
<ul style="list-style-type: none"> <li>• Recognising and responding to symptoms</li> </ul>	<ul style="list-style-type: none"> <li>• Have knowledge of their condition</li> </ul>
<ul style="list-style-type: none"> <li>• Using medications</li> </ul>	<ul style="list-style-type: none"> <li>• Follow a care plan agreed with their health professionals</li> </ul>
<ul style="list-style-type: none"> <li>• Managing acute episodes and emergencies</li> </ul>	<ul style="list-style-type: none"> <li>• Actively share in decision making with health professionals</li> </ul>
<ul style="list-style-type: none"> <li>• Maintaining good nutrition</li> </ul>	<ul style="list-style-type: none"> <li>• Monitor and manage signs and symptoms of their condition</li> </ul>
<ul style="list-style-type: none"> <li>• Maintaining adequate physical activity</li> </ul>	<ul style="list-style-type: none"> <li>• Manage the impact of the condition on their physical, emotional and social life</li> </ul>
<ul style="list-style-type: none"> <li>• Not smoking</li> </ul>	<ul style="list-style-type: none"> <li>• Adopt lifestyles that promote health</li> </ul>
<ul style="list-style-type: none"> <li>• Using relaxation and stress reducing technique</li> </ul>	<ul style="list-style-type: none"> <li>• Have confidence, access and the ability to use support services</li> </ul>
<ul style="list-style-type: none"> <li>• Interacting appropriately with health care providers</li> </ul>	
<ul style="list-style-type: none"> <li>• Seeking information and using community resources</li> </ul>	
<ul style="list-style-type: none"> <li>• Adapting work and other role functions</li> </ul>	
<ul style="list-style-type: none"> <li>• Communicating with significant others</li> </ul>	
<ul style="list-style-type: none"> <li>• Managing negative emotions and psychological response to illness</li> </ul>	

The Flinders Program is clinician led in a comprehensive face-to-face individual consultation and designed to be integrated with medical management. The programme utilises a number of standardised tools, i.e. *the Partners in Health Scale, Cue and Response Questionnaire, Problems and Goals, and Care Plan*. Clinicians who wish to become accredited to use the model in their practice are required to undertake a two-day training programme and submission and approval of three case studies. The Flinders Programme is very individualised and promotes a person-centred focus through emphasis on defining the person's goals rather than the clinical goals. Furthermore, the training promotes system change within an organisation to support chronic illness self-management and care. However, there are several limitations to the programme. The programme is time-consuming when implemented in the original format (using all tools). Some patients with chronic disease find the Flinders Program confronting and therefore the programme needs to be matched to where the person is in terms of readiness to change. Meanwhile, some clinicians report that

the training equips them to assess a person's self-management needs and create care plans, but does not provide the skills or tools for ongoing self-management support and facilitating behaviour change.<sup>118</sup>

Both programmes could be adapted to suit certain Indonesian health care settings and the range of patient needs. The Stanford CDSMP is more likely to suit publicly funded community health centres or hospital settings as it may be more cost-effective and realistic to be undertaken for targeting diabetic patients on a larger scale at centres with limited resources. Meanwhile, the Flinders Program is more likely to suit private hospitals and private practices of GPs, internal medical specialists, or endocrinologists. Additional time spent for individual consultations in providing detailed education can be charged with additional fees. This research project adapted the diabetes education programme conducted on a group basis, similar to the Stanford CDSMP, since the research setting of the project was CHCs. However, the education programme in the research project was performed by a clinician, i.e. the general practitioner researcher, which is similar to the Flinders Program.

## **2.5 THE ROLE OF CHRONIC DISEASE SELF-MANAGEMENT IN DIABETES EDUCATION**

### **2.5.1 Patient Education in Type 2 Diabetes**

The important role of diabetes education to support self-management programmes is outlined in a wide range of national policy initiatives in the United Kingdom, the United States and Australia, emphasising the need for patient education in T2D as an integral part of diabetes care. Recommendations, standards and guidance have been developed for establishing high quality patient education programmes for type 2 diabetes.<sup>19,103,119-122</sup>

In recent years, diabetes education has changed considerably, particularly with respect to the increased emphasis on patient-centred or collaborative approaches to care and education.<sup>31</sup> Generally, there are two models of patient education, namely the traditional medical-centred model and the model with patient-centred approach which are distinctive in terms of their underlying principles. The traditional medical-centred model involves compliance, adherence and behaviour change; while the patient-centred model emphasises on autonomy, patient participation, and empowerment. The rationale behind the patient-centred model is that patients make daily choices, such as diet, physical activity, medication, and stress management. The informed choices made by patients themselves have a much greater effect on the patients' overall health and quality of life than the decisions made by

their health care providers for them. Skelton outlines the comparison of the two patient education models,<sup>120,123</sup> as presented in **Appendix J**.

Colagiuri and Eigenmann define 'diabetes education' as *"an interactive process that facilitates and supports the individual and/ or their families, carers or significant social contacts to acquire and apply the knowledge, confidence, practical, problem solving and coping skills needed to manage their life with diabetes to achieve the best possible outcomes within their own unique circumstances"* (p.443).<sup>121</sup> The aim of patient education for people with T2D is to enhance their knowledge, skills and confidence, enabling them to take increasing control of their own condition and apply effective self-management into their daily lives. Diabetes education should have a structured, written curriculum and should be delivered by trained educators.<sup>120</sup> In a systematic review on the clinical effectiveness of education models for T2D, Lovemen et al. concludes that education delivered by a team of educator with some additional follow ups for reinforcement may provide the best opportunity for improving patient outcomes. This implicates the need for a clear programme for diabetes education, and for diabetes educators to provide time and resources to meet the needs of any structured patient education programmes.<sup>19</sup>

The National Institute for Clinical Excellence (NICE) recommends that *"structured patient education is made available to all people with diabetes at the time of initial diagnosis and then as required on an ongoing basis, based on a formal, regular assessment of need"* (p.4).<sup>119</sup> Structured education is defined as *"a planned and graded programme that is comprehensive in scope, flexible in content, responsive to an individual's clinical and psychological needs, and adaptable to his or her educational and cultural background"* (p.5).<sup>120</sup> Thus, structured education programmes for diabetes self-management are often multifaceted interventions providing information and management skills around diet, exercise, self-monitoring and medication use.<sup>19</sup>

In the National Evidence Based Guideline for Patient Education in Type 2 Diabetes, Colagiuri et al. suggests four recommendations and four practice points regarding patient education in T2D,<sup>18</sup> as presented in **Table 2-2**.

**Table 2-2 The summary of recommendations and practice points on patient education in type 2 diabetes<sup>18</sup>**

Recommendations	Practice Points
1. All people with type 2 diabetes should be referred for structured diabetes patient education (Grade A)	<ul style="list-style-type: none"> <li>Diabetes education, where possible, should be delivered by a multidisciplinary team</li> </ul>
2. Diabetes education should be delivered in groups or individually (Grade B)	<ul style="list-style-type: none"> <li>Education programs should be comprehensive and should include a component on physical activity</li> </ul>
3. Efforts to improve the cost-effectiveness of diabetes care should include patient education (Grade B)	<ul style="list-style-type: none"> <li>People with diabetes should be encouraged to actively participate in goal setting and decision making</li> </ul>

4. Diabetes education should be culturally sensitive and tailored to the needs of socio-economically disadvantaged populations (Grade B)
  - Educational interventions should be followed by regular reinforcement
- 

According to Colagiuri and Eigenmann, there are three overarching goals as the main purpose of the diabetes patient education: (1) optimal adjustment to living with diabetes; (2) optimal health (physical) outcomes (i.e. clinical outcomes); and (3) optimal cost-effectiveness (i.e. for the individual and for society). The goal of optimal adjustment to living with diabetes comprises four key outcomes which includes: (1) knowledge and understanding (i.e. knowledge, application of knowledge, problem solving skills); (2) self-management (i.e. practical skills, medication taking, physical activity, appropriate eating, risk reduction, appropriate attendance for medical care, carrying diabetes identification, hypoglycaemia management, sick day management, hospital admission for emergencies); (3) self-determination (i.e. self-efficacy, empowerment, coping skills, confidence with diabetes self-management, participation in goal setting and decision); and (4) psychological adjustment (i.e. well-being, quality of life, mental health state).<sup>121</sup>

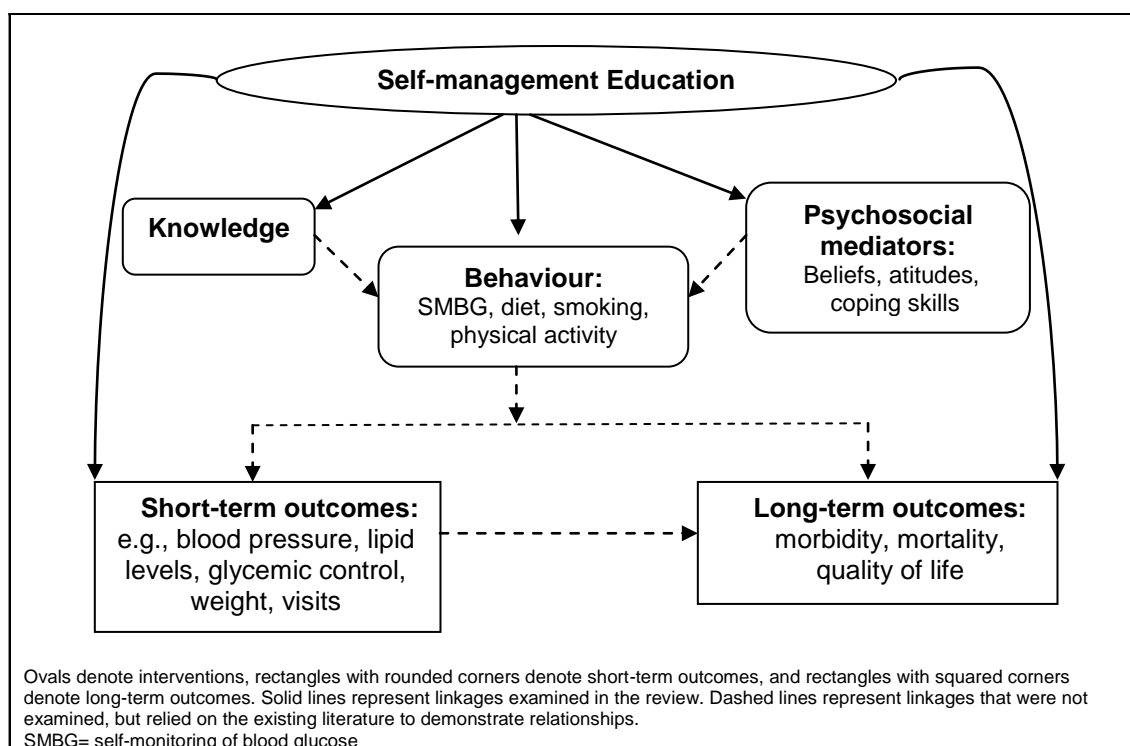
### 2.5.2 Diabetes Self-Management Education (DSME)

Self-management is widely recognised as the highlight of patient education in T2D. Diabetes Self-Management Education (DSME) has become a critical component of effective diabetes care and is required for improving patient outcomes. The findings of several reviews and meta-analysis have shown that DSME interventions result in positive impact on diabetes-related health and psychological outcomes, specifically increasing diabetes-related knowledge and improving blood glucose monitoring, dietary and exercise habits, foot care, medication taking, coping, and glycaemic control.<sup>16</sup>

Funnel et al. defines DSME as *“the ongoing process of facilitating the knowledge, skill, and ability necessary for diabetes self-care, incorporating the needs, goals, and life experiences of the person with diabetes and is guided by evidence-based standards”* (p.S89). The overall aims of DSME are to support informed decision-making, self-care behaviours, problem-solving and active collaboration with the health care team; and to enhance clinical outcomes, health status, and quality of life.<sup>122</sup>

In a systematic review on DSME interventions, Norries et al. outlined the analytic framework for DSME interventions which illustrates the relationship between the intervention, intermediate outcomes (knowledge, behaviours, psychosocial mediators), and short-term and long-term health and quality of life outcomes,<sup>124</sup> as presented in **Box 2-3**.



**Box 2-3 Analytic Framework for Diabetes Self-management Education Interventions<sup>124</sup>**

DSME has evolved from primarily didactic presentations to more theoretically based empowerment models. While there is no “best” education programme or approach, programmes incorporating behavioural and psycho-social strategies demonstrate improved outcomes. In the United States, the National Standards for Diabetes Self-management Education are designed to outline quality DSME and to help diabetes educators in various settings in providing evidence-based education,<sup>122</sup> as presented in **Appendix J**.<sup>122</sup>

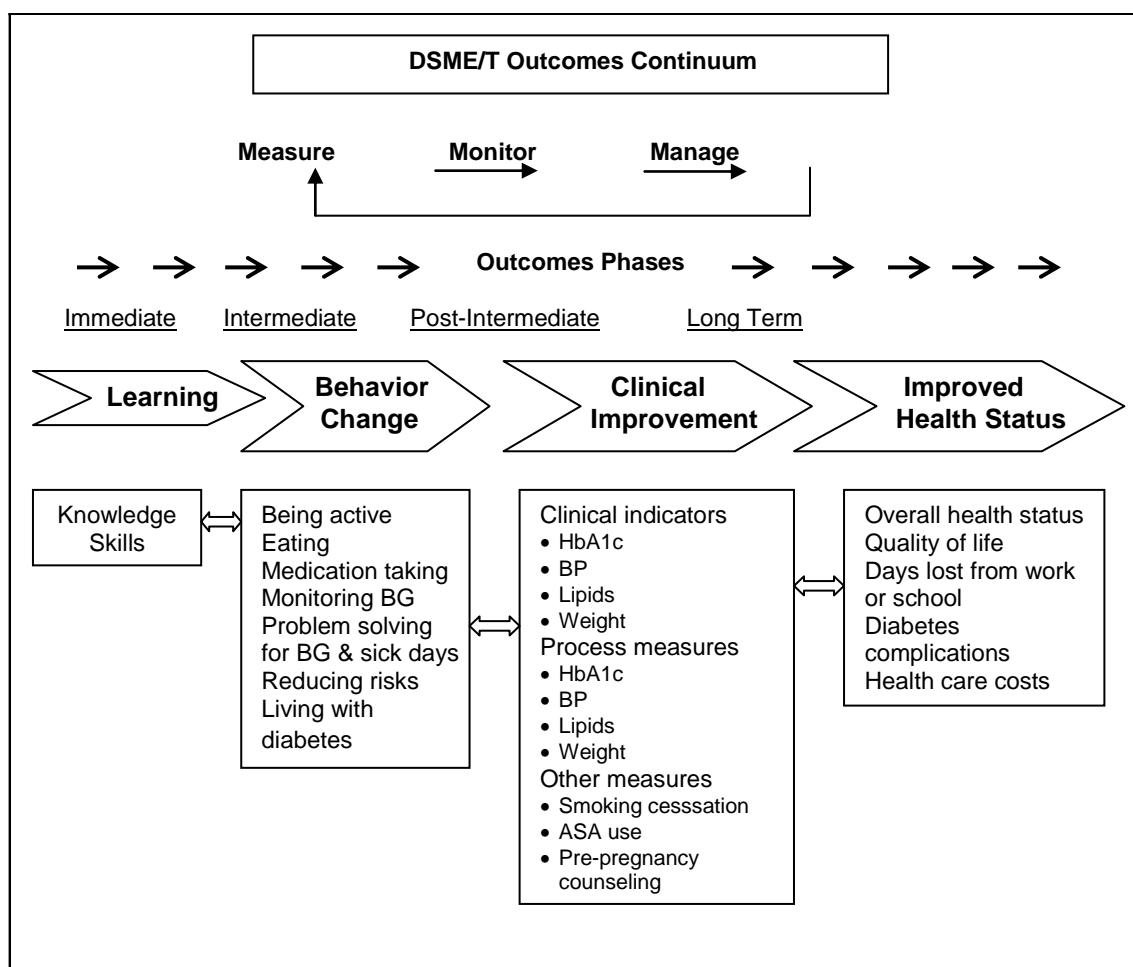
Although the evidence supports the effectiveness of DSME programmes as a whole, there is a considerable variability in programme elements – goals, outcome measures, length of intervention, frequency of sessions, learning format, and demographic background of participants – suggesting that there is no known prototype for the most favourable DSME programme. Some data support the hypothesis that group-based DSME, as compared to individual DSME, can be more cost-effective, lead to greater satisfaction with treatment, and is slightly more effective for lifestyle changes, such as diet and exercise. Additionally, the group setting can promote certain educational activities better than the individual setting, such as social modelling or problem based learning.<sup>16</sup> Another benefit of group-based approach i.e. it typically encourages greater interaction and interpersonal dynamics.<sup>125</sup> DSME programme with group-based approach is particularly appropriate in Indonesia, a developing country with a large population and limited resources, because such programme can target a larger scale of diabetic patients more cost-effectively.

Many group-based DSME programmes have been developed and conducted based on empowerment as the theoretical foundation to diabetes education and behaviour change. Tang et al. outlines the five guiding principles for empowerment-based DSME group programmes to inform the DSME programme design and implementation which include: (1) patient-centred (i.e. focus on concerns and questions introduced by patients); (2) problem based (i.e. use real problems encountered by participants to guide the teaching and learning process); (3) culturally relevant; (4) inclusive of the clinical, behavioural and psychosocial issues of living with diabetes; and (5) evidence based.<sup>16</sup>

### 2.5.3 Diabetes Self-Care Behaviours

The American Association of Diabetes Educators (AADE) has defined the AADE 7 Self-Care Behaviors™ as a framework for patient-centred diabetes self-management education and training (DSME/T) and care. The AADE suggests that measurable behaviour change is the desired outcome of diabetes education; and behaviour change can be most effectively fulfilled using this set of self-care behaviours. The AADE 7 Self-Care Behaviors™ serve both as an evidence-based framework for assessment, intervention and outcome measurement of diabetes education at the individual and population levels, and as a common framework for representing frequently used health and diabetes self-management related concepts. The seven self-care behaviours required for successful and effective diabetes care include: healthy eating, being active, monitoring, taking medication, problem solving, reducing risks, and healthy coping.<sup>126</sup> The details of the AADE 7 Self-Care Behaviors™ are presented in **Appendix J**.

The DSME/T Outcomes Continuum outlined by the AADE illustrates an iterative process of measuring, monitoring and managing outcomes phases, as presented in **Box 2-4**.<sup>127</sup> The AADE suggests that diabetes self-care behaviours should be assessed at the baseline and then at the regular intervals after the education programme. Furthermore, the outcomes continuum, including learning, behavioural, clinical, and health status, should be evaluated to show the interrelationship between DSME and behaviour change.<sup>128</sup> The Royal Australian College of General Practitioners outlined key aspects relating to the clients' ability to take on a self-management role which include: motivation, knowledge of condition, knowledge of symptom management plan, co-morbidities, health beliefs, self-efficacy, and social context,<sup>129</sup> as presented in **Appendix J**.

**Box 2-4 Diabetes Self-management Education/ Training Outcomes Continuum<sup>127</sup>****2.5.4 Underlying Philosophy and Theories for DSME**

The philosophy of patient empowerment has become an integral component of diabetes education practice.<sup>130</sup> Funnel et al. define ‘the process of empowerment’ as “*the discovery and development of one’s inherent capacity to be responsible for one’s own life*” (p.38).<sup>25</sup> Patient empowerment is a process designed to facilitate patients with T2D choose personally meaningful, realistic goals of self-directed behaviour changes related to diet, exercise and weight loss. This philosophy is particularly appropriate in T2D because the behaviour changes recommended generally involve various aspects deeply embedded in the patients’ daily lives. Thus, by becoming internally motivated (e.g. “Glycaemic control is really important to me”), rather than externally motivated by the health care providers (e.g. “My doctor wants me to have good glycaemic control”), the patients will maximize their chance for success.<sup>130</sup>

Several health behaviour and health education theories provide theoretical frameworks for the concepts of diabetes self-management and patient empowerment, including: (1) Self-Determination Theory<sup>131</sup>; (2) Self-Regulation Theory<sup>132</sup>; (3) Health Belief Model<sup>133</sup>; (4) The Transtheoretical Model<sup>134</sup>; and (5) Social Learning Theory.<sup>98</sup> These theories provide insights into the concepts in diabetes self-management education, as well as practical strategies to achieve the outcomes.<sup>102,129,135</sup>

The key to empowerment philosophy in DSME interventions is “informed choice” that is based on a humanistic view of the individual.<sup>135</sup> The empowerment philosophy emphasises a collaborative approach for facilitating the self-directed behaviour change of patients. Interventions using the empowerment philosophy have been based on Self-Determination Theory.<sup>31</sup> Self-Determination Theory posits that a person is more likely to be motivated to develop skills and capacity to self-regulate the behaviours required to function effectively if the person views those behaviours as personally meaningful. This refers to ‘autonomous motivation’, doing things for intrinsic reasons or for oneself, as opposed to ‘controlled motivation’, doing things for extrinsic reasons, including a provider pressure or pressure to satisfy a provider.<sup>31,102,131,135</sup> Autonomous motivation is predictive of successful self-care, glycaemic control, and weight loss.<sup>135-137</sup>

Empirical studies demonstrate a clear relationship between empowerment aspects and self-care behaviours. According to Skinner and Cradock, there are five key features of empowering consultations in the context of diabetes care which includes: (1) acceptance or unconditional positive regard, i.e. the respect that providers must have for a diabetic patient; (2) affect, i.e. the emotional aspect of an empowering consultation; (3) autonomy, i.e. the involvement and participation of a diabetic patient in the consultation; (4) alliance, i.e. providers should be working together with the diabetic patients; and (5) active participation of everyone in the consultation.<sup>138</sup>

DSME interventions have been developed using theoretical framework of autonomy support. Funnel et al. (2007) defines ‘autonomy support’ in the context of DSME as *“the degree to which health care providers and social support sources understand the patients’ diabetes-related priorities and needs, acknowledge patients’ feelings, provide meaningful self-management choices, offer relevant information, and avoid controlling patients’ behaviour”* (p.222). Evidence has shown that diabetic patients whose providers support autonomy motivation become more internally motivated to control their blood glucose levels, feel more competent at glucose monitoring, and demonstrate improved HbA1c levels.<sup>31,139</sup>

Self-Regulation Theory in the context of diabetes education describes individuals' illness representation or personal model of diabetes as a main determinant of their behavioural and emotional responses to the illness. This theory identifies five core elements that form illness representations across cultures, including: (1) identity (What is diabetes? What symptoms are experienced? What is actually wrong?); (2) cause (What caused my diabetes?); (3) timeline (How long will it last?); (4) consequences (How will diabetes affect me now and in the future?); and (5) treatment effectiveness (How good is my treatment at controlling or curing my diabetes?).<sup>132,135,140</sup> Research has shown that people with diabetes hold a various set of illness beliefs that do not suit the medical view of diabetes. These beliefs are strong and primary determinants of patients' emotional well-being and self-care behaviour.<sup>135,141</sup>

Within the Health Belief Model, individuals weigh up several personal beliefs or perceptions when deciding on their ability to carry out a behaviour. These considerations include: (1) perceived severity, i.e. perception of the seriousness of the illness; (2) perceived susceptibility, i.e. evaluation regarding the risk or vulnerability to a health threat; (3) perceived benefits, i.e. usefulness of the action taken to eliminate the threat of illness; and (4) perceived barriers, i.e. assessment of things that may prevent practising the proposed behaviour. The individuals' perceived threat or the expectation of outcome of changing a behaviour relates directly to individuals' self-efficacy – their perceived ability to carry out the action.<sup>129,133,142</sup>

The Transtheoretical Model identifies five basic stages of change that are a sequential, ongoing process, in order to adopt and maintain behaviour. These stages include: (1) pre-contemplation (not thinking of change); (2) contemplation (thinking of change); (3) preparation/ determination (ready for change); (4) action (changing behaviour); and (5) maintenance (maintaining change). The model suggests that appropriate strategies are required for each stage of change; otherwise the strategies may be counterproductive. Given the various diabetes self-care behaviours required to adopt, recognising that individuals may be at different stages of readiness for each one is essential.<sup>102,134</sup> An individual's motivation level or readiness to change may differ during the change process, creating relapse or repetition of a stage. However, these relapses must not be viewed as negative events, because experiences and skills are gained during a repetition of a stage that help the individual move onto the next stage.<sup>129,143</sup>

Bandura's Social Learning Theory, relabelled Social Cognitive Theory holds that behaviour is determined by expectancies and incentives, including: (1) situation-outcome expectancies; (2) action-outcome expectancies; (3) efficacy expectation, i.e. self-efficacy; and (4) incentive or reinforcement. 'Situation-outcome expectancies' are related to the belief

that some consequences are determined by the environment, separated from personal control. 'Action-outcome expectancies' are based on the perception that one's actions are influential to a particular outcome. 'Self-efficacy' refers to confidence in one's own ability to perform a particular behaviour. 'Incentive' or reinforcement refers to the value of a particular object or outcome. The outcome may include health status, physical appearance, approval of others, economic gain. This theory thus predicts that behaviours are carried out if an individual perceives control over the outcomes, few external barriers, and confidence in one's own ability.<sup>98,133,144</sup> Considerable research has examined self-efficacy engaged in various behavioural challenges, including preventive and disease management behaviours.<sup>30</sup> Evidence has shown that self-efficacy is one of the most consistent predictors of successful self-care behaviours. Self-efficacy has been incorporated into most health psychology models.<sup>135,145</sup>

### 2.5.5 Patient Empowerment in the Self-Management of Diabetes

In the traditional approach of diabetes care, the success of patients to manage their diabetes has been judged by 'compliance' and 'adherence' to prescribed therapeutic regimens. Attempts have been devoted to develop assessments for compliance, and strategies for promoting adherence. Within the traditional medical model designed to treat acute health problems, HCPs are viewed to know best, and efforts are made to encourage patients to follow the recommendations of the HCPs. Patient education is generally prescriptive (e.g. "Do as I say!"), and therapeutic goals are determined by HCPs. This approach views that patients have to follow the guidance of their HCPs; and that the benefits of compliance outweigh the impact of HCPs' advice on the patients' quality of life. Education is designed to promote compliance or adherence using motivational and behavioural strategies for behaviour change.<sup>94,146</sup>

However, this traditional approach does not suit the reality of diabetes care. The serious and long-standing nature of diabetes, the complex management and the multiple daily self-care decisions required implies that adherence to a predetermined care plan is basically insufficient over the course of a patients' life with diabetes. Considerable evidence indicates that the traditional medical model underlining compliance is not effective in diabetes care. Another approach is thus needed in diabetes care and education.<sup>93,94,146</sup>

Anderson and Funnel, two of the leading researchers in the area of diabetes education, self-management, and patient empowerment, have promoted an empowerment approach to diabetes education and care for more than two decades.<sup>25,91,147</sup> The idea to adopt the empowerment approach is based on three essential aspects of chronic illness,

namely 'choices', 'control' and 'consequences'. Firstly, the daily choices that patients make for their diabetes care have a greater impact on the outcomes than those made by their providers. Patients are responsible of their self-care behaviours. Secondly, once patients leave the patient-physician encounter, they are in control, whether or not, to implement the providers' recommendations. Thirdly, the consequences of the patients' decisions naturally accrue to themselves directly; the patients thus have both the right and responsibility to manage diabetes in the way most suitable to their lifestyles and culture. Therefore, empowerment is a patient-centred, collaborative approach that accommodates the essential realities of diabetes care.<sup>93,146</sup>

Patient empowerment approach is in line with the new chronic disease paradigm highlighting the patient-professional partnership that views both HCPs and patients as experts. The HCPs are experts on chronic disease care including diabetes, while the patients are the experts on their own lives.<sup>11</sup> This approach recognises that knowing about the disease does not automatically include knowing about the patient's life. Empowerment is not a technique or strategy, but rather a vision of HCPs that guides each encounter with their patients. This approach requires both professionals and patients adopt new roles. The role of professionals is to assist patients make informed choices in achieving their goals in disease management, and overcome barriers through education, appropriate care recommendations, expert advice, and support.<sup>146</sup> By embracing this philosophy, HCPs need to give up feeling responsible 'for' their patients, instead become responsible 'to' them. This way, diabetes care thus becomes a collaboration between two equal parties: HCPs bring knowledge and expertise in diabetes care, while patients bring expertise on their lives and what will work for them.<sup>93,146</sup> For effective implementation of empowerment approach, patients need education designed to promote informed decision-making, while providers need to practice in ways that support patients efforts to become effective self-managers.<sup>146</sup>

Anderson and Funnel suggest that patient empowerment is both a process and an outcome in diabetes education. Empowerment is a process whereby an educational intervention aims to increase the patient's ability to think critically and act autonomously. When an enhanced sense of diabetes self-efficacy occurs as a result of the process, empowerment is then an outcome. Empowerment begins when the providers acknowledge that patients with T2D are in control of their daily diabetes care.<sup>130</sup>

The goal of patient education within the empowerment philosophy is to assist patients make decisions about their care and obtain clarity about their goals, values and motivations. It seeks to maximise the self-care knowledge, skills, self-awareness, and sense of personal autonomy of patients with T2D for enabling them to take charge of their diabetes care. Patient needs to learn about diabetes and its biopsychosocial impact on their lives.

They also need to learn information about various treatment options including the benefits and costs, how to make changes in their behaviours, and how to solve problems. Moreover, they need to understand their critical role in decision making and how to assume responsibility for their own diabetes care.<sup>91,146,147</sup>

Patient education within the empowerment philosophy incorporates interactive teaching strategies designed to involve patients in problem solving, and a more comprehensive and person-centred approach addressing their psychosocial and cultural needs. Patients’ experiences are used as the curriculum to individualise group educational programmes and ensure that the content provided is relevant for the needs of the group.<sup>146</sup> Anderson and Funnel compare and contrast the essential assumptions underlying the traditional model and empowering educational model,<sup>148</sup> as presented in **Table 2-3**.

**Table 2-3 Comparison of traditional and empowering educational models<sup>148</sup>**

Traditional Educational Model	Empowering Educational Model
1. Diabetes is a physical illness	1. Diabetes is a biopsychosocial illness
2. Relationship of provider and patient is authoritarian based on provider expertise	2. Relationship of provider and patient is democratic based on shared expertise
3. Problems and learning needs are usually identified by professional	3. Problems and learning needs are usually identified by patient
4. Professional is viewed as problem solver and caregiver, i.e. professional is responsible for diagnosis and outcome	4. Patient is viewed as problem solver and caregiver, i.e. professional acts as a resource and helps the patient set goals and develop a self-management plan
5. Goal is behaviour change. Behavioural strategies are used to increase compliance with recommended treatments. A lack of compliance is viewed as a failure of patient and provider	5. Goal is to enable patients to make informed choices. Behavioural strategies are used to help patients experiment with behaviour changes of their choosing. Behaviour changes that are not adopted are viewed as learning tools to provide new information that can be used to develop future plans and goals
6. Behaviour changes are externally motivated	6. Behaviour changes are internally motivated
7. Patient is powerless, professional is powerful	7. Patient and professionals are powerful

Anderson and Funnel integrated the key concepts of empowerment into the design of their educational programmes emphasising on the whole person and personal strengths, as presented in **Appendix K**. The problem solving process conducted in empowerment-based DSME group programmes follows the five-step empowerment model using the Behaviour Change Protocol, as presented in **Appendix K**.<sup>148</sup>

Health care providers are also expected to redesign their interactions with patients and practices to better support their patients’ self-management efforts. The first important step is that HCPs and their team need to define their shared vision of diabetes care and education. The vision can be expressed in each encounter and communication with patients and in the relationships created. The vision and the new collaborative roles need to be communicated, particularly in starting out an interaction with a new patient.<sup>146</sup>



According to Funnel and Anderson, there are strategies that can be used by HCPs and strategies that can be implemented within a practice to promote patient empowerment. The most important thing is that HCPs need to listen to their patients and ask what they need to obtain from the interactions with HCPs for managing their diabetes better.<sup>146</sup> In the Diabetes Attitudes Wishes and Needs (DAWN) study, diabetic patients have identified that they have many concerns and issues about living with their illness that are seldom addressed by their HCPs.<sup>146,149</sup> Providers need to spend more time listening and less time offering advice to their patients.<sup>146,150</sup> During interactions, HCPs need to ask questions and use active listening techniques, thereby can help their patients to reflect on issues or problems they are facing, thus lead to identification of effective problem solving strategies to which patients are willing to commit.<sup>146</sup> Providers must develop and practise listening and communication skills to support the effective management of the psychosocial needs of people with diabetes.<sup>151</sup>

Furthermore, HCPs need to become more patient-centred and collaborative, hence will improve patient outcomes and satisfaction with their care. Providers also need to show that they care about their patients as individuals first and about their diabetes second, providing a personal care. There are also system-specific strategies for promoting patient empowerment and diabetes self-management that can be implemented by a practice. They are most readily achieved through a team approach to diabetes care. Funnel and Anderson outlined strategies for promoting patient empowerment that can be used by HCPs and implemented within a practice,<sup>146</sup> as summarised and presented in **Appendix K**.

### **2.5.6 Diabetes Self-Management Support for Patient Empowerment**

DSME programmes that have become more patient-centred and theoretically based usually have short-term interventions with or without some degree of follow-up. This approach can be favourable for the initial acquisition of basic diabetes self-management skills. However, for effective diabetes management over a life time, ongoing support programmes are needed to sustain the self-management gains made by patients as a result of diabetes education. These programmes need to reflect the dynamic and evolving conditions of the patients' 'real world' environment and life circumstances. The most important thing is that this support structure should be equally accessible to all patients regardless of economic, social and environmental circumstances.<sup>31</sup>

One example of an ongoing DSME support is the Lifelong Management (LM) programme. LM programme is an extension of a previously short term problem-based DSME programme. It is a community-based, patient centred, long-term self-management

intervention that was found to be feasible for and culturally acceptable to African-American adults with T2D living in the greater Detroit area. A prerequisite for the programme is a basic level of diabetes education, either from a patient education course or individual education with diabetes-specialty health care professionals within the past three years. The LM pilot programme comprised 24 weekly sessions conducted over a period of 6 months. Each session lasted for 90 minutes and facilitated by a two-person team consisting of a certified diabetes educator and a clinical psychologist. Patient-identified interests, concerns, and experiences guided the direction and flow of each session. Patients were encouraged to attend sessions as frequently as needed depending on their life situations and circumstances. Sessions were held in the mornings and afternoons at different locations throughout the community to accommodate varying patients' schedules. Patients received compiled educational materials called the Lifelong Management Guidebook at the outset of the program. The guidebook consisted of seven sections reflecting the DSME major components including: eating and diet; taking medications; exercise; monitoring glucose; problem solving for glucose management; reducing risks; and living with diabetes.<sup>16,31</sup>

The LM sessions were generally structured with five components including: reflecting on relevant experiences; discussing the role of emotion; engaging in a systematic problem solving; answering clinical questions; and providing feedback. To help trigger group discussions about diabetes-related experiences, major self-management areas were outlined on a poster board. The empowerment model was used throughout the LM sessions, as presented in **Appendix K**. Helpful hints for diabetes educators for facilitating empowerment-based DSMS programmes are listed in **Appendix K**.<sup>16,31</sup>

The LM programme was piloted with 65 African-American patients with T2D. Given that patients were encouraged to attend sessions as needed, an average attendance of 10-15 participants per morning or afternoon session was anticipated. The results indicated that the expected weekly attendance for the morning group was exceeded (average 16, range 10-27), and the expectations for afternoon group were met (average 8, range 2-18). Analysis using paired *t*-tests of pre-post intervention data demonstrated significant improvements in BMI and total, HDL, and LDL cholesterol levels. There was improvement of mean HbA1c from 7.5% at baseline to 7.1% at follow-up, but the difference was not statistically significant. Significant improvements were also shown in daily self-care behaviours practised per week, including following a healthy diet, spacing carbohydrate consumption evenly throughout the day, exercising, examining feet, and monitoring blood glucose. Furthermore, psychosocial measures indicated a higher perceived quality of life, less difficulty in engaging in routine physical activity, and less difficulty in using a meal plan. This type of programme could provide a useful ongoing support for patients with T2D within a community. The LM study led

to the development of the Diabetes Lifetime Support Program providing weekly support held at community centres or churches for African Americans with T2D for the following three years.<sup>16,31</sup>

## 2.6 MODELS OF STRUCTURED PATIENT EDUCATION IN TYPE 2 DIABETES

### 2.6.1 The Diabetes X-PERT Programme

The Diabetes X-PERT Programme is a patient-centred, group-based self-management education designed by a diabetes research dietician taking on the role as a diabetes educator, in conjunction with patients and the local branch of Diabetes UK. The theoretical frameworks underpinning the programme are ‘patient empowerment’ – helping people discover and use their innate ability to gain mastery over their diabetes, and ‘discovery learning’ – the learner is a problem solver who uses tools and information to gain knowledge through discovery. The programme consists of six weekly two-hour sessions delivered by one diabetes educator and held in community venues. The number of participants in each programme is between 15 and 18; all are encouraged to attend the programme with a partner, either a family member or a friend. The programme aims to enhance knowledge, skills and confidence, enabling patients to make informed decisions regarding their diabetes self-care.<sup>152,153</sup> The content of the X-PERT programme<sup>153</sup> is presented in **Table 2-4**.

Deakin et al. conducted an RCT evaluating the effectiveness of the Diabetes X-PERT Programme on clinical, lifestyle and psychosocial outcomes involving 314 participants in ten programmes delivered at community venues. The intervention group received the Diabetes X-PERT Programme. The control group received individual appointments from GPs, practice nurses and dieticians, in addition to routine treatment. Outcomes were assessed at baseline, 4 and 14 months. Participation in the Diabetes X-PERT programme was shown at 14 months to have led to significant improvements in glycaemic control, total cholesterol level, body weight, BMI and waist circumference, requirement for diabetes medication, fruit and vegetables consumption, enjoyment of food, diabetes knowledge, self-empowerment, self-management skills and treatment satisfaction.<sup>152,153</sup> Deakin suggests that people with T2D who have participated in the X-PERT programme have become ‘the experts in diabetes self-management’.<sup>152</sup> The intervention in this research project adapted the intervention in the Diabetes X-PERT Programme with some modifications due to the needs of local patients, and time and resource constraints.

**Table 2-4 Content of the X-PERT Programme<sup>153</sup>**

Topic	Description
Week 1: What is Diabetes?	<ul style="list-style-type: none"> <li>• Explore what happens to food when we eat it; self-monitoring of diabetes; diabetes treatments; feelings about living with diabetes.</li> <li>• Dispel myths by using visual educational materials</li> </ul>
Week 2: Weight Management	<ul style="list-style-type: none"> <li>• Examine the 'balanced of good health' model and use food models to distinguish between food containing protein, fat and carbohydrate.</li> <li>• Inform about sensible eating whilst exploring barriers in doing so.</li> <li>• Advise about the benefits of exercise and give practical examples including information about local exercise-on-prescription schemes</li> </ul>
Week 3: Carbohydrates Awareness	<ul style="list-style-type: none"> <li>• Perform a group task, developed to show the effect of quantity and quality of carbohydrate food on blood glucose levels.</li> <li>• Use ping-pong ball models and laminated food pictures to dispel myths surrounding glucose, sucrose and starch</li> </ul>
Week 4: Supermarket Tour	<ul style="list-style-type: none"> <li>• Address some common confusion surrounding dietary fat, sugar and food labelling.</li> <li>• Encourage a diet that is enjoyable, variable and balance whilst dispelling the concept of 'good' and 'bad' foods.</li> </ul>
Week 5: Complication & Prevention	<ul style="list-style-type: none"> <li>• Discuss how to reduce the risk of developing longer-term complications through lifestyle changes, treatment and regular monitoring.</li> <li>• Use visual educational aids to explore medical conditions in layman terms such as nephropathy, retinopathy, arteriosclerosis, neuropathy and blood pressure.</li> </ul>
Week 6: Evaluation & Question Time	<ul style="list-style-type: none"> <li>• Play "Living with Diabetes", a board game to bring the X-PERT programme to a close in a relaxed manner, reinforcing the main messages whilst encouraging participants to reflect on how much they have learnt.</li> </ul>
Goal Setting: Last 20 minutes each week	<ul style="list-style-type: none"> <li>• The final 20-30 minutes each week involves the goal setting component of the empowerment model.</li> <li>• Participants obtain and examine their health results, the implications of them and acceptable ranges.</li> <li>• If participants make an informed decision to work on improving any of their health results, they work through the five step empowerment model</li> <li>• Psychosocial aspects of diabetes, i.e. fitting diabetes into life rather than fitting life into living with diabetes.</li> <li>• An important aspect of the empowerment model is to respect the decisions made by some of the participants not to goal-set</li> </ul>
Patient Manual	<ul style="list-style-type: none"> <li>• Resource manual given to participants at the beginning of the course. Background reading, health results and goal setting material added each week as appropriate</li> </ul>

## 2.6.2 The DESMOND Structured Group Education Programme

DESMOND stands for "Diabetes Education and Self-Management for Ongoing and Newly Diagnosed". DESMOND is a programme of patient education modules and related educator training for people with T2D which have been developed by a collaborative of NHS organisations in the UK and have a coordinating centre hosted by University Hospitals of Leicester NHS Trust. The programme is mainly delivered in primary care, as a part of the services offered by local primary care trusts and also run by specialist diabetes services in hospitals and diabetes centres in some areas. The modules have been designed to meet the standards outlined in national policies, such as the Diabetes NSF and the NICE Guideline on Type 2 Diabetes.<sup>154,155</sup>

The DESMOND programme is a six-hour group education delivered either one day or two half day equivalents and facilitated by two educators, i.e. mainly practice nurses,

diabetes specialist nurses or dieticians. DESMOND educators have been formally trained to deliver the programme and supported by an ongoing quality assurance and professional development programme. DESMOND programme is founded on patient empowerment philosophy and based on several psychological theories of learning, including: (1) Leventhal's Common Sense Theory; (2) Dual Process Theory; and (3) Social Cognitive Theory.<sup>155-157</sup>

The DESMOND programme is presently conducted in the community to a maximum of 10 people newly diagnosed with T2D who are accompanied by a partner, either a family member or a friend, with a maximum total number 20. Most of the curriculum focuses on lifestyle aspects, such as food choices, physical activity and cardiovascular risk factors. The programme motivates participants to consider their own personal risk factors and choose a specific, achievable goal of behaviour change to work on, based on self-efficacy theory.<sup>155,157</sup> Currently, there are four DESMOND education modules, including: (1) DESMOND Newly Diagnosed; (2) DESMOND Foundation (for those who have established diabetes); (3) DESMOND BME (course delivered in Gujarati, Punjabi, Urdu and Bengali); and (4) DESMOND Walking Away from Diabetes (for those at high risk of developing T2D).<sup>158</sup> The DESMOND programme is intended as the first step in an ongoing cycle of diabetes care, integrating education with clinical management.<sup>157</sup>

Davies et al. (2008) evaluated the effectiveness of a DESMOND programme on biomedical, psychosocial, and lifestyle measures in people with newly diagnosed T2D using a multicentre cluster RCT design in 207 general practices in 13 primary care sites in the U.K. The study recruited 824 participants, consisting of 55% men with mean age 59.5 years. The intervention was a structured group education programme for six hours delivered in the community by two trained HCP educators compared to usual care. Main outcome measures included HbA1c, blood pressure, weight, blood lipid levels, smoking status, physical activity, quality of life, beliefs about illness, depression, and emotional impact of diabetes. The outcome measures were collected at baseline and at 4, 8, and 12 months. The structured group education programme with newly diagnosed T2D resulted in greater improvements in weight loss, smoking cessation and positive improvements in beliefs about illness but no difference in HbA1c up to 12 months after diagnosis.<sup>156,157</sup> Most of the changes were sustained over 12 months without further reinforcement.<sup>157</sup>

## 2.7 SUMMARY

In summary, this literature review provides insights and concepts for designing a pilot model of group-based structured diabetes education programme incorporating diabetes

self-management and patient empowerment concepts for this research project in order to be introduced into the health care service in Indonesia. The setting of this research project was publicly funded community health centres, the predominantly primary health care facilities in Indonesia. These centres are mostly accessed by patients from lower socioeconomic groups, and generally considered as 'second class' health centres. By conducting the programme in community health centres, rather than in hospitals, it was expected to reach people from disadvantaged groups who are likely to benefit from such programme more than their wealthier peers who usually attend hospitals. Additionally, conducting the programme in group basis could target a larger scale of diabetic patients more cost-effectively.

This chapter has outlined descriptions about type 2 diabetes, diabetes care and national programmes, chronic disease self-management, the role of chronic disease self-management in diabetes education, and models of structured patient education in type 2 diabetes. The next chapter, Chapter 3, will discuss the country setting of the research.

# **CHAPTER 3 – Country Setting: Geography, Population, Government, and Health Care System of Indonesia**

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**A Structured Diabetes Education Programme  
in Indonesia**

### 3.1. INTRODUCTION

Chapter three provides a brief description of the country setting, i.e. geography, population, and health system in Indonesia, in order to present a thorough illustration of the study as a whole.

### 3.2. GEOGRAPHY AND POPULATION OF INDONESIA

Indonesia, officially named as Republic of Indonesia, is located in South-East Asia, between the Indian Ocean and Pacific Ocean, and between Asia and Australia. Its bordering countries are Malaysia, Papua New Guinea and Timor Leste. It is the world's largest archipelago nation with more than 17,000 islands; however only 6,000 are inhabited.<sup>8,159</sup> The five main islands of Indonesia are Papua or Irian Jaya, Borneo or Kalimantan, Sumatera, Sulawesi and Java. Java Island is the smallest among the five main islands, with only 6.77 percent of the whole area of Indonesia. However, it is the most populated island, having 58.1 percent of the national population in 2008.<sup>8</sup> The map of Indonesia is presented in **Figure 3-1**.

Figure 1-1 Map of Indonesia



Source: [http://www.streetdirectory.com/img/indonesia/mappage/indonesia\\_lvl1.gif](http://www.streetdirectory.com/img/indonesia/mappage/indonesia_lvl1.gif)

Indonesia is a country with a large population and diversity, not only in geography but also in culture. According to Population Reference Bureau, Indonesia has the fourth



largest population in the world after China, India and the United States, with an estimated 238.2 million people in mid-2011.<sup>5</sup> It has more than 300 native ethnicities. The Javanese ethnic group is the largest, contributing nearly 42 percent of the whole population. While the majority of Javanese people live on Java Island, millions have migrated to all of parts of the archipelago. The next largest ethnic groups are Sundanese, Malay, and Maduranese respectively. While the national language is Indonesian language or *Bahasa Indonesia*, there are approximately 742 different local languages and dialects, with the most widely spoken is Javanese.<sup>160</sup>

Indonesia has 33 provinces, including five special regions namely Special Capital Territory of Jakarta, Special Administrative Region of Aceh, Special Administrative Region of Yogyakarta, Special Autonomy Region of Papua, and Special Autonomy Region of West Papua.<sup>8</sup> The research project was carried out in Yogyakarta Province. Yogyakarta was granted the special region status, i.e. *Daerah Istimewa Yogyakarta (DIY)*, to recognise its paramount role in supporting the Indonesian Republicans during the Indonesia Revolution in 1940's. Located on Java, Yogyakarta is the smallest province in Indonesia (excluding the capital Jakarta). It is the only province that is still governed by a pre-colonial monarchy, the Sultan of Yogyakarta, serving as the hereditary governor of the province. Yogyakarta City is the capital of the province.<sup>161</sup>

Each province is subdivided into districts, i.e. regencies (*kabupaten*) and cities (*kota*). Each district is further subdivided into sub-districts (*kecamatan*), and each sub-district into villages (either *desa* or *kelurahan*). Based on the Indonesia's Health Profile 2008, there are a total of 495 districts comprising 399 regencies and 96 cities, whilst there are 6,579 sub-districts and 76,546 villages in Indonesia.<sup>8</sup>

### 3.3. STATISTICS OF INDONESIA

Indonesia is a developing nation and emerged as a lower-middle-income country with a nominal gross national income (GNI) per capita of US\$ 1,650 at US\$ 3,580 purchasing power parity (PPP) in 2007.<sup>160</sup> Data from the World Bank shows that the proportion of population living below US\$ 2 per day is 49 percent.<sup>162</sup> The proportion of the population living in poverty dropped considerably over the past four decades from 60 percent in 1970 to approximately 16.6 percent in 2007.<sup>163</sup>

Data from the World Bank indicates that spending on health is relatively low in Indonesia. The World Bank estimations show that Indonesia spends less than 3 percent of GDP on health; with public spending is less than 1 percent. This figure is below the average of other countries in the East Asia and Pacific region (6.1 percent) and the lower-middle-

income group of countries (5.9 percent). Neighbouring countries such as Philippines, Malaysia, and Vietnam spend higher percent of GDP on health and have better health outcomes. The health structure in Indonesia is also relatively less developed than its neighbours in the region. Many public health care facilities reportedly endure weak infrastructure and a lack of equipment. The health care system also suffers from a lack of doctors, nurses, and midwives, especially in rural and remote areas.<sup>4,160</sup>

The provision of health services in Indonesia continues to face challenges in the geographical distribution and quality of the health workforce. Indonesia has one of the lowest physician densities in Asia: 13 doctors per 100, 000 people, considerably lower in remote areas. Low physician coverage is exacerbated by high levels of absenteeism in community health centres. During official public working hours, up to 40 percent of doctors have been found not attending their posts without valid reasons. Meanwhile, nurses in Indonesia are numerous and well distributed. However, they are poorly qualified and not permitted to provide the required care. Indonesia has a large number of midwives due to the previous policy of placing midwives in every village (*Program Bidan Desa*). However, their distribution is also uneven. Moreover, midwives assigned to remote areas tend to be less experienced and manage fewer births, thus making it difficult for them to maintain and develop their professional midwifery skills.<sup>4</sup> Regional comparison of health performance indicators among Asian countries is presented in **Table 3-1**. Data is extracted from WHO in 2006, unless noted.<sup>160</sup>

A changing environment poses challenges for Indonesia's health system performance. This includes: (1) ongoing demographic and epidemiological transitions causing a shift to non-communicable diseases and injuries that are likely to increase demand and result in more costly and diverse health care; (2) additional pressure from emerging diseases and epidemics such as HIV/AIDS, H5N1 (avian influenza) and H1N1 (swine influenza); and (3) the implementation of Social Security Law 2004 will further increase demand and utilization of health care services. Moreover, the rising obesity rate and prevalence of risk factors among adults in Indonesia will change the burden of disease, thereby increasing the need for preventive measures that will demand more health resources. Fortunately, despite the global economic crisis, the macroeconomic picture of Indonesia is still favourable.<sup>164</sup>

**Table 3-1 Regional comparison of health performance indicators among Asian countries.**<sup>160</sup>

Indicator	Indonesia	Philippines	Thailand	Malaysia	China	Cambodia	Vietnam
<b>Health Financing</b>							
Total health expenditure (THE) as % of GDP	2.2	3.3	3.5	4.3	4.5	6	6.6
General government expenditure on health as % of THE	50	40	64	45	42	26	32
Private expenditure on health as % of THE	50	60	36	55	58	74	68
Out-of-pocket expenditure as % of private expenditure on health	66	80	77	73	93	84	90
<b>Health Status</b>							
Life expectancy at birth (years)	68	68	72	72	73	62	72
Infant mortality rate (per 1,000 live births)	26	24	7	10	20	65	15
Under-5 mortality rate (per 1,000 live births)	34	32	8	12	24	82	17
Maternal mortality ratio (per 100,000 live births)	420 <sup>f</sup>	230 <sup>f</sup>	110 <sup>f</sup>	62 <sup>f</sup>	45 <sup>f</sup>	540 <sup>f</sup>	150 <sup>f</sup>
Births attended by skilled personnel (%)	66 <sup>d</sup>	60 <sup>d</sup>	97	100 <sup>f</sup>	98	44 <sup>f</sup>	88
Contraceptive prevalence (%)	61	49 <sup>d</sup>	72	--	90 <sup>e</sup>	40 <sup>f</sup>	79 <sup>f</sup>
<b>Health Systems</b>							
Hospital beds (per 10,000 population)	2.5 <sup>f</sup>	13	22 <sup>a</sup>	19	22	6 <sup>b</sup>	26 <sup>f</sup>
Physician density (per 100,000 population)	13 <sup>d</sup>	58 <sup>a</sup>	37 <sup>a</sup>	70 <sup>a</sup>	106 <sup>b</sup>	16 <sup>a</sup>	53 <sup>b</sup>
Nursing density (per 100,000 population)	62 <sup>d</sup>	169 <sup>a</sup>	28 <sup>a</sup>	135 <sup>a</sup>	105 <sup>b</sup>	61 <sup>a</sup>	56 <sup>b</sup>
Midwife density (per 100,000 population)	20 <sup>d</sup>	45 <sup>a</sup>	1 <sup>a</sup>	34 <sup>a</sup>	3 <sup>b</sup>	23 <sup>a</sup>	19 <sup>b</sup>
<b>Key</b> : a)2000; b)2001; c)2002; d)2003; e)2004; f)2005							
<b>Source:</b> WHO (2006) and WHOSIS accessed at <a href="http://www.who.int/whosis/en/index.html">http://www.who.int/whosis/en/index.html</a>							

The Human Development Index (HDI) of Indonesia's ranked 124th amongst 187 countries in 2011. The HDI is based on the Human Development Report, an annual ranking of national achievement in health, education and income. The HDI is a summary measure for evaluating long-term progress in three basic dimensions of human development, including: (1) a long and healthy life, measured by life expectancy; (2) access to knowledge, measured by: (a) mean years of adult education, and (b) expected years of schooling for children of school-entrance age; and (3) a decent standard of living, measured by Gross National Income (GNI) per capita expressed in constant 2005 PPP\$.<sup>165</sup>

Indonesia's 2011 HDI value of 0.617 belongs to the medium human development category. Indonesia's HDI is steadily trending upwards,<sup>165</sup> as shown in **Table 3-2**.

**Table 3-0-2 The trends of Indonesia's HDI in 1980, 1990, 2000, 2010 and 2011.**<sup>165</sup>

Year	HDI Values	Life Expectancy at Birth (years)	Mean Years of Schooling (years)	Expected Years of Schooling (years)	GNI per Capita (constant 2005 PPP\$)
1980	0.423	57.6	3.1	8.7	1,318
1990	0.481	62.1	3.3	10.4	2,007
2000	0.543	65.7	4.8	11.1	2,478
2010	0.613	68.9	5.8	13.2	3,544
2011	0.617	69.4	5.8	13.2	3,716

Despite some improvements, Indonesia's HDI rank is still below five of its ASEAN (Association of South East Asian Nations) counterparts: Singapore, Brunei, Malaysia, Thailand and Philippines. The comparison of HDI ranks and values among ASEAN countries in 2011<sup>166</sup> is presented in **Table 3-3**.

**Table 3-0-3 The comparison of HDI ranks and values among ASEAN countries in 2011.**<sup>166</sup>

HDI Rank	ASEAN Countries	HDI Values	Life Expectancy at Birth (years)	Means Years of Schooling (years)	Expected Years of Schooling (years)	GNI per Capita (constant 2005 PPP\$)
26	Singapore	0.866	81.1	8.8	14.4	52,569
33	Brunei Darussalam	0.838	78.0	8.6	14.1	45,753
61	Malaysia	0.761	74.2	9.5	12.6	13,685
103	Thailand	0.682	74.1	6.6	12.3	7,694
112	Philippines	0.644	68.7	8.9	11.9	3,478
<b>124</b>	<b>Indonesia</b>	<b>0.617</b>	<b>69.4</b>	<b>5.8</b>	<b>13.2</b>	<b>3,716</b>
128	Vietnam	0.593	75.2	5.5	10.4	2,805
138	Laos	0.524	67.5	4.6	9.2	2,242
139	Cambodia	0.522	63.1	5.8	9.8	1,848
149	Myanmar	0.483	65.2	4.0	9.2	1,535

### 3.4. INDONESIA GOVERNMENT AND DECENTRALISATION POLICY

Indonesian government is a democratic republic. Indonesia has considerably recovered from political, economic, and social crises that happened in 1998-1999. As a part of democratisation efforts in reformation era after the crises, Indonesian government implemented a decentralisation policy in 2001. After undergoing major political, economic

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and social transformations that began in 1999, Indonesia has emerged as a lower-middle-income country with a dynamic democratic, decentralized government.<sup>4,160,162,167</sup>

The decentralisation policy recognizes two main issues: (1) different levels of regional autonomy, including province autonomy and district autonomy (regency or city); and (2) financial equality between central and regional government. This policy significantly increases transfer of funds from central government to district governments, such that the regencies and cities have become the key administrative units. The provincial government is given 'limited autonomy' related with delegation of responsibility, whilst also provided with a 'broader de-concentration' as representative of central government. Meanwhile, a 'broader decentralisation' is given to regency and city government levels. Regional government is also given an authority of 'support', implying that regional development has to be performed by regency or city, while the development at provincial level is limited to those not covered by regency or city and inter-regency or inter-city. The present role of central government, thus includes formulation of policy and standards, provision of guidance and supervision to province and district government.<sup>168</sup>

### 3.5. HEALTH CARE SYSTEM OF INDONESIA

The organizational structure of the health care system in Indonesia consists of three main levels: Ministry of Health as central level, Provincial Health Office as provincial level, and District Health Office as district level.<sup>168,169</sup> The infrastructure of the health care system includes government or public health care services and private sector, including religious organisations, non-governmental organisations (NGOs) and foreign aids.<sup>169,170</sup> The health care service system is generally classified into primary health care level (primary care) and hospital level (secondary and tertiary care). The primary care is predominantly served by government-owned community health centres at sub-district level.<sup>170</sup> Public and private hospitals are found at provincial and district levels. However, the best-equipped hospitals are those in provincial capitals or large cities.<sup>169</sup>

Although there is a government social security programme for the poor, Indonesia has neither a national health insurance nor retirement support system serving the entire population. Thus the people who are not covered by the social security programme have to pay for their health care services themselves, contributing to the high out-of-pocket payments which account for nearly 70 percent of private health expenditure in Indonesia.<sup>169,171</sup> Therefore, the rule of "*You get what you pay for*" – referring to only the haves can obtain good health care services – prevails in this health system.<sup>171</sup>

There have been major changes in Indonesia's health system in the past few years. These include the implementation of general decentralisation in 2001 affecting health sector; and the introduction of 'Askeskin' – a government subsidised social health insurance programme for the poor – in 2001. However, there are complexities in employing these bold reforms. The decentralisation has empowered provinces and districts to manage and finance human resources for health care services.<sup>4</sup> However, there have been long-standing problems of uneven distribution, low productivity and quality of health workers throughout the archipelago that are aggravated by decentralisation.<sup>170</sup> Meanwhile, the implementation of *Askeskin* programme has provided the opportunity to safeguard millions of vulnerable Indonesians against falling into poverty when they get ill.<sup>4,170</sup> This programme is beneficial for many poor families since there is good evidence that illness and poverty are interrelated. There are anecdotal phrases which are very popular among millions of Indonesian, including: "The poor are not allowed to get sick"; and "If you get sick, you will become poor". The latter is especially a warning for lower-middle-class people in Indonesia.<sup>83</sup>

However, the *Askeskin* programme has caused a considerable increase in government's health spending and provoked concerns regarding the financial sustainability of universal health insurance coverage.<sup>4</sup> Following some conflicts within the national management, in early 2008, the *Askeskin* programme was changed to '*Jamkesmas*' and managed collectively by *Askes Inc.* and the Ministry of Health.<sup>85</sup> This programme is planned to be changed into a social security programme called '*Jamkesmas*' based on the Social Security Law stipulated in 2004. This programme which will be implemented in 2014 attempts to achieve universal coverage in the health system of Indonesia.<sup>171</sup>

According to WHO South East Asia Regional Office (WHO SEARO), Indonesia is considered to have reasonably sufficient levels of provision at primary health care level: one community health centre per 30,000 people on average or per 10,000 people if sub-centres are included. However, huge disparity in geographic accessibility throughout the archipelago may mask these figures, for example people in remote areas or small islands usually have very poor access to health facilities.<sup>170</sup>

The provision of primary health care services was developed through a Presidential Instruction programme on basic social services, including health, called '*Inpres*', which started in the mid-1970s.<sup>4</sup> The central element of the programme on health was the development of community health centres at the sub-district level, complemented by a hospital at the district level. Staffing of these health facilities was conducted through a period of obligatory government service for all new graduates in medicine, nursing and midwifery.<sup>167,172</sup> This staffing system, however, ended in 2007 and has not been replaced.<sup>172</sup> The programme brought about a rapid increase in the numbers of health centres, doctors,

nurses and midwives in all parts of Indonesia although the provision of health services remains uneven between urban and rural or remote areas.<sup>4</sup>

Presently, in each sub-district in Indonesia there is at least one community health centre (CHC), commonly called '*puskesmas*'.<sup>8,168</sup> Community health centres are government-owned health care facilities at primary care. They are executive units of district health offices in organizing an integrated health service taking the role and function of centre for health-oriented development, mobilization of community participation, and primary health care services. In 2008, the total number of CHCs in Indonesia is 8,548 comprising 6,110 out-patient centres and 2,438 in-patient centres. The ratio of CHC per 100,000 population is 3.74.<sup>8</sup> Indonesia's public primary health care system is extensive, i.e. more than 90 percent of the population has access to primary care facilities.<sup>164</sup>

A CHC provides services of six basic health programmes, including: basic medical and dental care; mother and child health; family planning; nutrition; eradication of communicable diseases; and hygiene, sanitation and environmental health. Each CHC is managed by a general practitioner or public health scholar and is staffed by 3-6 general practitioners, 1-2 dentists, 5-7 nurses, 6-7 midwives, 1-2 nutritionists, 1-2 laboratory analysts, 1-2 public health officers, 1-2 sanitation officers, and other supporting staff. There is a minimal variation on organizational structure, human resources, funding and medical infrastructure among CHCs, thus they are by and large homogeneous.<sup>8</sup>

A CHC is supported by 1-3 sub-centres, usually called '*pustu*', the majority of which are managed by community nurses. The CHCs are also usually equipped with four-wheel drive vehicles or motorboats to serve as mobile health centres providing services to under-served populations in remote areas or small islands. At the village level, integrated health posts commonly called '*posyandu*' provides preventive and health promotion services. These health posts are established and managed by local health cadres and community leaders, with the assistance of the CHC staff. Furthermore, midwives are deployed to the villages for improving maternal and child health and establishing village maternity clinics, called '*polindes*'.<sup>8,168</sup>

In addition to CHCs, private primary care practices are operated by general practitioners, nurses or midwives, often by the same personnel employed in public facilities. As civil servants at the CHCs they earn low salaries, which they supplement through private practice work. They work at CHCs in the mornings and operate their private practices in the afternoons and evenings at their homes or other private facilities.<sup>168,169</sup> At the secondary care level, Indonesia has low levels of bed provision in hospitals. In 2006, the ratio for hospital

bed provision was 62.5 per 100,000 population. Hospital utilization was also low, i.e. bed occupancy rate in the vicinity was 56.2 % in both public and private facilities.<sup>168</sup>

The majority of health care providers (HCPs) engage in the provision of both public and private health services, not only at primary care level but also at hospital level. This practice blurs the distinction between public and private provision of health care services in Indonesia.<sup>160,169</sup> The role of the private sector in the provision of health care services in Indonesia has significantly increased over the past decade, particularly in large cities. There is a broad acceptance of private health services and products, even among the poor. However, there are large variations in the quality and prices of private health care services and products. Since there are no regulations or standards on quality and pricing of health care services and products, health care users are at risk of exposure to unnecessary treatment and expenses.<sup>160,169,170</sup>

With the implementation of radical decentralisation in 2001, there was a general expectation that the performance of the health system would improve. However, in a recent study on health system performance at the district level in Indonesia after decentralisation, Heywood and Choi suggest that there has been little improvement in performance despite significant increases in public funding for health, associated with several aspects as described in the following paragraphs.<sup>167</sup>

Indonesia's health system is primarily a private health system.<sup>167</sup> Currently, two-thirds of the health care financing and more than half of the health care services are private.<sup>4,160</sup> In particular, there is extensive distribution of health care facilities and providers at district level that allows consumers to exercise some selection of health care facility and/or provider. The private sector is the sector of choice for outpatient care for many because the private HCPs and facilities are much more consumer oriented and convenient than those in the public sector.<sup>167</sup>

The private system enjoys a substantial public subsidy, mainly for the salaries of the government HCPs. However, the government is reluctant to use this subsidy as a policy lever for civil service reform in health sector.<sup>167</sup> Furthermore, the government's capacity to manoeuvre is severely limited by its current policy to convert contract staff to permanent civil servants.<sup>167,172</sup>

The health system is fractured thus making it difficult to manage the system as a whole.<sup>167</sup> There are several fracture lines in the system at the district level, including: (1) between the public and private sectors; (2) between the district and central government; (3) between district hospital and district health office/ CHCs – probably the most serious fracture line; and (4) around the funds over which the district does or does not have discretion.<sup>167,173</sup>



The various fracture lines result in the failure of the districts to recognise the pivotal role of the private sector and provide incentives for private providers to contribute for improving the sector performance.<sup>167</sup> Moreover, another major issue is that accountability is lost. No party is held accountable for the performance of the health sector.<sup>167,173</sup>

The actual implementation of decentralisation is limited, particularly in health sector human resources.<sup>167,173</sup> The central government continues to fund and control the activities of permanent civil servants; and increasingly contract staff are being converted to permanent employees. Consequently, although district funding has increased, much of this money is not available for operational purposes.<sup>167</sup>

Incentives for innovation are very limited in the system that has not really changed under decentralisation. The structure of the district health services as well as the staffing and skills mix are essentially unchanged. Aside from sustaining low levels of performance and efficiency, there is little evaluation of the reasons for low performance and the required measures for improvement at the district level. Without structural reform, the innovations required for improved health system performance will not occur.<sup>167</sup>

There is low quality of health services in both public and private sectors.<sup>167</sup> Private nurses are the largest single group of health care providers. Their low service fee makes them the provider of choice for many of the poor.<sup>174</sup> Improving the quality of care provided by all groups, especially nurses, may improve quality of outpatient care, particularly for low income people. However, attempts for improving the nurses' skills are resisted on the basis that their private practice is illegal. Additionally, the health system in Indonesia does not monitor quality of care; moreover, there are no incentives for improvement.<sup>167</sup>

The analytic and planning capacity of staff at the district level is limited. Few health sector bureaucrats exercise real leadership and articulate a vision for future improvement in health status and health sector issues, thus may keep on clinging to the old system. It is difficult to improve performance due to the structural issues in the sector, the failure of decentralisation, and the extent to which government policies restrain innovation at the district level. Without innovation, consequently, this will remain a system with inefficiency, low productivity, low quality and low performance.<sup>167</sup>

### 3.6. SUMMARY

The country setting of the research project, i.e. Republic of Indonesia, a developing nation with the fourth most populous country in the world, has shown little improvement on health system performance at the district level despite the implementation of a radical decentralisation in 2001. Health care system in Indonesia is generally a private medical system and there is no integrated health care provision with specialist referral system, resulting in extensive freedom for people in utilising the health care system. In spite of extensive primary health care provision through publicly funded community health centres found in all sub-districts in Indonesia and mostly accessed by people from lower socioeconomic groups, these centres are generally still belittled.

Therefore, the researcher decided to conduct the research project at the predominantly primary health care facilities, i.e. community health centres. The purpose was to make the pilot structured diabetes education programme for promoting diabetes self-management and patient empowerment become available and accessible to everyone, and to empower these marginalised publicly funded primary care facilities in providing good quality care for type 2 diabetes.

This chapter has outlined the country setting of the research, which is an overview of the geography, population and government and health care system of Indonesia. The next chapter, Chapter 4, will discuss about various methods utilised in this research project

# **CHAPTER 4 – Research Methods**

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**A Structured Diabetes Education Programme  
in Indonesia**

## **4.1. INTRODUCTION**

Chapter three outlines an overview of the methods utilised in this research project. However, each research method is described separately in the subsequent chapters.

## **4.2. RESEARCH OVERVIEW AND CONCEPTUAL FRAMEWORK**

### **4.2.1. Research Overview**

The main aims of this research project were:

- 1) To develop a pilot model of a structured diabetes education programme for promoting diabetes self-management and patient empowerment in primary care setting to be incorporated into diabetes education and care in Indonesia; and
- 2) To evaluate the effectiveness of such a programme with respect to clinical outcomes and diabetes-related scores of knowledge, health beliefs, self-care behaviours, and self-efficacy in people with type 2 diabetes (T2D).

To fulfil these aims, two studies were conducted: a cross-cultural adaptation study, and a pilot cluster randomized-controlled trial, which was informed by scoping discussions before and after the trial. The studies were carried out in seven steps, as described in the following paragraphs.

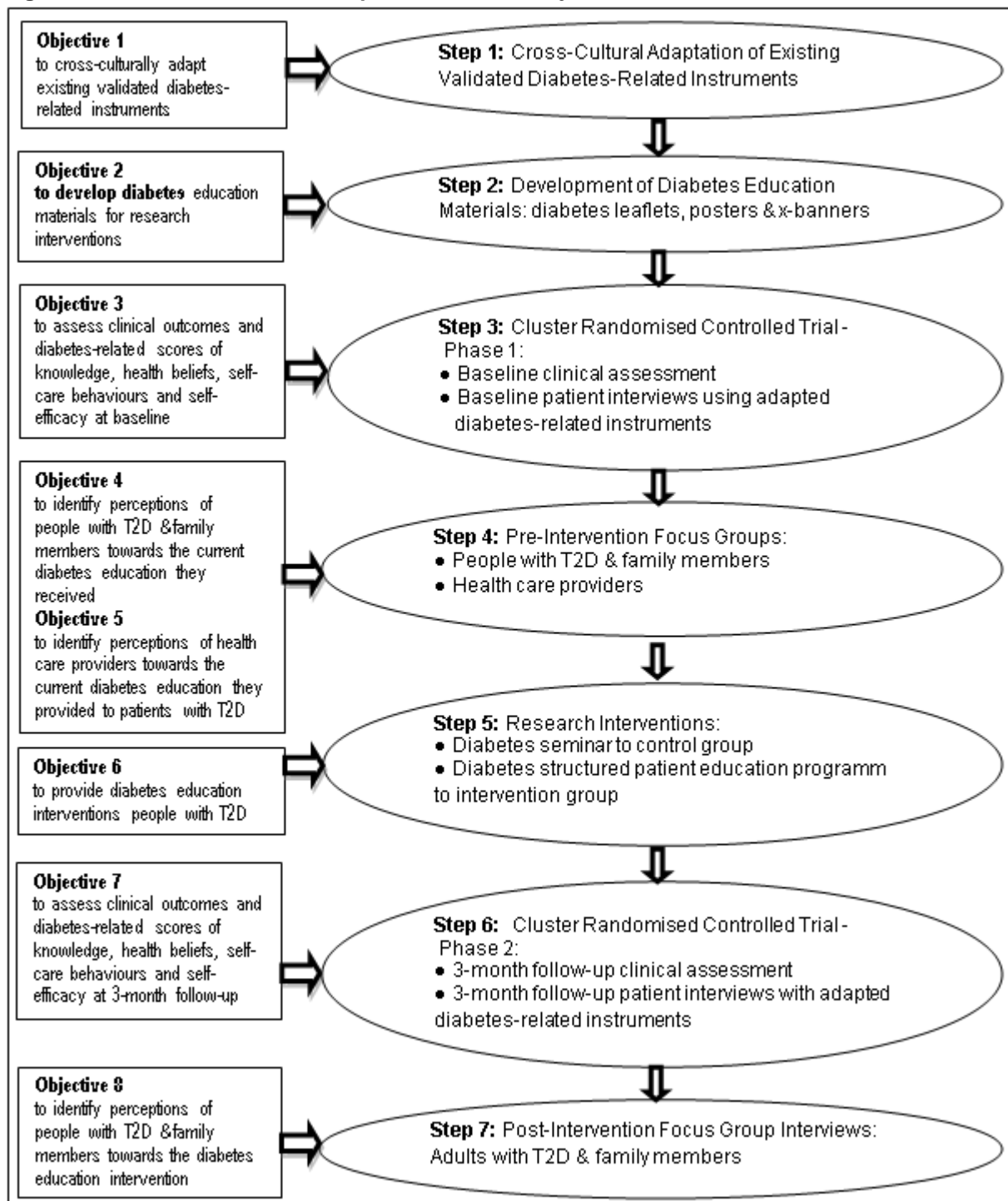
Step 1 of the study was a cross-cultural adaptation of existing validated diabetes-related instruments for use with an Indonesian population conducted in two community health centres in Yogyakarta City, Indonesia. Step 2 was development of diabetes education materials for use in the research interventions, including leaflets, posters and banners. Step 3 was phase 1 of the pilot cluster randomized controlled trial, including clinical assessment and patient interviews using adapted diabetes-related instruments at baseline. This was carried out in four community health centres different from the centres used in the cross-cultural adaptation study.

Step 4 of the study was scoping discussions, conducted before administering research interventions to enrich analysis of the quantitative data. Two scoping discussions were carried out with two groups of purposively selected participants, each from the control group and intervention group along with their family members, to explore their perceptions towards the current diabetes education they received. Another two scoping discussions were carried out with two groups of health care providers (i.e.: general practitioners, nurses and

nutritionists) working at four participating community health centres, to explore their perceptions towards the current diabetes education they provided to patients with T2D.

Step 5 involved the research interventions, namely a diabetes seminar for the control group and a structured diabetes education programme for the intervention group. Step 6 was phase 2 of the pilot cluster randomised controlled trial conducted at 3 months after the administration of research interventions, including clinical assessment and patient interviews using the adapted diabetes-related instruments. Finally, Step 7 was post-intervention scoping discussions carried out with the same two groups of research participants and their family members as previously. The purpose of this step was to explore their perceptions on the research interventions administered and their experiences in implementing what they had learned from the interventions, in order to obtain further enriching information for the data analysis. An overview of the research procedures along with research objectives is presented in **Figure 4-1**.

Figure 4-1 Overview of research procedures and objectives

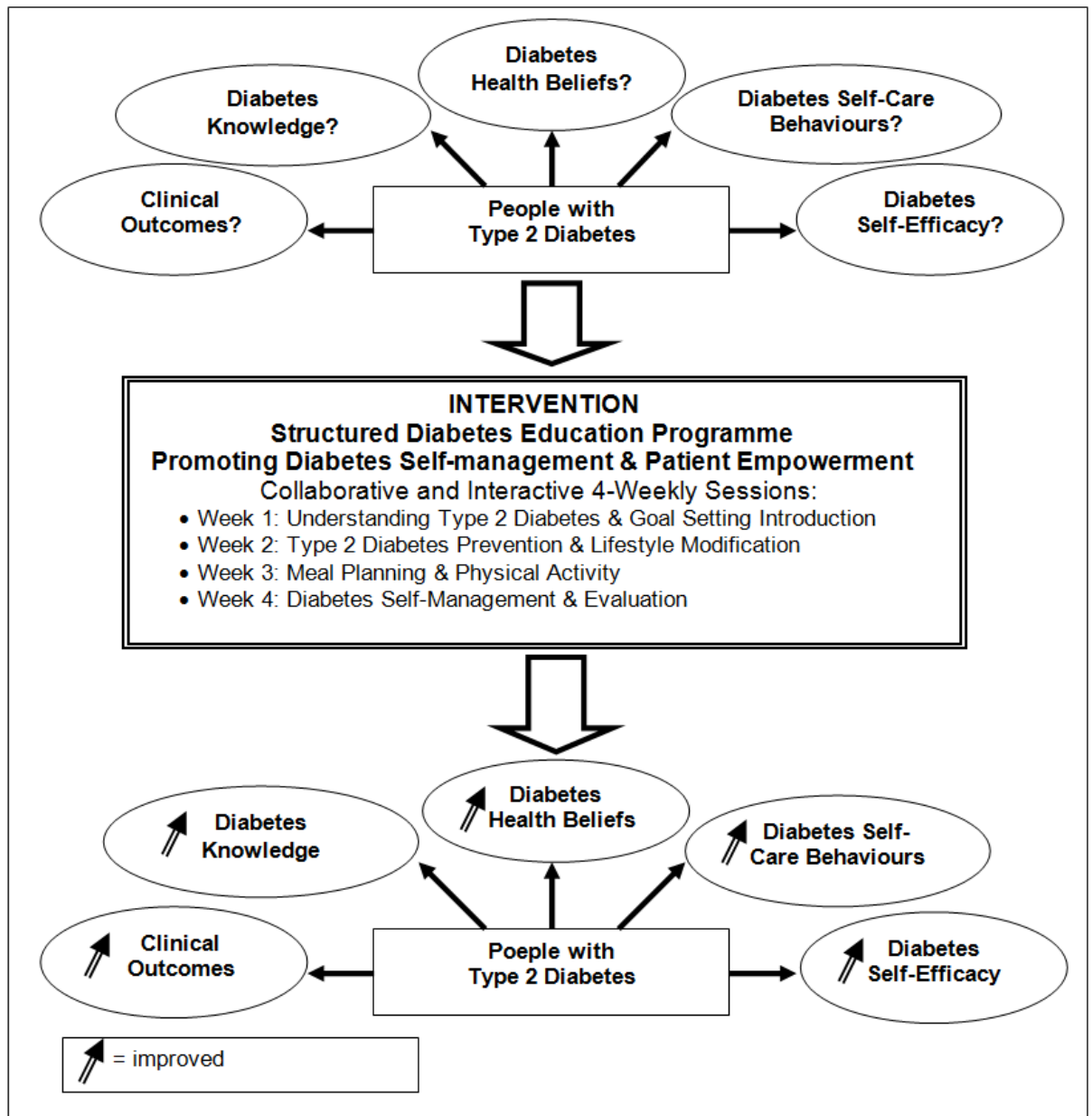


The cross-cultural adaptation of the existing validated diabetes-related instruments is discussed in Chapter 4. The development of diabetes education materials is described in Chapter 5. The cluster randomised controlled trial and scoping discussions are discussed in Chapter 6.

## 4.2.2. Research Conceptual Framework

The conceptual framework of the main study – a cluster randomised controlled trial – is illustrated in **Figure 4-2** as follows:

**Figure 4-2** Conceptual framework of the research



### 4.3. RESEARCH SETTING

This research project was carried out in primary care setting in Indonesia, at four community health centres (CHCs) in Yogyakarta City, within Special Administrative Region of Yogyakarta Province, located in Java Island. Yogyakarta Province has a population of approximately more than 3,400,000 people (2008 figures) and is the second most densely populated area after Special Capital Territory of Jakarta. Yogyakarta Province has five administrative regions, consisting of four regencies and one city. The latter is the capital city of Yogyakarta Province, called Yogyakarta City. It has the smallest area among the five regions. Yogyakarta City has 14 sub-districts and in each sub-district there are 1-2 CHCs, giving a total number of 18 CHCs in the region.<sup>8</sup> The participating CHCs in the research project were located in six of the 14 sub-districts in Yogyakarta City.

Although the provision of primary health care in Indonesia is reasonably good and extensive.<sup>164,170</sup>, with the absence of an integrated health care system with a referral system, there is extensive freedom of choice for people in utilising the health care system.<sup>78</sup> Patients from middle to upper socioeconomic groups tend to visit medical specialists or attend big hospitals directly for all their health problems, while people from lower socioeconomic groups tend to visit general practitioners and attend publicly funded CHCs. Health service fees at CHCs are generally cheap. The fee for a consultation with a general practitioner or a nurse including the provision of generic medications prescribed and blood tests needed vary from IDR 2,000 to 10,000 (equivalent to 20 cents to AUD 1) depending on the provinces. The fee in Yogyakarta Province is IDR 2,000 - 5,000, while in Jakarta or other richer provinces the fee is IDR 10,000. Being accessed mostly by people from lower socioeconomic groups, the health care service at CHCs is thus often belittled by the general public.<sup>79</sup> The general and dental clinics at the CHCs are walk-in clinics without appointment system and have limited opening hours from 8 am to midday, except a very few CHCs with in-patient care which have 24-hour emergency clinics.

Meanwhile, the treatment of T2D in Indonesia is mostly provided in secondary or tertiary care at hospitals or medical specialist private practices. People with T2D who seek treatment in primary care setting at CHCs or general practitioner practices are mostly those with money constraints. Traditional diabetes education is provided at CHCs, which is mostly didactic teaching, neither structured nor comprehensive, and conducted by a nutritionist focusing primarily on diabetes meal planning.

As the traditional model of diabetes education has been shown to be ineffective in bringing about the desired outcomes,<sup>25</sup> diabetes education emphasising self-management approaches – which involves patient judgement and values within the context of daily living



to inform how a comprehensive treatment plan can be best agreed and implemented<sup>26</sup> – needs to be introduced and incorporated into diabetes education and care in Indonesia. The International Diabetes Federation (IDF) suggests that, due to the critical importance of diabetes self-management education (DSME) as an integral component of diabetes prevention and care, DSME should be made available and accessible to everyone.<sup>17</sup>

Therefore, in contrast to existing practice for treatment of T2D at secondary or tertiary care, the researcher opted to conduct the research project in primary care setting – at predominantly primary health care facilities, i.e. CHCs. The purpose was to make the structured diabetes education programme for promoting diabetes self-management and patient empowerment to be available and accessible to everyone, and to empower these marginalised public primary care facilities in providing good quality care for T2D.

## **4.4. OPERATIONAL TERMS AND OUTCOME MEASUREMENTS**

### **4.4.1. Definitions of Operational Terms**

#### **4.4.1.1. Structured diabetes education programme**

In addition to the usual diabetes care provided at the CHCs, the intervention group received a research intervention: a structured diabetes education programme for promoting diabetes self-management and patient empowerment. This was a pilot programme especially developed as a research intervention for the intervention group in the cluster RCT.

This programme was a patient-centred, group-based diabetes self-management education founded on the theoretical framework of patient empowerment for helping people use their innate ability to gain mastery over their diabetes. This was a modification of the UK Diabetes X-PERT programme developed by Deakin, a diabetes research dietician, for empowering people with T2D by means of a structured educational course. The X-PERT programme involved six-weekly sessions covering six different topics: (1) What is diabetes?; (2) Weight management; (3) Carbohydrate awareness; (4) Supermarket tour; (5) Complications and prevention; and (6) Evaluation and question time. Each session lasted for two hours with the final 20-30 minutes used for goal setting based on empowerment model.<sup>152,153</sup>

However, due to time and resource constraints, as well as the needs of local patients, the original six-weekly sessions were modified into four-weekly sessions, each with a duration of 2.5 to 3 hours. Two of the sessions -- Weight Management and Supermarket Tour – were considered as not relevant for the participants due to local circumstances.

Therefore, these sessions were omitted. The other four topics were condensed and modified to meet local needs as follows:

- Week 1: Understanding type 2 diabetes and goal setting introduction
- Week 2: Type 2 diabetes prevention and lifestyle modification
- Week 3: Meal planning and physical activity
- Week 4: Diabetes self-management and evaluation

All participants received one set of comprehensive diabetes education materials consisting of nine leaflets and one booklet, as elaborated in Chapter 5 – Developing Diabetes Education Materials.

The needs of local patients were determined through direct observations during the researcher's practice in the area as well as informal discussions with colleagues and patients. A specific topic on "weight management" in the original UK Diabetes X-PERT programme was omitted because there were very few obese participants. A brief description of this topic was included in the modified week 2 topic, i.e. T2D prevention and lifestyle modification. Meanwhile, the topic on "supermarket tour" was omitted since the participants were mostly traditional people who shopped at traditional markets rather than supermarkets to buy their groceries. Additionally, commercial foods sold in supermarkets and traditional markets in Indonesia often do not have nutrition labels and therefore this was seen to be irrelevant to local needs. Each session was initially designed to last for only 2 hours. However, when implemented, there were many questions from the curious participants that needed to be addressed, leading to longer discussion times and therefore longer sessions.

Observations in several diabetes centres and participation in a national diabetes educator training in Yogyakarta and Jakarta revealed that a diabetes structured patient education has not been delivered or offered to patients with type 2 diabetes previously. This programme was thus a pilot for the provision of structured diabetes education programme in type 2 diabetes in Indonesia. Furthermore, this programme attempted to introduce and promote concepts of diabetes self-management and patient empowerment into diabetes education and care in Indonesia where these concepts are not widely known.

### **4.4.1.2. Diabetes Self-Management**

The structured diabetes education programme incorporated two major concepts of diabetes self-management as the framework for diabetes education, namely: (1) The 7 Self-Care Behaviors<sup>TM</sup>, developed by the American Association of Diabetes Educators (AADE),<sup>126</sup> and (2) Seven principles of self-management for chronic conditions, as defined in the Flinders Program<sup>TM</sup>.<sup>115</sup> The two concepts were included in one of new diabetes leaflet

developed for the research interventions, entitled “Seven Successful Steps for Diabetes Self-Care”. The diabetes leaflets are further elaborated in Chapter 5. Those two concepts are described in the following **Table 4-1**.

**Table 4-0-1 AADE 7™ Self-Care Behaviors<sup>126</sup> and the Principles of Self- Management of the Flinders Program™<sup>115</sup>**

AADE 7™ Self-Care Behaviors (American Association of Diabetes Educators)	The Principles of Self- Management: the Flinders Program™
<b>A good self-manager are individuals who:</b>	
1. Healthy Eating	1. Have knowledge of their condition
2. Being Active	2. Follow a care plan agreed with their health professionals
3. Monitoring	3. Actively share in decision making with health professionals
4. Taking Medication	4. Monitor and manage signs and symptoms of their condition
5. Problem Solving	5. Manage the impact of the condition on their physical, emotional and social life
6. Reducing Risks	6. Adopt lifestyles that promote health
7. Healthy Coping	7. Have confidence, access and the ability to use support services.

The AADE 7 Self-Care Behaviors™ are comprehensive and serve as augmentation of the four or five pillars of diabetes management that are widely introduced in diabetes education and care in Indonesia, including: education, meal planning, physical activity, medication, and sometimes added with monitoring.<sup>175</sup>

#### 4.4.1.3. Patient Empowerment

Patient empowerment is a process designed to facilitate patients with T2D choose personally meaningful, realistic goals of self-directed behaviour changes related to diet, exercise and weight loss. Empowerment approach in diabetes education interventions include both a process and an outcome.<sup>130</sup> The structured diabetes education programme incorporated the principles of the Empowerment Model for Diabetes Education outlined by Anderson and Fennel,<sup>148</sup> as presented in **Table 2-3**.

#### 4.4.1.4. Diabetes Seminar

Aside from the usual diabetes care provided in the CHCs, the control group also received a research intervention, i.e. a three-hour diabetes seminar. This was a didactic teaching on T2D conducted in a large group of approximately 50 participants. This type of diabetes seminar is quite common in large cities, usually held by large hospitals in collaboration with pharmaceutical companies and offered to diabetic patients and lay people with some fees for attendance.

The speakers of the diabetes seminar for the research intervention administered were an internal medicine specialist and a nutritionist, while the general practitioner researcher acted as a chairperson. The fee for the usual diabetes seminars may be quite expensive particularly for the research participants who were regular attendees of CHCs mostly coming from lower socioeconomic groups. However, for the purpose of the research project, the participants of the control group were invited to attend the diabetes seminar free of charge.

#### **4.4.1.5. Instruments for Measuring Diabetes Knowledge, Health Beliefs, Self-Care and Self-Efficacy**

At the outset of this research project, there were no validated instruments to measure diabetes knowledge, health beliefs, self-care behaviors and self-efficacy written in Indonesian language – *Bahasa Indonesia*. Therefore, for the research project, the researcher adapted existing validated diabetes-related instruments for validation in an Indonesian population. Important criteria to consider in selecting validated instruments for adaptation included widespread use, easy administration and validation with a similar population with the targeted population

##### **Instrument for Measuring Diabetes Knowledge**

Type 2 diabetes is a chronic condition that requires on-going management involving the patients' active role in their day-to-day care.<sup>13</sup> An acceptable level of knowledge is generally required for people with T2D to have good control of blood glucose.<sup>176,177</sup> A number of studies have shown that knowledge about diabetes medications, diet, exercise, blood-glucose monitoring, foot care and treatment modifications are essential for effective diabetes self-management.<sup>177-181</sup> Such knowledge will enable people with T2D to make informed decisions in their diabetes care. Although diabetes knowledge acquisition does not guarantee the desired behaviour modifications will occur<sup>177,181</sup>, assessing diabetes knowledge is an essential first step to evaluate the effectiveness of diabetes education programmes.<sup>181,182</sup>

A literature search on instruments measuring diabetes knowledge resulted in several instruments developed and validated mostly in Western countries, as presented in **Table 4-2**. The preparation of the research project was started in early 2009. The literature search indicated that the commonly used diabetes knowledge instruments were the Michigan Diabetes Knowledge Test (MKDT) and the 24-item Diabetes Knowledge Questionnaire (DKQ-24).

For the purpose of this study, the researcher decided to choose the DKQ-24,<sup>181</sup> printed bold in the above table, based on the following reasons:

- (1) The instrument was developed for and validated among patients with T2D.
- (2) The instrument items comprised comprehensive general diabetes knowledge. The original DKQ was designed based on the content recommendations in the National Standards for Diabetes Education Programs.<sup>183</sup>
- (3) The instrument consisted of 24 items with 'yes or no or don't know' format, thus it was easy to administer.
- (4) The instrument was designed for and validated among Mexican-American population in Starr County, Texas, that was of similar socioeconomic status as the intended study population in Yogyakarta City.<sup>181,184</sup> Selecting a measure validated with a similar population is crucial.<sup>185</sup> Yogyakarta Province is one of the provinces with the lowest cost of living and regional minimum wage in Indonesia.<sup>186</sup> Furthermore, the research participants were regular attendees of CHCs who mostly had low socioeconomic status (monthly family income of less than AUD 100) and low education levels (primary school).
- (5) When devising the original items, the instrument authors took into account the low educational level of the Starr County residents. The average educational level of the residents was sixth grade and most of population was unable to read because of visual impairments or illiteracy. Items were written in simple language and in a manner that could easily be read aloud to all study participants.<sup>181,187</sup> This was a big advantage for administering the instrument to the intended study population in Yogyakarta City with similar education level.

**Table 4-0-2 Existing validated instruments on diabetes knowledge**

No.	Diabetes Instruments	Components, Items and Scoring	Diabetes Type Use	Place of Development and Validation
1.	The Diabetes Knowledge Assessment (DKN) Scale, developed by Dunn et al (1984) <sup>188</sup>	General diabetes issues in parallel forms (each 15 items), i.e. DKNA, DKNB, and DKNC: multiple choice, true or false, and open-ended questions	Type 1 and type 2 diabetes	Australia
2.	The Michigan Diabetes Knowledge Test (MDKT), developed by Fitzgerald et al (1998) <sup>189</sup>	General diabetes issues (14 items) and insulin use (9 items): multiple choice questions	Type 1 and type 2 diabetes	USA
3.	<b>The 24-item Diabetes Knowledge Questionnaire (DKQ-24)</b> , developed by Garcia et al (2001) <sup>181</sup> , adapted from the original DKQ, a 60-item instrument developed by Villagomez in association with Brown and Hanis in 1989 <sup>187,190</sup>	A bilingual instrument in English and Spanish of general diabetes knowledge (a shortened version): 24 brief statements with 3 possible responses (1=Yes, 2= No, and 3= I don't know)	Type 2 diabetes	USA
4.	The Diabetes Numeracy Test (DNT) and DNT15, developed by Huizinga et al (2008) <sup>191</sup>	Numeracy skills for diabetes including food label interpretation, calculation of insulin dosing based on blood, glucose and carbohydrate corrections (a final	Type 1 and type 2 diabetes	USA

		version of 43 items and a shortened version of 15 items): open-ended questions		
5.	The PedCarbQuiz (PCQ), developed Koontz et al (2010) <sup>192</sup>	Carbohydrate food recognition and counting, and insulin-dosing knowledge (78 items): 'yes or no or don't know' format and multiple choice questions	Type 1 diabetes	USA
6.	The Revised Diabetes Knowledge Scale and the Simplified Diabetes Knowledge Scale, developed by Collins et al (2011) <sup>193</sup>	The Revised Diabetes Knowledge Scale is an adapted version of MKDT, consisting of 20 multiple-choice questions (17 on general diabetes knowledge and additional 3 for patients taking insulin). The Simplified Diabetes Knowledge Scale consists of 19 questions (on general diabetes knowledge and insulin use) where the multiple-choice responses were replaced by 'true or false'	Type 2 diabetes	UK
7.	The Spoken Knowledge in Low Literacy in Diabetes Scale (SKILLD), developed by Rothman et al (2005) <sup>194</sup> ; validated by Jeppesen et al (2011) <sup>195</sup>	General diabetes issues (10 items): open-ended questions	Type 2 diabetes	USA
8.	The Diabetes Knowledge Questionnaire developed by Eigenmann et al (2011) <sup>196</sup>	Fifteen items (multiple choice questions) including: - questions for people not taking diabetes medication and/ or insulin (12 items) - questions for people taking diabetes medication and/ or insulin (2 items) - an additional item for people with T1D only Seven additional demographic questions added if required	Type 1 and type 2 diabetes	Australia.
9.	The Diabetes Self-Care Knowledge Questionnaire of 30 items (DSCKQ-30) developed by Adibe et al (2011) <sup>197</sup>	Thirty items: close ended questions consisting of 15 true questions and 15 false questions with a 'yes or no' format	Type 2 diabetes	Nigeria

The DKQ-24<sup>181</sup> was a shortened version of the original 60-item Diabetes Knowledge Questionnaire developed by Villagomez in association with Brown and Hanis in 1989.<sup>187,190</sup> Content validity of the instrument was established by a panel of experienced nurses and researchers familiar with diabetes related issues of Mexican-Americans. Using the Kuder-Richardson formula, the instrument was found to have internal consistency reliability of 0.88.<sup>187</sup> The scores on the 60-item and the 24-item versions were well correlated ( $r = 0.85$ ,  $P < .001$ ). The coefficient alpha for the DKQ-24 was 0.78, indicating internal consistency and showed sensitivity to the intervention, suggesting construct validation. Items difficulties ranged from 0.14 to 0.96 with an average difficulty level of 0.57, which was desirable. Item discriminations averaged 0.31 for the total sample. The DKQ-24 was found to be a reliable and valid measure of diabetes knowledge, and relatively easy to administer for English and Spanish speakers. The DKQ-24 was administered as an interviewer-completed questionnaire.<sup>181</sup>

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### Instrument for Measuring Diabetes Health Beliefs

Aside from knowledge on diabetes, health beliefs are also considered crucial aspects in determining the effectiveness of a diabetes educational intervention, particularly in explaining potential changes or lack of changes in health outcomes after the intervention.<sup>184</sup> Initially developed to explain use of preventive services, the Health Belief Model (HBM) has been modified to explain the health behaviours of patients with chronic conditions.<sup>198,199</sup> Based on the model, patients' participation in their disease management is related to three aspects of beliefs: (1) belief in the disease severity; (2) belief in the efficacy of the prescribed treatment; and (3) belief that barriers to the favourable attainment of therapeutic behaviours can be overcome.<sup>198,200</sup> There is evidence suggesting that when these beliefs are modified, patients change their behaviours.<sup>198</sup>

Health beliefs have direct and indirect effect on diabetes metabolic control.<sup>201</sup> Moreover, health beliefs regarding an overall sense of control have been shown as a major predictor of improved metabolic control.<sup>184,202,203</sup> Substantial evidence supports the significance of attitudes and health beliefs in diabetes care outcome.<sup>204</sup>

A literature search on instruments measuring diabetes health beliefs resulted in several instruments developed and validated in Western countries, as presented in **Table 4-3**. For the purpose of this study, the researcher decided to choose the Diabetes Health Belief Measurement (DHBM) consisting of 25 items<sup>184</sup>, printed bold in the above table, based on the following reasons:

- (1) The instrument was developed for and validated among patients with T2D.
- (2) The instrument was developed for and validated among Mexican-American population in Starr County, Texas, that was similar socioeconomic status as the intended study population in Yogyakarta City. This is the same reason and explanation with reason no.4 for the above selection of diabetes knowledge instrument.

**Table 4-0-3 Existing validated instruments on diabetes health beliefs**

No.	Diabetes Instruments	Components, Items and Scoring	Diabetes Type Use	Place of Development and Validation
1.	The Diabetes Health Belief Model Scale of 76 items (HBM76) developed by Given et al (1983) <sup>198</sup>	Twelve concepts related to patients' beliefs about their disease and therapy: 76 statements, except one, all scored on a 5-point Likert Scale (ranging from strongly disagree, disagree, not sure, agree, to strongly agree)	Type 1 and type 2 diabetes	USA
2.	The Diabetes Health Belief Model Scale of 16 items (HBM16) developed by Becker & Janz (1985) <sup>205</sup> , adapted from the HBM76 by Given et al (1983) <sup>198</sup>	Consisting of four dimensions of health beliefs (perceived susceptibility, severity benefit, and barriers): 4 items for each dimension, scored on a 5-point Likert Scale (ranging from strongly disagree, disagree, not sure, agree, to strongly agree)	Type 1 and type 2 diabetes	USA
3.	The Diabetes Health Belief Scale developed by Harris et al (1987) <sup>206</sup>	Consisting of aspects of the Health Belief Model: 38 items, rated on 4-point scales (ranging from not at all to very much)	Type 1 and type 2 diabetes (mostly men)	USA
4.	The Diabetes Health Belief Questionnaire (DHBQ) developed by Brownlee-Duffeck et al (1987) <sup>207</sup>	Consisting of aspects of the Health Belief Model: 27 items, scored on a 5-point Likert Scale (ranging from strongly disagree, disagree, not sure, agree, to strongly agree)	Type 1 diabetes	USA
5.	The Diabetes Health Belief Model Scale of 11 items (HBM11) developed by Hurley (1990) <sup>208</sup> , adapted from the HBM76 by Given et al (1983) <sup>198</sup>	Eleven statements scored on a 5-point Likert Scale (ranging from strongly disagree, disagree, not sure, agree, to strongly agree); recommended for use for diabetic patients who use insulin	Type 1 and type 2 diabetes	USA
6.	The Health Belief Picture Scale (HB Picture Scale) for measuring children's health beliefs; and the Diabetes and Health Belief Instrument for measuring parent's health beliefs developed by Charron-Prochownik et al (1993) <sup>209</sup>	The HB Picture Scale consists of four health beliefs dimensions (2 items for each) and self-efficacy (3 items): 11 pairs of pictures, each showing opposing behaviours. The Diabetes and Health Belief Instrument: a close ended instrument consisting of 21 items, scored on a 5-point Likert Scale (ranging from strongly disagree, disagree, not sure, agree, to strongly agree)	Type 1 diabetes (children and parents)	USA
7.	The Diabetes Health Belief Measurement (DHBM) developed by Brown et al (2002) <sup>184</sup> , adapted from the HBM76 by Given et al (1983) <sup>198</sup>	Consisting of 4 sub-scales and 1 control item: 25 items, scored on a 5-point Likert Scale (strongly agree, agree, not sure, disagree, and strongly agree) .	Type 2 diabetes	USA



The DHBM<sup>184</sup> was adapted from the Health Belief Measurement of 76 items (HBM76) designed by Given et al.<sup>198</sup> The DHBM scored an 80 on the Flesch Reading Ease score, indicating a high number of people could readily understand the items. The Flesch-Kincaid Grade Level score was 4.8, indicating item wording at fifth-grade reading level. The DHBM was translated into Spanish and tested for content validity and for internal consistency reliability on Mexican Americans. The final instrument had 25 items with four subscales – ‘barriers’, ‘social support for diet’, ‘impact on job on therapy’, and ‘benefits of therapy’ – and one item to measure ‘control’. The authors of the 25-item DHBM did not report the reliability coefficient of the total scales, rather as internal consistency coefficients for the four subscales, i.e. 0.56, 0.62, 0.86 and 0.90, respectively. The DHBM was administered as an interviewer-completed questionnaire.<sup>184</sup>

### Instrument for Measuring Diabetes Self-Care Behaviours

People with T2D are basically in control over their chronic condition. The main responsibility for day-to-day diabetes care inherently lies on the patients themselves.<sup>13,148</sup> Self-care activities that help achieve glycaemic control and avoid diabetes-related complications are essential in diabetes management. Behaviour and lifestyle changes are key factors to successful diabetes self-management.<sup>204</sup> Diabetes management requires dedication to a range of demanding self-care behaviours, including healthy eating, regular exercise, taking diabetes medication, monitoring blood glucose, and checking one’s feet.<sup>210,211</sup> Diabetes thus requires daily self-management.<sup>212</sup> Therefore, measurable behaviour change is the desired outcome of a diabetes education intervention. Behaviour change for diabetes self-care activities is directly affected by education and a parameter of overall intervention achievement.<sup>126,212</sup>

A literature search on instruments measuring diabetes self-care behaviours resulted in only three instruments developed and validated in Western countries, as presented in **Table 4-4**. For the purpose of this study, the researcher decided to choose the revised Summary of Diabetes Self-Care Activities (SDSCA) scale consisting of 11 core items<sup>210</sup>, based on the following reasons:

- (1) The instrument was developed for and validated among patients with T2D.
- (2) The instrument items were comprehensive, consisting of five self-care dimensions: diet (general and specific), exercise, blood sugar testing, and foot care, with an additional item on smoking habit.
- (3) The instrument consisted of only 11 close ended questions on self-care activities during the past 7 days scored using the metric days per week (0 to 7 days). Thus, its brevity and ease of scoring made it practical to administer.

- (4) The instrument met all checklist criteria for critically appraising the suitability, validity, reliability, feasibility and sensitivity to change of available psychometric tools for diabetes education outcomes. Furthermore, the instrument has been widely used in a variety of studies on diabetes self-management education.<sup>213</sup> It has been translated and validated into several languages, including: Portuguese<sup>214</sup>, Spanish<sup>215</sup>, Maltese<sup>216</sup>, Turkish<sup>217</sup>, Brazilian Portuguese<sup>218</sup>, Korean<sup>219</sup>, and Malay language<sup>220</sup>.

**Table 4-0-4 Existing validated instruments on diabetes self-care behaviours**

No.	Diabetes Instruments	Components, Items and Scoring	Diabetes Type Use	Place of Development and Validation
1.	<b>The revised Summary of Diabetes Self-Care Activities Scale (SDSCA)</b> scale developed by Toobert et al (2000) <sup>210</sup>	Eleven core items of self-care on: - diet (4 items) - exercise (2 items) - blood sugar testing (2) - foot care (2 items) - smoking (1 item) Self-care activities during the past 7 days are scored using the metric days per week (0 to 7 days)	Type 2 diabetes	USA
2.	The Self-Care Inventory-revised (SCI-R) developed by Weinger et al (2005) <sup>211</sup>	Fifteen items on: - diet (4 items) - glucose monitoring (2) - medication administration (3) - exercise (1) - low glucose levels (2) - preventative/routine aspects of self-care (3) Scored over the previous 1-2 months using a 5-point Likert Scale ( 1='never do it' to 5='always do this as recommended, without fail) For patients with T2D, 3 items are not scored	Type 1 and type 2 diabetes	USA
3.	The Diabetes Self-Care Activities Questionnaire developed by Intas et al (2012)	Thirty-eight items on: socio-demographic risk factors physical & mental health physician-patient communication self-care activities self-care recommendation compliance with medical orders	Type 2 diabetes	Greece

The revised 11-item SDSCA scale assessed diabetes self-care activities by self-reported frequency. The internal consistency of the scale, assessed by average inter-item correlations was acceptable (mean = 0.47), except for specific diet. Test-retest correlations were moderate (mean = 0.40). The readability of the SDSCA was grade 7. The Flesch Reading Ease score was 71, with higher score indicating easier reading level. The SDSCA was administered as a self-completed questionnaire. The SDSCA also included 14

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supplemental items in an expanded version for more detailed information on the specific activities.<sup>210</sup> However, for practicality, the expanded version of SDSCA was not administered in this study.

### **Instrument for Measuring Diabetes Self-Efficacy and Empowerment**

According to Glasgow and Osteen, changes in knowledge and attitude through information transfer and instruction are not sufficient to attain the desired self-care behaviours. They suggest that diabetes education should include a patient perspective, that is the patient's self-efficacy.<sup>221</sup> Based on Bandura's theory, a key factor in achieving behavioural goals is self-efficacy, the confidence in one's own ability to perform specific behaviours needed to reach a desired goal. How people feel, think, motivate themselves and behave is determined by their self-efficacy beliefs.<sup>97-99</sup> Bandura's Self-Efficacy Theory has been applied in various areas of health education.<sup>222</sup> Self-efficacy is an important element of diabetes management and can be utilised to predict adherence to self-care behaviours.<sup>28</sup>

Anderson et al. suggest that people with T2D are fully responsible for the self-management of their illness, which is related with the characteristics of the disease. People with T2D inevitably have to make a series of daily decisions regarding nutrition, physical activity, diabetes medication, blood sugar monitoring, and stress management.<sup>30</sup> They also have to communicate and interact effectively with their HCPs, family members, friends, employers and colleagues to obtain the social support needed to manage their demanding chronic condition.<sup>30,223</sup> To cope effectively with the complex demands of diabetes management, a sufficient level of self-efficacy is required.<sup>224</sup>

According to Anderson et al., increases in self-efficacy are related to empowerment and improved outcomes.<sup>29</sup> Self-efficacy is a major concept in the patient empowerment approach to diabetes education and plays an important role in successful behaviour change. Therefore, enhancing the perceived self-efficacy of patients to self-manage their diabetes is an important goal of diabetes education and care.<sup>30</sup>

A literature search on instruments measuring diabetes self-efficacy and empowerment resulted in several instruments developed and validated in Western countries, as presented in **Table 4-5**. For the purpose of this study, the researcher decided to choose the Diabetes Empowerment Scale – Short Form (DES-SF), a valid and reliable instrument to measure overall diabetes-related psychosocial self-efficacy,<sup>225</sup> printed bold in the above table, based on the following reasons:

- (1) The instrument met all except one checklist criteria for critically appraising the suitability, validity, reliability, feasibility and sensitivity to change of available psychometric tools for diabetes education outcomes, i.e. no formal test-retest.<sup>213</sup>

- (2) The name of the instrument contained 'empowerment' term that was associated with the 'patient empowerment' concept to be specifically promoted and introduced into diabetes education and care in Indonesia.
- (3) The instrument consisted of only eight brief statements on diabetes self-efficacy. Thus, it was easy to administer.

**Table 4-0-5 Existing validated instruments on diabetes self-efficacy and empowerment**

No.	Diabetes Instruments	Components, Items and Scoring	Diabetes Type Use	Place of Development and Validation
1.	The Diabetes Management Self-Efficacy Scale (DMSES) developed by van der Bijl et al (1999) <sup>226</sup>	Twenty items representing three groups of diabetes self-care activities (performing activities, self-observation and self-regulating activities) Scored on a 5-point Likert Scale (yes, surely; probably yes; maybe yes/ maybe no; probably not; and no, surely not)	Type 2 diabetes	The Netherlands
2.	The Diabetes Empowerment Scale (DES) developed by Anderson et al (2000) <sup>30</sup>	Twenty-eight items with three subscales (managing psychosocial aspects of diabetes, assessing dissatisfaction & readiness to change, setting & achieving diabetes goals) Scored on a 5-point Likert Scale (strongly disagree, disagree, not sure, agree, and strongly agree)	Type 1 and type 2 diabetes	USA
3.	The Diabetes Empowerment Scale – short form (DES-SF) developed by Anderson et al (2003) <sup>225</sup>	Eight items scored on a 5-point Likert Scale (strongly disagree, disagree, not sure, agree, and strongly disagree)	Type 1 and type 2 diabetes	USA
4.	The Confidence in Diabetes Self-Care (CIDS) scale developed van der Ven et al (2003) <sup>224</sup>	Twenty items on the perceived ability to perform diabetes self-care tasks for patients with T1D Scored using a 5-point Likert Scale ( ranging from 1='No, I am sure I cannot' to 5='Yes, I am sure I can")	Type 1 diabetes	The Netherlands and USA
5.	The Australian/English version of the Diabetes Management Self-Efficacy Scale (DMSES-A/E) developed by McDowell et al (2005) <sup>227</sup>	Twenty items of diabetes self-care activities (managing blood glucose level, foot care, medication, diet and level of physical activity) Scored on a 11-point scale anchored with 'can do at all' (0), maybe yes/ maybe no' (5) and 'certain can do' (10)	Type 2 diabetes	Australia
6.	The modified Confidence in Diabetes Self-Care (CIDS-2) scale developed by Polonsky et al (2009) <sup>228</sup>	Twenty item and 16 item versions on the perceived ability to perform diabetes self-care tasks for patients with T2D Scored using a 5-point Likert Scale ( ranging from 1='No, I	Type 2 diabetes	The Netherlands and USA

		am sure I cannot' to 5='Yes, I am sure I can")		
7.	The Diabetes Management Self-Efficacy Scale UK (DSMES UK) developed by Sturt et al (2010) <sup>229</sup>	Fifteen items of diabetes self-care activities Scored on a 11-point scale anchored with: 0-1 'can do at all', 4/5 'maybe yes/ maybe no' and 9/10 'certain can do'	Type 2 diabetes	UK

The DES-SF was a shortened version of the original 28-item Diabetes Empowerment Scale, both developed by Anderson and colleagues.<sup>30,225</sup> The reliability of the DES-SF using the original dataset (n= 375 subjects) was  $\alpha = 0.85$ . The reliability of the DES-SF using data from the new sample (n= 229 subjects) was  $\alpha = 0.85$ . The DES-SF was administered as a self-completed questionnaire.<sup>225</sup>

#### 4.4.2. Description of Outcome Measurements

Both the intervention and control groups were assessed at baseline and 3-months after the administration of research interventions. Data collected from both groups consisted of outcome measurements that were grouped into the following seven sections (See Appendix E).

##### 4.4.2.1. Sociodemographic Characteristics

Data of sociodemographic characteristics collected from the research participants included: gender, age (years), marital status, highest educational qualification, employment, and estimated monthly family income.

##### 4.4.2.2. Medical History

Data of the participants' medical history collected included: known duration of T2D (years), diabetes patient education (individual or group session), known family history of T2D, self-monitoring of blood glucose (SMBG) using a glucometer, hypertension, smoking, diabetes treatment, diabetes complications, family support, and health insurance coverage.

##### 4.4.2.3. Diabetes Knowledge

Diabetes knowledge was measured using an adaptation of the 24-item Diabetes Knowledge Questionnaire (DKQ-24) for use with an Indonesian population. The DKQ-24 was designed to elicit information about the respondents' general diabetes knowledge, including the cause of diabetes, type of diabetes, self-management skills, and diabetes complications. The instrument consists of 24 brief statements with three possible responses: 1= *yes*, 2= *no*, and 3= *I don't know*. Responses are scored as correct or incorrect. The correct responses

are summed to attain a total score, with a maximal score of 24. The total score is converted into percentage, ranging from 0 to 100 percent. Higher scores indicate higher understanding about diabetes.<sup>181,230</sup>

#### **4.4.2.4. Diabetes Health Beliefs:**

Diabetes health beliefs were measured using an adaptation of the Diabetes Health Beliefs Measurement (DHBM) for use with an Indonesian population. The DHBM comprises five subscales, including control, barriers, social support for diet, impact of job on therapy, and benefits of therapy. The instrument consists of 25 statements and is scored on a 5-point Likert Scale: 1= *strongly disagree*, 2= *agree*, 3= *not sure*, 4= *agree*, and 5= *strongly agree*. The participants' responses are summed to attain a total score, with a maximal score of 125. The total score is converted into percentage, with a maximal score of 100 percent. Higher scores indicate higher beliefs in the ability to manage diabetes.<sup>184,230</sup>

#### **4.4.2.5. Diabetes Self-Care Behaviours:**

Diabetes self-care behaviours were measured using an adaptation of the Summary of Diabetes Self-care Activities (SDSCA) revised scale for use with an Indonesian population. The SDSCA revised scale consists of 11 core items. Scoring of items 1-10 (excluding smoking) uses the days per week on a scale of 0-7. For each group of self-care activities (general diet, specific diet, exercise, blood sugar testing, and foot care), a mean number of days is calculated, with a reversed scoring on item no.4. Higher scores indicate higher levels of self-care activities.<sup>210</sup>

#### **4.4.2.6. Diabetes Self-Efficacy:**

Diabetes self-efficacy was measured using an adaptation of Diabetes Empowerment Scale – Short Form (DES-SF) for use with an Indonesian population. The DES-SF consists of eight brief statements of diabetes-related psychosocial self-efficacy and is scored using a 5-point Likert Scale: 1= *strongly disagree*, 2= *agree*, 3= *not sure*, 4= *agree*, and 5= *strongly agree*. The participants' responses are summed to attain a total score, with a maximal score of 40. The total score is converted into percentage, with a maximal score of 100 percent. Higher scores indicate higher levels of psychosocial self-efficacy in managing diabetes.<sup>30,225</sup>

#### **4.4.2.7. Clinical Outcomes:**

The primary outcome of this research project was glycated haemoglobin or HbA1c (%) at 3-month follow-up. Other clinical outcomes include: fasting blood glucose (FBG) or fasting plasma glucose (FPG) (mmol/L and mg/dL); two-hour postprandial plasma glucose

(2-h PPG) (mmol/L & mg/dL); systolic and diastolic blood pressure (mmHg); body weight (kilogram); body mass index (BMI) ( $\text{kg/m}^2$ ); and waist circumference (centimetres).

Section A, B, C, D, E, and F were measured using one single questionnaire collected from patient interviews conducted by trained research assistants. The clinical outcomes (Section G) came out from blood tests conducted by a nationally accredited clinical pathology laboratory and from physical measurements conducted by community nurses.

## **4.5. RESEARCH ETHICS**

Ethical approval was granted from the Human Research Ethics Committee of the University of Adelaide for undertaking the research project in Yogyakarta City, Indonesia. Research permit was also secured from the Yogyakarta Provincial Local Government and Yogyakarta City Local Government, as well as Yogyakarta Provincial and District Health Offices.

Written consent was obtained from all participants before participation in the project and undertaking all research activities. No participant was individually identifiable in any publications that might arise from the work and any personal information provided was treated in confidence. The information obtained was only used for the research purpose.

All participants were provided with an introductory information sheet and a complaint form. There were no adverse events anticipated to arise from the project. Participation in the study conducted in groups might even indirectly benefit participants by increasing the social support and networking opportunity of participants. No participants exhibited emotional distress arising from revealing their own unfavourable experiences of having diabetes and past experiences of health care services received. In fact, the majority of the participants were excited and pleasantly surprised for being given ample time by a health care provider to ask questions and share their experiences regarding their illness.

## **4.6. SUMMARY**

In summary, this research project was conducted in two studies – i.e. cross-cultural adaptation study, and a pilot cluster randomized-controlled trial enriched by several scoping discussions – and carried out in seven steps. This chapter has outlined the overview and conceptual framework, the research setting, the operational terms and outcome measurements and the ethics of the research project, providing a general overview of the PhD research project. The next chapter, Chapter 5, will discuss about the cross-cultural adaptation of the four selected validated diabetes-related instruments.

# **CHAPTER 5 – Cross-Cultural Adaptation of Diabetes-Related Instruments**

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**A Structured Diabetes Education Programme  
in Indonesia**



## 5.1. INTRODUCTION

Chapter 4 outlines the cross-cultural adaptation of four validated diabetes-related instruments that had been selected to be used in the main study, cluster randomised controlled trial. This is the first study of the three studies within this research project. This chapter describes the steps of cross-cultural adaptation process, the psychometric issues and statistical analysis of the selected diabetes-related instruments previously validated in English-speaking populations for use in an Indonesian population.

## 5.2. BACKGROUND

Although there are many established questionnaires and scales in the international literature on diabetes-related knowledge, health beliefs, attitudes, self-care behaviours, self-efficacy, and quality of life, adequate diabetes-related instruments written in Indonesian language (*Bahasa Indonesia*) were scarce, particularly instruments catering to the research objectives. Most questionnaires and scales that measure health status were developed and validated in English-speaking countries.<sup>231</sup> Wherever possible, researchers should use previously validated instruments, being careful not to make significant changes in the validated instruments without revalidating instrument content, constructs and reliability.<sup>232</sup> Therefore, when addressing research questions to a population whose language is not English, translation of previously developed and validated instruments may frequently be the preferred choice.<sup>233</sup> Following completed translation, further tests should be conducted on the psychometric properties of the adapted instrument.<sup>234,235</sup>

Developing a research instrument should ideally take into account the perspective of the culture of population being studied. However, this process often requires considerable time and resources which can be impractical.<sup>233</sup> Due to time and resource constraints, the researcher thus opted to translate, adapt and test previously validated diabetes-related instruments that were carefully selected to align with the research objectives. It was anticipated that the adaptation would be challenging, as an instrument developed for use in one language and culture often contain semantic, idiomatic and cultural differences when applied in another language and culture.<sup>233,236</sup>

As previously described in Chapter 3, the following four existing diabetes-related instruments were carefully selected to be used in the cluster randomised controlled study:

- 1) The 24-item Diabetes Knowledge Questionnaire (DKQ-24).<sup>181</sup>
- 2) The Diabetes Health Beliefs Measure (DHBM).<sup>184</sup>
- 3) The revised 11-item Summary of Diabetes Self Care Activities (SDSCA).<sup>210</sup>
- 4) The Diabetes Empowerment Scale – Short Form (DES-SF).<sup>225</sup>

These four instruments were then validated with an Indonesian population using a cross-cultural adaptation technique.<sup>231,235</sup> Although the four established instruments were already in the public domain, as a courtesy, the researcher contacted the original developers of the instruments by electronic mails to seek their permission to cross-culturally adapt the instruments. However, only two people of the original developers responded: Robert Anderson, the developer of the DES-SF<sup>225</sup>, and Bill Given, the developer of DHBM76<sup>198</sup> whose work was adapted by Brown et al.<sup>184</sup> Both gave their permission. Meanwhile, the authors of the SDCSA revised scale wrote in their article as follows: “*We have deliberately placed the SDSCA in the public domain and encourage its use*” (p.948).<sup>210</sup> Based on this knowledge, the researcher thus proceeded to conduct the cross-cultural adaptation process of the four selected instruments.

The term ‘cross-cultural adaptation’ encompasses a process addressing both language translation and cultural adaptation issues in preparing an instrument for use in another setting. The cross-cultural adaptation process aims to achieve equivalency between source (where it was developed) and target (where it is going to be used) in four areas: semantic equivalence (including meaning and grammar), idiomatic equivalence (including colloquialism or idiom), experiential equivalence (including daily life experiences) and conceptual equivalence (including cultural context).<sup>235</sup> According to Guillemin et al., comparing the language and culture of the target setting and the source setting is faced with several different scenarios where cross-cultural adaptations should be considered. The first scenario, where it is to be used in the same language and culture, no adaptation is necessary. The last scenario is the opposite extreme, the application of an instrument in a different country, language and culture, that requires translation and cultural adaptation<sup>231</sup>. The last scenario of cross cultural adaptation was applied in this research project. The four selected English diabetes-related instruments required to be cross-culturally adapted into *Bahasa Indonesia*. Therefore, the aim of this study was to cross-culturally adapt the four selected diabetes-related instruments, namely the DKQ-24, the DHBM, the revised SDSCA scale, and the DES-SF, for use in an Indonesian population.

### 5.3. AIMS

The main aims of this study were to cross-culturally adapt the following diabetes-related instruments for use in an Indonesian population:

- 1) The 24-item Diabetes Knowledge Questionnaire (DKQ-24)
- 2) The Diabetes Health Beliefs Measure (DHBM)
- 3) The revised 11-item Summary of Diabetes Self Care Activities (SDSCA)
- 4) The Diabetes Empowerment Scale – Short Form (DES-SF)

### 5.4. METHODS

#### 5.4.1. Procedure of Cross-Cultural Adaptation

For the purpose of this study, the four selected diabetes-related instruments were compiled into one questionnaire, named as “diabetes self-management questionnaire”. However, they were analysed independently. Based on the international norms, these four selected diabetes-related instruments underwent the following steps of cross cultural adaptation process.<sup>231,233,235</sup>

##### 5.4.1.1. Forward Translation

The four English diabetes-related instruments were forward-translated to *Bahasa Indonesia* by two bilingual English-Indonesian translators at a university language training centre, the home university of the researcher. Both of them had no health or medical background. They translated the instruments with consideration of the Indonesian culture. They worked independently and were not aware or informed of the study objectives and concepts examined. In this way, the two translations could be compared and any discrepancies that might reflect ambiguous wording in the translation process could be noted.<sup>235</sup>

##### 5.4.1.2. Synthesis of the Translations

The two Indonesian translated versions were compared and analysed by the bilingual general practitioner researcher who used to also work at the same university language centre. The synthesis of these translations was then discussed with the bilingual external supervisor, resulting in an initial Indonesian version of the instruments.

### 5.4.1.3. Backward Translation

The initial Indonesian version of the instruments was then backward-translated to English by another two bilingual translators from the same language training centre. They were different persons from the previous forward translators. Both of them also had no health or medical background. They also worked independently and were neither aware nor informed of the study objectives and concepts examined. They were totally blind to the original English version. This was a process of validity checking to ascertain that the Indonesian version reflected the same item content as the original English version. Furthermore, this process aimed to avoid information bias and to elicit unexpected meanings of the items in the previously translated version.<sup>235</sup> The original and the back-translated versions were then compared by the researcher and the external supervisor to check for conceptual discrepancies. Minor revisions were made to obtain the translated Indonesian versions to be pre-finalised by the expert panel.

### 5.4.1.4. Content Validity

Content validity was evaluated using the Content Validity Index (CVI), the proportion of experts that judge an item as content valid.<sup>237</sup> The translated Indonesian instruments were then assessed by a panel of 8 Indonesian experts in the field, consisting of 1 endocrinologist, 1 internal medicine specialist, 2 general practitioner diabetes educators, 2 nurse diabetes educators, 1 health promotion practitioner, and 1 public health practitioner. They were asked to compare the original English instruments with the translated Indonesian instruments for conceptual and content equivalency.<sup>233</sup>

Each panel expert was asked to rate each item in four Indonesian instruments using a 4-point Likert scale: 1= *not relevant or equivalent*, 2= *somewhat different*, 3= *almost relevant or equivalent*, 4 = *very relevant or equivalent*. The rating of each item was based on two criteria: 1) the relevance of content with local culture and research objectives; and 2) the clarity and equivalence of phrasing. The CVI for each item is the proportion of experts who rate the item as content valid with a score of 3 or 4. The CVI for the entire instrument is the proportion of total items judged content valid.<sup>237</sup> A CVI score of minimum 0.80 is considered to have good content validity.<sup>238</sup>

The translated Indonesian instruments obtained the following average total CVI scores: the DKQ-24 = 0.81; the DHBM = 0.83; the revised SDSCA = 0.89; and the DES-SF = 0.88. All of them showed satisfactory results. The panel experts were also asked to give additional comments on the instrument items in relation to cultural relevance and phrasing clarity. There were suggestions from the panel experts on content and word phrasing based

on local context. This was followed by further revisions to obtain the pre-final Indonesian versions for pre-test.

Item no.23 of the DKQ-24 was slightly modified based on the local context. The original item was *“Tight elastic hose or socks are not bad for diabetics”*. Elastic hose was not known among the target population. It might only be known among fashion industry community in metropolitan cities such as Jakarta, the capital city of Indonesia. Therefore, the words ‘elastic hose’ were omitted. The modified sentence became: *“Tight socks are not bad for diabetics”*.

Item no.1 of the revised SDSCA on general diet was added with a national campaign jargon for a healthful eating plan that has been used for years for public education in community health centres. The jargon was ‘4 Sehat 5 Sempurna’, literally translated as ‘4 Healthy 5 Perfect’. This refers to eating all four kinds of food sensibly, including carbohydrate food (e.g.: rice, noodles, bread), protein food (e.g.: beef, chicken, egg, tofu, tempeh or soybean cake), vegetables and fruits, and complemented with milk to make it perfect. The jargon was recently revised as ‘*Tumpeng Gizi Seimbang*’ or ‘balanced diet pyramid’.<sup>239,240</sup> However, the former nutritional jargon is much more popular than the latter among the general public. The original item was *“How many of the last SEVEN DAYS have you followed a healthful eating plan?”* The nutritional jargon was added at the end of the sentence within parentheses. This was aimed to make the item easier to relate to for the participants.

#### **5.4.1.5. Pre-test of the Pre-Final Indonesian Version of Four Instruments**

This step was a readability test of the pre-final Indonesian instruments conducted with a convenience sample of ten adults with type 2 diabetes (T2D) at a community health centre in Yogyakarta City. The pretested diabetes self-management questionnaire consisted of four translated instruments: the DKQ-24 (24 items), the DHBM (25 items), the revised SDSCA (11 items) and the DES-SF (8 items), with additional six items on sociodemographic characteristics and ten items on medical history, giving a total of 84 items (See **Appendix F**). Anticipating that the majority of the target population had low education levels, the questionnaire was thus not for self-completion, but as a one-on-one patient interview. The participant’s spoken answers were then transferred to the questionnaire by the interviewer. This process was conducted by the researcher herself.

For all ten adults with T2D interviewed, it was their first experience to complete such a diabetes questionnaire. It took some time to explain to them the different instructions for all instruments and for them understand the questions. Some items in all four instruments needed further explanation before the participants could understand and answer. It took approximately 75–120 minutes to conduct one patient interview and complete the whole

questionnaire. The time taken also depended on the patients. Some patients were talkative wanting to tell their stories about their illness experience, and asked questions about diabetes-related issues. Therefore, the interviews took longer time than expected. This was not surprising since many of the participants were excited to be given ample time to talk to a health care provider, an experience which is rare in Indonesian public primary health care facilities.

At the end of the interviews, the participants were asked to comment on the questionnaire items. In general, the participants stated that they could understand the questions, although some items were confusing and needed more explanation. Some participants also commented on the large number of the questions which could become overwhelming. It was possible that those comments arose from the fact that this was their first time encountering a diabetes questionnaire and most had a low level of education. Upon completion of the interview, each participant was given a small gift.

Based on the comments of earlier pre-test participants, the researcher used a number of strategies in the remaining patient interviews. For example, when the participants became bored or tired during the interviews, the researcher would include more personal questions about family, children, work and diabetes experience. In the culture of the target population and the researcher, the Javanese culture, talking about personal issues is a cultural norm, even among people who have met for the first time. It is not considered impolite nor intruding someone's privacy. In this way, the interviewer could provide a more pleasant ambience for the participants. However, this did mean that a longer time was needed to complete the patient interviews.

The pre-testing of the pre-final Indonesian instruments resulted in some more revisions, particularly of the items which needed more explanations, generating the final Indonesian versions for field test. Moreover, based on the experiences of interviews with the pre-test participants, the researcher developed additional notes highlighting items to be paid more attention during the patient interviews. These notes provided additional information on how to explain the items in more details to the participants for the DHBM, the SDSCA and the DES-SF as presented in **Table 5-1**. In particular for the DES-SF instrument, because all eight items on psychosocial self-efficacy are very abstract, thus more detailed explanation was needed. These additional notes would allow the participants to relate the items with their diabetes experiences and help them understand the items better. Additional notes for the DKQ-24 were not deemed necessary because the items on diabetes knowledge were quite straightforward. These additional notes were also used in training research assistants recruited to conduct patient interviews.

Table 5-0-1 Additional notes for the DHBM, the SDSCA and the DES-SF instruments

Instrument	Number and Items	Additional Notes for Explaining Items
<b>DHBM</b>	1. My diabetes is well controlled [having good results of blood sugar testing].	<ul style="list-style-type: none"> <li>Item bolded to explain more about “well controlled” Additional explanation was given in brackets</li> </ul>
	2. I would have to change too many habits to follow my diet (diabetic foods).	<ul style="list-style-type: none"> <li>Item bolded to explain more about “change too many habits”</li> </ul>
	5. I would have to change too many habits to take my medication.	<ul style="list-style-type: none"> <li>Item bolded to explain more about “change too many habits”</li> </ul>
	10. If I changed “jobs” I would be easier to follow my diet (diabetic foods).	<ul style="list-style-type: none"> <li>Item bolded to explain more about “if I changed jobs”</li> <li>For participants who did not have jobs, the term ‘jobs’ was changed to “daily activities”</li> </ul>
	11. My work makes me so tired that it’s hard to follow my diet (diabetic foods).	<ul style="list-style-type: none"> <li>Item bolded to explain more about “my work”</li> <li>For participants who did not have jobs, the term “work” was changed to “daily activities”</li> </ul>
	12. I could control my weight if the pressures of my job weren’t so great.	<ul style="list-style-type: none"> <li>Item bolded to explain more about “my job”</li> <li>For participants who did not have jobs, the term “job” was changed to “daily activities”</li> </ul>
	13. If I changed “jobs,” it would be easier to take my medication.	<ul style="list-style-type: none"> <li>Item bolded to explain more about “If I changed jobs”</li> <li>For participants who did not have jobs, the term ‘jobs’ was changed to “daily activities”</li> </ul>
	14. I worry so much about my job that I can’t take my medication.	<ul style="list-style-type: none"> <li>Item bolded to explain more about “my job”</li> <li>For participants who did not have jobs, the term “job” was changed to “daily activities”</li> </ul>
	17. I believe that my diet (diabetic foods) will control my diabetes [make my blood sugar level not elevated].	<ul style="list-style-type: none"> <li>Item bolded to explain more about “will control my diabetes”</li> <li>Additional explanation was written in brackets</li> </ul>
	24. I must take my diabetes medication even if I don’t think I am getting better	<ul style="list-style-type: none"> <li>Item bolded to explain more carefully about the sentence because the participants found the concept difficult</li> </ul>
<b>SDSCA</b>	1. How many of the last SEVEN DAYS have you followed a healthful eating plan [ <i>“4 sehat 5 sempurna”</i> ]?	<ul style="list-style-type: none"> <li>Item bolded to explain more on “a healthful eating plan”</li> <li>Additional explanation was written in brackets using the national campaign jargon on a healthful eating plan for public education, i.e. “4 sehat 5 sempurna”, literally translated as “4 healthy 5 perfect”</li> </ul>
<b>DES-SF</b>	1. I know what part(s) of taking care of my diabetes that I am dissatisfied with.	<ul style="list-style-type: none"> <li>Recheck whether the participants really understand the question by asking the following question: “What are you dissatisfied with?”</li> </ul>
	2. I am able to turn my diabetes goals into a workable plan.	<ul style="list-style-type: none"> <li>Recheck whether the participants really understand the question by asking the following question: “What are the examples..?”</li> </ul>
	3. I can try out different ways of overcoming barriers to my diabetes goals.	<ul style="list-style-type: none"> <li>Recheck whether the participants really understand the question by asking the following question: “What are the barriers?”; “How do you overcome them?”</li> </ul>
	4. I can find ways to feel better about having diabetes.	<ul style="list-style-type: none"> <li>Recheck whether the participants really understand the question by asking the following question: “What are the examples..?”</li> </ul>
	5. I know the positive ways I cope with diabetes-related stress.	<ul style="list-style-type: none"> <li>Recheck whether the participants really understand the question by asking the following question: “What are the examples..?”</li> </ul>
	6. I can ask for support for having and caring for my diabetes when I need it.	<ul style="list-style-type: none"> <li>Recheck whether the participants really understand the question by asking the following question: “To whom...?”</li> </ul>
	7. I know what helps me stay motivated to care for my diabetes.	<ul style="list-style-type: none"> <li>Recheck whether the participants really understand the question by asking the following question: “What are they...?”</li> </ul>
	8. I know enough about myself as a person to make diabetes care choices that are right for me.	<ul style="list-style-type: none"> <li>Recheck whether the participants really understand the question by asking the following question: “What are the examples..?”</li> </ul>

Based on the findings of the pre-test of the pre-final Indonesian version of the SDSCA, responses for two items on blood sugar testing were possibly largely different from the purpose of measurement of the original instrument. These two items were: *“On how many of the last SEVEN DAYS did you test your blood sugar?”* and *“On how many of the last SEVEN DAYS did you test your blood sugar the number of times recommended by your health care provider?”* The items on blood sugar testing were most likely for addressing patients with T2D living in Western countries who have a glucometer for regular self-monitoring blood-glucose (SMBG). However, patients attending Indonesian community health centres (CHCs) who mostly came from lower socioeconomic groups generally did not have the capacity for SMBG using a glucometer nor were they advised to do so. The frequency for blood sugar testing for diabetic patients based on the local practice guidelines at the CHCs was once a month. This was particularly for patients who were covered by the government health security programme for poor people. This practice was confirmed by the attending health care providers (HCPs). Thus, the responses for the two items on blood sugar testing were mostly either 0 or 1 depending on the time the interview was conducted, within the week of their monthly blood sugar testing or not. Patients who had more than one blood sugar testing in a month were most likely ‘general patients’ who paid out-of-pocket medical service fees and blood tests out of their pocket or had additional tests in private clinical pathology laboratories.

Therefore, additional items were needed to allow responses suitable with the local setting. After discussions with the external supervisor, two additional items were developed measuring: (1) the frequency of blood sugar testing in a month; and (2) the frequency of blood sugar testing recommended by the HCPs in a month. Some participants stated that the HCPs did not give any recommendations about the frequency of blood sugar testing. These two additional items were not included for the analysis for the original instrument, but served to clarify the responses to the relevant original items.

The scoring for the additional items did not use the number of days per week on a scale of 0-7 as in the original items on blood sugar testing (item no.7 and 8), but rather the structure provided for the original item on smoking (item no.11), that is: *“No”* and *“Yes. If yes, how many cigarettes did you smoke on an average day?”*. The two additional items were labelled 7A and 8A. The additional items and their scoring are presented in **Table 5-2**, along with the original items on blood sugar testing and smoking for comparison.



**Table 5-0-2 Additional items and several original items of the SDSCA**

No.	Items	Answers
7.	On how many of the last SEVEN DAYS did you test your blood sugar?	0 1 2 3 4 5 6 7
<b>7A.</b>	<b>Have you had your blood sugar tested in the last MONTH? *</b>	<b>0. No</b> <b>1. Yes. If yes, how many times?</b> Number of blood tests: ...../ month
8.	On how many of the last SEVEN DAYS did you test your blood sugar the number of times recommended by your health care provider?	0 1 2 3 4 5 6 7
<b>8A.</b>	<b>How many times in the past MONTH did your health care providers recommend you to have your blood sugar tested? *</b>	<b>0. Not recommended</b> <b>1. Recommended:</b> Number of blood tests recommended: ...../ month
11.	Have you smoked a cigarette—even one puff—during the past SEVEN DAYS?	0. No 1. Yes. If yes, how many cigarettes did you smoke on an average day? Number of cigarettes: ...../ day

\* Items printed bold are additional items

#### 5.4.1.6. Field Test of the Final Indonesian Version of Four Instruments

In this step, the four final Indonesian instruments, compiled into one diabetes self-management questionnaire, were distributed to adult patients with T2D registered at two community health centres in Yogyakarta City. The questionnaire consisted of 84 items: the DKQ-24 (24 items), the DHBM (25 items), the SDSCA (11 original items and 2 additional items), and the DES-SF (8 items), sociodemographic characteristics (6 items) and medical history (10 items) (See **Appendix F**). The questionnaire was complemented with additional notes for the DHBM, the SDSCA and the DES-SF (See **Table 5-1**). The results were evaluated for internal consistency reliability using Cronbach's alpha coefficient and corrected item-total correlation analysis.

#### 5.4.2. Research Design

A convenience sample survey was used to test the reliability of the final Indonesian versions of the DKQ-24, the DHBM, the SDSCA, and the DES-SF in an Indonesian population.

#### 5.4.3. Sample Size

For studies based on the Theory of Planned Behaviour (TPB), it is reasonable to assume at least a moderate effect size<sup>241</sup>, to determine statistical power analysis; a sample

size of 80 would generally be acceptable.<sup>242</sup> Thus, a minimum sample size of 80 participants was recruited in this study.

#### **5.4.4. Preparation**

For conducting one-on-one patient interviews in the field test, several research assistants were required. Two general practitioners and six medical clerks from the home medical school of the researcher were recruited. Each general practitioner was asked to supervise 3 medical clerks in conducting the interviews. All research assistants were trained to conduct one-on-one patient interviews using the diabetes self-management questionnaire to simulated and real patients with T2D. They were taught to use the additional notes to help them explain the items to patients in more details during the patient interviews. This was particularly important because the majority of patients had primary school education and it was highly anticipated that it might be the first time for patients encountering research of this type and this experience could be overwhelming. The assistants were also instructed to make the interviews as pleasant as possible by engaging the patients with questions about their family, children, work and social life would make the patients feel more relaxed and familiar with the interviewer. This would also enhance a good rapport during the interviews. Additionally, the assistants were instructed to inform the patients that all questions raised by patients about diabetes-related issues would be addressed after the interviews were completed.

### **5.5. Participants**

Two community health centres (CHC) in two sub-districts in Yogyakarta City, namely Tegalrejo CHC and Gedong Tengen CHC were approached to take part in the study. The two CHCs which had collaboration with the researcher's home medical school for family medicine clerkship agreed to take part in the study. Research participants were identified from the patient registers at the centres. Included participants were adult patients with T2D aged above 18 years old who were willing to participate. Patients with T2D referred to hospital, house-bound patients and those with reduced cognitive ability, and illiterate and/ or unable to speak *Bahasa Indonesia* (the national language) were excluded.

Recruitment for adults with T2D registered at the CHCs was conducted through open advertisement placed on announcement boards and consulting rooms of the attending health care providers (general practitioners and nurses). The providers were also requested to offer participation in the study to their patients with T2D during patient-provider encounters. The providers who mostly knew their patients well provided valuable assistance

in the participant recruitment. Another valuable assistance surprisingly came from the research participants. Many participants spontaneously and happily supplied information about other diabetic people they knew in the vicinity to be invited to participate in the study. They were very excited to ask their relatives, friends and neighbours to also participate in the study. However, there was no possible way to determine how many participants were recruited from each strategy, and it was apparent from discussion with participants, that many were recruited through multiple strategies.

Javanese people, like most Indonesian people, hold a collectivist culture. The people are culturally very communal, creating closely-knit communities. Having identities based on the social network, they highly value togetherness and maintenance of social harmony, thus there is little expectation of privacy in the communities. They are helpful and inter-dependent to others and like to work and share with neighbours. There are many regular weekly and monthly community gatherings at village, hamlet and neighbourhood levels. Traditionally, people help each in various activities, such as building homes and public facilities, maintenance of public facilities, taking care of orderliness and security, farming and harvesting, and disaster management. On special occasions, such as weddings, births, illness, funeral services, many people living in the community voluntarily help the hosting family in organizing the events.<sup>243,244</sup> People living in one hamlet or neighbourhood know each other very well and sometimes even know their 'businesses' including family illnesses and problems. Local people who attend a CHC are neighbours and know each other well. It is very common for patients who go to the same CHC or sub-centres to talk about their illnesses and share information. Thus, the participants knew very well about other diabetic people in their neighbourhood.

A total of 85 adult patients with T2D registered in the two CHCs were interested in the study. Two people were not eligible due to being illiterate. The 83 eligible participants were given participant information and complaint sheets. It was emphasised that participation in the study would not influence any existing care they received at the CHCs. After signing the consent form, the participants were interviewed by trained research assistants using the diabetes self-management questionnaire consisting of the four final Indonesian instruments. Because the CHCs were very crowded during office hours, the participants were asked whether they preferred to be interviewed at the CHCs or at their homes. Many participants preferred to be interviewed at their homes because they indicated that they would feel more relaxed at home. A small gift as a token of appreciation, worth IDR 10,000 (AUD 1), was given to each participant after completing the interview.

## 5.6. Instruments and Data Analysis

### 5.6.1. The Final Indonesian Version of the 24-item Diabetes Knowledge Questionnaire (DKQ-24)

The DKQ-24 consists of 24 items about general diabetes knowledge. The items have three optional responses: *yes*, *no* and *don't know*.<sup>181</sup> All questions and their optional responses were read aloud to the participants by the research assistants. The instrument was supplemented with a large flash card containing the three optional answers. After each question was read to the participants, the research assistants asked the participants to look at the flash card and choose the response. The participants' spoken responses were then transferred to the questionnaire. In general, the participants completed the interview on the DKQ-24 in 15-20 minutes.

All data collected were entered, analysed and digitally stored using the Statistical Package for Social Sciences (SPSS) version 18. The analysis of the DKQ-24 was performed by scoring 1 for a correct response and 0 for an incorrect or don't know response. Each participant's responses were summed to attain a total raw score (0-24). The total raw score was converted into a percentage score, ranging from 0 to 100 percent. Zero indicates the lowest level of diabetes knowledge and 100 indicates the highest level diabetes knowledge.<sup>181,230</sup>

Each instrument item was analysed for the difficulty factor. This is a measure of how difficult the question was to answer. The difficulty factor of a question is the proportion of participants selecting the correct answer to that question. It is calculated by the number of correct responses divided by the total number of participants. The higher the difficulty factor, the easier the question is. For a test to discriminate between different levels of achievement, items with difficulty values between 0.3 and 0.7 are most effective. The optimal level should be 0.5.<sup>245</sup> Values above 0.9 indicate very easy items and below 0.2 indicate difficult items.<sup>246</sup>

The internal consistency reliability of the DKQ-24 instrument was assessed using Cronbach's alpha coefficient<sup>247</sup>, the most widely used reliability index of a scale.<sup>248</sup> Internal consistency indicates the extent to which all the items in a test measure the same concept or construct. Hence, it is associated with the inter-relatedness of the items within the test. Before administering a test for research or examination purposes, internal consistency should be determined to ensure validity.<sup>249</sup> Cronbach's alpha reliability coefficient is expressed as a number between 0 and 1. The closer Cronbach's alpha coefficient is to 1.0,

the greater the internal consistency of the items in the scale. A value of  $> 0.70$  is regarded as having good internal consistency.<sup>250</sup> George and Mallery (2006) suggest the following rules of thumb for Cronbach's alpha coefficient values: “  $> 0.9$  - excellent;  $> 0.8$  - good;  $> 0.7$  - acceptable;  $> 0.6$  - questionable;  $> 0.5$  - poor; and  $< 0.5$  - unacceptable” (p.231).<sup>251</sup> If omitting an item increases Cronbach's alpha significantly, then excluding the item will increase the homogeneity of the scale.<sup>250</sup>

Before translated, the original English version of the DKQ-24 was analysed for the readability index using the Flesch Reading Ease. This reading formula is a simple tool to assess the grade level of the reader. It estimates the reading comprehension level required to understand a written document based on the average number of syllables per word and the average number of words per sentence. Scores range from 0 to 100 indicating the difficulty level in understanding the document. Higher scores indicate easier reading. An average document has a score of Flesch Reading Ease between 60 and 70. As a rule of thumb, an average 5th grader can understand documents with a score of 90-100; scores of 60-70 can be understood by students of 8th and 9th grade; and scores of 0-30 can only be understood by college graduates.<sup>252</sup>

The Flesch Reading Ease is not applicable to Indonesian language, since this reading formula is primarily for assessing the difficulty of a reading passage written in English.<sup>252</sup> Therefore, the readability index of the original English instrument was used as an indicator of the readability index of the Indonesian translated instrument.

However, there might be a problem with how the readability of an instrument in one language relates to its readability in another language. In particular, a study by Kithinji and Kass (2010) showed that out of 10 pairs of forms written in English and Kiswahili, seven of the English-language forms were significantly more readable than their Kiswahili counterparts. This indicated that a readable-language consent form did not necessarily result in a readable form once translated into Kiswahili.<sup>253</sup>

### **5.6.2. The Final Indonesian Version of the Diabetes Health Belief Measure (DHBM)**

The DHBM consists of 25 items comprising one item on control (item 1) and four subscales: barriers (item 2-6), social support for diet (item 7-9), impact of job on therapy (item 10-14), and benefits of therapy (item 15-25). The responses are scored on a 5-point Likert Scale: 1= *strongly disagree*, 2= *agree*, 3= *not sure*, 4= *agree*, and 5= *strongly agree*.<sup>184,230</sup> All questions and their optional responses were read aloud to the participants by the research assistants using a two-stage approach. Obtaining Likert-scale responses using a two-stage approach with the help of flash cards was found to be most effective.<sup>184</sup> First, the

participants were asked whether they agreed or disagreed or were unsure about a statement. A large flash card containing the five optional answers was shown to them. Once the participants selected a response, they were guided to the next level: slightly agree/disagree or strongly agree/disagree. In most cases, the participants grasped the process well after answering three to five items. The participants' spoken responses were then transferred to the questionnaire. In general, the participants completed the interview on the DHBM in 20-40 minutes.

Each participant's responses were summed to attain a total raw score (5-125). The total raw score was converted into a percentage score, with a maximal score of 100 percent. A total average score for each subscale was obtained by dividing the total raw score for each subscale with completed items within the subscale. Several scores were computed because different authors of similar studies reported different DHBM scores. Higher scores indicate higher beliefs in the ability to manage diabetes.<sup>184,230,254</sup>

The internal consistency reliability of the DHBM instrument was assessed using Cronbach's alpha coefficient, with an expected value of  $> 0.70$ .<sup>247,250</sup> The original English DHBM instrument was analysed for the readability index using the Flesch Reading Ease to be used as an indicator of the readability index of the Indonesian translated instrument, with an expected score between 60 and 70.<sup>252</sup>

### **5.6.3. The Final Indonesian Version of the revised Summary of Diabetes Self-Care Activities (SDSCA)**

The SDSCA consists of 11 core items comprising five groups of self-care activities (subscales): diet, consisting of general diet (item 1-2) and specific diet (item 3-4), exercise (item 5-6), blood sugar testing (item 7-8), foot care (item 9-10), and smoking (item 11). For items 1-10 (excluding smoking), scoring is performed using the days per week on a scale of 0-7.<sup>210</sup> All questions and their optional responses were read aloud to the participants by the research assistants. The instrument was supplemented with a large flash card containing the eight optional answers (0-7 days). After each question was read to the participants, the research assistants asked the participants to look at the flash card and choose the response. The participants' spoken responses were then transferred to the questionnaire. In general, the participants completed the interview on the SDSCA in 15-20 minutes.

For each subscale, a mean number of days was calculated, with a reversed scoring on item no.4. The SDSCA revised scale authors recommend scoring of subscales separately because self-care activities vary across groups. Higher scores indicate more positive self-care activities.<sup>210</sup>

The internal consistency reliability of the SDSCA instrument was assessed using Cronbach's alpha coefficient, with an expected value of  $> 0.70$ .<sup>247,250</sup> However, the internal consistency of the original revised 11-item SDSCA was assessed using average inter-item correlations, due to the concern that Cronbach's alpha value is affected by the number of items in the scale.<sup>216</sup> If the number of items is low, the value of Cronbach's alpha is reduced.<sup>248,255</sup> Clark and Watson suggest that examining the average inter-item correlation, which is a straightforward measure of internal consistency, is more useful than alpha coefficient per se. They recommend that a mean inter-item correlation should fall in the range of 0.15 to 0.20 for scales that measure broad characteristics and between 0.40 to 0.50 for narrower constructs.<sup>256</sup> The original English SDSCA instrument was analysed for the readability index using the Flesch Reading Ease to be used as an indicator of the readability index of the Indonesian translated instrument, with an expected score between 60 and 70.<sup>252</sup>

#### **5.6.4. The Final Indonesian Version of the Diabetes Empowerment Scale – Short Form (DES-SF)**

The DES-SF consists of eight brief statements of diabetes-related psychosocial self-efficacy. The responses are scored using a 5-point Likert Scale: 1= *strongly disagree*, 2= *agree*, 3= *not sure*, 4= *agree*, and 5= *strongly agree*.<sup>30,225</sup> All questions and their optional responses were read aloud to the participants by the research assistants using a two-stage approach, as in the DHBM instrument described above (**Section 4.4.1.2**). Since this was the second instrument using the Likert scale, the participants had grasped the process more quickly. However, because the instrument questions were somewhat abstract, the research assistants had to ask additional questions (See **Table 5-1**) in order to confirm whether the participants really understood the questions. Consequently, sometimes the time taken to complete this eight-item-only instrument was often prolonged. The participants' spoken responses were then transferred to the questionnaire. In general, the participants completed the interview on the DES-SF in 15-20 minutes.

Each participant's responses were summed to attain a total raw score (5-40). The total raw score was converted into a percentage score, with a maximal score of 100 percent. A total average score was obtained by dividing the total raw score by the number of completed items ( $n=8$ ). Higher scores indicate higher levels of psychosocial self-efficacy in managing diabetes.<sup>30,225</sup> Patients who score 3.00 or less are placed in a negative attitude group, whereas patients who score greater than 3.00 are placed in the positive attitude group.<sup>257,258</sup> Several scores were computed because different authors of similar studies reported different DES-SF scores.<sup>259,260</sup>

The internal consistency reliability of the DES-SF instrument was assessed using Cronbach's alpha coefficient, with an expected value of  $> 0.70$ .<sup>247,250</sup> The original English DES-SF instrument was analysed for the readability index using the Flesch Reading Ease to be used as an indicator of the readability index of the Indonesian translated instrument, with an expected score between 60 and 70.<sup>252</sup>

## 5.7. RESULTS

### 5.7.1. Sociodemographic Characteristics and Medical History

Two heads of CHCs in Yogyakarta City consented to take part in the study. A total of 83 adults with T2D registered at the two CHCs participated in the study. They completed the interviewer-administered diabetes self-management questionnaire containing the final Indonesian version of four diabetes-related instruments. Sociodemographic characteristics of the participants are shown in **Table 5-3**.

**Table 5-0-3 Sociodemographic characteristics of the participants ( $n = 83$ )**

Characteristics	Frequency (%)	Mean (SD)
Age (years) (mean and SD)		59.36 (9.21)
Gender (%)		
Female	58 (69.9%)	
Male	25 (30.1%)	
Marital status (%)		
Unmarried	3 (3.6%)	
Married	59 (71.1%)	
Divorced	2 (2.4%)	
Widowed	19 (22.9%)	
Highest educational qualification (%)		
Primary school	41 (49.4%)	
Junior and high school	36 (43.4%)	
College and university	6 (7.2%)	
Employment (%)		
Home duties (house wife)	35 (42.2%)	
Self-employed and informal sector job	31 (37.3%)	
Public servant, police and military force	3 (3.6%)	
Private company employee	3 (3.6%)	
Retirement	11 (13.3%)	
Estimated monthly family income (in IDR and AUD equivalence) (%)		
< IDR 1,000,000 (AUD 100)	56 (67.5%)	
IDR 1,000,000 – 2,999,999 (AUD 100 – 299.99)	21 (25.3%)	
IDR 3,000,000 – 7,999,999 (AUD 300 – 799.99)	6 (7.2%)	



Mean age of the participants was 59.4 (SD 9.21; range 40-78 years). Many of the participants were elderly people (aged 60 years old and above) (53%). Female participants (69.9%) outnumbered male participants (30.1%). Most of the participants were married and had estimated monthly family income less than IDR 1,000,000 (AUD 100). Nearly half of the participants had primary school education and performed home duties as housewives. Medical history items of the participants are shown in **Table 4-4**.

**Table 5-0-4 Medical history of the participants (n = 83)**

Characteristics	Frequency (%)	Mean (SD)
Known duration of T2D (years) (mean and SD)		5.6 (6.4)
Patient education on T2D (individual or group session) (%)	14 (16.9%)	
Known family history on T2D (%)	33 (39.8%)	
Self-monitoring of blood glucose (SMBG) using a glucometer (%)	2 (2.4%)	
Hypertension (%)	38 (45.8%)	
Smoking (%)	24 (28.9%)	
Diabetes treatment *		
1. Diet (%)	73 (88%)	
2. Exercise (%)	60 (72.3%)	
3. Oral antidiabetic (%)	81 (97.6%)	
4. Insulin (%)	7 (8.4%)	
Diabetes complications *		
1. Neuropathy (nerve damage) (%)	53 (63.9%)	
2. Vision disorders (retinopathy/ glaucoma/ cataract/ corneal disease) (%)	53 (63.9%)	
3. Nephropathy (kidney disease) (%)	4 (4.8%)	
4. Erectile dysfunction (impotence) (%)	13 (15.7%)	
5. Heart disease (%)	7 (8.4%)	
6. Stroke (%)	1 (1.2%)	
7. Peripheral vascular disease (foot ulcers/ gangrene) (%)	20 (24.1%)	
Family and social support for managing T2D (%)		
No	9 (10.8%)	
Yes	74 (89.2%)	
Health insurance coverage (%)		
No insurance	33 (39.8%)	
Government health security for poor people (Jamkesmas)	28 (33.7%)	
Government health insurance (Askes)	22 (26.5%)	

\* Multiple responses were selected

Mean known duration of diabetes was 5.6 (SD = 6.4; range = 1-30 years). Only a small number of participants (16.9%) stated that they received diabetes education, either as individual sessions (conducted by general practitioners, nurses or nutritionists) or groups sessions as in diabetes seminars (usually conducted by internal medicine specialists and nutritionists). One participant admitted of not having any diabetes treatment modalities (i.e.: diet, exercise, oral antidiabetics, and insulin), and one participant used only insulin.

Meanwhile, only four participants used all four diabetes treatment modalities. Only two participants performed SMBG using a glucometer, although there were seven participants using insulin injections. While most common complications found among the participants were neuropathy (63.9%) and vision disorders (63.9%), nearly 46% participants had both complications. Eleven participants (13.3%) had no complications at all. The majority of participants (89.2%) had family and social support for managing their diabetes which mostly came from the members of their nuclear family. Nearly forty percent of the participants did not have any health insurance.

### **5.7.2. The 24-item Diabetes Knowledge Questionnaire (DKQ-24)**

The Flesch Reading Ease index for the original DKQ-24 was 63.2, which was scored as 'standard'. The Cronbach's alpha value for the Indonesian version of the DKQ-24 instrument was 0.603, below the recommended value of above 0.7. The difficulty factor and the corrected item-total correlation of all items are shown in **Table 5-5**.

Corrected item-total correlations were used to identify items which did not agree well with the other items. The values for corrected item-total correlations should exceed 0.3 to be considered as acceptable.<sup>261</sup> Based on this criterion, 19 items did not meet the requirement. The Cronbach's alpha value for each item representing the effect of removing the item from the calculation of overall Cronbach's alpha value was also computed. The results showed that the internal consistency of the DKQ-24 instrument remained close to the overall Cronbach's alpha of 0.603 with the removal of any of these items. Therefore, all 24 items were retained.

The range of difficulty factor for 24 items were 0.05–0.95 with a mean (SD) of 0.47(0.29), which was desirable. Out of 24 questions, sixteen items (66.67%) had values between 0.3 and 0.7, indicating most effective. Seven items (29.17%) had values below 0.2, indicating difficult items. One item (4.17%) had a difficulty factor more than 0.90, indicating a very easy item.<sup>245,246</sup> The results showed that the DKQ-24 instrument was able to effectively discriminate between different levels of achievement on diabetes knowledge.

Mean of the DKQ-24 total raw score was 11.03 (SD = 3.04; range = 4-20); mean of the percentage score was 47.10 (SD = 12.66; range 16.67-83.33). Most participants (73.5%) had a percentage score of 50 or less (total raw score of 12 or less), indicating that the test was fairly difficult for the participants. This showed that the baseline level of diabetes knowledge among the participants was low.

**Table 5-0-5 Psychometric properties of the Indonesian version of DKQ-24 instrument**

No.	Item and Correct Answer	Difficulty Factor	Corrected Item-Total Correlation	Cronbach's Alpha if Item Deleted
1.	Eating too much sugar and other sweet foods is a cause of diabetes. [No]	0.05	-0.027	0.609
2.	The usual cause of diabetes is lack of effective insulin in the body. [Yes]	0.46	0.416	0.559
3.	Diabetes is caused by failure of the kidneys to keep sugar out of the urine. [No]	0.18	0.334	0.576
4.	Kidneys produce insulin. [No]	0.17	0.388	0.569
5.	In untreated diabetes, the amount of sugar in the blood usually increases. [Yes]	0.90	0.206	0.594
6.	If I am diabetic, my children have a higher chance of being diabetic. [Yes]	0.59	0.321	0.574
7.	Diabetes can be cured. [No]	0.36	0.285	0.579
8.	A fasting blood sugar level of 210 is too high. [Yes]	0.80	0.277	0.582
9.	The best way to check my diabetes is by testing my urine. [No]	0.49	0.211	0.590
10.	Regular exercise will increase the need for insulin or other diabetic medication. [No]	0.17	0.244	0.587
11.	There are two main types of diabetes: Type 1 (insulin-dependent) and Type 2 (non-insulin dependent). [Yes]	0.35	0.282	0.580
12.	An insulin reaction is caused by too much food. [No]	0.17	0.319	0.578
13.	Medication is more important than diet and exercise to control my diabetes. [No]	0.40	0.260	0.583
14.	Diabetes often causes poor circulation. [Yes]	0.76	0.114	0.602
15.	Cuts and abrasions on diabetes heal more slowly. [Yes]	0.76	0.039	0.611
16.	Diabetics should take extra care when cutting their toenails. [Yes]	0.95	0.034	0.605
17.	A person with diabetes should cleanse a cut with iodine and alcohol. [No]	0.06	-0.078	0.613
18.	The way I prepare my food is as important as the foods I eat. [Yes]	0.70	-0.050	0.624
19.	Diabetes can damage my kidneys. [Yes]	0.81	0.201	0.591
20.	Diabetes can cause loss of feeling in my hands, fingers and feet. [Yes]	0.83	0.055	0.607
21.	Shaking and sweating are signs of high blood sugar. [No]	0.17	0.143	0.598
22.	Frequent urination and thirst are signs of low blood sugar. [No]	0.53	-0.033	0.625
23.	Tight elastic hose or socks are not bad for diabetics. [No]	0.45	0.297	0.577
24.	A diabetic diet consists mostly of special foods. [No]	0.22	0.138	0.599

### 5.7.3. The Diabetes Health Belief Measure (DHBM)

The Flesch Reading Ease index for the original DHBM was 65, which was scored as 'standard'. The overall Cronbach's alpha coefficient for the Indonesian version of the DHBM instrument was 0.737, within the recommended value of above 0.70. The internal consistency coefficients for the four subscales were 0.462, 0.826, 0.723, and 0.688, respectively. The psychometric properties of the DHBM are shown in **Table 5-6**.

The corrected item-total correlations of all items were examined to identify items which did not agree well with the other items. The values for corrected item-total correlations should exceed 0.3 to be considered as acceptable.<sup>261</sup> Using this criterion, 13 items did not meet the requirement. The Cronbach's alpha value for each item representing the effect of removing the item from the calculation of overall Cronbach's alpha value was also computed. The results showed that the internal consistency of the DKQ-24 instrument remained close to the overall Cronbach's alpha of 0.737 with the removal of any of these items. Therefore, all 25 items were retained.

Mean of the DHBM total raw score was 91.81 (SD = 6.46; range = 69-102); mean of the percentage score was 73.45 (SD 5.16; range 55.20-81.60). The majority of participants (71.1%) had a percentage score of 70.4 or above (total raw score of 88 or above). This showed that the baseline level of diabetes health beliefs among the participants was relatively high.

However, among the four adapted instruments, the DHBM was considered as the most challenging and time-consuming instrument by the research assistants during patient interviews. The research assistants reported that many participants were confused in their attempts to understand and answer the questions.

Table 5-0-6 Psychometric properties of the Indonesian version of DHBM instrument

No.	Item and Correct Answer	Cronbach's Alpha Coefficient of Subscales	Corrected Item-Total Correlation	Cronbach's Alpha if Item Deleted
<b>Control of Diabetes</b>				
1.	My diabetes is well controlled.		0.047	0.741
<b>Barriers Subscale</b>		0.462		
2.	I would have to change too many habits to follow my diet (diabetic foods).		-0.086	0.756
3.	It has been difficult following the diet (diabetic foods) the doctor ordered for me.		0.446	0.713
4.	I am confused by all the medication the doctor has given me.		0.211	0.734
5.	I would have to change too many habits to take my medication.		0.357	0.722
6.	Taking my medication interferes with my normal daily activities.		0.151	0.736
<b>Social Support Subscale</b>		0.826		
7.	I have others around me who remind me to eat the right foods.		0.170	0.738
8.	I can count on my family when I need help following my diet (diabetic foods).		0.262	0.730
9.	My husband/wife helps me follow my diet (diabetic foods).		0.253	0.730
<b>Impact of Job on Therapy Subscale</b>		0.723		
10.	If I changed "jobs" I would be easier to follow my diet (diabetic foods).		0.495	0.710
11.	My work makes me so tired that it's hard to follow my diet (diabetic foods).		0.521	0.707
12.	I could control my weight if the pressures of my job weren't so great.		0.192	0.739
13.	If I changed "jobs", it would be easier to take my medication.		0.457	0.713
14.	I worry so much about my job that I can't take my medication		0.404	0.719
15.	I believe that my diet (diabetic foods) will help prevent diseases (complications) related to diabetes.		0.357	0.725
16.	Following a prescribed diet (diabetic foods) is something a person must do no matter how hard it is.		0.394	0.723
<b>Benefits of Therapy Subscale</b>		0.688		
17.	I believe that my diet (diabetic foods) will control my diabetes		0.338	0.727
18.	I must follow my diet (diabetic foods) even if I don't think I am getting better.		0.337	0.725
19.	In general, I believe that my diet (diabetic foods) for diabetes will help me to feel better.		0.307	0.731
20.	Controlling weight is something one must do no matter how hard it is.		0.256	0.730
21.	I believe that my medication will help prevent diseases (complications) related to diabetes.		0.018	0.739
22.	Taking medication is something one must do no matter how hard it is.		0.176	0.734
23.	I believe that my medication will control my diabetes.		0.267	0.731
24.	I must take my diabetes medication even if I don't think I am getting better.		0.303	0.7270
25.	I believe that my medication for diabetes will help me to feel better.		0.205	0.734

### 5.7.4. The Summary of Diabetes Self-Care Activities (SDSCA)

The Flesch Reading Ease index for the original SDSCA was 72, which was scored as ‘fairly easy to read’. The Cronbach’s alpha value for the Indonesian version of the SDSCA instrument was 0.473, below the recommended value of above 0.7. The psychometric properties of the SDSCA are shown in **Table 5-7**. The average inter-item correlation was 0.075, below the recommended value range (0.15-0.50).

**Table 5-0-7 Psychometric properties of the Indonesian version of SDCSA instrument**

No.	Item and Correct Answer	Cronbach’s Alpha Coefficient of Subscales	Corrected Item-Total Correlation	Cronbach’s Alpha if Item Deleted
<b>General Diet</b>		0.914		
1.	How many of the last SEVEN DAYS have you followed a healthful eating plan?		0.509	0.318
2.	On average, over the past month, how many DAYS PER WEEK have you followed your eating plan?		0.496	0.732
<b>Specific Diet</b>		-0.619		
3.	On how many of the last SEVEN DAYS did you eat five or more servings of fruits and vegetables?		0.187	0.431
4.	On how many of the last SEVEN DAYS did you eat high fat foods such as red meat or full-fat dairy products?		-0.096	0.507
<b>Exercise</b>		0.180		
5.	On how many of the last SEVEN DAYS did you participate in at least 30 minutes of physical activity? (Total minutes of continuous activity, including walking).		0.170	0.439
6.	On how many of the last SEVEN DAYS did you participate in a specific exercise session (such as swimming, walking, biking) other than what you do around the house or as part of your work?		0.215	0.420
<b>Blood Sugar Testing</b>		0.830		
7.	On how many of the last SEVEN DAYS did you test your blood sugar?		0.173	0.450
8.	On how many of the last SEVEN DAYS did you test your blood sugar the number of times recommended by your health care provider?		0.083	0.458
<b>Foot Care</b>		0.444		
9.	On how many of the last SEVEN DAYS did you check your feet?		0.145	0.452
10.	On how many of the last SEVEN DAYS did you inspect the inside of your shoes?		0.168	0.444
<b>Smoking</b>				
11.	Have you smoked a cigarette—even one puff—during the past SEVEN DAYS?		-0.080	0.473
<b>Overall scale</b>		0.457		

The corrected item-total correlations of all items were examined to identify items which did not agree well with the other items. The values for corrected item-total correlations should exceed 0.3 to be considered as acceptable.<sup>261</sup> Using this criterion, 9 items did not meet the requirement. The Cronbach's alpha value for each item representing the effect of removing the item from the calculation of overall Cronbach's alpha value was also computed. The results showed that the internal consistency of the SDSCA instrument remained close to the overall Cronbach's alpha of 0.457 with the removal of any of these items. Therefore, all 11 items were retained.

The additional two items (7A and 8A) were not included in the analysis of the SDSCA, but analysed separately in descriptive statistics, as shown in **Table 5-8**.

**Table 5-0-8 Additional items of the Indonesian version of SDSCA instrument**

No.	Additional Items	Frequency (%)	Mean (SD)
7A.	Have you had your blood sugar tested in the last MONTH? [%]		1.16 (0.93)
	None	14 (16.9%)	
	Yes, 1 x in a month	54 (65.1%)	
	Yes, 2 x in a month	7 (8.4%)	
	Yes, 3 x in a month	4 (8.4%)	
	Yes, 4 x in a month	4 (8.4%)	
8A.	How many times in the past MONTH did your health care providers recommend you to have your blood sugar tested?		1.47 (1.38)
	Not recommended	32 (38.6%)	
	Recommended, 1 x in a month	42 (50.6%)	
	Recommended, 2 x in a month	3 (3.6%)	
	Recommended, 3 x in a month	1 (1.2%)	
	Recommended, 4 x in a month	5 (6.0%)	

The responses for additional item 7A were mostly blood sugar testing once a month, as predicted. The responses for additional item 8A were also mostly blood sugar testing recommendation once a month.

Mean scores of the SDSCA subscales were as follows: general diet was 5.06 (SD = 2.18; range = 0-7); specific diet was 4.23 (SD = 1.49; range = 1-7); exercise was 3.25 (SD = 2.04; range = 0-7); blood sugar testing was 0.54 (SD = 0.52; range = 0-1.5), and foot care was 2.46 (SD = 2.55; range = 0-7). The number of current smokers was 13 people (15.7%), range number of cigarettes smoked was 1-24. Among the subscales, blood sugar testing had the lowest mean score and range of values.

### 5.7.5. The Diabetes Empowerment Scale – Short Form (DES-SF)

The Flesch Reading Ease index for the original DES-SF was 65, which was scored as 'standard'. The Cronbach's alpha value for the Indonesian version of the DHBM instrument was 0.555, below the recommended value of above 0.7. The psychometric properties of the DHBM are shown in **Table 5-9**.

**Table 5-0-9 Psychometric properties of the Indonesian version of DES-SF instrument**

No.	Item and Correct Answer	Corrected Item-Total Correlation	Cronbach's Alpha if Item Deleted
<b>In general, I believe that:</b>			
1.	I know what part(s) of taking care of my diabetes that I am dissatisfied with.	0.205	0.541
2.	I am able to turn my diabetes goals into a workable plan.	0.179	0.547
3.	I can try out different ways of overcoming barriers to my diabetes goals.	0.246	0.549
4.	I can find ways to feel better about having diabetes.	0.555	0.422
5.	I know the positive ways I cope with diabetes-related stress.	0.366	0.483
6.	I can ask for support for having and caring for my diabetes when I need it.	0.033	0.592
7.	I know what helps me stay motivated to care for my diabetes.	0.114	0.559
8.	I know enough about myself as a person to make diabetes care choices that are right for me.	0.478	0.443

The corrected item-total correlations of all items were examined to identify items which did not agree well with the other items. The values for corrected item-total correlations should exceed 0.3 to be considered as acceptable.<sup>261</sup> Using this criterion, 5 items did not meet the requirement. The Cronbach's alpha value for each item representing the effect of removing the item from the calculation of overall Cronbach's alpha value was also computed. The results showed that the internal consistency of the DES-SF instrument remained close to the overall Cronbach's alpha of 0.555 with the removal of any of these items. Therefore, all 8 items were retained.

Mean of the DES-SF total raw score was 30.01 (SD = 2.65; range = 20-33); mean of the percentage score was 75.03 (SD = 6.62; range = 50-82.5); mean of average score was 3.75 (SD = 0.33; range= 2.5-4.13). The majority of participants (92.8%) had an average score above 3 (a total raw score above 26; a percentage score above 65%), having positive attitudes towards diabetes psychosocial self-efficacy.



## 5.8. DISCUSSION

The cross-cultural adaptation provided preliminary evidence of the validity and reliability of the Indonesian version of four previously validated diabetes-related instruments: the DKQ-24, the DHBM, the SDSCA and the DES-SF. The four instruments underwent several steps of the cross-cultural adaptation process: forward translation, synthesis of the translations, backward translation, content validity, pre-test of the pre-final Indonesian version, and field test of the final Indonesian version of the instruments process.<sup>231,233,235</sup> The final Indonesian version of the four instruments were compiled into one diabetes self-management questionnaire, which also contained sociodemographic and medical history items, giving a total of 84 items.

To cross-culturally adapt the four diabetes-related instruments from English-speaking population to an Indonesian population with a totally different culture was very challenging. The major challenge was administering instruments that were previously developed for self-completion among patients living in Western countries with a higher level of education and greater exposure to research methods, to the research participants with a lower level of education and less exposure to research methods. Therefore, the diabetes questionnaire was not for self-completion, rather as one-on-one patient interviews conducted by trained research assistants based on the questionnaire items and guided by large flash cards containing optional answers for each instrument.

The four selected diabetes instruments for adaptation were originally administered differently. Two instruments, i.e. the 24-item DKQ and the DHBM, were developed and validated among Mexican Americans with low SES and low level of education who were similar with the target research participants, and administered in structured interviews. The other two instruments, the SDSCA and the DES, were developed and validated among people in Western countries who were generally had better SES and higher level of education than the target research participants, and therefore were administered as self-completed questionnaires. However, in order to suit the local conditions since the participants were generally had low SES, low level of education and little research exposure, all adapted instruments were administered in structured interviews. In the community where most people have poor literacy skills, self-completed questionnaire would be impractical since they would not be able to complete it. Face-to-face interviews overcame this problem.

Administering interviewer-completed questionnaires conducted by trained interviewers had both advantages and disadvantages. Structured interviews provided several advantages. In particular, the personal contact of face-to-face interviews was helpful for this

long research questionnaire that combined 4 different instruments. The presence of an interviewer allowed for complex questions to be explained to the interviewee, if necessary. Additionally, the structured interviews were seen as rewarding experiences by the participants. Meanwhile, the disadvantages were: 1) The interviewer-completed questionnaires were more time consuming to complete due to the necessary provision of more explanation or even out-of-topic chats during the interviews; 2) Face-to-face interviews might obtain less accurate answers, particularly for sensitive or controversial questions which might be affected by social desirability considerations (giving acceptable rather than true answers); 3) The observable characteristics (e.g. gender, race, class) of even the best trained interviewers could affect responses; 4) Some interviewers could contaminate results by placing their own interpretation on questions, revealing their opinions, or even fabricating results; and 5) The presence of another person (e.g. a family member, a friend, another patient, the interviewer) could affect responses.<sup>262</sup>

As expected, completing the interviewer-administered questionnaires took longer time than self-administered questionnaires. This was particularly because more time was required in order to explain the instructions for the instruments and the meaning of individual questions, coupled with the need for some additional questions for clarifications. For example, for the DES-SF (8 items) which requires only 5 minutes of self-completion<sup>258</sup>, it took 10-15 minutes to be completed during patient interviews in the current study. The average time taken to complete the whole 84-item questionnaire with a patient interview was 75-120 minutes.

In general, as reported by the research assistants, the participants were very pleased to be interviewed about their diabetes. Although the participants might be overwhelmed by the number of questions and were unaccustomed to answering questionnaires, they were excited to be given ample time to talk to health personnel, since this was a rare experience for them. Many participants were very talkative wanting to tell more about their diabetes experience, beyond what was asked. The research assistants then had to guide the participants back to the questionnaire items. The participants greatly appreciated the interviews and thanked the research assistants for their time to interview and chat with them.

However, among the four adapted instruments, the DHBM was considered as the most challenging and time-consuming instrument by the research assistants during patient interviews, and reported as confusing. This is possibly because the DHBM is lengthy with 25 items and comprises long sentences that have similarities from one to another.

The original English version of the four instruments had a Flesch Reading Ease index range of 63.2 to 72. These are within the preferred range score of 60-70, indicating that the instruments are suitable for the average adult to read.<sup>252</sup> The results of the readability index of the original English instruments were used to gauge the readability index of the Indonesian translated versions. The standard level of the original instruments' readability index indicated that the instruments were suitable for use in the current population, particularly since additional efforts were made to explain the questions to the participants.

The content validity of the four translated instruments, evaluated using the Content Validity Index (CVI), was assessed by a panel of 8 Indonesian experts in the field. The translated Indonesian instruments obtained satisfactory average total CVI scores: the DKQ-24 = 0.81; the DHBM = 0.83; the SDSCA = 0.89; and the DES-SF = 0.88. A CVI score of minimum 0.80 is considered to have good content validity.<sup>238</sup>

The Cronbach's alpha coefficient for the Indonesian version of the DKQ-24 instrument was 0.603. This value is classified as 'questionable', while values above 0.7 are considered acceptable and above 0.8 are preferable.<sup>251</sup> The original DKQ-24 was validated among low socioeconomic group of Mexican Americans with a reliability coefficient of 0.78,<sup>181</sup> and has been used to measure diabetes-related knowledge in diabetes educational intervention studies conducted among English and Spanish speaking communities.<sup>230,254,263,264</sup>

The low value of Cronbach's alpha in the current study was possibly related to the small range of diabetes knowledge in the study sample indicating a low baseline understanding of diabetes. The majority of the DKQ-24 total score of the participants were mostly 50 or less, with a mean of 47.10 (SD = 12.66). In contrast, in a previous study, Lujan et al. reported the mean baseline DKQ-24 scores for the intervention and control group was 69.1 (SD = 13.6) and 66.9 (SD = 15.2), respectively,<sup>230</sup> which were much higher than the results obtained in the present study. Lower baseline mean DKQ-24 scores were reported by Brown et al. in the original Starr County community study for the intervention and control group: 36.23 (SD = 6.17) and 37.30 (SD = 6.28).<sup>184</sup>

The mean difficulty index of the current study was 0.47 (SD = 0.29), which is desirable. The average difficulty level of the original DKQ-24 was 0.57.<sup>181</sup> Most items of the DKQ-24 had effective difficulty index values between 0.3 and 0.7, indicating that the instrument was able to effectively discriminate between different levels of achievement on diabetes knowledge in the study population. However, for the participants in the study, the DKQ-24 instrument most likely contained fairly difficult items as shown in the low DKQ-24 scores. The low baseline level of diabetes knowledge among the participants was possibly

related to the very low number of participants (16.9%) who received diabetes education from their health care providers. Furthermore, the traditional diabetes education received by patients at CHCs was primarily focused on diabetes meal planning, mostly conducted by a nutritionist. Underlying mechanisms of T2D and its related symptoms and complications were rarely discussed in the diabetes education. Meanwhile, approximately two-thirds of the DKQ-24 items are about underlying diabetes mechanisms. The participants were most likely unfamiliar with the questions containing diabetes mechanisms and found them difficult.

The participants were regular attendees of the CHCs who mostly had low socioeconomic status (with very low monthly family income) and had low education levels (primary school). This indicated a more homogenous sample which might also contribute to the low Cronbach's alpha value.<sup>248,265</sup>

Nunnally recommended an alpha value of 0.50 to 0.60 for the early stages of research in the first version of his book,<sup>266</sup> although he then increased it to 0.70 in later versions of his book.<sup>255,267</sup> However, Clark and Watson suggest that some contemporary researchers define the Cronbach's alpha values in the 0.60s and 0.70s as good or adequate.<sup>256</sup> Since this was a preliminary cross cultural adaptation study of the DKQ-24 for an Indonesian population, the Cronbach's alpha value of 0.603 could therefore be considered having adequate internal consistency reliability for use in an Indonesian population.

Despite somewhat low Cronbach's alpha value and low corrected item-total correlations of the DKQ-24, it was important to retain all items of a previously validated instrument since this enabled the results in the current study to be compared with other studies using the instrument.<sup>268</sup> According to Straub, researchers using previously validated instrument should be careful not to make significant changes in the validated instrument without revalidating instrument content, constructs and reliability.<sup>232</sup> Juniper suggests that validated questionnaires should not be modified; cultural adaptation should meet the original specifications for the instrument, and the measurement properties remain the same as those of the original.<sup>269</sup> Additionally, the cross cultural adaptation – a pilot study and the first of its kind in Indonesia – was conducted for scoping reasons. However, the study was conducted particularly among participants with low SES and low level of education at community health centres. Therefore retaining all items was deemed necessary for further studies which include more heterogenous population, i.e. also covering middle to upper SES and education level.

The overall Cronbach's alpha coefficient for the Indonesian version of the DHBM instrument was 0.737. This is regarded as 'acceptable'.<sup>251</sup> The internal consistency

coefficient for the four subscales - 'barriers', 'social support for diet', 'impact of job on therapy', and 'benefits of therapy' - were 0.462, 0.826, 0.723, and 0.688, respectively. These results were comparable with the alpha coefficients of the original DHBM subscales: 0.56, 0.62, 0.86 and 0.90, respectively. The original DHBM was validated among low socioeconomic group of Mexican Americans,<sup>184</sup> and has been used to measure diabetes-related health beliefs in diabetes educational intervention studies conducted among English and Spanish speaking communities.<sup>230,254,264</sup> Despite somewhat low corrected item-total correlations of the DHBM, it was important to retain all items of the instrument in the current study for the same reasons as discussed for the DKQ-24 above.<sup>232,268,269</sup>

The majority of the participants' DHBM scores in the current study were above 70, with a mean of 73.45 (SD = 5.16), indicating that the participants had relatively high beliefs in their ability to manage diabetes. Lujan et al. reported the mean baseline DHBM score of 56.4 (SD = 12.2) and 57.0 (SD = 11.2) for intervention and control group respectively, which was lower than the current result. The high DHBM score of the current study was particularly interesting given the low baseline level of diabetes knowledge among this sample. This may reflect the general attitude of the participants as Javanese people. The Javanese people are the largest ethnic group in Indonesia and have been generally identified among other ethnic groups as having 'soft' characteristics in their everyday life due to their life philosophy "*Nrimo ing pandum*" (in Javanese local language). This literally means "accepting things wholeheartedly without protesting or rejecting as they have been preordained to happen". Thus when Javanese people face life's ordeals, such as conflicts, poverty, illness, they culturally tend to manage the situation with this philosophy. Applying this life philosophy helps to manage the emotions they feel inside.<sup>270</sup> The participants had possibly applied this life philosophy in their condition of having diabetes, thus contributing to the participants' positive attitude towards managing their diabetes.

The Cronbach's alpha coefficient for the Indonesian version of the SDSCA instrument was 0.473. This is regarded as 'unacceptable'.<sup>251</sup> The internal consistency of the original SDSCA was assessed using the average inter-item correlation (mean = 0.47)<sup>210</sup>, rather than Cronbach's alpha, due to the low number of items in the scale.<sup>216</sup> The average inter-item correlation of the current study was 0.075, which was also below the recommended value (0.15-0.50).<sup>256</sup> Despite somewhat low Cronbach's alpha value and low corrected item-total correlations of the SDSCA, it was important to retain all items of the instrument in the current study for the same reasons as discussed for the DKQ-24 above.<sup>232,268,269</sup>

A low Cronbach's alpha coefficient was also reported in the Maltese version of the 11-item SDSCA ( $\alpha = 0.503$ ).<sup>216</sup> Choi et al. reported a moderate overall Cronbach's alpha

coefficient for the Korean version of the 11-item SDSCA ( $\alpha = 0.66$ ). By deleting item 4 (high fat foods) and item 11 (smoking), the Cronbach's alpha coefficient improved to 0.69, resulting in the final Korean version of the SDSCA (SDSCA-K) with 9 items.<sup>219</sup> The Spanish version of the SDSCA was reported to have a Cronbach's alpha coefficient of 0.68. This Spanish version of the scale had 12 items, with an additional item on diabetes medications.<sup>215</sup> The Turkish version of the SDSCA was reported to have a good internal consistency reliability coefficient ( $\alpha = 0.72$ ). This Turkish version of the scale also had 12 items, with an additional item on diabetes medications.<sup>217</sup> The Malay version of the SDSCA was reported to have a Cronbach's alpha coefficient of 0.735, calculated on ten items, excluding an item on smoking.<sup>220</sup>

The much lower Cronbach's alpha coefficient and average inter-item correlation in the current study as compared to the original SDSCA and other language versions of the scale was most likely related to blood testing items (item 7 and 8). As previously anticipated, there was a low variability of responses on these two items based on the local protocol on blood sugar testing at the CHCs, i.e. once a month, which was confirmed by attending HCPs. The protocol, which was more administrative than clinical-based, was particularly applied for patients with T2D who were covered by Jamkesmas, the government health security for poor people, due to limited funds. Patients who paid for blood tests out of pocket could have blood sugar testing more frequently as they wished. Nearly one-third of the participants were covered by Jamkesmas. The majority of the responses thus were either be 0 or 1 day per week, which was shown in the low mean score of blood sugar testing as compared to mean scores of other subscales. Although calculation of Cronbach's alpha coefficient within the blood testing subscale was high ( $\alpha = 0.830$ ), this low variability of item responses within this subscale possibly affected the calculation of the low overall scale.

The low variability in the responses was also supported by responses of the additional items on blood testing (item 7A and 8A) particularly developed to clarify the problem. Nearly two-thirds of the participants' responses for additional item 7A were once a month blood sugar testing. More than half of the participants' responses for additional item 8A were once a month blood sugar testing recommendation.

While the small number of items in the scale ( $n = 11$ ) most likely resulted in the low Cronbach's alpha value,<sup>248,255</sup> the homogeneity of the study sample, as discussed above, possibly also contributed to the low alpha value.<sup>248,265</sup> The research participants mostly came from lower socioeconomic groups in the community who tended to access publicly funded CHCs for their first contact care. Service fees at the CHCs were generally cheap. The fee of a medical consultation with a general practitioner or a nurse including the provision of generic medications prescribed and laboratory tests needed was only IDR 2,000–10,000

(Australian 20 cents to AUD 1), depending on the provinces. The fees at the CHCs in Yogyakarta City were IDR 2,000. The government health security for poor people, Jamkesmas, obliges the covered poor people to access CHCs as their first contact care. No payment is charged for the patients covered by Jamkesmas.

The Cronbach's alpha coefficient for the Indonesian version of the DES-SF instrument was 0.555. This is classified as 'poor'.<sup>251</sup> The internal consistency reliability of the original DES-SF was 0.84.<sup>225</sup> Despite somewhat low Cronbach's alpha value and low corrected item-total correlations of the DES-SF, it was important to retain all items of the instrument in the current study for the same reasons as discussed for the DKQ-24 above<sup>232,268,269</sup>.

The low Cronbach's alpha coefficient of the DES-SF in the current study possibly related to several factors, as previously described, including: the small number of items in the scale ( $n=8$ ),<sup>248,255</sup> and the homogeneity of the study sample.<sup>248,265</sup> Furthermore, Kline (1999) suggests that for items with psychological constructs, Cronbach's alpha values below 0.70 can realistically be expected due to the diversity of the constructs being measured.<sup>261</sup>

The majority of participants (92.8%) had a total raw score above 24 with a mean of 30.01 (SD = 2.65) or an overall score above 3 with a mean of 3.75 (SD = 0.33), indicating a high baseline level of diabetes psychosocial self-efficacy among the participants. The high baseline DES-SF score in the current study was particularly interesting given the low baseline level of diabetes knowledge among this sample. This may reflect the positive general attitude of the participants as Javanese people by implementing a life philosophy of "*Nrimo ing pandum*",<sup>270</sup> as previously discussed. The participants had possibly applied this life philosophy in their condition of having diabetes, thus contributing to the participants' positive attitude towards managing their diabetes.

Anderson et al (2005) reported a mean baseline DES-SF score of 3.89 (0.73) of the whole study sample in a problem-based empowerment programme for African Americans with diabetes.<sup>259</sup> In a culturally tailored diabetes education intervention for rural African Americans, Utz et al (2008) reported a mean baseline DES-SF total raw score of 33.0 (4.57) and 34.25 (4.27) for group education and individual education, respectively.<sup>260</sup> These DES-SF scores from previous studies conducted in English speaking populations in the United States, as anticipated, were higher than the results of the present study.

Among the four adapted diabetes-related instruments, the Indonesian version of the DHBM yielded the most adequate result of internal consistency reliability ( $\alpha = 0.737$ ). The DHBM is therefore a valid and reliable instrument for use in an Indonesian population to measure diabetes-related health beliefs. The Indonesian version of the DKQ-24 ( $\alpha = 0.603$ ).

and the DES-SF ( $\alpha = 0.555$ ), although having lower Cronbach's alpha coefficients than the recommended value, having previously discussed circumstances, were still considered as adequate for use in Indonesian population. The Indonesian version of the SDSCA had the lowest Cronbach's alpha coefficient ( $\alpha = 0.473$ ), which was an unacceptable value. However, as this was a preliminary study and having previously discussed circumstances, the Indonesian SDSCA was still considered for use in the main study, i.e. a cluster randomised controlled study.

Despite the varying results of internal consistency reliability in this preliminary cross-cultural adaptation study, due to limited time and resources, it was decided to still proceed and use all four Indonesian versions of diabetes-related instruments to evaluate a diabetes self-management education intervention in the main study. Psychometric analysis of the adapted instruments was planned to be performed again on a larger sample in the main study.

## **5.9. LIMITATIONS**

The homogeneity of the study sample which mostly consisted of people with low socioeconomic status and low education level, as one of the factors causing the low Cronbach's alpha value was a limitation of the study. Conducting the field test in a more heterogeneous population with a larger sample, i.e. including patients with T2D attending secondary and tertiary care in hospitals or medical specialist practices, in order to represent more diverse socioeconomic groups with a broader range of diabetes-related capacity, would possibly yield a better result. Other limitations of the study include not conducting test-retest reliability and construct validity, in response to unfavourable preliminary results of internal consistency reliability.

While there are several readability formulas for English texts, there is very little in the academic literature about foreign language readability assessment. The problem of gauging the readability of non-English materials is rarely discussed. There is one readability formula which holds promise for assessing text difficulty in other languages including English. This is the Lix Readability Formula, developed by Carl-Hugo Bjornsson, a Swedish scholar.<sup>271</sup> We intend to use this readability formula for future studies, since there is no readability formula for Indonesian language.



## 5.10. CONCLUSIONS AND RECOMMENDATIONS

### 5.10.1. Conclusions

Several conclusions could be drawn from this chapter as follows:

- 1) The process of cross-cultural adaptation was challenging, particularly administering instruments that were previously developed for self-completion among patients living in Western countries with higher education levels and greater exposure to research methods than the research participants attending Indonesian community health centres. The research participants in this study had low education levels and no previous exposure to research.
- 2) However, the cross-cultural adaptation did provide preliminary evidence of the validity and reliability of the Indonesian version of four previously validated diabetes-related instruments, namely the DKQ-24, the DHBM, the SDSCA and the DES-SF, with varying results.
- 3) In particular, the DHBM instrument demonstrated satisfactory validity and reliability to be used in an Indonesian population. Despite the low Cronbach's alpha coefficients, it was demonstrated that the DKQ-24 and the DES-SF were adequate for use as research instruments in the main study – a cluster randomised controlled trial of a pilot model of a structured diabetes education programme. Having the lowest Cronbach's alpha coefficient in this preliminary study, the SDSCA was also still considered for use as a research instrument in this research project. However, more work was needed to adapt the other three instruments to an Indonesian context.
- 4) The low reliability coefficients demonstrated in the present study were most likely related to the homogeneity of the study sample that inclined towards low socioeconomic status and low education level, showing a small range of diabetes related capacity.
- 5) Despite the low reliability coefficients of three adapted instruments, due to time and resource constraints, all four Indonesian versions of diabetes-related instruments were used in the main study. The internal consistency reliability regarding the adapted instruments was reassessed in the cluster randomised controlled study.

### 5.10.2. Recommendations

The recommendations which emerged from this chapter include:

- 1) Further cross-cultural adaptation studies of the four adapted diabetes-related instruments with a more heterogeneous sample are required. For example, a suitable sample would include patients with type 2 diabetes coming from higher socioeconomic status and education level in order to represent more diverse population groups with a broader range of diabetes-related capacity. These patients usually attend secondary and tertiary care in hospitals or medical specialist practices.
- 2) New diabetes-related instruments for use in an Indonesian population as a developing nation which take into account the perspectives of Indonesian culture and context are needed. These new instruments could also be used in other developing countries.

### 5.11. SUMMARY

In summary, the underlying reason to cross-culturally adapt existing validated diabetes-related instruments was the limited availability of adequate diabetes-related instruments written in *Bahasa Indonesia*, particularly instruments catering to the research objectives. The “cross-cultural adaptation” encompasses a process addressing both language translation and cultural adaptation issues in preparing an instrument for use in another setting, based on international norms, including: forward translation, synthesis of translations, backward translation, content validity, pre-test of the pre-final Indonesian version of the four instruments, and field test of the final Indonesian version of the four instruments.

This chapter has outlined the steps of cross-cultural adaptation process, the psychometric issues and statistical analysis of the selected diabetes-related instruments previously validated in English-speaking population for use in an Indonesian population. The next chapter, Chapter 6, will discuss about the development of diabetes education materials for use in the research interventions.

# **CHAPTER 6 – Development of Diabetes Education Materials**

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**A Structured Diabetes Education Programme  
in Indonesia**

## 6.1. INTRODUCTION

Chapter 6 describes the development of education materials on type 2 diabetes for use in the research interventions. This chapter begins with an explanation of existing diabetes education materials generally available in Yogyakarta Province and Indonesia. It is followed by a description of the development of new diabetes education materials written in *Bahasa Indonesia*, the distribution and use of the new diabetes education materials, a method for evaluating the diabetes leaflets, the results of the evaluation, and discussion. This chapter is completed with conclusions and recommendations.

## 6.2. EXISTING DIABETES EDUCATION MATERIALS

One of the essential parts of this research project was the conduct of research interventions in each research group, namely a structured diabetes education programme for the intervention group, and a diabetes seminar for the control group. In order to provide comprehensive information on type 2 diabetes (T2D) for the research participants,<sup>18</sup> it was planned to distribute diabetes leaflets to all research participants and use diabetes posters as teaching aids for conducting a diabetes structured patient education for the intervention group. Therefore, diabetes leaflets and posters written in *Bahasa Indonesia* were needed for conducting the research interventions.

To collect existing materials in use for diabetes education in Indonesia, the researcher examined the websites of leading diabetes organisations in Indonesia and contacted a number of health organisations located in Yogyakarta Province and Jakarta, the capital city of Indonesia, to obtain diabetes leaflets and posters either for free or with payment. Among the three leading diabetes organisations in Indonesia – *PERKENI* (the Indonesian Society of Endocrinology), *PERSADIA* (the Indonesian Diabetes Association), and *PEDI* (the Indonesian Diabetes Educator Association) – only *PERKENI* and *PERSADIA* have organisation websites. However, these websites only highlight the organisations' activities, have very limited information on T2D, and do not provide any downloadable diabetes education materials for public use. Meanwhile, although *PEDI* has been conducting national diabetes educator training annually since 2002, it does not have any website for public access of information and education of T2D.

The organisations contacted were *PEDI*, *PERKENI* and *PERSADIA*, four diabetes centres at secondary and tertiary hospitals, three local health offices and three pharmaceutical companies selling blood sugar testing tools and diabetes supplements. Unfortunately, no suitable materials could be sourced since no institutions had diabetes leaflets and posters for sale, and those organisations which provided free distribution had no

stocks of diabetes posters and only a small number of leaflets. The researcher obtained a few samples of diabetes leaflets written in *Bahasa Indonesia* from four organisations, including: one diabetes centre, one local health office, and two pharmaceutical companies. However, the limited number of the diabetes leaflets obtained, 34 different leaflets from four different organisations, meant that there were not enough leaflets to distribute to all research participants recruited in this study (n=101). Moreover, the diabetes leaflets obtained generally had limited information on them or were full of texts with limited graphics or were only photocopied materials, unsuitable for the needs of the research.

Providing comprehensive information on T2D in an interesting and engaging way is essential to enable the research participants learn well about the disease. However, the diabetes education materials to be developed would have to be easily understood. Using easy-to-read written patient educational materials to support instructions given orally has been demonstrated to largely increase patient understanding.<sup>272</sup> Particularly, since the target audience was mostly low-literate readers. There is a significant correlation between literacy, and both education and income levels.<sup>273,274</sup> Furthermore, low literacy is negatively related to chronic disease management including T2D, hypertension and asthma.<sup>274</sup> The research participants were people with T2D regularly attending community health centres (CHCs) who mostly had low socioeconomic status and low education levels.

Generally, the common characteristics of available diabetes leaflets are as follows:

- The content consisted of a small amount of information written in one leaflet, and was mostly confined to the definition, signs and symptoms, complications, and the four pillars of diabetes management, i.e.: education, medication, meal planning and exercise. Sometimes, a detailed diabetes meal planning was included or provided in a separate leaflet.
- The information was written only in texts with no or limited graphics.
- The information was printed in small fonts ( $\leq 12$  font).
- The leaflets were often printed in black ink on standard white or colour printing paper of 70 grams per square metre (gsm) or were simply photocopied.

The researcher observed that several diabetes posters were used for teaching aids and display in several diabetes centres visited. Like the leaflets, the content of diabetes posters was confined to the definition, signs and symptoms, complications, and the four pillars of diabetes management. However, the researcher could not obtain these posters for free or even with payment from any centres visited. Therefore, the researcher set out to develop a complete set of diabetes leaflets and posters written in *Bahasa Indonesia* for diabetes education materials in the research interventions that cater to the research

objectives. This activity took 4 months from preparation and design to final printing at a printing shop.

### 6.3. DEVELOPMENT OF NEW DIABETES EDUCATION MATERIALS

To communicate effectively with low-literate readers, the new diabetes education materials should be developed short and simple with culturally sensitive graphics that encourage desired behaviours.<sup>272</sup> According to National Cancer Institute (NCI), developing effective print materials for low-literate readers involves five standard steps,<sup>273</sup> as presented in **Table 6-1**.

**Table 6-0-1 Summary of the Guidelines for Developing Effective Print Materials for Low-Literate Readers<sup>273</sup>**

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**The five standard steps in developing print materials:**

**Step 1: Define the target audience**

**Step 2: Conduct target audience research**

**Step 3: Develop a concept for the product**

**Step 4: Develop content and visuals**

**Step 5: Pre-test and revise draft materials**

**Step 1: Define the target audience**

Common characteristics of low-literate readers:

- Tendency to think in concrete rather than abstract terms
- Literal interpretation of information
- Insufficient language fluency to comprehend and apply information from written materials
- Difficulty with information processing, such as reading a menu, following medical instructions, or reading a prescription label

**Step 2: Conduct target audience research**

Information needed about the audience:

- Age, sex, ethnicity, income, education levels, places of work and residence
- Causative/ preventive behaviours related to the topic
- Related knowledge, attitudes and practices
- Patterns of use of related services
- Cultural habits, preferences, and sensitivities related to your topic
- Barriers to behaviours of change
- Effective motivators (e.g. benefits of change, fear of consequences, incentives, or social support)

**Step 3: Develop a concept for the product**

Five principles for developing the concept for a low-literacy publication:

- Define the behavioural objective(s) of the material
  - Determine the key information points the reader needs to achieve the behavioural objective(s)
  - Select the most appropriate presentation methods (e.g. audio, audiovisual, print, radio, TV, interactive computer programmes)
  - Decide on the reading level for the material if you select a print presentation
  - Organize topics in the way the person will use them
-

**Step 4: Develop content and visuals**

Checklist for key principles of effective low-literacy print materials include content/ style, layout and visuals as follows:

Content/Style:

- The material is interactive and allows for audience involvement
- The material presents “how-to” information
- Peer language is used whenever appropriate to increase personal identification and improve readability
- Words are familiar to the reader. Any new words are defined clearly
- Sentences are simple, specific, direct, and written in the active voice
- Each idea is clear and logically sequenced (according to audience logic)
- The number of concepts is limited per piece
- The material uses concrete examples rather than abstract concepts
- The text highlights and summarizes important points

Layout:

- The material uses advance organizers or headers
- Headers are simple and close to text
- Layout balances white space with words and illustrations
- Text uses upper and lower case letters
- Underlining or bolding rather than all caps give emphasis
- Type style and size of print are easy-to-read; type is at least 12 point

Visuals:

- Visuals are relevant to text, meaningful to the audience, and appropriately located
- Illustrations and photographs are simple and free from clutter and distraction
- Visuals use adult rather than childlike images
- Illustrations show familiar images that reflect cultural context
- Visuals have captions. Each visual illustrates and is directly related to one message
- Different styles such as photographs without background detail, shaded line drawings, or simple line drawings, are pretested with the audience to determine which is understood best
- Cues, such as circles or arrows point out key information
- Colours used are appealing to the audience (as determined by pretesting)

**Step 5: Pre-test and revise draft materials**

Key issues to probe for pretesting include:

Comprehension:

- Important aspects include:
- Suitability of the words used?
- Distinguishing key details?
- Meaning or relationship of visuals to text?

Attraction:

- What kind of feelings does the material generate? Enthusiasm? Just OK? Or a “turnoff”?

Acceptability:

- Compatibility with local culture?
- Supportive of ethnic practices?
- Suitability for both sexes and all ages?
- Personal involvement or relevance?

However, in developing diabetes leaflets and posters for educational materials in this study, not all steps were able to be conducted meticulously due to limited time and resources. Furthermore, step 2 for conducting target audience research was previously conducted during the cross-cultural study of existing validated diabetes-related instruments which provided the sociodemographic characteristics of the audience. The steps carried out were modified including:

## **1. Preparation**

This preparation phase includes several activities, as follows:

- Participation in a national diabetes educator training in Jakarta and three structured diabetes education programmes in community centres in South Australia;
- Visits to several diabetes education centres in Yogyakarta City and Jakarta for observing existing diabetes leaflets and posters;
- Collecting hard copies of diabetes leaflets and posters available locally, nationally and the ones from South Australia;
- Internet browsing for various diabetes leaflets and posters available internationally as samples of reference; and
- Hiring a graphic designer who was a medical doctor and one of the research assistants trained for this study.

## **2. Defining the target audience**

The target audience was regular attendees of CHCs who mostly had low socioeconomic status and low education levels, thus most likely were low-literate readers.<sup>273,274</sup> While most people at all literacy levels use visual cues to reinforce learning and prefer written materials that are simple and attractive,<sup>275</sup> these facts are particularly more essential for poor readers. Therefore, developing simple and attractive diabetes education materials supported with colourful graphics was critical for these research participants.

## **3. Developing a concept for the product**

One of important things in developing the concept is defining the behavioural objectives of the materials. Objectives should focus on the desired behaviours rather than simply informational.<sup>273</sup> The behavioural objectives for these diabetes education materials were particularly involving the management of T2D including:

- The reader will engage in continuous diabetes education.
- The reader will practice healthy eating.
- The reader will do regular physical activity.
- The reader will monitor his/her blood sugar level.
- The reader will take diabetes medications as prescribed regularly.

## **4. Developing content and visuals:**

Designing the new diabetes leaflets and posters was based on the defined research objectives and samples of existing diabetes leaflets and posters available locally, nationally and internationally, taking into account the checklist of content/ style, layout and visuals.



## 5. Pre-testing and revising draft materials

Due to limited time and resources, pretesting was conducted to only five members of the intended target audience, i.e. adults with T2D.<sup>273</sup> Each individual was shown draft materials of diabetes leaflets in a short individual interview for a simple readability test and inputs on comprehension, attraction and acceptability. The draft designs were also distributed to five general practitioners to obtain broader perspectives. The majority of them gave positive inputs on comprehension, attraction and acceptability. There were only minor inputs, particularly on the layout, colours and use of graphics. The draft materials were revised based on the inputs obtained. Lastly, the final designs diabetes leaflets and posters were printed at a printing shop.

There are several tips for writing low literacy materials as described by Miller (2001),<sup>276</sup> and by Potter and Martin (2005).<sup>275</sup> They are presented in **Table 6-2** and **Table 6-3**.

**Table 6-0-2 Quick tips for writing low literacy materials<sup>276</sup>**

Quick Tips for Writing Low Literacy Materials
• Keep writing style simple
• Use active voice and conversational style
• Sequence main points in a logical manner
• Make you sub-points clearly correspond to the main point
• Use short words and sentences
• Avoid double negative expressions
• Use the same word consistently rather than synonyms to avoid confusion
• For lengthy materials, use a table of contents to point the way
• Write short summaries at the end of long sections
• Use a larger type than 12 points for the text
• Enlarge or bold the type in headings and sub-headings
• Use extra white space to separate sections
• Use age appropriate illustrations
• Place illustrations close to the related text
• Use simple grids, site maps, and other visuals to ease the reading of the text

**Table 6-0-3 The most helpful written materials for all users, especially poor readers<sup>275</sup>**

The Most Helpful Written Materials for All Users, Especially Poor Readers
• Emphasize the desired behaviour rather than medical facts. Education is more important than information
• Have just one or two educational objectives – what the reader needs to learn and do
• Use clear headings and bullets, instead of paragraphs, and ample white space
• Use short sentences, active voice and conversational language
• Use pictures and examples to illustrate important points
• Supplement written materials with conversation, video and audio sources

Generally, in developing the new diabetes education materials, the researcher tried to follow these three guidelines as much as possible. In contrast to the existing diabetes leaflets which generally look mundane, the new diabetes leaflets were developed to attract and engage diabetic patients. There were several characteristics of the research participants that were taken into account when developing the diabetes leaflets, including: (1) many of the participants were elderly people who might have difficulty in reading small print; and (2) majority of the research participants had low education levels (primary school), and thus might need information written in a simple language and supported with a lot graphics to make it easier for them to absorb the information.

In order to make the diabetes leaflets look as interesting and eye-catching as possible, while also taking into account these factors, the leaflets were developed as follows: (1) written in a simple language and supported with colourful graphics; (2) printed in large font size i.e. Arial 14; and (3) printed on colourfully glossy and thick A-4 sized printing papers with 170 gsm.

The guidelines suggest that the number of concepts and educational objectives should be limited, and the desired behaviours should be emphasised rather than the medical facts.<sup>273,275</sup> However, these rules were not completely followed due to several considerations which include: (1) limited information on the existing diabetes leaflets available, and (2) the research participants previously had very little access of diabetes information and education. Therefore, for the particular purpose of providing comprehensive information on T2D to the research participants, the researcher opted to include a large amount of information the new diabetes leaflets. The researcher thus developed nine diabetes leaflets and one diabetes booklet (See **Appendix M**) as follows:

- Leaflet 1: “Recognise Diabetes Mellitus and Act on it”
- Leaflet 2: “Meal Planning for Diabetics 1”
- Leaflet 3: “Meal Planning for Diabetics 2”
- Leaflet 4: “Meal Planning for Diabetics 3”
- Leaflet 5: “Physical Activity for Diabetics 1”
- Leaflet 6: “Physical Activity for Diabetics 2”
- Leaflet 7: “Foot Care And Foot Exercise for Diabetics”
- Leaflet 8: “Target for Management of Diabetes Mellitus”
- Leaflet 9: “Seven Successful Steps for Diabetes Self-Care”
- Booklet 1: “Food Exchanges and Menu for Diabetics”

The nine leaflets were printed in a A4-sized paper folded in three columns and double sided. The booklet was printed in a A-4 sized paper folded in two columns and double

sided in eight pages. All nine diabetes leaflets and one booklet are collectively called 'the diabetes leaflets' throughout this chapter.

Furthermore, the NCI 2003 guidelines state that the illustrations used should reflect culturally familiar images.<sup>273</sup> However, this was not possible to follow. Since culturally relevant materials were scarce, most of the graphics used for the new leaflets were downloaded from the internet, which were mostly from Western cultures. These Westernised graphics were inevitably included in the new leaflets. Designing culturally relevant graphics specifically for the new diabetes leaflets would require more time and resources. However, for further roll-out of the diabetes leaflets in the future, the Westernised graphics will be changed to depict Indonesian people.

According to the NCI 2003 guidelines, the reading level for the education materials should be determined. The reading level refers to the number of education years required for a reader for understanding a written passage. Experts' suggestions for this reading level include: (1) aiming for a level that is two to five grades lower than the highest average grade the audience achieved to justify a probable decline in reading skills over time; and (2) a third to fifth grade level is generally appropriate for low-literate readers.<sup>273</sup> To estimate reading level, readability formulas are used, such as the Flesch Reading Ease, the Flesch-Kinkaid Grade Level, the Fog Scale, and the SMOG Index.<sup>273,276</sup> However, these readability formulas are specifically designed and used for English texts, and cannot be used for other languages. Furthermore, there are no such readability formulas in *Bahasa Indonesia*. Therefore, the reading level for these diabetes education materials could not be determined.

In addition, 14 diabetes posters were developed for teaching aids in diabetes structured patient education sessions. The content of the posters was taken from the corresponding diabetes leaflets focusing on the most important issues with fewer words and more pictures. The posters were printed in colourful glossy A1-sized printing papers with special outdoor material. The diabetes posters developed (See **Appendix N**) are entitled as follows:

- Poster 1: "What Happens in Type 2 Diabetes? Mechanism of Insulin"
- Poster 2: "Risk Factors of Type 2 Diabetes"
- Poster 3: "Symptoms of Type 2 Diabetes"
- Poster 4: "Hypoglycaemia"
- Poster 5: "Hyperglycaemias"
- Poster 6: "Complications of Type 2 Diabetes"
- Poster 7: "Management of Type 2 Diabetes"
- Poster 8: "Meal Planning for Diabetics"

- Poster 9: “Balanced Diet for Diabetics”
- Poster 10: “Portion Control for Diabetics”
- Poster 11: “Physical Activity for Diabetics”
- Poster 12: “Targets of Type 2 Diabetes Management”
- Poster 13: “Foot Care for Diabetics”
- Poster 14: “Diabetes Self-Management”

These fourteen diabetes posters were also reproduced in x-banner compositions for display in the function room during the diabetes seminar for the control group. The goal was to help getting the message of diabetes information taught across more effectively.

### **6.3.1. Leaflet 1: “Recognise Diabetes Mellitus and Act on it”.**

Leaflet 1, in gold colour, provides an overview of T2D, an introduction and foundation to the remainder of the diabetes leaflets developed. This leaflet is entitled “Recognise Diabetes Mellitus and Act on it”. The title is intended to send a strong message to the readers that understanding this chronic illness is an important first step to take actions in managing T2D well. Underneath, there are two green boxes which contain the following statements: “*Knowledge is Power*” and “*Recognising diabetes mellitus is a key to making a friend and living healthily with diabetes for life*”. This leaflet contains information on T2D including: (1) definition; (2) classification; (3) risk factors; (4) diagnosis criteria; (5) signs; (6) acute complications (definition and things to do): hypoglycaemia and hyperglycaemia; (7) chronic complications; (8) five principles of diabetes management, namely continuous education, meal planning, regular exercise, blood sugar monitoring and medication; and (9) mechanism of insulin hormone.<sup>7,175,277,278</sup>

### **6.3.2. Leaflet 2, 3 and 4: “Meal Planning for Diabetics 1, 2, 3”.**

Leaflet 2, 3 and 4, in green-yellow colour, illustrate meal planning for diabetics. These leaflets provide information about food well beyond provided in any existing diabetes leaflets found in Indonesia. The three leaflets about diabetes meal planning provide thorough information on food, including ‘good fats’ and ‘bad fats’, ‘good carbohydrates’ and ‘bad carbohydrates, and ‘glycaemic index’. This information was not found in the diabetes leaflets for free public distribution obtained. Food information in existing diabetes leaflets usually only covers food exchanges and menu samples with calorie counting. During observations conducted in several diabetes centres in Yogyakarta Province, diabetes education did not include any information on glycaemic index at all which was acknowledged by the attending diabetes educator nutritionists. In contrast, diabetes structured education programmes held

in community centres in South Australia in which the researcher participated included the concept of glycaemic index.

Leaflet 2 is entitled “Meal Planning for Diabetics 1”. On its front cover, there is a yellow box stating: “*We are what we eat*”. This leaflet contains information on the principles of healthy eating including: (1) simple guide for healthy eating, particularly the three basic principles, namely amount of calorie consumed daily, schedule of eating and type of food; (2) balanced eating for diabetics, i.e.: food pyramid and portion of balanced eating; (3) measurement of food portions, i.e.: plan your portions and plate method; and (4) food types: carbohydrate, protein and fat. At the back cover, there is a yellow box with a question: “*Are all fats not good for you?*”. This question is followed with a statement: “The answer can be found in the leaflet entitled ‘Meal Planning for Diabetics 2’”. The question was written in order to raise curiosity about the true facts of fat of which diabetic patients and the general public might be unaware.<sup>96,175</sup>

Leaflet 3 is entitled “Meal Planning for Diabetics 2”. This leaflet contains food information including: (1) types of fat: good fats and bad fats; (2) cholesterol; (3) sodium; (4) artificial sweetener; and (5) calcium. Meanwhile, leaflet 4 is entitled “Meal Planning for Diabetics 3” and contains information including: (1) fibre; (2) glycaemic index; (3) glycaemic load; (4) list of the glycaemic index of several foods; (4) the difference of good carbohydrates versus bad carbohydrates; and (5) simple tips for diet with good carbohydrates.<sup>96,175</sup>

### **6.3.3. Leaflet 5 and 6: “Physical Activity for Diabetics 1, 2”**

Leaflet 5 and 6, in light blue colour, are about physical activity for diabetics. Leaflet 5 is entitled “Physical Activity for Diabetics 1”. In the front cover, there are two yellow boxes stating: “*Physical activity is not only exercise*” and “*Be active everyday in various ways*”. The leaflet contains information on physical activity in general including: (1) benefits of exercise/physical activity; (2) recommendation for physical activity; (3) practical tips for physical activity; (3) burning calories with daily activities; and (4) tips for overcoming barriers of physical activity.<sup>96,175</sup>

Leaflet 6 is entitled “Physical Activity for Diabetics 2”. On the front cover, there is a yellow box stating “*Diabetics who regularly do exercise can reduce their dependence on medicine*”. On the back cover, there is another yellow box stating “*A weight loss of 5% from original body weight can reduce the risks of heart disease and type 2 diabetes*”. The leaflet contains information on physical activity in general and specifically for diabetics which include: (1) concept of frequency, intensity, time, and type (FITT) for exercise; (2) principles of exercise; and (3) tips for exercising for diabetics.<sup>96,175</sup>

### **6.3.4. Leaflet 7: “Foot Care and Foot Exercise for Diabetics”**

Leaflet 7, in light purple colour, is entitled “Foot Care and Exercise for Diabetics”. The leaflet focuses on foot care including: (1) foot care in 10 steps with simple instructions illustrated in pictures; and (2) foot exercise in 9 movements, also with simple instructions illustrated in pictures.<sup>175</sup>

### **6.3.5. Leaflet 8: “Target for Management of Diabetes Mellitus”**

Leaflet 8, in khaki colour, is entitled “Target for Management of Diabetes Mellitus”. The leaflet contains information including: (1) value targets of several clinical outcomes (e.g. HbA1c, fasting blood glucose, 2-hour postprandial plasma glucose, total cholesterol, LDL cholesterol, HDL cholesterol, triglycerides, blood pressure, body mass index and waist circumference); (2) explanation on HbA1c (since this clinical outcome is not widely known by general public and not yet a routine procedure in diabetes monitoring); and (3) goal setting with SMART (specific, measurable, achievable, realistic, and time line) method, accompanied with some examples of its usage.<sup>96,277,278</sup>

### **6.3.6. Leaflet 9: “Seven Successful Steps for Diabetes Self-Care”.**

Leaflet 9 is entitled “Seven Successful Steps for Diabetes Self-Care”. The leaflet focuses on two major concepts of diabetes self-care, including: (1) Seven steps for diabetes self-care from AADE 7™ self-care behaviours as developed by American Association of Diabetes Educators;<sup>126</sup> and (2) Seven principles of self-management for chronic conditions, as defined in the Flinders Program™.<sup>115</sup> The two concepts are elaborated in Chapter 3 (**Section 3.5.1.2 - Diabetes Self-Management**).

### **6.3.7. Booklet 1: “Food Exchanges and Menu”**

Booklet 1, in yellow colour, is entitled “Food Exchanges and Menu”. ‘Food exchanges’ are a method for meal planning for diabetes. Foods are clustered into groups that can be ‘exchanged’ according to similarities in nutritional content. There are eight food groups in all. Similar foods approximately have equal amounts of carbohydrates, protein, fat and calories per serving size. Serving sizes are established to keep all foods within a group at approximately the same amount nutritional values.<sup>279,280</sup> The booklet focuses on information about the eight groups of food exchanges used in Indonesia, accompanied with other relevant information including: (1) household serving sizes; (2) food exchanges for group 1 – carbohydrates; (3) food exchanges for group 2 – animal proteins; (4) food

exchanges for group 3 – plant proteins; (5) food exchanges for group 4 – vegetables; (6) food exchanges for group 5 – fruits; (7) food exchanges for group 6 – milk; (8) food exchanges for group 7 – fats; (9) food exchanges for group 8 – food without calories; (10) energy needs; and (11) example and planning of daily menu.<sup>175</sup>

## **6.4. DISTRIBUTION AND USE OF NEW DIABETES EDUCATION MATERIALS**

### **6.4.1. Distribution of Diabetes Leaflets**

The diabetes leaflets were distributed to all research participants in both groups at the start of each research intervention. The research intervention for the control group was a diabetes seminar, i.e. a three-hour didactic teaching in T2D performed by an internal medicine specialist and a nutritionist acting as diabetes educators, while the researcher acted as a chairperson. The control group participants received 9 out of 10 diabetes leaflets during the diabetes seminar, and did not receive leaflet 9 entitled “Seven Successful Steps for Diabetes Self-Care”. The participants received leaflet 9 during the 3-month follow-up clinical assessment. Meanwhile, the research intervention for the intervention group was a structured diabetes education programme conducted in four weekly sessions by the general practitioner researcher acting as the diabetes educator in an interactive and collaborative way using a biopsychosocial approach. The intervention group participants received all 10 diabetes leaflets from the beginning of the intervention.

During the four-weekly sessions of the structured diabetes education programme, the educator discussed all the diabetes leaflets one by one with the intervention group participants. In contrast, during the diabetes seminar, the diabetes educators (i.e. internal medicine specialist and nutritionist) did not discuss about the diabetes leaflets at all. However, the researcher who acted as the chair person requested the control group participants to read all diabetes leaflets received to get comprehensive information about T2D.

### **6.4.2. Use of Diabetes Posters and Banners**

The diabetes posters were particularly used for diabetes teaching during the four weekly sessions of structured diabetes education programme for the intervention group. Four different topics of diabetes structured education were presented using power point slides supported with the diabetes posters developed.

Meanwhile, the diabetes posters were not used at all during the diabetes seminar for the control group. The internal medicine specialist and nutritionist conducted diabetes teaching using their usual power point presentations. However, to substitute the posters, the 14 colourful diabetes banners were displayed neatly in the function room during the diabetes seminar. The diabetes information was made engaging and interesting to enable the participants get interested and read more on the information about T2D.

## 6.5. EVALUATION METHOD OF THE NEW DIABETES LEAFLETS

A large amount of information on T2D was included in the diabetes leaflets to provide comprehensive information to the research participants. However, these might be overwhelming and discouraging for them. The use of westernised graphics in the leaflets might also be distracting or intimidating. The readability test to determine the reading level was not conducted that might result in higher reading level for the research participants. In order to find out about the participants' feedback about the leaflets and to obtain suggestions for improving the leaflets in the future, an evaluation of the diabetes leaflets was conducted.

After receiving the diabetes leaflets, all participants were asked to complete an evaluation of the diabetes leaflets through an anonymous one-page evaluation form. The evaluation form was distributed to be completed during the second clinical assessment to give the participants from both groups ample time to read, learn and absorb all the information written and illustrated in the diabetes leaflets.

The evaluation consisted of 5 items using a rating scale of 1 to 10 provided in each question with the explanation of the meaning, as shown in **Table 6-4**.

**Table 6-0-4 Evaluation of the diabetes leaflets**

No.	Variable	Questions	Rating
1.	Language usage	"How do you rate the usage of language in the diabetes leaflets?" Use a rating scale of 1 to 10.	1 2 3 4 5 6 7 8 9 10 1= very difficult to understand; 10= very easy to understand
2.	Font size	"How do you rate the font size in the diabetes leaflets?" Use a rating scale of 1 to 10.	1 2 3 4 5 6 7 8 9 10 1= very difficult to read; 10= very easy to read
3.	Use of pictures	"How do you rate the use of pictures in the diabetes leaflets?" Use a rating scale of 1 to 10.	1 2 3 4 5 6 7 8 9 10 1= very uninteresting; 10= very interesting
4.	Content of diabetes information	"How do you rate the content of information in the diabetes leaflets?" Use a rating scale of 1 to 10.	1 2 3 4 5 6 7 8 9 10 1= very complicated; 10= very simple
5.	Suggestions for improvement	"What are your suggestions for improving the diabetes leaflets?"	This was an open ended question with blank space for the answer.



## 6.6. RESULTS OF THE EVALUATION OF DIABETES LEAFLETS

There was a slight difference in the distribution of the diabetes leaflets to the two research groups. The control group initially received 9 out of 10 diabetes leaflets during the diabetes seminar and did not receive leaflet 9 entitled “Seven Successful Steps for Diabetes Self-Care” until the second clinical assessment, while the intervention group received all 10 diabetes leaflets from the beginning. Therefore, the results of the evaluation of diabetes leaflets in both groups were analysed separately. All data were entered and analysed using the SPSS version 18. Descriptive statistics were used to analyse the results in each group. The comparison of the evaluation results in both groups was analysed using independent samples *t-test*.

### 6.6.1. Evaluation of Diabetes Leaflets in the Control Group

In the control group, there were 50 participants, 45 of them attended the diabetes seminar, and 42 of them completed the evaluation form. The results of the evaluation forms are shown in **Table 6-5**. For the first four questions, most the participants in the control group (81% - 90.8%) rated the diabetes leaflets in the range 7-10, while only a few (9.2% - 14.3%) rated in the range 5-6 and none rated < 5. Most of the research participants in this group considered that the diabetes leaflets were easy to understand, easy to read, interesting, and simple.

For question no.5, the majority of the participants (83.3%) gave general comments on what they thought about the leaflets without providing suggestions for improvement. The most common statement was: “*The diabetes leaflets are already good and easy to understand*”. Two of the participants also added: “*...particularly as a guide for diabetics.*” and “*...particularly for daily life which include meal planning and exercise.*” Another participant clearly expressed that the leaflets increased his knowledge. However, two other participants only expressed their hopes as follows: “*Hopefully the leaflets will be better in the future*”.

Table 6-0-5 Results of the evaluation of diabetes leaflets in the control group (n = 42)

Evaluation Question	Rating	Total Chosen	Percentage
<b>1. How do you rate the usage of language in the diabetes leaflets?</b>  1 = very difficult to understand 10 = very easy to understand	1	-	-
	2	-	-
	3	-	-
	4	-	-
	5	4/42	9.5%
	6	4/42	9.5%
	7	7/42	16.7%
	8	12/42	28.6%
	9	2/42	4.8%
	10	13/42	30.9%
<b>2. How do you rate the font size in the diabetes leaflets?</b>  1 = very difficult to read 10 = very easy to read	1	-	-
	2	-	-
	3	-	-
	4	-	-
	5	2/42	4.8%
	6	2/42	4.8%
	7	2/42	4.8%
	8	17/42	40.5%
	9	3/42	7.1%
	10	16/42	38.1%
<b>3. How do you rate the use of pictures in the diabetes leaflets?</b>  1 = very uninteresting 10 = very interesting	1	-	-
	2	-	-
	3	-	-
	4	-	-
	5	2/42	4.8%
	6	2/42	4.8%
	7	1/42	2.4%
	8	16/42	38.1%
	9	5/42	11.9%
	10	16/42	38.1%
<b>4. How do you rate the content of information in the diabetes leaflets?</b>  1 = very complicated 10 = very simple	1	-	-
	2	-	-
	3	-	-
	4	-	-
	5	2/42	4.8%
	6	4/42	9.5%
	7	11/42	26.2%
	8	6/42	14.3%
	9	8/42	19.0%
	10	11/42	26.2%
<b>5. What are your suggestions for improving the diabetes leaflets?"</b>			
<b>General comments on the leaflets (35/42=83.3%):</b>			
A. "The leaflets are already good and easy to understand, including the contents and pictures..." (32/42); "...particularly as a guide for diabetics" (1/42=); "...particularly for daily life which include meal planning and exercise." (1/42)			
B. "Hopefully the leaflets will be better in the future." (2/42)			
C. "The leaflets are very good, I'm so glad. They can increase my knowledge on diabetes" (1/42)			
<b>Suggestions for improvements (11/42=26.2%):</b>			
A. "Some content of information are still difficult to understand, thus give information with simpler language and more pictures..." (4/42); "...particularly because not all diabetics can well translate the contents and pictures in the leaflets,...moreover because many diabetics do not get sufficient supervision from a doctor and a nutritionist." (1/42)			
B. "Distribute the leaflets to other diabetics in other community health centres..." (2/42); "...so that others also have the same opportunity just like me and other friends here." (1/42)			
C. "Compile all leaflets into one book to make it orderly and not easy to get lost." (2/42); "...thus it can be a reminder for the disease." (1/42)			
D. "Give more examples of problems in living with diabetes and overcoming the problems in more details." (1/42)			
E. "Convert the foot exercise in the leaflet into a VCD (video compact disc)." (1/42)			
F. "Doctors at the community health centre should provide more education to diabetics." (1/42)			

Meanwhile, only 11 participants (26.2%) provided suggestions for improving the diabetes leaflets in the future. Four participants gave the following suggestion and the underlying reasons, i.e.: *“Some content of information are still difficult to understand, thus give information with simpler language and more pictures”*. One of those four participants elaborated the reasons as follows: *“...particularly because not all diabetics can translate the contents of information in the leaflets well...moreover because many diabetics do not get sufficient supervision from a doctor and a nutritionist”*. Two participants suggested the need for broader distribution of the leaflets as follows: *“Distribute the leaflets to other diabetics in other community health centres”*. One of those two participants also added this was *“...so that others also have the same opportunity just like me and other friends here”*. Two other participants expressed the need for compiling all the diabetes leaflets into one book and the reason for it as follows: *“Compile all leaflets into one book to make it orderly and not easy to get lost.”* One of those two also indicated this was because: *“...thus it can be a reminder for the disease”*. Lastly, three other participants suggested the following 3 things: *“Give more examples of problems in living with diabetes and overcoming the problems in more details”*; *“Convert the foot exercise in the leaflet into a VCD (video compact disc)”*; and *“Doctors at the community health centre should provide more education to diabetics”*.

### 6.6.2. Evaluation of Diabetes Leaflets in the Intervention Group

There were 51 participants in the intervention group, 49 of them attended the structured patient education on diabetes self-management and 46 of them completed the evaluation form. The results of the evaluation are shown in **Table 6-6**. Similar to the results of the control group, for the first four questions, almost all of the participants in the intervention group (93.4% - 100%) rated the diabetes leaflets in the range 7-10, while only very few (0%-6.6%) rated in the range 5-6 and none rated < 5. Almost all of the research participants in this group found that the diabetes leaflets were easy to understand, easy to read, interesting, and simple.

Like the control group, majority of the participants (76%) gave general comments about the leaflets for question no.5 without providing suggestions for improvement in the future. The most common statement was also: *“The diabetes leaflets are already good and easy to understand...”* Three of the participants added that: *“...the information and pictures are good.”*; and *“...they are more than enough for me.”* Four other participants were very positive about the value of the leaflets as follows: *“The leaflets are already complete/perfect”*; *“The leaflets provide good information”*; and *“The leaflets encourage us to have a discipline and fighting spirit”*.

Meanwhile, 17 participants (40%) provided suggestions for improving the diabetes leaflets in the future. Like the control group, six participants also suggested the need for compiling all the diabetes leaflets into one book. Three of participants gave their reasons for this i.e.: *“... to make it handy to carry and read”* and *“...as a complete guide book for diabetics”*. Four other participants also suggested the need for broader distribution of the leaflets as follows: *“Distribute the leaflets to other diabetics in other centres/ in all parts of Indonesia...”* One participant suggested this because: *“....so that other diabetics do not take the disease as a burden and they will know what they have to do with their condition”*. Three other participants gave suggestions related to the diabetes structured patient education sessions they experienced as follows: *“Hopefully this programme can be maintained and continued with more sessions”*. Four other participants suggested several things to be incorporated in the leaflets i.e.: *“Include spiritual aspects to the leaflets”*; *“Include emotional aspects to the leaflets”*, and *“Include more samples of simple and affordable menus.”*

**Table 6-0-6 Results of the evaluation of diabetes leaflets in the intervention group (n = 46)**

Evaluation Question	Rating	Total Chosen	Percentage
<b>1. How do you rate the usage of language in the diabetes leaflets?</b>  1 = very difficult to understand 10 = very easy to understand	1	-	-
	2	-	-
	3	-	-
	4	-	-
	5	1/46	2.2%
	6	1/46	2.2%
	7	10/46	21.7%
	8	15/46	32.6%
	9	8/46	17.4%
	10	11/46	23.9%
<b>2. How do you rate the font size in the diabetes leaflets?</b>  1 = very difficult to read 10 = very easy to read	1	-	-
	2	-	-
	3	-	-
	4	-	-
	5	1/46	2.2%
	6	0/46	-
	7	2/46	4.4%
	8	20/46	43.5%
	9	11/46	23.9%
	10	12/46	26.1%
<b>3. How do you rate the use of pictures in the diabetes leaflets?</b>  1 = very uninteresting 10 = very interesting	1	-	-
	2	-	-
	3	-	-
	4	-	-
	5	0/46	0%
	6	0/46	0%
	7	2/46	4.4%
	8	15/46	32.6%
	9	12/46	26.1%
	10	17/46	37.0%
<b>4. How do you rate the content of information in the diabetes leaflets?</b>  1 = very complicated 10 = very simple	1	-	-
	2	-	-
	3	-	-
	4	-	-
	5	1/46	2.2%
	6	2/46	4.4%
	7	13/46	28.2%
	8	12/46	26.1%
	9	9/46	19.6%
	10	9/46	19.6%
<b>5. What are your suggestions for improving the diabetes leaflets?"</b>			
<b>General comments on the leaflets (35/46=76%):</b>			
A. "The leaflets are already good and easy to understand..." (31/46); "...the information and pictures are good" (2/46); "...they are more than enough for me" (1/46)			
B. "The leaflets are already complete/ perfect" (2/46)			
C. "The leaflets provide good information" (1/46)			
D. "The leaflets encourage us to have a discipline and fighting spirit" (1/46)			
<b>Inputs for improvements (17/46=40%):</b>			
A. "Compile all leaflets into one book...." (6/46); "... to make it handy to carry and read." (2/46) "...as a complete guide book for diabetics." (1/46)			
B. "Distribute the leaflets to other diabetics in other centres in all parts of Indonesia." (4/46); "...so that other diabetics do not take the disease as a burden and they will know what they have to do with their condition (1/46)			
C. "This programme (structured patient education) hopefully can be maintained and continued with more sessions." (3/46)			
D. "Include spiritual aspects to the leaflets." (2/46).			
E. "Include emotional aspects to the leaflets." (1/46).			
F. "Include more samples of simple and affordable menus." (1/46)			

### 6.6.3. Comparison of the Results of Diabetes Leaflet Evaluation in Both Groups

The comparison of the evaluation results of diabetes leaflets in both groups is presented in **Table 6-7**. The intervention group rated higher than the control group for all the first four questions. In particular for question no.3 about the use of pictures in the leaflets, all intervention group participants who completed the evaluation form rated 7-10 for the leaflet. However, there was no significant difference among the question ratings between the two groups ( $p > 0.05$ ). For question no.5, more participants in the intervention group (40%) gave suggestions for improving the diabetes leaflets than in the control group (26.2%).

**Table 6-0-7 Comparison of the results of diabetes leaflet evaluation in both groups**

Evaluation Question	Rating Range	Control Group (n = 42)		Intervention Group (n = 46)		Mean Difference	P-value
		%	Mean (SD)	%	Mean (SD)		
1. How do you rate the usage of language in the diabetes leaflets?	5-6	19%		4.4%		0.30 (-0.32, 0.92)	0.33
	7-10	81%	8.02 (1.66)	95.6%	8.33 (1.25)		
2. How do you rate the font size in the diabetes leaflets?	5-6	9.6%		2.2%		0.10 (-0.43, 0.64)	0.70
	7-10	90.4%	8.55 (1.42)	97.8%	8.65 (1.06)		
3. How do you rate the use of pictures in the diabetes leaflets?	5-6	9.6%		0%		0.34 (-0.33, 0.93)	0.19
	7-10	90.4%	8.62 (1.40)	100%	8.96 (0.94)		
4. How do you rate the content of information in the diabetes leaflets	5-6	14.3%		6.6%		0.03 (-0.56, 0.63)	0.91
	7-10	85.7%	8.12 (1.53)	93.4%	8.15 (1.28)		
5. What are your suggestions for improving the diabetes leaflets?		<b>Control Group</b>		<b>Intervention Group</b>			
General comments on the leaflets		35/42 (83.3%)		35/46 (76%)			
Suggestions for improvements:		11/42 (26.2%)		17/46 (40%)			
• The need for compiling the diabetes leaflets into one book		2		6			
• The need for broader distribution of the diabetes leaflets		2		4			
• Giving information with simpler language and more pictures		4		0			
• Maintaining & continuing the programme (diabetes structured patient education sessions)		0		3			

## 6.7. DISCUSSION

The diabetes education materials for conducting research interventions that were suitable to the research objectives were hardly obtained. Thus, there was a need for developing new diabetes leaflets and posters written in *Bahasa Indonesia* in order to provide comprehensive information on type 2 diabetes to the research participants<sup>18</sup>. While most diabetes education materials available provide too much information, present overly complex concepts and use language for high-literate individuals,<sup>281</sup> in developing the new diabetes education materials, the researcher tried to follow guidelines on developing print materials for low-literate readers<sup>273,275,276</sup> as much as possible.

However, not all rules could be well followed, particularly on the amount of information and educational objectives provided, the use of culturally familiar illustrations, and determining the reading level. There was a lot of information on T2D included in the new diabetes leaflets that might be overwhelming and discouraging for the research participants. The westernised pictures and graphics downloaded from the internet were inevitably used in the leaflets that might be distracting and intimidating. Producing new pictures and graphics with local content and people would require more time and resources. The readability test to determine the reading level was not conducted due to the unavailability of any reading formula for use in *Bahasa Indonesia*. This might have resulted in higher reading level for the research participants. All of these were the limitations in developing the new diabetes education materials, which were mostly related to limited time and resources.

In order to find out about the participants' feedback about the leaflets and to obtain suggestions for improving the leaflets in the future, an evaluation of the diabetes leaflets was conducted. The evaluation consisted of 5 items including language use, font size, use of pictures, content of information and suggestions for improvement in the future. Although the intervention group rated higher than the control group for all the first four questions, there was no significant difference among the question ratings between the two groups. The research participants from both groups highly favoured the diabetes leaflets distributed to them. The participants gave high ratings on all evaluation items including language use, font size, use of pictures and content of information. They indicated that the diabetes leaflets were easy to understand, easy to read, interesting, and simple.

This might due to the following reasons: (1) Diabetes leaflets are rarely found in health care facilities in Yogyakarta, especially in community health centres; (2) Patient education on diabetes is not routinely conducted by health care providers in the community health centres; (3) It was the first time for all research participants to receive diabetes leaflets, thus they were very excited about the leaflets; (4) Above all, the research

participants received not only one mundane diabetes leaflet, but “a set of colourful leaflets with such comprehensive information”, which increased their enthusiasm about the leaflets. They were pleased to obtain handy comprehensive information on diabetes which they could refer to anytime. They even asked for more leaflets to be distributed to their family members, relatives and friends who also had T2D hoping that others also may know their illness better.

The diabetes leaflets were very well received and highly appreciated by the research participants from both groups. Instead of giving suggestions, the majority of the participants from both groups also gave very positive statement about the leaflets. The research participants indicated that getting “a set of colourful leaflets with such comprehensive information” was much beyond their previous expectation or imagination. This was clearly pointed out by some participants in the following words: ‘complete’, ‘perfect’, ‘more than enough’, ‘providing good information’, ‘encouraging for discipline and fighting spirit, and ‘increasing my diabetes knowledge’. Meanwhile, a number of research participants from both groups gave several suggestions for improving the diabetes leaflets in the future.

Aside from giving higher ratings for the evaluation items, the intervention group also had more participants than the control group in giving suggestions for improving the diabetes leaflets in the future. This might be related to the different nature of the research interventions conducted to both groups. The structured diabetes education programme was conducted in an interactive and collaborative way using a biopsychosocial approach as opposed to the usual didactic teaching of the diabetes seminar. During the four-weekly structured patient education sessions, the educator discussed all the diabetes leaflets one by one with the participants of the intervention group. This kind of discussion was not conducted in the diabetes seminar. The intense interaction and group dynamic among the participants and the educator in the structured patient education sessions might therefore bring out the participants’ higher attention and interest in the diabetes leaflets. The sessions were highly appreciated by the participants. There were demands from the participants to sustain the structured diabetes education programme as directly expressed by them during the session interactions and stated in the evaluation form. The participants who commented indicated that they enjoyed the structured diabetes education programme so much that they expected it to be maintained and continued. Therefore, structured diabetes education programme should be established more in the communities to respond to the needs and demands of the diabetics.

There were valuable suggestions which emerged from the research participants for improving the diabetes leaflets in the future. Developing new diabetes education materials for the research interventions was an initial step for developing these materials for broader



diabetes communities. These suggestions were therefore essential for developing the revised diabetes leaflets in the future.

The most frequent suggestion was “the need for compiling all the diabetes leaflets into one book” so that it could serve as a complete guide book and reminder for diabetics; because it would make the leaflets orderly, handy to carry, easy to read and not easily lost. This was indeed a smart suggestion. However, developing a complete guide book for free distribution will be very costly and the idea of reading the whole complete guide book might not make it practical to read particularly for poor readers. However, a simple diabetes handbook containing simple instructions on the five principles of diabetes management and other essential diabetes self-management behaviours might be useful for diabetics. This handbook should also contain value targets of clinical outcomes to be achieved, such as HbA1c, fasting blood glucose, 2-hour postprandial plasma glucose, total cholesterol, LDL cholesterol, HDL cholesterol, triglycerides, blood pressure, body mass index and waist circumference. Furthermore, this handbook can be provided with blank spaces to record the results of clinical outcomes from regular examinations thus can indicate whether the diabetes is well or poorly controlled. This diabetes handbook will therefore have double functions: as a diabetes education material as well as serving as a diabetes record book which should be brought every time the diabetic goes to see health care providers. A sample of this diabetes record book is “Diabetes Self-Management Clinical data Record Book” developed by Australian Disease Management Association.<sup>282</sup> Hopefully, this double function diabetes handbook can increase the diabetic’s insight and awareness of the disease, its management and diabetes self-care practices. Meanwhile, loose diabetes leaflets with different topics are still needed to provide longer description of each topic. A combination of a simple diabetes handbook and various diabetes leaflets should be made available for free distribution for the general public.

Another frequent suggestion was “the need for broader distribution of the leaflets”, not only in other community health centres, but also in other parts of Indonesia so that others might have the same opportunity to engage actively with the management of the disease. The research participants clearly noticed the usefulness of having diabetes leaflets in hand and wanted the leaflets to be disseminated to broader diabetes communities. This was very much in line with the goal and expectation of the researcher. However, there was another possibility of conducting broader distribution of the diabetes leaflets. Considering that the leading diabetes organisations in Indonesia do not have website or do not provide diabetes education materials in their websites, developing a website for providing diabetes education materials to be downloaded for free will be very useful for the general public.

In order to do develop a simple diabetes handbook and various diabetes leaflets for free distribution and a website for providing free downloadable diabetes education materials, a lot of support and resources from the government and other relevant organisations are required. Advocacy to the Republic of Indonesia Department of Health and local health offices on developing diabetes education materials and structured diabetes education programme in diabetes, and writing proposals for international grants on these topics should be conducted.

Although majority of the research participants highly favoured the diabetes leaflets, there were a few participants who still considered that the content of information could be improved with simpler language and more pictures. In particular two reasons were identified, including: the problem of understanding the content of information and limited supervision from health care providers. The problem of understanding the content of information might be related to the education level of the participants the majority of whom have primary school education level. The limited supervision from health care providers was consistent with findings from the scoping discussions with the health care providers in the community health centres (See **Section 6.5.4**). In the findings, the providers indicated that they did not provide sufficient diabetes education to their diabetic patients.

Other suggestions for improving the diabetes leaflets include: (1) Give more examples of problem solving for living with diabetes; (2) Incorporate psychological and spiritual aspects; and (3) Give more samples of simple and affordable menus for diabetics. Some of these suggestions were already included during discussions in the structured group education programme sessions, but not yet written in the leaflets, or already included in the leaflets but with little information.

The structured diabetes education programme was conducted using a biopsychosocial approach where the educator explored various biopsychosocial problems faced by the participants then discussed the problems and provided some problem solving skills. Diabetics continuously face situations and problems that require them to make quick and informed decisions on adjusting their food, activity and medications.<sup>126</sup> Situations and problems such as a very high or low blood sugar episode, a sick day, performing a religious fasting for 13 hours (for Moslems), other physical problems, emotional problems, social problems, and management strategies were discussed in the structured patient education sessions. In contrast, only physical problems were discussed in the usual diabetes seminar. Some problem solving for hyperglycaemia and hypoglycaemia were included in the leaflet entitled “Recognise Diabetes Mellitus and Act on It”. Some information about problem solving was also included in the leaflet entitled “Seven Successful Steps of Diabetes Self-Care”, however there were no examples of problem solving in the leaflet. Incorporating a number of

actual examples of problem solving in the revised leaflets will be useful for diabetics as a quick reference for solving particular problems.

Discussions about biopsychosocial problems and problem solving skills during the structured diabetes education programme sessions also included spiritual aspects since religion plays a major role in the everyday life of Indonesian people. According to International Religious Report 2010 on Indonesia, there are a number of religions practiced in Indonesia i.e. Islam (88%), Protestantism (6%), Catholicism (3%), Hinduism (2%), and others including Buddhism, traditional indigenous religions, Jewish and other Christian denominations (<1%).<sup>283</sup> The collective influence of religions is significantly manifest in the country's political, economic and cultural life. Religion fundamentally inspires the Indonesian public life, as illustrated in the state foundation, *Pancasila*, which begins with the principle of 'One Godhead'. *Pancasila*, which means the five pillars, consists of Belief in One God, Humanitarianism, National Unity, Representative Democracy and Social Justice.<sup>284</sup> However, description of spiritual aspects was not included in the leaflets. Incorporating spiritual aspect across faiths in the revised diabetes leaflets in the future will accommodate the needs of Indonesian patients with T2D more comprehensively.

Meanwhile, some simple menus for diabetics were included in the diabetes booklet on entitled "Food Exchanges and Menu". However the menu samples written in the booklet only consists of 3 meals and 3 snacks for one day. Providing more samples of simple and affordable menus in the leaflets will be more useful for diabetics for encouraging more ideas in food preparation and meal planning. All the above suggestions will be considered to be incorporated into the revised diabetes leaflets to be developed in the future.

Another suggestion which emerged from the evaluation was "developing a VCD/DVD on foot exercise". The participants of the intervention group were guided to do foot exercise in the third session of structured patient education programme, following all the ten steps of foot exercise as illustrated in the leaflet entitled "Feet Care and Exercise". They enjoyed it very much and were very surprised that the seemingly simple exercise completed within 20 minutes was so physically demanding. In contrast, the participants from the control group were not guided to do the foot exercise, rather they were only asked to do the exercise by themselves following the instructions and illustrations in the leaflet. Developing a lively audio-visual media on foot exercise will provide a useful resource for diabetics to follow than just looking at the paper-based instructions and illustrations of foot exercise in the leaflet. Developing a VCD/DVD on foot exercise will be included into the plan of writing proposals for international grants on developing the revised diabetes education materials and establishing structured diabetes education programme in diabetes in the communities.

The last suggestion which emerged from the evaluation, and certainly not the least, was “a call for health care providers to conduct adequate patient education to diabetics”. This was certainly a very important suggestion since it was very much in line with one of the research objectives set by the researcher. This will be followed up with an intense advocacy to health care providers to conduct adequate patient education to diabetics. More importantly, an advocacy to Department of Health should be conducted to encourage and fund the development of national and local structured group education programmes in T2D and the provision of free comprehensive diabetes education materials. This will require networking and collaboration with local, national, regional and international relevant organisations in order to obtain broader support for these initiatives.

## **6.8. CONCLUSIONS AND RECOMMENDATIONS**

### **6.8.1. Conclusions**

Several conclusions could be drawn from this chapter as follows:

- 1) Diabetes education materials providing comprehensive information on type 2 diabetes were rarely found in health care facilities in Yogyakarta Province and Indonesia.
- 2) Therefore, developing new diabetes education materials written in *Bahasa Indonesia*, which provide comprehensive information on type 2 diabetes, was greatly needed in order to cater to the research objectives. These materials included a set of diabetes leaflets (9 leaflets and 1 booklet) for distribution to the research participants, and 14 diabetes posters and banners for teaching aids during the research intervention sessions.
- 3) The new diabetes education materials substantially contributed to the success of the research interventions conducted.
- 4) The diabetes leaflets developed were well received and highly appreciated by the research participants from both groups and; and the leaflets contributed to the participants' understanding of type 2 diabetes.
- 5) There were a number of suggestions provided by the research participants for improving the diabetes leaflets in the future, most importantly compiling the diabetes leaflets into one book as a diabetes guide book and broader distribution of the diabetes leaflets to all parts of Indonesia.

- 6) Additionally, structured diabetes education programmes should be established more in the communities to respond to the needs and demands of people with type 2 diabetes.

### **6.8.2. Recommendations**

The recommendations which emerged from this chapter include:

- 1) The new diabetes education materials should be revised in order to take into account the suggestions provided by the research participants and address their current limitations.
- 2) There is a strong need to roll-out of the revised new diabetes education materials in the future. However, in order to be more widely accepted, the westernised graphics will be changed to depict Indonesian people.
- 3) There is a strong need for advocacy to the Republic of Indonesia Ministry of Health and local health offices to encourage and fund the development of national and local structured diabetes education programmes and the provision of free comprehensive diabetes education materials.
- 4) This will require networking and collaboration with local, national, regional and international relevant organisations in order to obtain broader support for these initiatives.
- 5) International financial support for the development of the revised diabetes education materials and the establishment of structured diabetes education programmes in the communities should be sought.

### **6.9. SUMMARY**

In summary, the underlying reason to develop new diabetes education materials written in *Bahasa Indonesia* needed for the research interventions was the limited availability and quality of diabetes leaflets and posters obtained from health institutions, particularly which cater to the research objectives. The new diabetes education materials were a substantial component of the research interventions conducted. Participants from both intervention and control groups highly favoured the diabetes leaflets distributed to them.

This chapter has outlined the existing diabetes education materials, the steps for developing the new diabetes education materials written in *Bahasa Indonesia*, the distribution and use of the new diabetes education materials, and the evaluation method for

the diabetes leaflets. The next chapter, Chapter 6, will discuss about the main study, a cluster-randomised controlled trial of a structured diabetes education programme.

**CHAPTER 7 – The Feasibility of a  
Structured Diabetes Education  
Programme: A Pilot Cluster  
Randomised Controlled Trial**

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**A Structured Diabetes Education Programme  
in Indonesia**

## 7.1. INTRODUCTION

Chapter 7 outlines the main study, namely the pilot cluster randomised controlled trial of a structured diabetes education programme. This study is the second study in the research project. However, because the previous cross-cultural adaptation of four validated diabetes-related instruments yielded varying results of Cronbach's alpha coefficients, the internal consistency reliability of the adapted instruments was reassessed using the same population sample as the main study. The findings of the pilot cluster randomised controlled trial were further enriched by the results of several scoping discussions conducted with groups of patients with type 2 diabetes and their family members, and health care providers working at the participating community health centres.

## 7.2. BACKGROUND

While there is currently no cure for type 2 diabetes (T2D), this chronic condition can be managed by maintaining good metabolic control through lifestyle modification and diabetes medication.<sup>285</sup> Improving glycaemic control is important to prevent the onset or delay the progression of micro- and macro-vascular complications of T2D.<sup>286</sup> It has been shown that improving metabolic control can be achieved through diabetes self-management education (DSME) and participation in active diabetes self-management behaviours.<sup>287,288</sup> Patient hospitalisations resulting from uncontrolled diabetes are often due to lack of diabetes knowledge and self-management skills.<sup>27</sup>

DSME is defined as *“the process of providing the person with diabetes with the knowledge and skills needed to perform self-care, manage crises, and make lifestyle changes required to successfully manage this disease”* (p. 1204). The goal of the process is thus *“to enable the patient to become the most knowledgeable and hopefully the most active participant in his or her diabetes care”* (p.1204).<sup>27</sup> The importance of diabetes self-management education (DSME) has long been recognised in helping diabetic patients engage actively in their own diabetes self-management.<sup>27,287-290</sup> DSME has been included in diabetes clinical practice recommendations in many Western countries.<sup>18,40,121,291</sup> A series of national standards for DSME, along with diabetes self-management support (DSMS), have been developed.<sup>122,292-294</sup> Elements that have been shown to improve effectiveness of DSME include using: a mixed intervention of educational and behavioural or psychological approaches; a combination of didactic and patient-provider interactive teaching; a face-to-face interaction strategy; increased number of sessions ( $\geq 6$ ); more total contact hours and longer duration of intervention; and delivery of a booster session.<sup>288</sup>



Structured diabetes education programmes enhance diabetes knowledge, attitudes and beliefs about diabetes, self-care behaviours, glycaemic control, and self-efficacy/empowerment in adults with T2D.<sup>18,40,287-290</sup> Effective structured diabetes education programmes generally have a sound philosophy or theoretical approach and are delivered face-to-face at a high intensity. They are also comprehensive, through the inclusion of physical activity component, psychosocial interaction, increased patient involvement, and delivery by trained educators.<sup>40,288,295,296</sup>

The philosophy most frequently used in DSME interventions is 'patient empowerment'. Patient empowerment involves a patient-centred approach and patient-provider collaboration, accommodating the essential realities of diabetes care.<sup>93,146</sup> The collaboration requires both the diabetes expertise of the provider and the equally important expertise of patients about their own lives, such as their priorities, concerns, goals, traditions, culture, values and resources.<sup>11,130</sup>

One theoretical education approach widely used in DSME interventions is self-efficacy, a key construct in the Social Cognitive Theory developed by Bandura. Self-efficacy refers to confidence in one's own ability to perform a particular behaviour.<sup>98,222</sup> Self-efficacy is a major concept in the patient empowerment approach to diabetes education and plays an important role in successful behaviour change. Therefore, enhancing the perceived self-efficacy of patients to self-manage their diabetes is an important goal of diabetes education and care.<sup>30</sup>

Two prominent models of structured diabetes education programmes are the UK Diabetes X-PERT Programme,<sup>152,153</sup> and the UK Diabetes Education and Self-management for Ongoing and Newly Diagnosed (DESMOND).<sup>156,157</sup> The intervention of the Diabetes X-PERT Programme trial, designed and facilitated by a single research dietician based on theories of empowerment and discovery learning, consisted of six two-hour weekly group sessions covering six different topics.<sup>152,153</sup> The design of the intervention in the present study was adapted particularly from this trial with some modifications. Meanwhile, the DESMOND intervention consisted of six-hour group education facilitated by two trained educators which was delivered over 1 day or 2 half-days, based on patient empowerment philosophy, and a series of psychological theories of learning: Leventhal's Common Sense Theory, the Dual Process Theory, and the Social Learning Theory.<sup>156,157</sup>

While DSME intervention has been widely applied and has become an integral part of T2D management in many Western and developed countries, its application in Indonesia – a developing country with a low Human Development Index rank and limited resources – has not been explored. Generally, traditional diabetes education can be found in hospitals and

community health centres in Indonesia. This patient education is mostly didactic teaching, neither structured nor comprehensive, and usually conducted by a nutritionist focusing primarily on diabetes meal planning to an individual patient with T2D alone or sometimes accompanied by a family member.

The other common forms of traditional diabetes education are conducted in group basis, including: diabetes public education conducted in publicly funded community health centres (CHCs), and diabetes seminar conducted in hospitals. Public education on infectious and chronic diseases, including T2D, is sometimes conducted in the communities within the working areas of CHCs, depending on the fund availability in the centres. Meanwhile, a diabetes seminar is a didactic teaching of T2D to a large group of people (100-200 people) performed by an internal medicine specialist or endocrinologist, and a nutritionist. This diabetes seminar is quite common in large cities, usually held by large hospitals in collaboration with pharmaceutical companies and offered to diabetic patients and lay people with some fees for attendance. However, such seminars are available on an ad hoc basis; and the fees may be quite expensive particularly for regular attendees of publicly funded CHCs who mostly came from lower social economic groups.

Diabetes self-management and patient empowerment are totally new concepts in diabetes education and care in Indonesia. This main study thus aimed to develop a pilot structured diabetes education programme for promoting diabetes self-management and patient empowerment in public primary care settings that was appropriate for Indonesian patients with T2D. The study also aimed to evaluate the effectiveness of such programme on clinical outcomes and diabetes-related scores of knowledge, health beliefs, self-care behaviours, and self-efficacy in people with T2D. Additionally, the study aimed to identify beliefs about the current diabetes education held by patients with T2D and their family members, and health care providers working at CHCs.

### **7.3. RESEARCH METHODS**

#### **7.3.1. Research Design**

A pilot randomised controlled trial (RCT) on individual patients with T2D was initially planned to be undertaken in each participating community health centre (CHC). However, the nature of close-knit community among regular attendees at one CHC could potentially result in participant contamination as shown in the previous cross-cultural adaptation study. Therefore, a pilot cluster randomised controlled trial (cluster RCT) consisting of a control and an intervention group was conducted at several CHCs in Yogyakarta City. These CHCs are

government-owned primary health care facilities found in each sub-district throughout all provinces in Indonesia. The centres provide six basic health care services to local people based on a national standard. These public centres are very similar in terms of the available resources and services provided.

This pilot cluster RCT was not registered for a clinical trial registration ID, i.e.: ClinicalTrials.gov, the WHO International Clinical Trial Registry Platform (ICTRP), and ISRCTN (International Standard Randomised Controlled Trials Number) Register.<sup>297,298</sup> This was particularly because as this was a pilot study, the trial was not deemed necessary to be registered. Furthermore, with the limited research funds, the researcher could not afford to pay for the expensive registration fee.

Additionally, several scoping discussions were conducted among patients with T2D and their family members, and among health care providers (HCPs) working at the participating CHCs in order to explore their perceptions of existing diabetes education. These scoping discussions served to enrich the results of the cluster RCT. The scoping discussions were carried out by the general practitioner researcher, using a semi-structured approach, guided by a list of open-ended questions.

Six scoping discussions were carried out, including: two groups of patients with T2D with their family members, each from the control and intervention group, conducted before the administration of research interventions; two with the same groups conducted after the administration of research interventions; and two with groups of HCPs working at the participating CHCs (.i.e. general practitioners, nurses and nutritionists). For the latter, two scoping discussions with the same topic were offered at two different times to allow the HCPs to choose a convenient time.

### **7.3.2. Sample Size**

The required sample size for the cluster RCT was calculated with HbA1c level as the primary outcome. The power was set at 80% with a level of significance of 0.05. As there is no published literature on effect size of glycaemic control measured by HbA1c in Indonesian populations, where HbA1c is not yet a routine blood test for diabetic patients, the conventional rule developed by Cohen (1988) for interpreting effect sizes was used to calculate the sample size.<sup>299,300</sup> Based on this, the value of effect size in a two-group test of mean difference was estimated at 0.20-0.49 for small effect, 0.50-0.79 for medium effect, and 0.80 for large effect.<sup>241</sup> To test for a significant difference between the two groups, a small effect size of 0.2 was arbitrarily adopted, assuming a common standard deviation of 3%, thus requiring a sample size of 74 or 37 participants in each group. In order to allow for

clustering and attrition, 50 participants in each group (100 participants in total) were recruited.

Participants for the scoping discussions were selected using purposive sampling from patients with T2D in both the control and intervention groups. Strategic selection was made, to maximise variation in age, sex, marital status, education level, and known duration. The selected participants were asked to bring one family member to the scoping discussions. For the HCP scoping discussions, the heads of the participating CHCs were requested to recruit three GPs, two nurses and one nutritionist from each CHC.

Ten participants from each control and intervention group were invited to attend scoping discussions with ten family members. Twenty four HCPs from the participating CHCs were invited to attend one of two scoping discussions. On average, 12-20 people were invited to participate in each focus group.

### 7.3.3. Preparation

For conducting patient interviews using an interviewer-administered questionnaire, eight medical doctors newly graduated from the researcher's home medical school were recruited. All research assistants were trained to conduct patient interviews using the 84-item diabetes self-management questionnaire to simulated and real patients with T2D diabetes. They were taught to use the additional notes (See **Table 4-1**) to help them explain the items to the patients during the patient interviews. This was particularly important because the majority of the participants had a low education level; and it was likely that it would be the first research experience for the participants. The assistants were also instructed to make the interviews as pleasant as possible by engaging the participants with questions about their family, children, work and social life. This approach was undertaken to build good rapport with the participants during the interviews. Additionally, the assistants were instructed to inform the patients that all questions raised by patients about diabetes-related issues would be addressed after the interviews were completed.

Eight community nurses were also recruited to carry out clinical measurement (e.g.: blood pressure, body weight, height, and waist circumference). They were trained to carry out the clinical measurement for the research.

### 7.3.4. Research Participants

It was estimated that each CHC could provide 30-50 patients with T2D who would meet the inclusion and exclusion criteria. This estimate was based on the previous survey in the cross cultural adaptation study. Therefore, four CHCs in Yogyakarta City were invited to

take part in the study. These CHCs were different from the CHCs used in the cross-cultural adaptation study. They comprised two CHCs who worked in partnership with the researcher's home medical school and two neighbouring CHCs who served similar populations. The four CHCs were Wirobrajan CHC, Ngampilan CHC, Kraton CHC and Jetis CHC. The heads of these four CHCs consented to take part of the study.

Participants for the cluster RCT were identified from the patient registers at the CHCs. Registered adult patients with T2D aged above 18 years old who were willing to participate were included. Participants were excluded if they were referred to hospital, house-bound or had reduced hearing and cognitive ability, and illiterate and/ or unable to speak *Bahasa Indonesia* (the national language).

Recruitment for adults with T2D registered at the CHCs was conducted through an open advertisement placed on announcement boards and consulting rooms of the attending HCPs (general practitioners and nurses). The HCPs were also requested to offer participation in the study to their patients with T2D during patient-provider encounters. The HCPs provided valuable assistance in participant recruitment. As in the cross-cultural adaptation study, patients with T2D told relatives, neighbours and friends who were diabetic about the study assisting in their recruitment.

One hundred and ten people (110) at four CHCs expressed interest in the study. Written consent was obtained from 107 (97.3%) volunteers. Three people (2.7%) did not consent to the study due to other commitments or change of mind. The participants were given participant information and complaint sheets. It was emphasised that participation in the study would not influence any existing care they received at the CHCs. After signing the consent form, the participants were interviewed by trained research assistants using the 84-item diabetes self-management questionnaire. Because the CHCs were very crowded during office hours, the participants were asked whether they preferred to be interviewed at the CHCs or at their homes. Many participants preferred to be interviewed at their homes. A small gift as a token of appreciation, worth AUD 1, was given to each participant after completing the interview.

Participants for the scoping discussions were purposively selected among the research participants from both control and intervention groups with a strategic selection, as described in **Section 6.3.2** above. A letter was sent to the selected participants explaining the purpose of the study and inviting them to participate. Meanwhile, the heads of participating CHCs were approached personally supported with a letter requesting them to facilitate recruitment of HCPs to participate in the scoping discussions (i.e. 3 GPs, 2 nurses and 1 nutritionist). A total of 23 participants participated in two pre-intervention scoping

discussions: 10 participants from the control group (8 patients and 2 family members), and 13 participants from the intervention group (9 patients and 4 family members). Twenty participants participated in two post-intervention scoping discussions: 10 participants from the control group (8 patients and 2 family members) and 10 participants from the intervention group (8 patients and 2 family members). Eighteen HCPs participated in two scoping discussions, each with 5 participants (3 GPs, 1 nurse and 1 nutritionist) and 13 participants (7 GPs, 4 nurses and 2 nutritionists). On average, the scoping discussions lasted for approximately 1-2 hours.

At the start of the scoping discussions with diabetic patients and their family members, the GP researcher carefully explained the procedure to the participants. For all of them, it was their first time to encounter a focus group. However, during the scoping discussions, instead of responding to the researcher's questions, several patients asked their own questions about diabetes-related problems to the GP researcher. The GP researcher thus had to keep reminding the participants that their own questions would be addressed at the end of the scoping discussions.

Written consent was obtained from the participants for audio recording. A travel compensation of IDR 30,000 (AUD 3) was given to each diabetic participant attending each focus group. A travel compensation of IDR 50,000 (AUD 5) was given to each HCP attending the focus group.

### **7.3.5. Randomization**

Individual patients were not randomised, instead, block randomisation was performed at centre level. The four participating CHCs were randomly assigned to either intervention or control group. One of two representatives of the two CHCs who worked in partnership with the researcher's home medical school was asked to choose from two sealed envelopes containing either number 1 or 2 (number 1 was for intervention group and number 2 was for control group). Similarly, one of two representatives of the two neighbouring CHCs was asked to choose from two sealed envelopes containing either number 1 or 2.

### **7.3.6. Blinding**

To maintain blind allocation, patient information sheet stated that the study was to compare the effectiveness of diabetes education programme at different CHCs. Participants were therefore less likely to identify if they were in the control or intervention group. This was particularly because of the nature of Indonesian close-knit communities which could potentially result in participant contamination if the participants were individually randomised

within one centre. Each research participant received a specifically designed patient information sheet depending on their cluster allocation. Each described, in detail, the specific program that the participants would be undertaking. Additionally, research concepts of “control and intervention group” would have been foreign to the participants who were basically traditional people with low scientific literacy and little research exposure. The use of these terms in the patient information would have caused confusion, and therefore they were omitted, even though this was contrary to the usual scientific practice.

It was not possible to blind those delivering the interventions. Clinical measurements were carried out by community nurses and blood tests by laboratory technicians who were blinded to treatment assignment. Patient interviews using the 84-item diabetes self-management questionnaire were conducted by research assistants also blinded to assignment.

### **7.3.7. Hypothesis**

The following research hypotheses were tested during the main study:

“People with type 2 diabetes who receive a primary care delivery of structured diabetes education programme promoting diabetes self-management and patient empowerment will have greater improvement in clinical outcomes and diabetes-related scores of knowledge, health beliefs, self-care skills, and self-efficacy than those who do not”.

### **7.3.8. Research Interventions**

In addition to the usual care provided at the CHC, the intervention group received a structured diabetes education programme promoting diabetes self-management and patient empowerment. Aside from the usual care, the control group was also given a research intervention, namely a diabetes seminar.

#### **7.3.8.1. Structured Diabetes Education Programme**

This research intervention was a pilot programme especially designed for the intervention group in the cluster RCT, to introduce and promote concepts of diabetes self-management and patient empowerment among patients with T2D and HCPs at CHCs. This programme was a patient-centred, group-based diabetes self-management education which was founded on the theoretical framework of patient empowerment for helping people use their innate ability to gain mastery over their diabetes. This was a modification of the UK Diabetes X-PERT Programme which involved six-weekly sessions covering six different topics.<sup>152,153</sup>

However, the original six-weekly sessions were modified into four weekly sessions in this research project, each with duration of 2.5 to 3 hours. Additionally, the topics were modified and condensed as follows:

- Week 1: Understanding type 2 diabetes and goal setting introduction
- Week 2: Type 2 diabetes prevention and lifestyle modification
- Week 3: Meal planning and physical activity
- Week 4: Diabetes self-management and evaluation

All participants received one set of comprehensive diabetes leaflets (9 leaflets and 1 booklet), as elaborated in **Chapter 5** – Developing Diabetes Education Materials.

This programme aimed to increase diabetes knowledge, develop skills and build confidence, thus enabling participants to make informed decisions regarding their diabetes self-care. The programme was designed and delivered by the general practitioner researcher taking on the role of a diabetes educator using a biopsychosocial approach in an interactive and collaborative way. Throughout the sessions, there were interactive discussions on biopsychosocial problems faced by the participants in living with diabetes and relevant problem solving solutions. The participants thus could learn from other participants' experiences and the educator's responses related to the raised issues in the discussions.

Each week, the session began with an interactive discussion on biopsychosocial issues in the first 30 minutes, then a 45-60 minute talk on one topic including relevant demonstrations (such as underlying diabetes mechanisms, samples of healthy food, simple weight training and foot exercise), followed by an interactive discussion on the topic for 45-60 minutes, and a goal setting in the last 30 minutes. A simple cognitive reframing technique was applied in the first 5 minutes of each talk to help participants cognitively reframe their perceptions towards diabetes.<sup>295,301,302</sup> The educator guided the participants to practice an attitude of positive thinking and feeling towards having diabetes and living well with diabetes, wrapped in a short prayer of conveying gratitude to God depending on each participant's faith. This simple practice was reapplied at the end of the session to help the participants get familiar with the cognitive reframing technique.

Each talk was delivered in a power point presentation, supported with A1-sized diabetes posters in colourful graphics. During the sessions, many discussions relating to lifestyle modifications and problem solving for diabetes-related issues occurred. In week 3, a nutritionist was invited to co-chair the session on diabetes meal planning; followed by a group foot exercise performed in the class guided by the diabetes educator researcher.

Furthermore, each participant was prompted to involve one family member in attending the group sessions to feature the patient's most important social support, i.e. family



support. The intervention group was divided into two groups based on the corresponding CHC, each consisting of 25 participants (and anticipated up to 50 participants if all patients and their family members came). The four sessions of each group were held in the corresponding CHC venues. A travel compensation of IDR 10,000 (AUD 1) was given to each participant attending each group session. When participants did not attend one session, text messages and telephone reminders were delivered to them. However, an 'intention to treat' analysis was carried out and outcome data was collected where possible.

### **7.3.8.2. Diabetes Seminar**

The diabetes seminar was a research intervention for the control group in the cluster RCT. This was a three-hour didactic teaching on T2D conducted in a large group of 50 participants, held in a function room of the researcher's home medical school. All participants also received one set of comprehensive diabetes leaflets. Eight leaflets and one booklet were distributed during the diabetes seminar, while one leaflet on "Seven Successful Steps for Diabetes Self-Care" was provided after the 3-month data collection was completed.

This diabetes seminar was similar to seminars provided on an ad hoc basis by large hospitals in collaboration with pharmaceutical companies with a fee for attendance. The speakers of the diabetes seminar conducted for the research intervention were an internal medicine specialist and a nutritionist, while the general practitioner researcher acted as a chairperson. The diabetes seminar was provided free of charge.

### **7.3.9. Research Outcomes**

Both intervention and control groups were assessed at baseline and 3 months after the completion of the research intervention in each group.

Data collected from both groups consisted of outcome measurements that were grouped into seven sections (See **Appendix E**):

- Section A - Sociodemographic Characteristics
- Section B - Medical History of the Participants
- Section C - The Indonesian Version of the DKQ-24
- Section D - The Indonesian Version of the DHBM
- Section E - The Indonesian Version of the SDSCA
- Section F - The Indonesian Version of the DES-SF
- Section G - Clinical Outcomes

Section A, B, C, D, E, and F were measured using one single questionnaire collected from patient interviews conducted by trained research assistants. The clinical

outcomes (Section G) came out from blood tests conducted by a nationally accredited clinical pathology laboratory and from physical assessments conducted by community nurses.

### **7.3.9.1. Primary Outcome and Other Clinical Outcomes**

The primary outcome of the research was glycated haemoglobin or HbA1c (%) at 3-month follow-up. HbA1c is not yet a routine blood sugar testing at CHCs since it is very expensive. The participants in the study were more familiar with fasting blood glucose and two-hour postprandial blood glucose tests conducted monthly under the direction of HCPs at CHCs for the purpose of blood glucose monitoring. HCPs may instruct patients with T2D to get random blood glucose tests for blood glucose monitoring. Since HbA1c was a new blood glucose test for the research participants, the researcher included a brief explanation on HbA1c in one of the diabetes leaflets developed for the research interventions (See Chapter 5 – Developing Diabetes Education Materials).

Therefore, as well as HbA1c testing, fasting blood/plasma glucose (FBG/FPG) (mmol/L and mg/dL) and two-hour postprandial plasma glucose (2-h PPG) (mmol/L and mg/dL) were also conducted to provide additional research outcomes for glycaemic control. Venous blood samples were collected by trained laboratory technicians and analysed at a nationally accredited clinical pathology laboratory using standard quality controlled methods.<sup>303</sup>

Blood pressure was measured using mercury sphygmomanometers, conforming to accepted methods.<sup>304</sup> Each systolic and diastolic blood pressure (mmHg) was measured 3 times 5-10 minutes apart with the patient resting quietly for at least 5 minutes; the readings were averaged to provide mean values. Acceptable ranges for blood sugar testing and blood pressures were obtained from recent clinical guide reports.<sup>46,87,304</sup>

Body height (metres) and weight (kilograms) were measured using ultrasonic height and weight machine. Body mass index (BMI) was calculated from height and weight measurements ( $\text{kg/m}^2$ ). Waist circumference (centimetre) was measured using the WHO recommended technique.<sup>305</sup>

### **7.3.9.2. Sociodemographic Characteristics and Medical History of the Participants**

Data of sociodemographic characteristics collected from the research participants included: gender, age (years), marital status, highest educational qualification, employment, and estimated monthly family income. Data of the participants' medical history collected included: known duration of T2D (years), diabetes patient education (individual or group

session), known family history of T2D, self-monitoring blood glucose (SMBG) using a glucometer, hypertension, smoking, diabetes treatment, diabetes complications, family support, and health insurance coverage.

### **7.3.9.3. The Indonesian Version of the 24-item Diabetes Knowledge Questionnaire (DKQ-24)**

Diabetes knowledge was measured using an adaptation of the 24-item Diabetes Knowledge Questionnaire (DKQ-24) for use with an Indonesian population (See **Chapter 4**). The DKQ-24 was designed to elicit information about the respondents' general diabetes knowledge, including the cause of diabetes, type of diabetes, self-management skills, and diabetes complications. The instrument consists of 24 brief statements with three possible responses: 1= *yes*, 2= *no*, and 3= *I don't know*. Responses were scored as correct or incorrect. The correct responses were summed to attain a total score, with a maximal score of 24. The total score was converted into a percentage, ranging from 0 to 100 percent. Higher scores indicated higher understanding about diabetes.<sup>181,230</sup>

### **7.3.9.4. The Indonesian Version of the Diabetes Health Belief Measure (DHBM)**

Diabetes health beliefs were measured using an adaptation of the Diabetes Health Beliefs Measure (DHBM) for use with an Indonesian population (See **Chapter 4**). The DHBM comprises five subscales, including control, barriers, social support for diet, impact of job on therapy, and benefits of therapy. The instrument consists of 25 statements and is scored on a 5-point Likert Scale: 1= *strongly disagree*, 2= *agree*, 3= *not sure*, 4= *agree*, and 5= *strongly agree*. The participants' responses were summed to attain a total score, with a maximal score of 125. The total score was converted into a percentage, with a maximal score of 100 percent. Higher scores indicated higher beliefs in the ability to manage diabetes.<sup>184,230</sup>

### **7.3.9.5. The Indonesian Version of the Summary of Diabetes Self-Care Activities (SDSCA)**

Diabetes self-care behaviours were measured using an adaptation of the Summary of Diabetes Self-care Activities (SDSCA) revised scale for use with an Indonesian population (See **Chapter 4**). The SDSCA consists of 11 core items. Scoring of items 1-10 (excluding smoking) uses the days per week on a scale of 0-7. For each group of self-care activities (general diet, specific diet, exercise, blood sugar testing, and foot care), a mean number of days was calculated, with a reversed scoring on item no.4. Higher scores indicated higher levels of self-care activities.<sup>210</sup>

### 7.3.9.6. The Indonesian Version of the Diabetes Empowerment Scale (DES-SF)

Diabetes self-efficacy was measured using an adaptation of Diabetes Empowerment Scale – Short Form (DES-SF) for use with an Indonesian population (See **Chapter 4**). The DES-SF consists of eight brief statements of diabetes-related psychosocial self-efficacy and is scored using a 5-point Likert Scale: 1= *strongly disagree*, 2= *agree*, 3= *not sure*, 4= *agree*, and 5= *strongly agree*. The participants' responses were summed to attain a total score, with a maximal score of 40. The total score was converted into a percentage, with a maximal score of 100 percent. Higher scores indicated higher levels of psychosocial self-efficacy in managing diabetes.<sup>30,225</sup>

### 7.3.9.7. Open Ended Questions for Scoping Discussions

The scoping discussions were semi-structured, guided by a list of open-ended questions (See **Appendix G**). Ten of the questions in the interview guides were posed to both groups of HCPs and groups of diabetic patients with their family members before the administration of the research interventions. These questions related to: (1) current provision of diabetes care; (2) current provision of diabetes education; (3) how the diabetes information should be provided; (4) the diabetes knowledge level of the patients with T2D; (5) support needed by the patients with T2D; (6) the expectations of the diabetic patients for diabetes support from HCPs; (7) the expectations of the diabetic patients for care from their family; (8) the impact of T2D on the patient's life and family; (9) understanding of diabetes self-management and patient empowerment concepts; and (10) the implementation of the concepts of diabetes self-management and patient empowerment.

Four questions were asked to the same two groups of diabetic patients with their family members after the administration of the research interventions which included: (1) the diabetes seminar or the diabetes structured patient education sessions administered and the diabetes leaflets provided; (2) implementing what had been learned from the diabetes education sessions and the diabetes leaflets; (3) the perceptions of the diabetic patients about their diabetes knowledge, ability, motivation, compliance, and family and social support to perform diabetes self-care activities; and (4) further expectations from the HCPs for the provision of diabetes care. Follow-up questions also emerged depending on the participants' responses to the listed questions.

### 7.3.10. Data Analysis

All quantitative data were double-entered for verification, analysed and digitally stored using SPSS statistical software version 18. Descriptive statistics were used to

examine sociodemographic characteristics and medical history outcome variables. Cronbach's alpha coefficients were performed to reassess the internal consistency reliability of the Indonesian version of the DKQ-24, the DHBM, the SDSCA, and the DES-SF. *T*-tests were used to analyse differences on continuous data between mean scores for the intervention and control groups. Categorical data were analysed using Chi-square statistics to test the significance of different proportions. Repeated measures ANOVA were used to assess the group differences on clinical outcomes and diabetes-related scores of diabetes knowledge, health beliefs, self-care behaviours and self-efficacy.

Scoping discussions were audiotaped and notes of important issues were taken during the scoping discussions. Loose transcription of interviews and interview notes were combined to generate a summary of key findings. When necessary, verbatim transcription was conducted to report full quotes of important issues. Full qualitative analysis was not undertaken since this was beyond the scope of this research project.

## 7.4. RESULTS

### 7.4.1. Sociodemographic Characteristics and Medical History

The heads of four community health centres (CHCs) in Yogyakarta City consented to take part in the study. The CHCs were randomly assigned to either intervention or control group (2 intervention and 2 control). Each group consisted of one centre working in partnership with the researcher's home medical school and one neighbouring centre. Of 107 adults with T2D registered at the four participating CHCs who consented to the study, 101 participants completed baseline assessment on clinical measurement and diabetes-related scores. They consisted of 33 men and 68 women aged 30 to 77 years with mean age 59.3 (SD = 9.6). Many of the participants were elderly people (aged 60 and above) (49.5%). The sociodemographic characteristics of the participants are shown in **Table 7-1**.

The participants in the two groups had similar baseline sociodemographic characteristics. Almost all variables showed no statistically significant differences between the intervention and control groups ( $p > 0.05$ ). Estimated monthly family income showed a borderline  $p$ -value. However, this was not a problem, as the variable was not strongly associated with the outcomes. The treatment groups were allocated by randomisation, thus any differences in the baseline characteristics were by definition due to chance.<sup>306-308</sup>

**Table 7-0-1 Comparison of sociodemographic characteristics of the intervention and control group participants at baseline (n = 101)**

Variables	Intervention Group, n=51	Control Group, n=50	Difference (95% CI)	P-value
	Mean (SD) or n (%)	Mean (SD) or n (%)		
Age (years) (mean and SD)	60 (10.4)	58.6 (8.7)	1.4 (-2.3, 5.2)	0.45 <sup>a</sup>
Gender (%)				0.53 <sup>b</sup>
Men	15 (29.4%)	18 (36.0%)		
Women	36 (71.6%)	32 (64.0%)		
Marital Status (%)				0.88 <sup>b</sup>
Unmarried	1 (2.0%)	1 (2.0%)		
Married	34 (66.6%)	35 (70.0%)		
Divorced	1 (2.0%)	2 (4.0%)		
Widowed	15 (29.4%)	12 (24.0%)		
Highest educational qualification (%)				0.13 <sup>b</sup>
Primary school	13 (25.5%)	18 (36.0%)		
Junior and senior high school	28 (54.9%)	25 (50.0%)		
College and university	10 (19.6%)	7 (14.0%)		
Employment (%)				0.16 <sup>b</sup>
Home duties (housewives)	17 (33.3%)	16 (32.0%)		
Self-employed and informal sector job	10 (19.6%)	21 (42.0%)		
Public servant, police and military force	6 (11.8%)	2 (4.0%)		
Private company employee	4 (7.8%)	2 (4.0%)		
Retirement	14 (27.5%)	8 (16.0%)		
Estimated monthly family income (in IDR and AUD equivalence) (%)				0.04 <sup>b</sup>
< IDR 1,000,000 (AUD 100)	25 (49.0%)	35 (70.0%)		
IDR 1,000,000 – 2,999,999 (AUD 100 – 299.99)	20 (39.2%)	14 (28.0%)		
IDR 3,000,000 – 7,999,999 (AUD 300 – 799.99)	6 (11.8%)	1 (2.0%)		

<sup>a</sup> Analysis by *t*-test <sup>b</sup> Analysis by chi-square

Medical history of the participants is shown in **Table 7-2a** and **Table 7-2b**. The participants in the two groups also had similar medical history. Most variables showed no statistically significant differences between the intervention and control groups ( $p > 0.05$ ), except on diet treatment, stroke complication and health insurance coverage. However, these baseline differences were purely due to chance associated with randomisation.<sup>306-308</sup> According to Fayers and King, even when randomisation is properly conducted, approximately 5% of variables tested are expected to have  $p$ -values less than 0.05.<sup>309</sup>

**Table 7-0-2a Comparison of medical history of the intervention and control group participants at baseline (n = 101)**

Variable	Intervention Group, n=51	Control Group, n=50	Difference (95% CI)	P-value
	Mean (SD) or n (%)	Mean (SD) or n (%)		
Known duration of T2D (years) (mean and SD)	4.8 (3.7)	5.8 (5.9)	-1.0 (-2.9, 1.0)	0.32 <sup>a</sup>
Traditional patient education on T2D (individual or group session) (%)				0.35 <sup>b</sup>
No	41 (80.4%)	38 (76.0%)		
Yes	10 (19.6%)	12 (24.0%)		
Known family history on T2D (%)				0.96 <sup>b</sup>
No	24 (47.0%)	23 (46.0%)		
Yes	27 (53.0%)	27 (54.0%)		
Self-monitoring of blood glucose (SMBG) using a glucometer (%)				
No	47 (92.2%)	48 (96.0%)		0.72 <sup>b</sup>
Yes	4 (7.8%)	2 (4.0%)		
Hypertension (%)				0.24 <sup>b</sup>
No	25 (49.0%)	29 (58.0%)		
Yes	26 (51.0%)	21 (42.0%)		
Smoking (%)				
No	46 (90.1%)	43 (86.0%)		0.63 <sup>b</sup>
Yes	5 (9.8%)	7 (12.0%)		
Diabetes treatment #				
1. Diet (%)				0.03 <sup>b</sup>
No	10 (19.6%)	19 (38.0%)		
Yes	41 (80.4%)	31 (62.0%)		
2. Exercise (%)				0.4 <sup>b</sup>
No	19 (37.3%)	17 (34.0%)		
Yes	32 (62.7%)	33 (66.0%)		

**Table 7-2b Comparison of medical history of the intervention and control group participants at baseline (n = 101)**

Variable	Intervention Group, n=51	Control Group, n=50	Difference (95% CI)	P-value
	Mean (SD) or n (%)	Mean (SD) or n (%)		
3. Oral antidiabetics (%)				0.1 <sup>b</sup>
No	5 (9.8%)	1 (2.0%)		
Yes	46 (90.2%)	49 (98.0%)		
4. Insulin (%)				0.63 <sup>b</sup>
No	47 (92.2%)	46 (92.0%)		
Yes	4 (7.8%)	4 (8.0%)		
5. Herbal/ traditional remedies (%)				0.29 <sup>b</sup>
No	31 (60.8%)	34 (68.0%)		
Yes	20 (39.2%)	16 (32.0%)		
<b>Diabetes complications #</b>				
1. Neuropathy (nerve damage) (%)				0.53 <sup>b</sup>
No	15 (29.4%)	14 (28.0%)		
Yes	36 (70.6%)	36 (72.0%)		
2. Vision disorders (retinopathy/ glaucoma/ cataract/ corneal disease) (%)				0.37 <sup>b</sup>
No	31 (60.8%)	33 (66.0%)		
Yes	20 (39.2%)	17 (34.0%)		
3. Nephropathy (kidney disease) (%)				0.11 <sup>b</sup>
No	46 (90.2%)	49 (98.0%)		
Yes	5 (9.8%)	1 (2.0%)		
4. Erectile dysfunction (impotence) (%)				0.28 <sup>b</sup>
No	44 (86.3%)	40 (80.0%)		
Yes	7 (13.7%)	10 (20.0%)		
5. Heart disease (%)				0.58 <sup>b</sup>
No	42 (82.4%)	41 (82.0%)		
Yes	9 (17.6%)	9 (18.0%)		
6. Stroke (%)				0.01 <sup>b</sup>
No	44 (7.8%)	50 (100%)		
Yes	7 (7.8%)	0 (0.0%)		
7. Peripheral vascular disease (foot ulcers/ gangrene) (%)				0.28 <sup>b</sup>
No	44 (86.3%)	40 (80.0%)		
Yes	7 (13.7%)	10 (20.0%)		
Family and social support for managing T2D (%)				0.22 <sup>b</sup>
No	10 (19.6%)	6 (12.0%)		
Yes	41 (80.4%)	44 (88.0%)		
Health insurance coverage (%)				0.02 <sup>b</sup>
No insurance	11 (19.6%)	12 (12.0%)		
Government health security for poor people (Jamkesmas)	9 (80.4%)	22 (88.0%)		
Government health insurance (PT. Askes)	27 (19.6%)	13 (12.0%)		
Work force social security (PT.Jamsostek)	4 (80.4%)	3 (88.0%)		
# Multiple responses were selected				
<sup>a</sup> Analysis by <i>t</i> -test				
<sup>b</sup> Analysis by chi-square				



## 7.4.2. Reassessment of the Internal Consistency Reliability of the Indonesian Version of Four Diabetes-Related Instruments

The internal consistency reliability of the four adapted Indonesian diabetes-related instruments examined in the cross-cultural adaptation ( $n = 83$ ) resulted in varying results (See **Chapter 4**). Only the Indonesian version of DHBM instrument showed a satisfactory Cronbach's alpha coefficient ( $\alpha = 0.737$ ). The Cronbach's alpha coefficients of the Indonesian DKQ-24, the DES-SF and SDSCA were 0.603, 0.555, and 0.457, respectively. The adapted instruments were reassessed using the sample population of the cluster randomised controlled trial (See **Section 6.4.1**) (hereafter called 'the cluster RCT sample').

### 7.4.2.1. The Indonesian Version of the 24-item Diabetes Knowledge Questionnaire (DKQ-24)

The Cronbach's alpha coefficient of the Indonesian version of the DKQ-24 instrument using the cluster RCT sample ( $n = 101$ ) was 0.723, an increased value as compared to the reliability coefficient yielded in the cross cultural adaptation study ( $\alpha = 0.603$ ). This was within the recommended value ( $\alpha =$  above 0.7). The psychometric properties of the DKQ-24 instrument are shown in **Table 7-3**. Having satisfactory internal consistency reliability, the Indonesian version of the DKQ-24 is valid and reliable for use in an Indonesian population.

### 7.4.2.2. The Indonesian Version of the Diabetes Health Belief Measure (DHBM)

The overall reliability coefficient for the Indonesian version of the DHBM instrument using the cluster RCT sample ( $n = 101$ ) was 0.718, a slightly decreased value as compared to the reliability coefficient yielded in the cross cultural adaptation study ( $\alpha = 0.737$ ). However, this was still within the recommended value ( $\alpha =$  above 0.7). The reliability coefficients for the four subscales were 0.479, 0.772, 0.590, and 0.851, respectively. Two of the subscales were below the recommended value. The findings were comparable with the reliability coefficients of the subscales obtained in the cross cultural adaptation study (0.462, 0.826, 0.723, and 0.688, respectively). The psychometric properties of the DHBM instrument are shown in **Table 7-4**. Having satisfactory overall internal consistency reliability, the Indonesian version of the DHBM is valid and reliable for use in an Indonesian population.

**Table 7-3 Psychometric properties of the Indonesian version of the DKQ-24 instrument (n=101)**

No.	Item and Correct Answer	Corrected Item-Total Correlation	Cronbach's Alpha if Item Deleted
1.	Eating too much sugar and other sweet foods is a cause of diabetes. [No]	-0.580	0.731
2.	The usual cause of diabetes is lack of effective insulin in the body. [Yes]	0.434	0.699
3.	Diabetes is caused by failure of the kidneys to keep sugar out of the urine. [No]	0.136	0.723
4.	Kidneys produce insulin. [No]	0.449	0.700
5.	In untreated diabetes, the amount of sugar in the blood usually increases. [Yes]	0.155	0.721
6.	If I am diabetic, my children have a higher chance of being diabetic. [Yes]	0.374	0.705
7.	Diabetes can be cured. [No]	0.452	0.697
8.	A fasting blood sugar level of 210 is too high. [Yes]	0.174	0.720
9.	The best way to check my diabetes is by testing my urine. [No]	0.428	0.700
10.	Regular exercise will increase the need for insulin or other diabetic medication. [No]	0.178	0.722
11.	There are two main types of diabetes: Type 1 (insulin-dependent) and Type 2 (non-insulin dependent). [Yes]	0.349	0.707
12.	An insulin reaction is caused by too much food. [No]	0.204	0.718
13.	Medication is more important than diet and exercise to control my diabetes. [No]	0.334	0.708
14.	Diabetes often causes poor circulation. [Yes]	0.299	0.711
15.	Cuts and abrasions on diabetes heal more slowly. [Yes]	0.259	0.715
16.	Diabetics should take extra care when cutting their toenails. [Yes]	0.263	0.716
17.	A person with diabetes should cleanse a cut with iodine and alcohol. [No]	-0.240	0.731
18.	The way I prepare my food is as important as the foods I eat. [Yes]	0.334	0.708
19.	Diabetes can damage my kidneys. [Yes]	0.424	0.702
20.	Diabetes can cause loss of feeling in my hands, fingers and feet. [Yes]	0.360	0.709
21.	Shaking and sweating are signs of high blood sugar. [No]	0.114	0.725
22.	Frequent urination and thirst are signs of low blood sugar. [No]	0.233	0.717
23.	Tight elastic hose or socks are not bad for diabetics. [No]	0.285	0.713
24.	A diabetic diet consists mostly of special foods. [No]	0.007	0.732

**Table 7-4 Psychometric properties of the Indonesian version of the DHBM instrument (n=101)**

No.	Item and Correct Answer	Cronbach's Alpha of Subscales	Corrected Item-Total Correlation	Cronbach's Alpha if Item Deleted
<b>Control of Diabetes</b>				
1.	My diabetes is well controlled		0.181	0.717
<b>Barriers Subscale</b>		0.479		
2.	I would have to change too many habits to follow my diet (diabetic foods)		-0.091	0.737
3.	It has been difficult following the diet (diabetic foods) the doctor ordered for me		0.096	0.728
4.	I am confused by all the medication the doctor has given me		0.120	0.721
5.	I would have to change too many habits to take my medication		0.155	0.718
6.	Taking my medication interferes with my normal daily activities		0.491	0.695
<b>Social Support Subscale</b>		0.772		
7.	I have others around me who remind me to eat the right foods		0.069	0.726
8.	I can count on my family when I need help following my diet (diabetic foods)		0.132	0.721
9.	My husband/wife helps me follow my diet (diabetic foods)		0.122	0.722
<b>Impact of Job on Therapy Subscale</b>		0.590		
10.	If I changed "jobs" I would be easier to follow my diet (diabetic foods)		0.197	0.715
11.	My work makes me so tired that it's hard to follow my diet (diabetic foods)		0.252	0.711
12.	I could control my weight if the pressures of my job weren't so great		0.104	0.432
13.	If I changed "jobs", it would be easier to take my medication		0.205	0.714
14.	I worry so much about my job that I can't take my medication		0.189	0.714
15.	I believe that my diet (diabetic foods) will help prevent diseases (complications) related to diabetes		0.485	0.695
16.	Following a prescribed diet (diabetic foods) is something a person must do no matter how hard it is		0.453	0.694
<b>Benefits of Therapy Subscale</b>		0.851		
17.	I believe that my diet (diabetic foods) will control my diabetes		0.558	0.692
18.	I must follow my diet (diabetic foods) even if I don't think I am getting better		0.183	0.716
19.	In general, I believe that my diet (diabetic foods) for diabetes will help me to feel better		0.611	0.691
20.	Controlling weight is something one must do no matter how hard it is		0.258	0.710
21.	I believe that my medication will help prevent diseases (complications) related to diabetes		0.605	0.689
22.	Taking medication is something one must do no matter how hard it is		0.338	0.705
23.	I believe that my medication will control my diabetes		0.615	0.692
24.	I must take my diabetes medication even if I don't think I am getting better		0.396	0.699
25.	I believe that my medication for diabetes will help me to feel better		0.579	0.694

### 7.4.2.3. The Indonesian Version of the Summary of Diabetes Self-Care Activities (SDSCA)

The Cronbach's alpha coefficient for the Indonesian version of the SDSCA instrument using the cluster RCT sample ( $n = 101$ ) was 0.433. This was a slightly decreased value as compared to the reliability coefficient obtained in the cross cultural adaptation study ( $\alpha = 0.457$ ), and below the recommended value ( $\alpha =$  above 0.7). The average inter-item correlation was 0.094; although slightly increased from the value obtained in the cross cultural adaptation study (0.075), this was still below the recommended value range (0.15-0.50). The psychometric properties of the SDSCA instrument are shown in **Table 7-5**.

**Table 7-5 Psychometric properties of the Indonesian version of the SDSCA instrument ( $n=101$ )**

No.	Item and Correct Answer	Cronbach's Alpha of Subscales	Corrected Item-Total Correlation	Cronbach's Alpha if Item Deleted
<b>General Diet</b>		0.930		
1.	How many of the last SEVEN DAYS have you followed a healthful eating plan?		0.435	0.329
2.	On average, over the past month, how many DAYS PER WEEK have you followed your eating plan?		0.415	0.333
<b>Specific Diet</b>		0.167		
3.	On how many of the last SEVEN DAYS did you eat five or more servings of fruits and vegetables?		0.280	0.367
4.	On how many of the last SEVEN DAYS did you eat high fat foods such as red meat or full-fat dairy products?		0.168	0.411
<b>Exercise</b>		0.506		
5.	On how many of the last SEVEN DAYS did you participate in at least 30 minutes of physical activity? (Total minutes of continuous activity, including walking).		0.84	0.435
6.	On how many of the last SEVEN DAYS did you participate in a specific exercise session (such as swimming, walking, biking) other than what you do around the house or as part of your work?		0.202	0.395
<b>Blood Sugar Testing</b>		0.747		
7.	On how many of the last SEVEN DAYS did you test your blood sugar?		0.123	0.427
8.	On how many of the last SEVEN DAYS did you test your blood sugar the number of times recommended by your health care provider?		0.098	0.432
<b>Foot Care</b>		0.515		
9.	On how many of the last SEVEN DAYS did you check your feet?		0.302	0.350
10.	On how many of the last SEVEN DAYS did you inspect the inside of your shoes?		0.294	0.354
<b>Smoking</b>				
11.	Have you smoked a cigarette—even one puff—during the past SEVEN DAYS?		0.202	0.605
<b>Overall scale</b>		0.433		

Item 11 on smoking had a different construct from the rest of instrument items (item 1 – item 10), which contributed to the low Cronbach's alpha value related to the diversity of the constructs being measured.<sup>261</sup> When item 11 was deleted, the coefficient alpha increased to 0.605. Although this value was still below the recommended value, this was considered adequate for pilot studies.<sup>256,267</sup> Therefore, the Indonesian version of SDSCA had 10 items, excluding the smoking item. The 10-item Indonesian version of SDSCA was adequate for use as a research instrument in the main study.

#### 7.4.2.4. The Indonesian Version of the Diabetes Empowerment Scale – Short Form (DES-SF)

The Cronbach's alpha coefficient for the Indonesian version of the DES-SF instrument using the cluster RCT sample ( $n = 101$ ) was 0.595, an increased value as compared to the reliability coefficient obtained in the cross cultural adaptation study ( $\alpha = 0.555$ ). However, this was still below the recommended value ( $\alpha =$  above 0.7). This instrument only has eight items, therefore inter-item correlations were examined. The average inter-item correlation was 0.164, within the recommended value range (0.15-0.50). The psychometric properties of the DES-SF instrument are shown in **Table 7-6**. Although the Cronbach's alpha coefficient was below the recommended value ( $\alpha =$  above 0.7), this was considered adequate for pilot studies.<sup>256,267</sup> The Indonesian version of DES-SF was adequate for use as a research instrument in the main study.

**Table 7-6 Psychometric properties of the Indonesian version of the DES-SF instrument ( $n=101$ )**

No.	Item and Correct Answer	Corrected Item-Total Correlation	Cronbach's Alpha if Item Deleted
<b>In general, I believe that:</b>			
1.	I know what part(s) of taking care of my diabetes that I am dissatisfied with.	0.203	0.587
2.	I am able to turn my diabetes goals into a workable plan.	0.240	0.514
3.	I can try out different ways of overcoming barriers to my diabetes goals.	0.190	0.617
4.	I can find ways to feel better about having diabetes.	0.290	0.547
5.	I know the positive ways I cope with diabetes-related stress.	0.185	0.577
6.	I can ask for support for having and caring for my diabetes when I need it.	0.185	0.577
7.	I know what helps me stay motivated to care for my diabetes.	0.227	0.579
8.	I know enough about myself as a person to make diabetes care choices that are right for me.	0.228	0.532

A summary of the Cronbach's alpha coefficients of the four adapted Indonesian diabetes-related instruments obtained in the cross-cultural adaptation and in the cluster randomised controlled trial is presented in **Table 7-7**.

**Table 7-7 Summary of the internal consistency reliability of the four adapted Indonesian diabetes-related instruments**

Instruments	Cronbach's alpha coefficient in the cross-cultural adaptation ( <i>n</i> =83)	Cronbach's alpha coefficient in the cluster randomised controlled trial ( <i>n</i> =101)
The DKQ-24	0.603	0.723
The DHBM	0.737	0.718
The SDSCA	0.473 (11 items)	0.605 (10 items)
The DES-SF	0.555	0.595

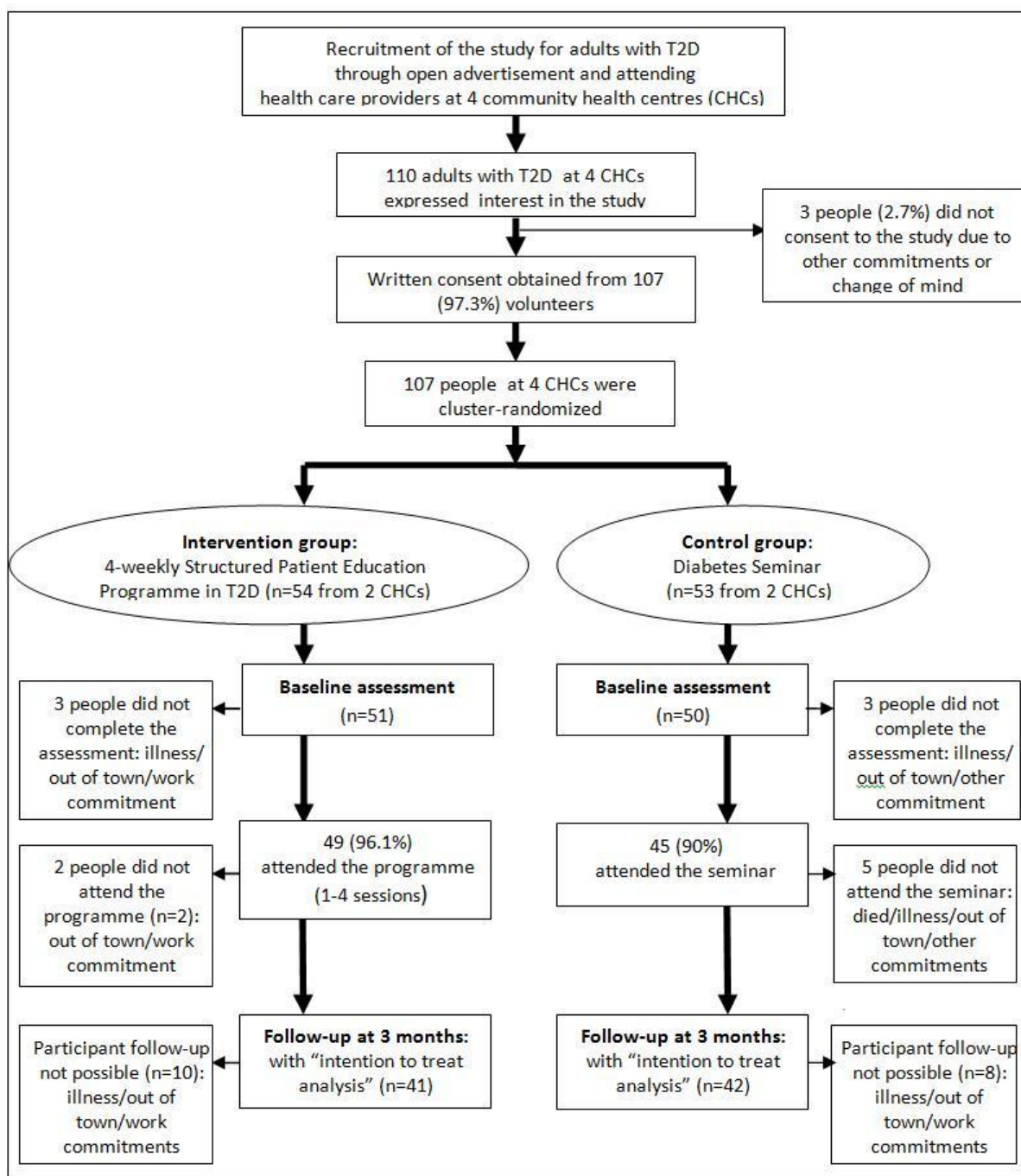
### 7.4.3. Assessment of Key Outcome Variables of the Main Study

One hundred and one adults with T2D (intervention group = 51; and control group = 50) completed baseline assessment on clinical measurement and diabetes-related scores of knowledge, health beliefs, self-care activities and self-efficacy. These participants were invited to attend the research interventions according to the research group: the 3-hour diabetes seminar for the control group, and the four-weekly sessions of structured diabetes education programme for the intervention group. Each participant of the intervention group was prompted to attend the sessions with one family member. However, since all the sessions were conducted during school and office hours, i.e. between 9 am to 1 pm, not all family members could attend the sessions due to other commitments.

Forty-five participants in the control group attended the diabetes seminar (90%). Forty-nine participants in the intervention group attended 1-4 sessions (96.1%). Twenty-nine participants attended all sessions (56.9%), nine people attended 3 sessions (17.6%), three people attended 2 sessions (5.9%), and eight people attended only 1 session (15.7%). On average, the number of family members attending each session in each intervention group was 4-10 people.

Eighty three participants completed 3 month follow-up assessment. Details regarding participant flow are presented in **Figure 7-1**.

Figure 7-1 Flow of participants through study



Comparison of key outcome variables between groups at baseline is presented in **Table 7-8**. The participants in the two groups had similar clinical outcomes and diabetes related scores. Most variables showed no statistically significant differences between the intervention and control groups ( $p > 0.05$ ), except 2-hour postprandial plasma glucose (2-hour PPG). The participants in the intervention group had higher mean level of 2-hour PPG than the control group. This baseline difference was purely due to chance associated with randomisation.<sup>306-309</sup>

**Table 7-8 Comparison of key outcome variables of the intervention and control groups at baseline (n=101)**

Outcomes	Intervention Group, n=51	Control Group, n=50	t	P-value
	Mean (SD)	Mean (SD)		
HbA1c (%)	9.04 (2.09)	8.95 (1.94)	0.23	0.82
Fasting blood glucose (FBG)				
In mmol/L	9.20 (3.55)	8.57 (3.66)	0.88	0.38
In mg/dL	165.96 (63.95)	154.38 (65.92)	0.89	0.37
Two-hour postprandial plasma glucose (2-hour PPG)				
In mmol/L	12.75 (4.83)	10.53 (3.66)	2.59	0.01
In mg/dL	229.57 (87.02)	189.78 (65.96)	2.59	0.01
Systolic BP (mmHg)	131.14 (17.32)	126.83 (17.14)	1.26	0.21
Diastolic BP (mmHg)	79.12 (6.75)	77.07 (7.94)	1.40	0.17
Body weight (kg)	60.20 (12.19)	58.80 (12.80)	0.56	0.58
BMI (kg/m <sup>2</sup> )	25.67 (5.78)	24.84 (5.07)	0.77	0.45
Waist size (cm)	91.19 (12.83)	88.40 (11.35)	1.16	0.25
Diabetes knowledge score (the DKQ-24) *	52.05 (15.49)	51.67 (15.93)	0.12	0.91
Diabetes health beliefs score (the DHBM) *	74.98 (5.44)	74.75 (6.68)	0.19	0.85
Diabetes self-care activities score (the SDSCA) **				
General Diet	1.93 (2.29)	1.27 (2.17)	1.49	0.14
Specific Diet	4.20 (1.52)	4.31 (1.97)	-0.33	0.75
Exercise	3.75 (2.22)	3.92 (2.34)	-0.39	0.70
Blood Sugar Testing	0.42 (0.51)	0.41 (0.55)	0.11	0.91
Foot Care	3.27 (2.89)	3.45 (2.89)	-0.34	0.74
Diabetes self-efficacy score (the DES-SF) *	73.77 (7.67)	74.00 (8.00)	-0.15	0.89

\* Percentage score

\*\* Mean score of subscales

In this main study, the hypotheses that structured diabetes education programme led to greater improvement in clinical outcomes and diabetes-related scores of knowledge, health beliefs, self-care skills, and self-efficacy were tested. A one-between-one-within ANOVA was conducted with 2 x 2 design (group x time) on clinical outcomes and diabetes-related scores. Group or intervention method was the 'between' subjects factor, because the study looked at differences *between* groups using a different intervention method. Time was



the 'within' subjects factor, because the study measured each group twice (baseline and 3-month follow up). The difference *within* each group over time was also examined.

The assumptions for the repeated measures ANOVA were examined on the key outcome variables, as follows: (1) the dependent variables were continuous; (2) the dependent variables were approximately normally distributed; and (3) the variances and the correlations among the dependent variables were equal (by Mauchly's Test of Sphericity,  $p > 0.05$ ). If Mauchly's Test of sphericity shows  $p > 0.05$  (the variances are equal), it reports the standard univariate results. If Mauchly's Test of Sphericity shows  $p < 0.05$ , it reports either the multivariate results (Wilk's Lambda) for the time factor and for the interaction between group and time, or the univariate results with an epsilon correction (e.g.: Greenhouse-Geisser, Huynh-Feldt).<sup>310</sup>

Repeated measures ANOVA were conducted to test the main effects of group and time, and group by time interaction of the intervention method on key outcome variables. The comparison of clinical outcomes and diabetes related scores between the intervention and control groups at baseline and 3-month follow-up is shown in **Table 7-9**.

**Table 7-9 Comparison of clinical outcomes and diabetes-related scores between intervention and control groups at baseline and 3-month follow-up**

Outcomes	Baseline Data (n=101)			Three-month Data (n=83)			Overall Change  Repeated measures ANOVA P-value <sup>#</sup>
	Intervention Group (SD) n=51	Control Group (SD) n=50	Difference in Means (95% CI)	Intervention Group (SD) n=41	Control Group (SD) n=42	Difference in Means (95% CI)	
HbA1c (%)	9.04 (2.09)	8.95 (1.94)	0.09 (-0.71, 0.89)	8.38 (2.23)	8.53 (1.81)	- 0.15 (-1.03, 0.74)	0.69
Fasting blood glucose							
In mmol/L	9.20 (3.55)	8.57 (3.66)	0.63 (-0.80, 2.05)	8.52 (3.36)	8.87 (3.76)	- 0.36 (-1.92, 1.20)	0.68
In mg/dL	165.96 (63.95)	154.38 (65.92)	11.58 (-14.06, 37.22)	153.46 (60.46)	160.02 (67.77)	- 6.56 (-34.63, 21.51)	0.66
Two-hour postprandial glucose							
In mmol/L	12.75 (4.83)	10.53 (3.66)	2.21 (0.52, 3.91)	12.03 (5.41)	12.65 (4.65)	- 0.62 (-2.82, 1.58)	0.02
In mg/dL	229.57 (87.02)	189.78 (65.96)	39.79 (9.26, 70.32)	216.76 (97.41)	228.02 (83.89)	- 11.27 (-50.94, 28.40)	0.02
Systolic BP (mmHg)	131.14 (17.32)	126.83 (17.14)	4.32 (-2.49, 11.12)	123.80 (18.52)	120.87 (17.52)	2.93 (-4.95, 10.80)	0.79
Diastolic BP (mmHg)	79.12 (6.75)	77.07 (7.94)	2.05 (-0.86, 4.96)	76.06 (15.51)	77.13 (8.68)	- 1.07 (-6.54, 4.41)	0.20
Body weight (kg)	60.20 (12.19)	58.80 (12.80)	1.40 (-3.54, 6.33)	59.72 (12.85)	58.43 (13.70)	1.29 (-4.52, 7.10)	0.53
BMI (kg/m <sup>2</sup> )	25.67 (5.78)	24.84 (5.07)	0.83 (-1.32, 2.98)	25.66 (6.13)	24.69 (5.40)	0.98 (-1.54, 3.50)	0.57
Waist circumference (cm)	91.19 (12.83)	88.40 (11.35)	2.79 (-2.00, 7.57)	86.87 (13.13)	87.38 (12.71)	- 0.51 (-6.15, 5.14)	0.04
Score of the DKQ-24 *	52.05 (15.49)	51.67 (15.93)	0.37 (-5.83, 6.58)	68.80 (14.94)	60.71 (15.53)	8.09 (1.43, 14.75)	0.004
Score of the DHBM *	74.98 (5.44)	74.75 (6.68)	0.23 (-2.17, 2.63)	74.48 (6.11)	75.67 (5.84)	- 1.19 (-3.8, 1.42)	0.18
Score of the SDSCA **							
General Diet	1.93 (2.29)	1.27 (2.17)	0.66 (-0.22, 1.54)	3.13 (2.30)	2.66 (2.51)	0.48 (-0.57, 1.53)	0.54
Specific Diet	4.20 (1.52)	4.31 (1.97)	- 0.11 (-0.81, 0.58)	4.42 (1.36)	4.54 (1.78)	- 0.12 (-0.81, 0.57)	0.92
Exercise	3.75 (2.22)	3.92 (2.34)	- 0.18 (-1.07, 0.73)	4.15 (2.23)	4.71 (1.94)	- 0.57 (-1.48, 0.35)	0.34
Blood Sugar Testing	0.42 (0.51)	0.41 (0.55)	0.01 (-0.20, 0.22)	0.85 (1.38)	0.46 (0.88)	0.39 (-0.11, 0.89)	0.24
Foot Care	3.27 (2.89)	3.45 (2.89)	- 0.19 (-1.27, 0.90)	4.20 (2.61)	4.24 (2.41)	- 0.04 (-1.14, 1.06)	0.86
Score of the DES-SF *	73.77 (7.67)	74.00 (8.00)	- 0.23 (-3.32, 2.87)	76.65 (5.74)	75.89 (8.00)	0.75 (-2.29, 3.80)	0.91

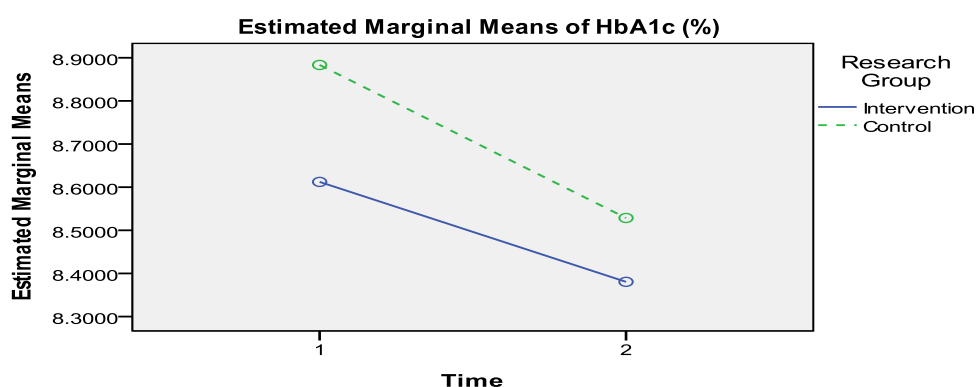
\* Percentage score \*\* Mean score of subscales # Unadjusted

### 7.4.3.1. HbA1c (%)

The main effect for group of HbA1c was not significant,  $F(1, 81) = 2.82$ ,  $p = 0.60$ , partial eta squared = 0.003. The main effect for time was marginally significant, Greenhouse-Geisser adjusted  $F(1, 81) = 3.53$ ,  $p = 0.06$ , partial eta squared = 0.042. Regardless of the group, HbA1c decreased by 0.29 on average between Time 1 and Time 2. The group by time interaction was also not significant, Greenhouse-Geisser adjusted  $F(1, 81) = 0.16$ ,  $p = 0.69$ , partial eta squared = 0.002.

Although not statistically significant, there was some evidence that HbA1c had decreased over time for both groups after receiving the interventions, as shown in **Figure 7-2**. The HbA1c decrease in the control group (mean difference = 0.35) was greater than in the intervention group (mean difference = 0.23). These results cannot support the hypothesis that people with T2D who receive a primary care delivery of structured diabetes education programme will have lower HbA1c than those who do not.

**Figure 7-2** The interaction between group and time for HbA1c (%)



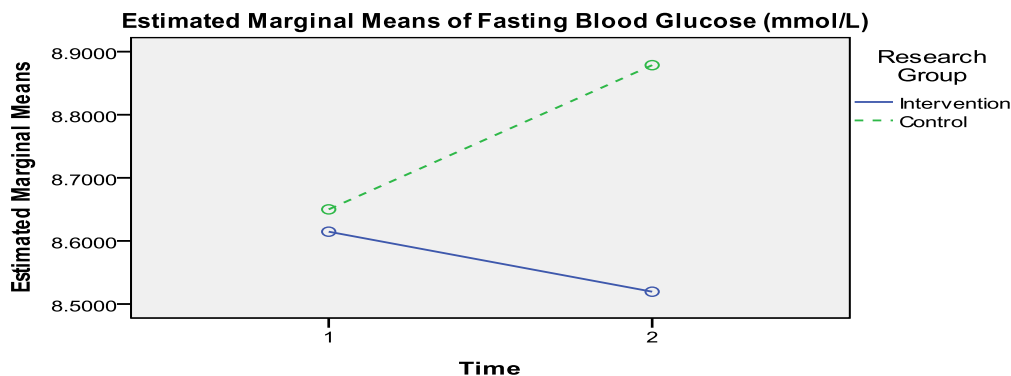
### 7.4.3.2. Fasting Blood Glucose (FBG) in mmol/L

The main effect for group of FBG (mmol/L) was not significant,  $F(1, 81) = 0.08$ ,  $p = 0.78$ , partial eta squared = 0.001. The main effect for time was also not significant, Greenhouse-Geisser adjusted  $F(1, 81) = 0.03$ ,  $p = 0.87$ , partial eta squared = 0.000. The group by time interaction was also not significant, Greenhouse-Geisser adjusted  $F(1, 81) = 0.17$ ,  $p = 0.68$ , partial eta squared = 0.002.

Although not statistically significant, there was a decreasing trend of FBG in the intervention group after receiving the intervention (mean difference = 0.1). In contrast, the control group showed an increasing trend of FBG following the intervention (mean difference = 0.23), as shown in **Figure 7-3**. However, some caution was warranted given that the mean difference between both groups at Time 2 was only 0.36. These results cannot support the

hypothesis that people with T2D who receive a primary care delivery of structured diabetes education programme will have lower FBG level than those who do not.

**Figure 7-3** The interaction between group and time for fasting blood glucose (mmol/L)

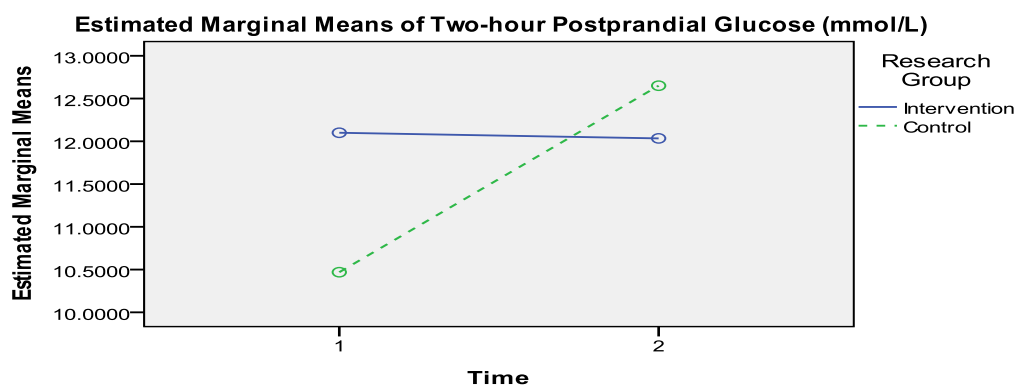


#### 7.4.3.3. Two-hour Postprandial Plasma Glucose (2-hour PPG) in mmol/L

The main effect for group of 2-hour PPG (mmol/L) was not significant,  $F(1, 81) = 0.32$ ,  $p = 0.57$ , partial eta squared = 0.004. There was a significant main effect for time, Greenhouse-Geisser adjusted  $F(1, 81) = 5.34$ ,  $p = 0.02$ , partial eta squared = 0.062, indicating a moderate size effect. There was also a significant group by time interaction, Greenhouse-Geisser adjusted  $F(1, 81) = 6.02$ ,  $p = 0.02$ , partial eta squared = 0.07, indicating a moderate size effect.<sup>241</sup>

To interpret the significant interaction of group by time, independent pairwise comparisons were conducted. The significance of the interaction is most likely due to the control group showing a significant increase in 2-hour PPG (mmol/L) over time on average ( $p = 0.001$ ; mean difference = 2.18), while the intervention group had a minimal decrease over time ( $p = 0.92$ ; mean difference = 0.07). Thus, these results can support the hypothesis that people with T2D who receive a primary care delivery of structured diabetes education programme will have lower 2-hour PPG level than those who do not. The graph of the interaction between group and time for two-hour postprandial plasma glucose is shown in **Figure 7-4**.

**Figure 7-4** The interaction between group and time for two-hour postprandial plasma glucose (mmol/L)

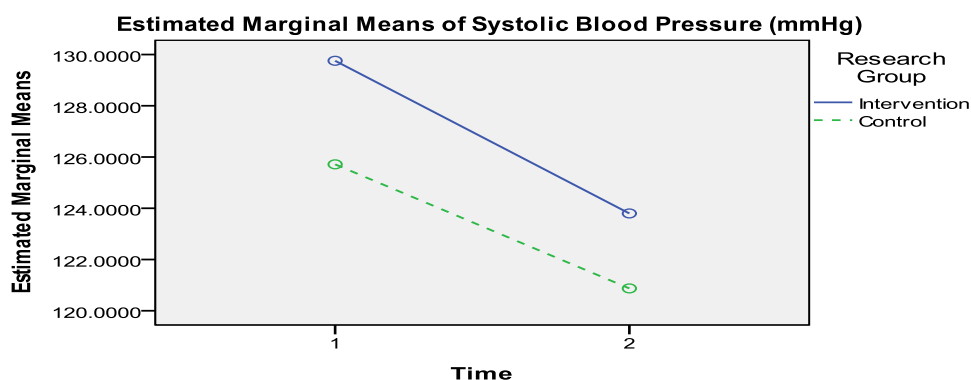


#### 7.4.3.4. Systolic Blood Pressure (mmHg)

The main effect for group of systolic blood pressure (mmHg) was not significant,  $F(1, 81) = 1.09$ ,  $p = 0.30$ , partial eta squared = 0.013. There was a significant main effect for time, Greenhouse-Geisser adjusted  $F(1, 81) = 0.03$ ,  $p = 0.005$ , partial eta squared = 0.092, indicating a moderate effect. Regardless of the group, systolic blood pressure decreased by 5.40 on average between Time 1 and Time 2. The group by time interaction was not significant,  $F(1, 81) = 0.09$ ,  $p = 0.77$ , partial eta squared = 0.001.

Although not statistically significant, there was some evidence that systolic blood pressure had decreased over time for both groups after receiving the interventions, as shown in **Figure 7-5**. The systolic blood pressure decrease in the intervention group (mean difference = 5.96) was greater than in the control group (mean difference = 4.84). These results cannot support the hypothesis that people with T2D who receive a primary care delivery of structured diabetes education programme will have lower systolic blood pressure than those who do not.

**Figure 7-5** The interaction between group and time for systolic blood pressure (mmHg)

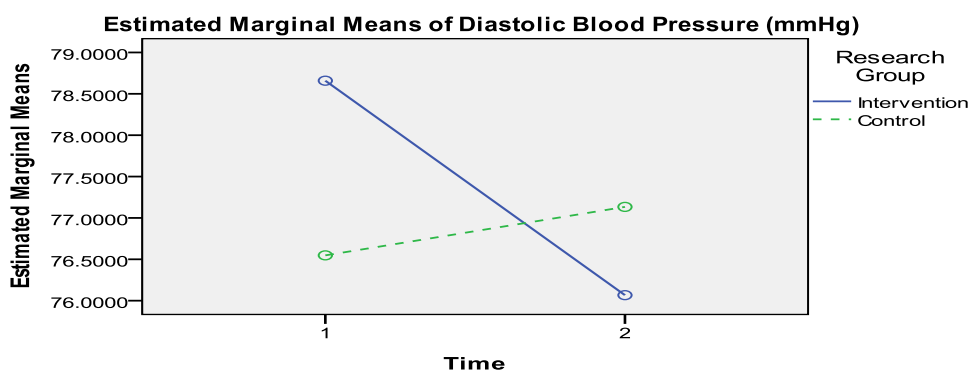


### 7.4.3.5. Diastolic Blood Pressure (mmHg)

The main effect for group of diastolic blood pressure (mmHg) was not significant,  $F(1, 81) = 0.08$ ,  $p = 0.78$ , partial eta squared = 0.001. The main effect for time was also not significant, Greenhouse-Geisser adjusted  $F(1, 81) = 0.65$ ,  $p = 0.42$ , partial eta squared = 0.008. The group by time interaction was also not significant, Greenhouse-Geisser adjusted  $F(1, 81) = 1.64$ ,  $p = 0.20$ , partial eta squared = 0.02.

Although not statistically significant, there was some evidence that diastolic blood pressure had decreased over time in the intervention group after receiving the intervention (mean difference = 2.6). In contrast, the control group showed an increasing trend following the intervention (mean difference = 0.59), as shown in **Figure 7-6**. These results cannot support the hypothesis that people with T2D who receive a primary care delivery of structured diabetes education programme will have lower diastolic blood pressure than those who do not.

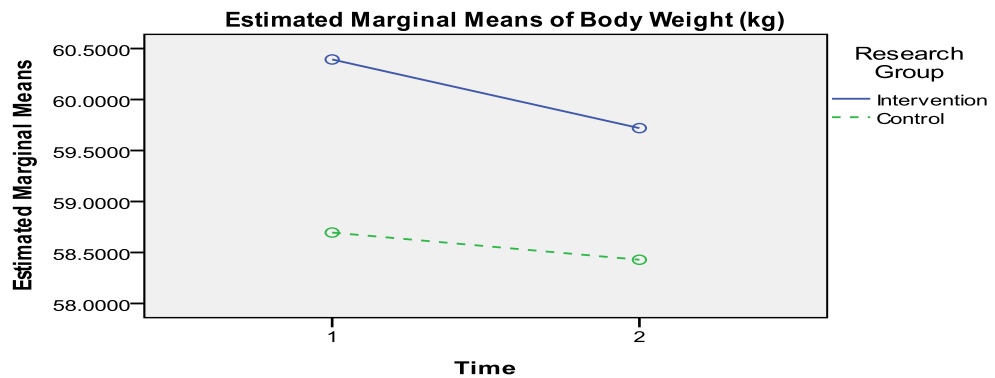
**Figure 7-6** The interaction between group and time for diastolic blood pressure (mmHg)



### 7.4.3.6. Body Weight (kg)

The main effect for group of body weight (kg) was not significant,  $F(1, 81) = 0.26$ ,  $p = 0.61$ , partial eta squared = 0.003. The main effect for time was also not significant, Greenhouse-Geisser adjusted  $F(1, 81) = 2.10$ ,  $p = 0.15$ , partial eta squared = 0.025. The group by time interaction was also not significant, Greenhouse-Geisser adjusted  $F(1, 81) = 0.39$ ,  $p = 0.53$ , partial eta squared = 0.005.

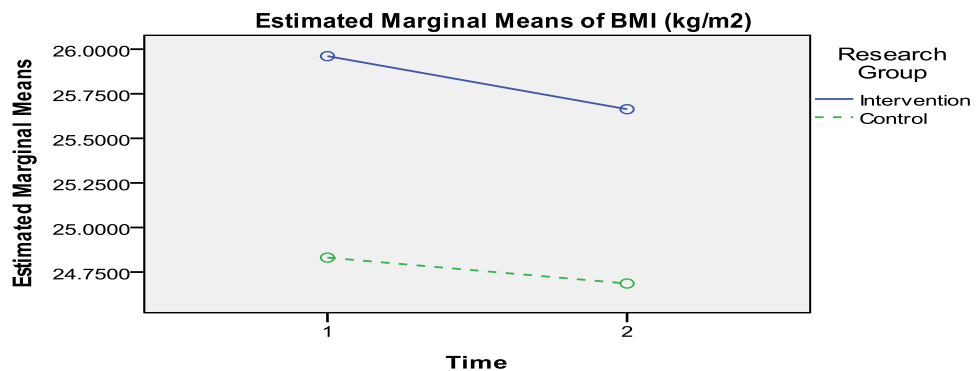
Although not statistically significant, there was some evidence that body weight had decreased over time for both groups after receiving the interventions, as shown in **Figure 7-7**. The body weight decrease in the intervention group (mean difference = 0.67) was greater than in the control group (mean difference = 0.27). These results cannot support the hypothesis that people with T2D who receive a primary care delivery of structured diabetes education programme will have lower body weight than those who do not.

**Figure 7-7** The interaction between group and time for body weight (kg)

#### 7.4.3.7. Body Mass Index (BMI) (kg/m<sup>2</sup>)

The main effect for group of BMI (kg/m<sup>2</sup>) was not significant,  $F(1, 81) = 0.70$ ,  $p = 0.40$ , partial eta squared = 0.009. The main effect for time was also not significant, Greenhouse-Geisser adjusted  $F(1, 81) = 2.74$ ,  $p = 0.10$ , partial eta squared = 0.033. The group by time interaction was also not significant, Greenhouse-Geisser adjusted  $F(1, 81) = 0.32$ ,  $p = 0.57$ , partial eta squared = 0.004.

Although not statistically significant, there was some evidence that BMI had decreased over time for both groups after receiving the interventions, as shown in **Figure 7-8**. The BMI decrease in the intervention group (mean difference = 0.30) was greater than in the control group (mean difference = 0.15). These results cannot support the hypothesis that people with T2D who receive a primary care delivery of structured diabetes education programme will have lower BMI than those who do not.

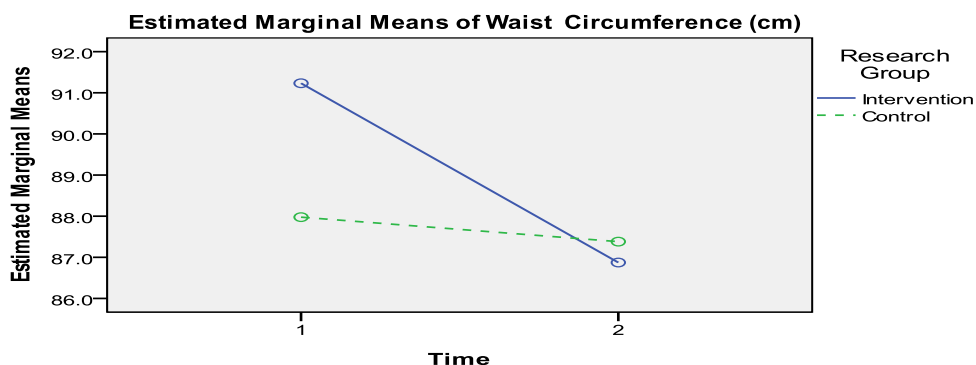
**Figure 7-8** The interaction between group and time for body mass index (kg/m<sup>2</sup>)

### 7.4.3.8. Waist Circumference (cm)

The main effect for group of waist circumference (cm) was not significant,  $F(1, 81) = 0.26$ ,  $p = 0.61$ , partial eta squared = 0.003. There was a significant main effect for time, Greenhouse-Geisser adjusted  $F(1, 81) = 7.08$ ,  $p = 0.009$ , partial eta squared = 0.08, indicating a moderate effect. Regardless of the group, waist circumference decreased by 2.48 on average between Time 1 and Time 2. There was also a significant group by time interaction, Greenhouse-Geisser adjusted  $F(1, 81) = 4.09$ ,  $p = 0.046$ , partial eta squared = 0.048, indicating a small size effect.<sup>241</sup>

To interpret the significant interaction of group by time, independent pairwise comparisons were conducted. The significance of the interaction is due to the intervention group showing a significant decrease in waist circumference (cm) over time on average ( $p = 0.001$ ; mean difference = 4.36), whereas the control group showed a small decrease between T1 and T2 ( $p = 0.65$ ; mean difference = 0.60). These results can support the hypothesis that people with T2D who receive a primary care delivery of structured diabetes education programme will have lower waist circumference than those who do not. The graph of the interaction between group and time for waist circumference is shown in **Figure 7-9**.

**Figure 7-9** The interaction between group and time for waist circumference (cm)



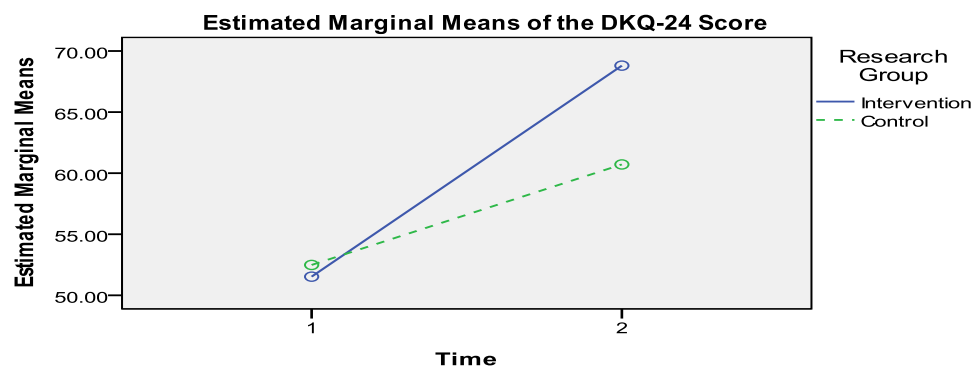
### 7.4.3.9. The Score of the Diabetes Knowledge Questionnaire (DKQ-24)

The main effect for group of the DKQ-24 score (percentage score) was not significant,  $F(1, 81) = 1.44$ ,  $p = 0.23$ , partial eta squared = 0.018. There was a significant main effect for time, Greenhouse-Geisser adjusted  $F(1, 81) = 70.29$ ,  $p = 0.000$ , partial eta squared = 0.465, indicating a large effect. Regardless of the group, the DKQ-24 score increased by 12.75 on average between Time 1 and Time 2. There was also a significant group by time interaction, Greenhouse-Geisser adjusted  $F(1, 81) = 8.85$ ,  $p = 0.004$ , partial eta squared = 0.098, indicating a moderate size effect.<sup>241</sup>



To interpret the significant interaction of group by time, independent pairwise comparisons were conducted. There was a significant increase of the DKQ-24 score in both groups, but the intervention group had a greater increase by twice as much (intervention group:  $p = 0.000$ , mean difference = 17.28; control group:  $p = 0.000$ , mean difference = 8.23). These results can support the hypothesis that people with T2D who receive a primary care delivery of structured diabetes education programme will have higher diabetes knowledge than those who do not. The graph of the interaction between group and time for the DKQ-24 score is shown in **Figure 7-10**.

**Figure 7-10** The interaction between group and time for the Diabetes Knowledge Questionnaire (DKQ-24) score

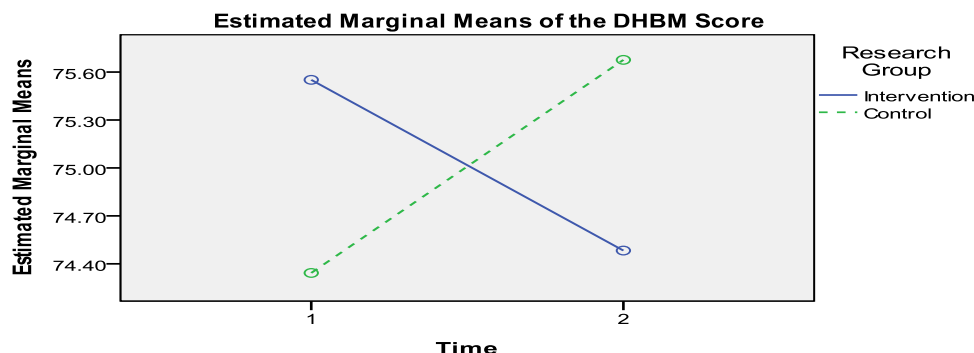


#### 7.4.3.10. The Score of the Diabetes Health Beliefs Measure (DHBM)

The main effect for group of the DHBM score (percentage score) was not significant,  $F(1, 81) = 0.00$ ,  $p = 0.99$ , partial eta squared = 0.000. The main effect for time was also not significant, Greenhouse-Geisser adjusted  $F(1, 81) = 0.02$ ,  $p = 0.88$ , partial eta squared = 0.000. The group by time interaction was also not significant, Greenhouse-Geisser adjusted  $F(1, 81) = 59.83$ ,  $p = 0.18$ , partial eta squared = 0.02.

There was a decreasing trend of the DHBM score in the intervention group after receiving the intervention; meanwhile, the control group showed an increasing trend following the intervention, as shown in **Figure 7-11**. These results cannot support the hypothesis that people with T2D who receive a primary care delivery of structured diabetes education programme will have higher diabetes health belief score than those who do not.

**Figure 7-11** The interaction between group and time for the Diabetes Health Beliefs Measure (DHBM) score



#### 7.4.3.11. The Score of the Summary of Diabetes Self-Care Activities (SDSCA)

The SDSCA was scored using separate mean scores of five subscales: general diet, specific diet, physical activity, blood testing and foot care.<sup>210</sup> The tests of the main effects and the group by time interaction are presented respectively in the following paragraphs.

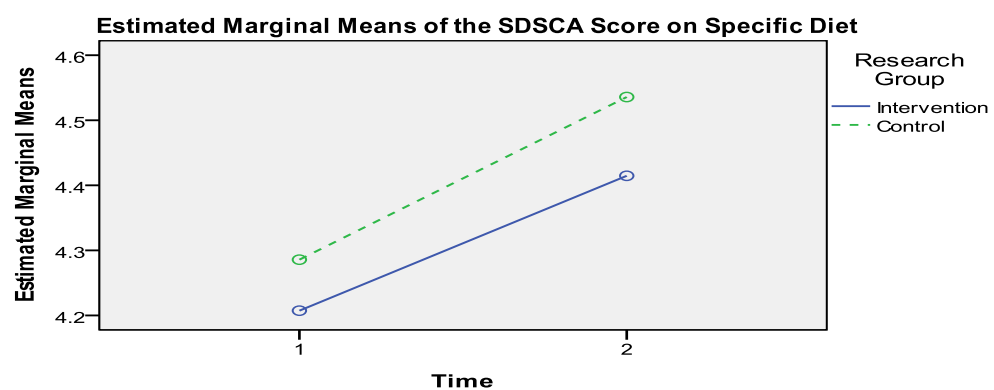
The main effect for group of the SDSCA score on general diet was not significant,  $F(1, 81) = 2.48$ ,  $p = 0.12$ , partial eta squared = 0.03. There was a significant main effect for time, Greenhouse-Geisser adjusted  $F(1, 81) = 19.72$ ,  $p = 0.000$ , partial eta squared = 0.196. Regardless of the group, the SDSCA score on general diet increased by 1.31 on average between Time 1 and Time 2. The group by time interaction was not significant, Greenhouse-Geisser adjusted  $F(1, 81) = 0.39$ ,  $p = 0.54$ , partial eta squared = 0.005.

Although not statistically significant, there was some evidence that general diet score had increased over time for both groups after receiving the interventions, as shown in **Figure 7-12**. The increase of the general diet score in the control group (mean difference = 1.49) was greater than the intervention group (mean difference = 1.12). These results cannot support the hypothesis that people with T2D who receive a primary care delivery of structured diabetes education programme will have greater self-care activity on general diet than those who do not.

**Figure 7-12** The interaction between group and time for the SDSCA score on general diet

The main effect for group of the SDSCA score on specific diet was not significant,  $F(1, 81) = 0.13$ ,  $p = 0.72$ , partial eta squared = 0.002. The main effect for time was also not significant, Greenhouse-Geisser adjusted  $F(1, 81) = 1.07$ ,  $p = 0.30$ , partial eta squared = 0.013. The group by time interaction was also not significant, Greenhouse-Geisser adjusted  $F(1, 81) = 0.001$ ,  $p = 0.92$ , partial eta squared = 0.000.

Although not statistically significant, there was some evidence that specific diet score had increased over time for both groups after receiving the interventions, as shown in **Figure 7-13**. The increase of the specific diet score in the control group (mean difference = 0.25) was slightly greater than the intervention group (mean difference = 0.21). These results cannot support the hypothesis that people with T2D who receive a primary care delivery of structured diabetes education programme will have greater self-care activity on specific diet than those who do not.

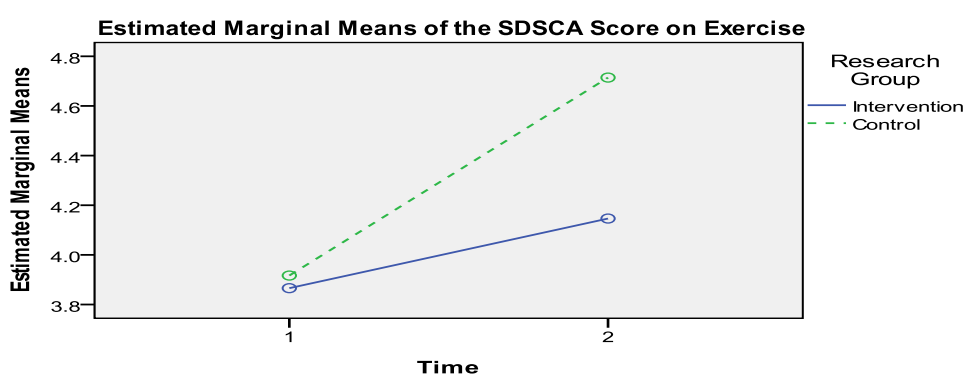
**Figure 7-13** The interaction between group and time for the SDSCA score on specific diet

The main effect for group of the SDSCA score on exercise was not significant,  $F(1, 81) = 0.58$ ,  $p = 0.45$ , partial eta squared = 0.007. The main effect for time was marginally significant, Greenhouse-Geisser adjusted  $F(1, 81) = 3.95$ ,  $p = 0.05$ , partial eta squared = 0.047. Regardless of the group, the exercise score increased by 0.23 on average between

Time 1 and Time 2. The group by time interaction was not significant, Greenhouse-Geisser adjusted  $F(1, 81) = 0.91$ ,  $p = 0.34$ , partial eta squared = 0.011.

Although not statistically significant, there was some evidence that exercise score had increased over time for both groups after receiving the interventions, as shown in **Figure 7-14**. The increase of the exercise score in the control group (mean difference = 0.80) was greater than the intervention group (mean difference = 0.28). These results cannot support the hypothesis that people with T2D who receive a primary care delivery of structured diabetes education programme will have greater self-care activity on exercise than those who do not.

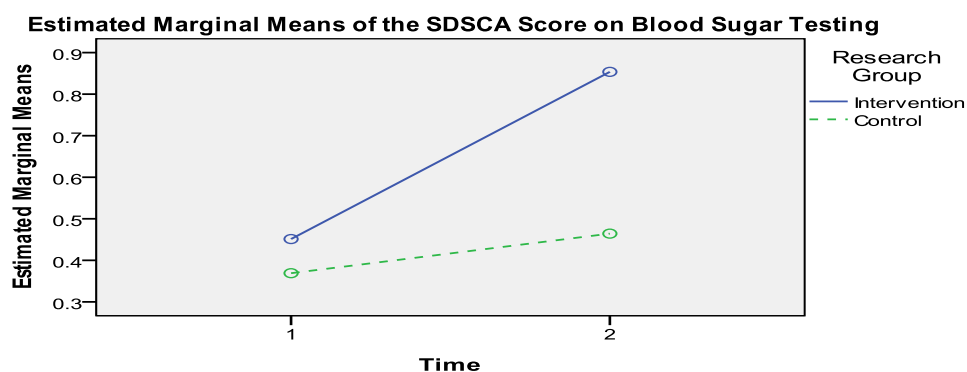
**Figure 7-14** The interaction between group and time for the SDSCA score on exercise



The main effect for group of the SDSCA score on blood sugar testing was not significant,  $F(1, 81) = 2.58$ ,  $p = 0.11$ , partial eta squared = 0.031. The main effect for time was marginally significant, Greenhouse-Geisser adjusted  $F(1, 81) = 3.66$ ,  $p = 0.06$ , partial eta squared = 0.043. Regardless of the group, the blood sugar testing score increased by 0.25 on average between Time 1 and Time 2. The group by time interaction was not significant, Greenhouse-Geisser adjusted  $F(1, 81) = 1.39$ ,  $p = 0.24$ , partial eta squared = 0.017.

Although not statistically significant, there was some evidence that blood sugar testing score had increased over time for both groups after receiving the interventions, as shown in **Figure 7-15**. The increase of the blood testing score in the intervention group (mean difference = 0.40) was greater than the control group (mean difference = 0.10). These results cannot support the hypothesis that people with T2D who receive a primary care delivery of structured diabetes education programme will have greater self-care activity on blood sugar testing than those who do not.

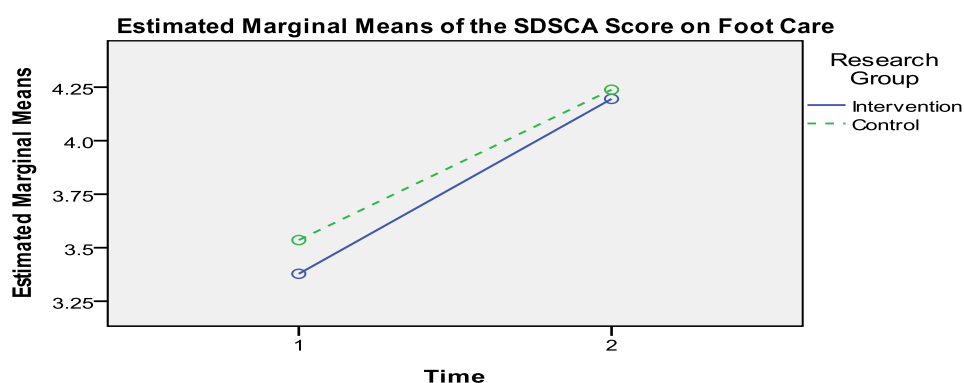
**Figure 7-15** The interaction between group and time for the SDSCA score on blood sugar testing



The main effect for group of the SDSCA score on foot care was not significant,  $F(1, 81) = 0.05$ ,  $p = 0.83$ , partial eta squared = 0.001. There was a significant main effect for time, Greenhouse-Geisser adjusted  $F(1, 81) = 5.28$ ,  $p = 0.02$ , partial eta squared = 0.061. Regardless of the group, the blood sugar testing score increased by 0.76 on average between Time 1 and Time 2. The group by time interaction was not significant, Greenhouse-Geisser adjusted  $F(1, 81) = 0.03$ ,  $p = 0.86$ , partial eta squared = 0.000.

Although not statistically significant, there was some evidence that foot care score had increased over time for both groups after receiving the interventions, as shown in **Figure 7-16**. The increase of the foot care score in the intervention group (mean difference = 0.82) was greater than the control group (mean difference = 0.70). These results cannot support the hypothesis that people with T2D who receive a primary care delivery of structured diabetes education programme will have greater self-care activity on foot care than those who do not.

**Figure 7-16** The interaction between group and time for the SDSCA score on foot care

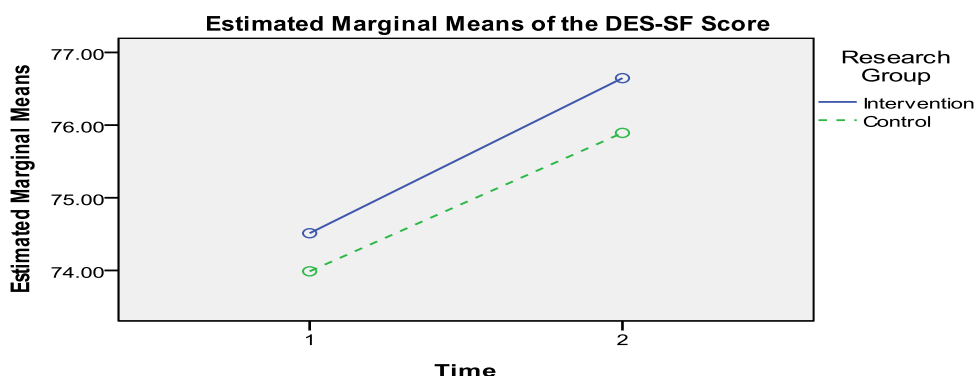


#### 7.4.3.12. The Score of the Diabetes Empowerment Scale – Short Form (DES-SF)

The main effect for group of the DES-SF score (percentage score) was not significant,  $F(1, 81) = 0.31$ ,  $p = 0.58$ , partial eta squared = 0.004. The main effect for time was marginally significant, Greenhouse-Geisser adjusted  $F(1, 81) = 0.01$ ,  $p = 0.05$ , partial eta squared = 0.046. Regardless of the group, the DES-SF score increased by 2.02 on average between Time 1 and Time 2. The group by time interaction was not significant, Greenhouse-Geisser adjusted  $F(1, 81) = 0.01$ ,  $p = 0.91$ , partial eta squared = 0.000.

Although not statistically significant, there was some evidence that the DES-SF score had increased over time for both groups after receiving the interventions, as shown in **Figure 7-17**. The increase of the DES-SF score in the intervention group (mean difference = 2.13) was greater than in the control group (mean difference = 1.91). These results cannot support the hypothesis that people with T2D who receive a primary care delivery of structured diabetes education programme will have higher self-efficacy score than those who do not.

**Figure 7-17** The interaction between group and time for the Diabetes Empowerment Scale – Short Form (DES-SF) score



#### 7.4.3.13. Summary of Repeated Measures ANOVA Results of the Key Outcome Variables

The summary of the results of the repeated measures ANOVA for the key outcome variables is presented in **Table 7-10a** and **Table 7-10b**.

**Table 7-10a Summary of results of repeated measures ANOVA for the clinical outcomes and diabetes-related scores (n= 83)**

Effect	df	Greenhouse-Geisser Adjusted F	Effect Sizes (Eta square)	P-value
<b>HbA1c (%)</b>				
Group	1, 81	0.28	0.003	0.60
Time	1, 81	3.53	0.042	0.06
Group x Time	1, 81	0.16	0.002	0.69
<b>Fasting blood glucose (mmol/L)</b>				
Group	1, 81	0.08	0.001	0.78
Time	1, 81	0.03	0.000	0.87
Group x Time	1, 81	0.17	0.002	0.68
<b>Two-hour postprandial glucose (mmol/L)</b>				
Group	1, 81	0.32	0.004	0.57
Time	1, 81	5.34	0.062	0.02
Group x Time	1, 81	6.03	0.069	0.02
<b>Systolic BP (mmHg)</b>				
Group	1, 81	1.09	0.013	0.30
Time	1, 81	0.65	0.008	0.42
Group x Time	1, 81	1.64	0.020	0.20
<b>Diastolic BP (mmHg)</b>				
Group	1, 81	0.08	0.001	0.78
Time	1, 81	0.65	0.008	0.42
Group x Time	1, 81	1.64	0.020	0.20
<b>Body weight (kg)</b>				
Group	1, 81	0.26	0.003	0.61
Time	1, 81	2.10	0.025	0.15
Group x Time	1, 81	0.39	0.005	0.53
<b>BMI (kg/m<sup>2</sup>)</b>				
Group	1, 81	0.70	0.009	0.40
Time	1, 81	2.74	0.033	0.10
Group x Time	1, 81	0.32	0.004	0.57
<b>Waist circumference (cm)</b>				
Group	1, 81	0.26	0.003	0.61
Time	1, 81	7.08	0.080	0.01
Group x Time	1, 81	4.09	0.048	0.04
<b>Score of the DKQ-24 *</b>				
Group	1, 81	1.44	0.018	0.23
Time	1, 81	70.29	0.465	0.00
Group x Time	1, 81	8.85	0.098	0.00
<b>Score of the DHBM *</b>				
Group	1, 81	0.00	0.000	0.99
Time	1, 81	0.02	0.000	0.88
Group x Time	1, 81	1.86	0.022	0.18

**Table 7-10b Summary of results of repeated measures ANOVA for the clinical outcomes and diabetes-related scores (n= 83)**

Effect	df	Greenhouse-Geisser Adjusted F	Effect Sizes (Eta square)	P-value
Score of the SDSCA **				
General Diet				
Group	1, 81	2.48	0.030	0.12
Time	1, 81	19.72	0.196	0.00
Group x Time	1, 81	0.39	0.005	0.54
Specific Diet				
Group	1, 81	0.13	0.002	0.72
Time	1, 81	1.07	0.013	0.30
Group x Time	1, 81	0.01	0.000	0.92
Exercise				
Group	1, 81	0.58	0.007	0.45
Time	1, 81	3.95	0.047	0.05
Group x Time	1, 81	0.91	0.011	0.34
Blood Sugar Testing				
Group	1, 81	2.58	0.031	0.11
Time	1, 81	3.66	0.043	0.06
Group x Time	1, 81	1.39	0.017	0.24
Foot Care				
Group	1, 81	0.05	0.001	0.83
Time	1, 81	5.28	0.061	0.02
Group x Time	1, 81	0.31	0.000	0.86
Score of the DES-SF *				
Group	1, 81	0.31	0.004	0.58
Time	1, 81	3.94	0.046	0.05
Group x Time	1, 81	0.01	0.000	0.91

#### 7.4.4. Summary of Key Findings of Scoping discussions

A total 61 people participated in six scoping discussions, consisting of 43 patients with T2D and their family members, and 18 HCPs (5-13 participants in each group) (See **Section 6.3.1**). The summary of key findings is presented in the following sections based on the themes that emerged within similar topics. The key findings of four scoping discussions for exploring the perceptions of HCPs and patients with T2D towards the current provision of diabetes care and education at the CHCs are presented in **Section 7.4.4.1** to **Section 7.4.4.9**. Meanwhile, the key findings of two scoping discussions for exploring the perceptions of patients with T2D towards the diabetes education intervention administered are presented in **Section 7.4.4.10** to **Section 7.4.4.13**. The full findings of scoping discussions are presented in **Appendix H**.



#### **7.4.4.1. The Perceptions of HCPs and Patients with T2D on Diabetes Care Provided by the HCPs**

In general, the HCPs believed that the diabetes care they provided at the CHCs was adequate based on the Guidelines of Basic Treatment at Community Health Centre developed by the Ministry of Health,<sup>311</sup> and the CHC's local protocol. The HCPs advised all diabetic patients to measure their blood sugar monthly, particularly with random blood sugar test. The HCPs provided regular prescribing of diabetes medicines to be dispensed at the CHCs for a period of 3-5 days, depending on the local protocol. The diabetes education was provided particularly on diabetes meal planning by a nutritionist working at the CHC. Newly diagnosed patients with T2D were offered a referral to the nutritionist with an additional fee (IDR 5,250 or Australian 52.5 cents for patients having Yogyakarta City identity card and IDR 7,000 or Australian 70 cents for patients living outside Yogyakarta City). This referral was optional, not a mandatory protocol for all patients newly diagnosed with T2D.

Meanwhile, the diabetic patients provided various responses with respect to the diabetes care provided, ranging from 'not satisfying', 'quite adequate' to 'satisfying'. However, patients who stated 'satisfying' were referring to the diabetes care provided by specialist doctors at a tertiary public hospital, particularly because of the more detailed diabetes education provided.

Many patients who were dissatisfied with the diabetes care provided at the CHCs related their dissatisfaction to the inadequate provision of diabetes education. The patients complained that during patient-provider encounters, the HCPs usually only asked about presenting complaints and prescribed medicines, without further investigation or provision of diabetes information unless the patients were proactive in asking questions. The patients speculated that the HCPs might think that the patients already knew about T2D. Nevertheless, patients indicated that such practice at the CHCs was understandable because of time constraints in providing services to the many patients in public funded CHCs. Several patients were dissatisfied with the recommended monthly blood sugar testing or bimonthly testing for patients covered by *Jamkesmas* (the government subsidised public health security programme for poor people) – and wished for more frequent testing.

#### **7.4.4.2. The Perceptions of HCPs and Patients with T2D on Diabetes Education Provided by the HCPs**

Many HCPs acknowledged that the diabetes information they provided to patients with T2D was not sufficient, detailed or clear as it should be. The HCPs indicated that not all diabetic patients were treated equally in the provision of diabetes education. Diabetes

education was primarily provided to patients newly diagnosed with T2D, while less education was provided to ongoing patients with T2D as they were considered already knowing a lot about the disease.

The HCPs indicated that inadequate provision of diabetes education was particularly due to underlying problems at CHCs associated with constrained resources and patient characteristics. The biggest problem was lack of human resources to provide services to the many patients using the publicly funded CHCs – the health care of choice for many people – prompting time constraint in each patient-provider encounter.

The HCPs indicated that most general clinics at CHCs were manned by 3 GPs and 3 nurses who also had other administrative and field duties. Due to the shortage of GPs, sometimes nurses also saw and examined patients independently. This made it difficult for them to provide diabetes education properly. Moreover, each CHC usually only had one nutritionist with various administrative and field duties, thus the nutritionist was not available everyday to provide nutritional consultation to diabetic patients. Accordingly, the HCPs admitted that many diabetic patients failed to get the recommended nutritional consultation. The HCPs also revealed that funds were inadequate to provide effective diabetes education materials and public education in the community.

The HCPs believed that several patient characteristics contributed to the inadequate provision of diabetes education, including: low socioeconomic status, low education level, old age and language barriers. The HCPs indicated that patients attending CHCs mostly had low socioeconomic status and low education level. Many of CHC patients were covered by *Jamkesmas*. The HCPs suggested that many diabetic patients refused to obtain a consultation from a nutritionist as recommended because of the additional fee charged. The HCPs indicated that many diabetic patients at CHCs were elderly with impaired hearing which resulted in poor communication. In addition, many elderly patients spoke Javanese, not *Bahasa Indonesia* (the national language), which was a barrier for providing diabetes information for HCPs whose background was not Javanese.

The HCPs revealed that if diabetes information conveyed to patients with a low education level was too detailed and complicated, the patients would be overwhelmed and fearful. The HCPs thus suggested that when dealing with such patients, they had to use a 'different' language, which was a simpler language and included jokes.

Meanwhile, the patients provided a range of responses towards the diabetes education provided, ranging from 'not sufficient' or 'not complete' or 'not understandable' to 'sufficient'. The patients who stated that the information received was sufficient were generally patients with longer diabetes duration (above 10 years). The diabetes advice

provided by HCPs included: diabetes meal planning, regular exercise, regular medication taking, regular blood sugar testing, and the need for precaution in cutting finger nails.

The patients who stated that the information received was not sufficient or not complete were generally patients with shorter diabetes duration (less than 2 years). These patients revealed that they did not receive information on certain issues they believed were essential, including: frequency of follow-up consultations, explanation about diabetes medications prescribed, how long patients should take diabetes medications, and which foods to eat and avoid. These patients stated that every time they saw an HCP, the HCP only gave a prescription and did not attempt to explain about these issues.

In contrast with the perceptions of the HCPs, the patients generally described only two underlying factors for the insufficient diabetes information. Firstly, there was time constraint in providing services to the many patients at the publicly funded CHCs; and secondly, the CHC doctors had limited knowledge about the disease, due to limited diabetes educator training.

#### **7.4.4.3. The Perceptions of HCPs and Patients with T2D on Diabetes Education That Should be Provided by the HCPs**

The HCPs acknowledged that a lot of diabetes information should be provided to diabetic patients. However, due to underlying problems described previously, the HCPs revealed that they had to be selective, and therefore only limited information was conveyed.

The HCPs described the minimal diabetes information should contain: diabetes definition, symptoms, complications, and ‘the four pillars of diabetes management’ (i.e. education, meal planning, physical activity and medication). However, the HCPs acknowledged that the information on diabetes management was mostly limited to regular medication taking and diabetes meal planning; with the latter was mostly provided by a nutritionist. Detailed information on medication and physical activity was not provided, but might be discussed in the context of presenting complaints or symptoms raised by the patients. Several HCPs acknowledged that diabetic patients were not informed about the mechanism of diabetes because the topic was deemed too complex. However, the information might be conveyed in response to a patient’s direct question on diabetes medicines.

The HCPs described issues which were most frequently asked about by patients, including queries on: (1) foods to eat and avoid; (2) the side effects of taking diabetes medications for a long time; (3) high blood sugar level despite patients’ efforts to control it; (4) the effectiveness of herbal plants or alternative treatments for diabetes commonly used in

the community; and (5) community beliefs about diabetes. Meanwhile, patients described several topics of diabetes information that should be provided by HCPs, including: (1) detailed explanation about diabetes medications and their side effects, especially during Ramadhan fasting; (2) detailed explanation about the recommended blood sugar tests: fasting and 2-hour-after-meal blood sugar; (3) healthy lifestyle: diet, exercise and sleep, including during Ramadhan fasting; (4) the difference between 'hypo' and 'hyper' (hypoglycaemia and hyperglycaemia); (5) the effect of T2D on the body; (6) the age at which T2D begins; (7) how to overcome weakness; (8) precautions to take when undertaking a tooth extraction; (9) herbal and alternative treatments for T2D; and (10) type of diabetes, particularly 'wet' and 'dry' diabetes.

#### **7.4.4.4. The Perceptions of HCPs and Patients with T2D on the Patients' Diabetes Knowledge Level to Live Well**

The HCPs indicated that the diabetes knowledge level of diabetic patients at CHCs varied. There were patients who did not care about their diabetes management even though they had been repeatedly informed and warned about the risks of poor glucose control. In contrast, the HCPs believed that some patients were 'overreacting' with their diabetes care, such as testing blood sugar more frequently than the recommended once-a-month practice and keeping notes of all results of blood sugar tests.

Generally the HCPs considered that the patients' basic knowledge of diabetes management – referred as "I have T2D, which cannot be cured, and I have to take medications for the rest of my life" – was sufficient for the patients to manage their diabetes successfully. Nevertheless, several HCPs indicated that sometimes the fact that "T2D cannot be cured and diabetic patients have to take medications for the rest of their life" might not be well understood. In particular, sometimes on getting a normal result of blood sugar test, patients would stop their medication, eat inappropriately or change to herbal or alternative treatment. Even where patients already had good diabetes knowledge, patients had difficulty controlling their diet, particularly when attending social gatherings such as wedding parties. The HCPs also suggested that many patients, particularly the elderly ones, had accepted the condition and exercised resignation towards the consequences of long-term diabetes.

Meanwhile, when the patients were asked about their diabetes knowledge to live well, their responses ranged from 'not sufficient at all', 'only a little' to 'sufficient'. As previously, the participants who stated 'sufficient' were generally patients with longer diabetes duration, and the participants who stated 'not sufficient at all' or 'only a little' were patients with shorter diabetes duration.

The general understanding about T2D as described by patients included that it is a chronic disease which cannot be cured but can be controlled. The patients described several causes of T2D and the components required for effective diabetes management, including: good meal planning, regular exercise, regular medication and blood sugar testing. Furthermore, several patients suggested that accepting the condition with a big heart, not taking it as a burden, and just enjoying life had helped them in managing T2D. Several patients admitted that along with taking the diabetes medication, they also tried various herbal and alternative treatments recommended by relatives and friends.

#### **7.4.4.5. The Perceptions of HCPs and Patients with T2D on the Support Needed by Diabetic Patients**

The HCPs suggested that diabetic patients needed a range of support including: provider, family, peer and community supports. The HCPs suggested that patients primarily needed support, motivation and encouragement from the HCPs for continuous treatment, because sometimes patients became demotivated due to the long-term nature of diabetes treatment.

Many HCPs indicated that family support was very important, particularly in reminding the patients to take diabetes medication, supporting good meal planning, escorting patients to attend CHCs, and on-going care including wound management and giving insulin injections. HCPs indicated that patients often shared their illness experiences with other patients which could help them gain more understanding about T2D. Moreover, a few diabetes meetings and groups were established in the community.

Meanwhile, when the patients were asked about the support they needed, they described a similar range of support sources as indicated by the HCPs (i.e. provider, family, peer, and community), with an additional support: self-awareness. However, in contrast with the HCPs' responses, some of patients' responses reflected not only needed support they were getting, but also support they expected to get.

The patients suggested that diabetic patients need self-awareness on life motivation for living with T2D, and should neither fear nor underestimate the condition. Patients described the provider support needed including: reminders about what foods to eat and avoid, and motivation in order not to become discouraged. The family support needed, including: motivating patients to manage the condition; showing patience about the demands of the disease; reminding patients to take their medications, control eating, do exercise and attend follow-up consultations; escorting patients to attend CHCs; preparing meals based on diabetes diet; and advising herbal and alternative treatments for T2D. The patients indicated that they received support in the community, such as receiving advice on herbal and

alternative treatments for T2D, and not being served with sweet snacks or drinks during regular village gatherings.

#### **7.4.4.6. The Perceptions of HCPs and Patients with T2D on the Expectations of Diabetic Patients from Their HCPs Regarding Their Diabetes Care**

The HCPs revealed that there were many requests from patients to increase the amount of oral diabetes medications dispensed to at least 10 days or even to 30 days (as practiced at the district hospital), rather than the usual 3-5 days. Provision of insulin injections at the CHCs was also requested. The HCPs also acknowledged that many patients requested blood sugar testing to be performed more frequently than monthly and free of charge. The HCPs indicated that patients requested ongoing CHC facilitated diabetes group meetings which would permit diabetic patients to obtain peer support and further diabetes education.

In contrast to the HCPs' responses, the expectations of diabetic patients were primarily related to the inadequate provision of diabetes education. Many participants suggested that the HCPs should provide more detailed diabetes education, not only giving prescriptions. The participants also expected the HCPs to remind them about diabetes management, particularly about food choices, during their patient-provider encounters.

The patients expected the HCPs to increase the amount of diabetes medications prescribed and dispensed, from 3 days to at least 7 days but preferably enough for 30 days (as was the practice at the district hospital), so that the patients would not need to attend the CHCs too frequently or buy the medication from pharmacies outside the CHCs. Patients also expected that subsidised insulin injections should be available at the CHCs.

#### **7.4.4.7. The Perceptions of HCPs and Patients with T2D on the Impact of T2D on the Patients' Life and Family**

The initial descriptions by HCPs about the impact of T2D on patients mostly focused on physical impact. Only after further prompting by the researcher, did the HCPs describe psychological and financial impacts. HCPs primarily described the physical implications of the disease, including: easily getting sick, decreased vision, diabetic foot, and erectile dysfunction. The HCPs also indicated that the diabetic patients had to make life adjustments regarding changes to their diet, work, and lifestyle, and attend CHCs more frequently post diagnosis.

The HCPs indicated that many patients became bored with the long-term nature of diabetes treatment, particularly when the patients' blood sugar level did not decrease despite

diETING and regular diabetes medication. In such cases, sometimes patients increased or decreased their medication dosage by themselves or changed to herbal or alternative treatments.

The HCPs suggested that since diabetic patients easily became sick and had decreased vision, their work productivity might decrease which consequently would decrease their usual income as craftsmen or tradespersons. The HCPs described how patients had to spend more money on diabetes medication and blood sugar testing, transportation for attending CHCs weekly, and buying artificial sweetener.

Meanwhile, the responses of patients described larger range of issues, including the physical, psychological, financial and social impact of diabetes. The patients described the physical implications of diabetes, including: feeling weak, sluggish, tired, easily getting sick, decreased vision, diabetic foot, and erectile dysfunction. However, the patients suggested that developing the condition had made them more careful in eating and more diligent in doing physical activity.

The patients described the distress and shock they experienced when newly diagnosed with T2D, and revealed that over time they became bored over with the condition and the ongoing diabetes treatment. It was particularly difficult to be required to restrict their diet at social gatherings, particularly wedding parties. A few patients also revealed that they easily became emotional and angry with family members over small things and they attributed this behaviour to their illness.

The patients described how their physical symptoms interfered with their capacity to work, their work productivity decreased, and, as tradespersons, this affected their income. Some also described that they had to buy costly supplements. Finally, the social impact of T2D included: reluctance to attend social gatherings due to inability to eat the foods served during the events, and limited mobility due to frequent urination.

#### **7.4.4.8. The Perceptions of HCPs and Patients with T2D on the Concepts of Diabetes Self-Management and Patient Empowerment**

All HCPs indicated that they had not heard about the concept of diabetes self-management. One GP argued that the common term is only 'diabetes management', not 'diabetes self-management'. However, they made several assumptions about the concept; one of which may reflect about the concept, i.e. "People with T2D should take care of themselves daily, which is mandatory, because patients do not see HCPs everyday"

All HCPs indicated that they had not heard about the concept of patient empowerment. One GP argued that the term did not exist, but indicated that while presently

diabetic patients depended heavily on the HCPs, in the future, the practice should be to work towards patient empowerment. Nevertheless, the HCPs made several assumptions about the concept. However, the assumptions made did not reflect the concept suitably.

As anticipated, all diabetic patients also stated that they had not heard about the concept of diabetes self-management. However, they described several aspects which might be seen to be diabetes self-management, such as implementing healthy lifestyle changes, and being active in one's own diabetes care.

Moreover, all diabetic patients stated that they had not heard about the concept of patient empowerment. However, they described several aspects which might be considered to support the patient empowerment notion, such as diabetes education and establishing a diabetes group in the community.

#### **7.4.4.9. The Perceptions of HCPs and Patients with T2D on the Implementation of Diabetes Self-Management and Patient Empowerment Concepts**

Very few HCPs contributed to this discussion topic since few understood the issues sufficiently to comment. The HCPs suggested that the implementation of the concepts would rely on patient and provider factors. Patient characteristics that would influence the implementation include socioeconomic status, education level, age of the diabetic patients, and patients' priorities. This was particularly because many diabetic patients at CHCs having low socioeconomic status struggled to meet daily living costs, and therefore were more preoccupied with earning enough to buy food rather than managing their diabetes.

The HCPs suggested that the most influential factor for successful implementation was the political will and support from the head of district health office or CHC. Additionally, the CHC diabetes educators should update their knowledge through diabetes educator training. However, the HCPs suggested that the CHCs were not ready for such implementation due to the existing problems at CHCs, since many diabetic patients were elderly and mostly had low socioeconomic status and low education levels.

The HCPs argued that the concepts would be more suitable for communities with better socioeconomic status and more resources; thus must begin with diabetic patients who attend hospitals, particularly private hospitals, because these patients cared more about their health and had T2D as a priority. The HCPs suggested that the concepts could be implemented, but implementation would require additional funding from the district health office.

One GP acknowledged that despite the lack of knowledge and existing resources, patients and their families should be empowered by giving education and trust. Patient



empowerment would reduce dependency on the HCPs. This GP indicated that the implementation of the concepts was appropriate because if the community was not involved and empowered with respect to T2D, the number of T2D cases in Indonesia would increase drastically.

The HCPs admitted that actually there may be many advantages associated with implementation, including: knowledgeable and independent patients that would ease the work of HCPs; and increased community awareness about diabetes that would improve diabetes screening.

However, the HCPs also described a few potential disadvantages of such implementation, including: potential risks could occur if blood sugar self-testing not properly taught; and if not adequately supported, patient to patient education could cause erroneous knowledge that could be embedded in the community and thus difficult to change. Finally, the HCPs wondered if the community became independent then the income of HCPs might decrease.

The HCPs suggested several enablers for implementation, including: readiness of the HCPs at CHCs to enact this programme because they were already conducting home care teaching diabetic patients and their family members to take care of the patients themselves at home; and diabetes group meetings and programs had been initiated by the CHCs and the District Health Office. However, the HCPs also described several barriers to implementation, including: understaffed CHCs; the low expectations of HCPs at CHCs about themselves that they could only manage easy tasks and not the complicated ones; persons in charge of diabetes programmes were frequently replaced due to regular rotation of human resources within one district; and poor training of the CHC diabetes educators.

Meanwhile, only a few patients commented on this topic. The comments were particularly about the advantages of such implementation, including: motivating and giving hope for patients in managing the condition; and providing improved diabetes knowledge which could prevent family members and other people from getting T2D.

#### **7.4.4.10. The Perceptions of Patients with T2D on the Research Interventions Administered and the Diabetes Leaflets Provided**

The majority of the participants from the control group indicated that the diabetes seminar was very beneficial, including: increasing diabetes knowledge; motivating patients to manage their condition; reminding about diabetes management; and enabling family members to learn about T2D through the diabetes leaflets provided. Participants suggested that the diabetes seminar should be held more frequently

The majority of the participants from the intervention group indicated that there were many benefits to the diabetes structured patient education sessions, including: increasing diabetes knowledge; enabling patients to learn about diabetes meal planning, exercise (particularly foot exercise), and how to handle diabetes-related problems; and maintaining improved blood sugar level and feeling physically healthier after implementing what had been learned from the sessions and leaflets. Participants suggested that the programme should be continued and not stop after four sessions. Participants gave additional suggestions, including: incorporating the technique for administering insulin injections, improving intimacy among the participants of the diabetes sessions; and incorporating the aspect of cheerfulness into the diabetes leaflets, not only included during the sessions.

#### **7.4.4.11. The Experiences of Patients with T2D in Implementing the Recommended Diabetes Management**

The patients described positive experiences and enablers for implementing the recommended diabetes management, including: making healthy lifestyle changes through controlling food intake or regular exercise resulting in a stable blood sugar level; living a long life for raising children and grandchildren was a powerful motivation to make lifestyle changes; and trying various herbal and alternative treatments was helpful to decrease blood sugar levels. The patients also described barriers to implementing the recommended diabetes management, including: varying difficulties in making healthy lifestyle changes; easily getting tired and sleepy while working; becoming distressed because of the lifelong nature of diabetes; becoming desperate and bored with the condition because despite complying with the doctors' recommendations, the blood sugar level did not decrease; and having other life problems (such as financial and family problems).

#### **7.4.4.12. The Perceptions of Patients with T2D on Their Own Diabetes Knowledge, Ability, Motivation, Compliance, Family and Social Support to Perform Diabetes Self-care Activities**

The patients indicated that their diabetes knowledge had increased. Patient responses about changes in their ability to perform diabetes self-care activities such as meal planning and regular exercise varied. Some patients found their ability to perform one of these tasks – but not the other – had improved, in the following ways: combining diabetes medication with herbal and alternative treatments, taking smaller amount and fewer type of diabetes medication than before, eating more green vegetables and fruits, and losing weight.

The patients described their motivation for performing diabetes self-care activities, including: wishing to live a long life to raise their children and grandchildren, learning from the

experiences of other patients who developed severe complications, and gaining motivation and hopes from prayers. The patients suggested that they had tried their best to follow the doctors' recommendations, and considered their compliance as good and in some cases better than before; but it was difficult to follow the recommendations when they were sick. Generally the patients described good family and social support for performing diabetes self-care activities (such as reminding them about diabetes management); however, a few described problems with family support.

#### **7.4.4.13. Further Expectations and Suggestions of Patients with T2D for the Diabetes Care Provided by HCPs**

Generally participants described the same expectations and suggestions as previously. Additionally, patients suggested that the diabetes care could be improved by HCPs through: becoming more friendly, smiling, communicative and informative during patient-provider encounters; adjusting the medication dosage to results of blood sugar testing rather than maintaining the same dosage as was the current practice; farther distribution of the diabetes leaflets; and posting diabetes posters and leaflets in public places.

## **7.5. DISCUSSION**

The discussion of this main study covers the results of three studies, including: the reassessment of internal consistency reliability of the Indonesian versions of four diabetes-related instruments, the cluster RCT, and the qualitative scoping discussions. The results of the cluster RCT were informed by the results of the scoping discussions.

### **7.5.1. Sociodemographic Characteristics and Medical History**

In the cluster RCT sample ( $n = 101$ ), female participants (67.3%) outnumbered male participants (32.7%). This was similar to the participant profile in the cross-cultural adaptation and reflected that the majority of patients attending CHCs were females. Many of the participants in the main study were housewives (32.7%), self-employed and working in the informal sector (30.7%), or retired employees (21.8%). In general, the clinics at the CHCs are walk-in clinics without appointment system and have limited opening hours from 8 am to midday, except a very few CHCs with in-patient care which have 24-hour emergency clinics. The nature of these publicly funded health centres might influence the certain characteristics of patients who access CHCs.

The cluster RCT sample had a higher percentage (52.5%) of participants with secondary school education (junior and senior high school), and a lower percentage (30.7%) of primary school education, as compared to the sample of the cross-cultural adaptation (primary school education 49.4% and secondary school education 43.4%). The sample of the cross-cultural adaptation had a higher percentage of participants (67.5%) with very low monthly family income (less than IDR 1,000,000 or AUD 100) than the cluster RCT sample (59.4%). The cross-cultural adaptation also had a higher percentage of participants (53%) with old age (60 years old and above) as compared to the cluster RCT sample (49.5%). The findings indicated that the cluster RCT sample had better participant profiles as compared to the sample of the cross-cultural adaptation study, particularly with respect to socioeconomic status, education level and old age. The findings also indicated that many of the regular attendees of the CHCs had low socioeconomic status, low education levels, and older age. This was consistent with the descriptions suggested by HCPs in the scoping discussions.

The participants in the intervention and control groups were well matched for sociodemographic characteristics, medical history and key outcome variables, except in the case of monthly family income, diet therapy, stroke complication and health insurance coverage, and 2-h PPG level. However, such anomalies are not uncommon in a pragmatic cluster randomised controlled trial.<sup>157</sup>

### **7.5.2. Reassessment of the Internal Consistency Reliability of the Indonesian Versions of Four Diabetes-Related Instruments**

The reassessment of internal consistency reliability of the Indonesian version of four diabetes-related instruments using the sample of the main study ( $n = 101$ ) generated better results as compared to the results in the cross-cultural adaptation ( $n = 83$ ). This might be related to the use of a bigger sample with a better participant profile in terms of socioeconomic status, education level and old age. The cluster RCT sample had a greater number of participants with better education level, a smaller number of participants with very low monthly family income, and a smaller number of elderly people. Older age is associated with decreased hearing affecting patient-provider communication, as suggested by the HCPs in the scoping discussions. These factors might contribute to the patients' better understanding and communication during patient interviews in completing the interviewer-administered questionnaires, generating better and more diverse patient responses. A more heterogeneous sample is associated with higher Cronbach's alpha values.<sup>248,265</sup>

The reliability coefficient of the Indonesian version of the DKQ-24 using the cluster RCT sample ( $\alpha = 0.723$ ) was comparable with the reliability coefficient of the original DKQ-24

( $\alpha = 0.78$ ).<sup>181</sup> Therefore, the Indonesian version of the DKQ-24 is valid and reliable for use with an Indonesian population.

The overall reliability coefficient of the Indonesian version of the DHBM using the cluster RCT sample was satisfactory ( $\alpha = 0.718$ ). The original developer of the 25-item DHBM did not report the overall reliability coefficient of the instrument, rather as reliability coefficients of the four subscales – barriers, social support, impact of job, benefits of therapy. The reliability coefficients of the four subscales obtained in this main study (0.479, 0.772, 0.590, and 0.851, respectively) were comparable with the results of the original DHBM (0.56, 0.62, 0.86 and 0.90, respectively).<sup>184</sup> The reliability coefficients of two subscales in both instruments were below the recommended value. Therefore, although the Indonesian version of the DHBM is valid and reliable for use with an Indonesian population, the adapted instrument still needs to be tested over time with other Indonesian populations.

The reliability coefficient of the Indonesian version of the 10-item SDSCA using the cluster RCT sample – deleting the smoking item – had improved to 0.605, which was adequate for pilot studies.<sup>256,267</sup> Therefore the instrument was adequate for use as a research instrument in the main study. This finding was similar to results obtained elsewhere. The final Korean version of the 9-item SDSCA, deleting item 4 (high fat foods) and item 11 (smoking), had a comparable reliability coefficient ( $\alpha = 0.66$ ).<sup>219</sup> The Spanish version of the 12-item SDSCA, with an additional item on diabetes medications, also had a comparable reliability coefficient ( $\alpha = 0.68$ ).<sup>215</sup> The Turkish version of the 12-item SDSCA, with an additional item on diabetes medications, had a better reliability coefficient ( $\alpha = 0.72$ ).<sup>217</sup> The Malay version of the 12-item SDSCA, excluding the smoking item, also showed a better reliability coefficient ( $\alpha = 0.735$ ).<sup>220</sup> Meanwhile, the Maltese version of the 11-item SDSCA displayed a lower reliability coefficient ( $\alpha = 0.503$ ).<sup>216</sup>

The reliability coefficient of the Indonesian version of the DES-SF using the cluster RCT sample had improved to 0.595, which was adequate for pilot studies.<sup>256,267</sup> Therefore the instrument was adequate for use as a research instrument in the main study. However, the finding was much lower than the reliability coefficient the original DES-SF was 0.85.<sup>225</sup> The patient characteristics of CHC regular attendees – inclining towards low socioeconomic status, low education level, and older age – which reflected a homogenous sample might contribute to this low Cronbach's alpha value.<sup>248,265</sup>

In summary, the Indonesian versions of DKQ-24 and the DHBM had satisfactory internal consistency reliability. These instruments are valid and reliable for use in an Indonesian population. Meanwhile, the Indonesian versions of 10-item SDSCA and the DES-SF had adequate internal consistency reliabilities to be used as research instruments for a

pilot study. The Indonesian version of the DKQ-24, the DHBM, the 10-item SDSCA and the DES-SF were therefore used to measure diabetes education interventions in the cluster RCT. These four adapted diabetes-related instruments will be disseminated more widely in Indonesia.

However, due to time and resource constraints, the test-retest reliability was not conducted and the construct validity was not assessed within an Indonesian context. These were limitations of the cross-cultural adaptation in this research project.

### **7.5.3. The Cluster Randomised Controlled Trial and Scoping Discussions**

In the cluster randomised controlled trial (cluster RCT), we tested the hypotheses that the structured diabetes education programme led to improvement of clinical outcomes and diabetes-related scores on knowledge, health beliefs, self-care skills, and self-efficacy. The study supported these hypotheses in three research outcomes. Compared to the control group, participation in the structured programme led to significant improvements in diabetes knowledge ( $p = 0.004$ ), 2-hour postprandial plasma glucose levels ( $p = 0.02$ ) and waist circumference at 3-month follow-up ( $p = 0.04$ ). These findings were consistent with the results of a meta-analysis by Fan et al (2009) on the effectiveness of diabetes self-management education (DSME) elements who also found that the greatest effect size of DSME interventions was in knowledge gain, followed by metabolic control outcomes and self-management behaviours.<sup>288</sup>

In the main study, both groups received diabetes education interventions: a structured diabetes education programme for the intervention group, and a diabetes seminar for the control group. This indicated that all participants were provided with additional diabetes education and diabetes leaflets aside from their usual care at the CHCs. Participants from both groups positively received the interventions and expected the sessions to be continued.

The finding that only 22 of the 101 participants in the main study (21.8%) indicated receiving traditional diabetes education from HCPs previously – either in individual or group session – suggested inadequate provision of diabetes education at the CHCs, as confirmed by both HCPs and patients with T2D in the scoping discussions. Meanwhile, the research participants generally showed a keen interest and curiosity in knowing sufficiently about T2D. This enthusiasm was not only among patients with shorter diabetes duration (less than 2 years) – as pointed out by HCPs in the scoping discussions – but also among patients with longer diabetes duration (above 10 years). Unsurprisingly, the participants used every

encounter with the GP researcher to ask a lot of questions about their diabetes-related issues they were concerned of during the course of research activities, including the scoping discussions. The participants praised the GP researcher of being communicative and informative and expected the HCPs at the CHCs to be like that.

Therefore, with this 'hunger of diabetes information', a 3-hour didactic teaching of diabetes seminar was possibly already a significant improvement on current provision of diabetes education, particularly, since the diabetes seminar included a distribution of a set of comprehensive diabetes leaflets (9 leaflets and 1 booklet). The diabetes seminar and leaflets might have increased the diabetes knowledge in the control group participants and provided motivation to perform the recommended diabetes self-care activities. This was confirmed by the control group participants during the post-intervention scoping discussion. These factors thus might have contributed to the improvements in many outcome variables in the control group such that changes were comparable to the intervention group.

In contrast to this work, many researchers in diabetes self-management education (DSME) intervention studies did not administer additional interventions aside from the usual care to the control group. Results from these studies were highly variable, but generally resulted in greater improvements in more outcomes variables as compared to the present study. For example, an RCT of a diabetes self-management programme in the Texas-Mexico border by Sixta and Ostwald showed a significant improvement of the DKQ-24 scores in the intervention group at 3 and 6 months but no significant differences between the intervention and control groups in HbA1c, the DKQ-24 and the DHBM scores.<sup>264</sup> Similarly, a cluster RCT of DESMOND programme by Davies et al. resulted in significant improvements in weight loss and smoking cessation and positive improvements in beliefs about illness in the intervention group at 4, 8 and 12 months, but no significant difference in HbA1c levels was observed.<sup>157</sup>

Moreover, an RCT of a structured education group programme in Brazil by Scain et al. showed significant improvements in diabetes knowledge and HbA1c levels in the intervention group at 4 and 12 months.<sup>312</sup> An RCT of a hospital-based clinic intervention in China by Shi et al. showed significant improvements in glycaemic control self-efficacy and glycaemic control behaviour at 4 months.<sup>21</sup> An RCT of brief structured education programme in Malaysia by Tan et al. resulted in significant improvements in glycaemic control (HbA1c), diabetes knowledge and self-care practices at 12 weeks.<sup>24</sup> An RCT of the chronic care model in diabetic care in Hong Kong by Lee et al. showed significant improvements in HbA1c level, DM self-efficacy scale, BMI and dietary behaviours at 16 and 28 weeks.<sup>22</sup> An RCT of clinical pharmacy management of patients with T2D in Jordan by Jarab et al. demonstrated significant improvements in HbA1c and FBG levels, systolic and diastolic blood pressure, total cholesterol, LDL cholesterol and serum triglycerides levels at 6 months.<sup>313</sup> Meanwhile,

the present study demonstrated less number of outcome variables showing significant improvements in the intervention group, possibly because the control group was also provided with an alternative diabetes education intervention.

Some researchers placed the control group wait-listed for the intervention, with the control group eventually received the same diabetes education intervention after data collection was completed. In these studies there were also variable results, as demonstrated in the following studies. An RCT of a culturally competent DSME in the Texas-Mexico border by Brown et al. resulted in significant improvements in HbA1c and FBG levels and diabetes knowledge at 6 and 12 months.<sup>184</sup> An RCT of a problem-based empowerment programme for African Americans with T2D by Anderson et al. showed no significant differences between groups in HbA1c level, systolic and diastolic blood pressure, and the DES-SF score at 6 weeks.<sup>259</sup>

The baseline diabetes knowledge of the participants in both groups was low. The mean score of the DKQ-24 in the intervention group was 52.05 (SD = 15.49) and control group 51.67 (SD = 15.93). This finding was considerably lower than the baseline diabetes knowledge reported in a previous study by Lujan et al., i.e. 69.1 (SD = 13.6) and 66.9 (SD = 15.2) for intervention and control groups, respectively.<sup>230</sup> The low baseline level of diabetes knowledge amongst patients with T2D at the CHCs may be attributed to several factors. Very few participants had received previous diabetes education sessions with HCPs and there was little provision of diabetes education at the CHCs. The traditional diabetes education provided was mostly conducted by a nutritionist focusing primarily on diabetes meal planning, while the underlying mechanisms of T2D and its related symptoms and complications were rarely discussed. Since approximately two-thirds of the DKQ-24 items are about underlying diabetes mechanisms, it is not surprising that the participants were unfamiliar with diabetes mechanisms and found the questions difficult.

There was a significant difference between groups in diabetes knowledge (the DKQ-24 scores) at 3-month follow-up. The DKQ-24 scores in both groups had increased considerably following the research interventions, by 33.5% in the intervention and 15.7% in the control group. Similar findings were reported in a previous study by Brown et al. The intervention group showed a significant difference of diabetes knowledge, assessed by the DKQ-24 at 3 and 12 months. The diabetes knowledge at 3 months had increased by 14.4% in the intervention group as compared to 4.8% in the control group.<sup>184</sup> These results were lower than the findings in the present study. Different results were reported in a previous study by Lujan et al. The intervention group did not show a significant difference in the diabetes knowledge assessed by the DKQ-24 at 3 months, but improved significantly at 6 months. The diabetes knowledge at 3 months had increased by 4% in the intervention group



compared with 6.4% in the control group.<sup>230</sup> These results were also lower than the findings in the present study.

The glycaemic control in the present study was assessed using HbA1c (primary outcome), as well as fasting blood/plasma glucose (FBG/FPG) and 2-hour postprandial plasma glucose level (2-h PPG) measurements. HbA1c was a relatively new blood sugar test for patients with T2D at the CHCs; meanwhile, the patients were more familiar with the FBG and 2-h PPG tests. However, in the majority of DSME intervention studies, only HbA1c was used. Thus, it is difficult to compare the results of FBG and 2-h PPG levels in the present study with other studies.

HbA1c is the gold standard for monitoring long-term glycaemic control and serves as a surrogate measure for the risk of microvascular and macrovascular complications.<sup>314,315</sup> However there are limitations in monitoring glycaemic control using only HbA1c, including: (1) not providing information about glycaemic variability; (2) not differentiating among fasting, preprandial and postprandial glycaemia; and (3) variability and inaccuracies in test results as there are more than 30 different HbA1c assays currently available or due to some medical conditions or certain dietary effects. Therefore, daily SMBG serves as an important adjunct to HbA1c because it provides the ability to identify hypoglycaemic episodes and detect glycaemic excursions, and also permits accumulating evidence for improved glycaemic control in T2D.<sup>315</sup>

However, for the majority of regular attendees of CHCs who had low socioeconomic status with limited capacity to obtain a glucometer, the practice of daily SMBG was not possible. Blood glucose monitoring was conducted through clinic-based blood sugar testing on a monthly basis as recommended by the HCPs. Interestingly in the scoping discussions, the patients reported that many HCPs did not use the results of blood sugar tests to adjust the patients' medication dosage, but simply maintained the same dosage even when the patients' blood sugar level decreased or increased. Moreover, when patients requested to get blood sugar tests more frequently than just the recommended once-a-month practice and kept notes of all results of blood sugar tests, the patients would be labelled as 'overreacting' by the HCPs. While these patients' behaviours reflected a willingness to self-manage their diabetes, in contrast, the HCPs' attitudes did not support patients' efforts. The HCPs' attitudes might be attributed to the constrained resources at the publicly funded CHCs as suggested by HCPs in the scoping discussions, and might also reflect traditional beliefs about the respective roles of patients and HCPs in disease management.

In achieving optimal diabetes management, reduction in HbA1c levels have been considered as the most important clinical target, and efforts to reduce FPG levels have been

given considerable attention.<sup>316</sup> However, reducing the FPG level has been shown to be insufficient for achieving the HbA1c target of less than 7%. Control of 2-h PPG is essential for achieving this target.<sup>317</sup> The 2-h PPG is as important as (or even more important than) the FPG for the prevention of vascular complications in individuals with or without diabetes. Elevated FPG and 2-h PPG levels have been shown to be risks factors for vascular complications in T2D.<sup>318</sup>

In the present study, although there was no significant difference for HbA1c level between groups at 3-month follow-up, HbA1c levels had decreased by 2.69% in the intervention group as compared to 3.98% in the control group. Similar results were reported in the DESMOND study with no significant difference for HbA1c level. The HbA1c level at 3 months had decreased by 1.49% in the intervention group as compared to 1.21% in the control group.<sup>157</sup> The findings in the present study differed from results reported in other studies. A meta-analysis of the DSME intervention effect on glycaemic control suggested that, on average, the intervention decreased HbA1c by 0.76% more than the control group at immediate follow-up; by 0.26% at 1-3 months; and by 0.26% at  $\geq 4$  months. These results indicated that while DSME intervention improves glycaemic control at immediate follow-up, the benefit declines 1-3 months after the intervention ceases, suggesting that the learned behaviours change over time.<sup>287</sup> Another meta-analysis of randomised educational and behavioural interventions in T2D demonstrated reduction of HbA1c level by a mean of 0.43%.<sup>319</sup>

Similar to the HbA1c results, there was no significant difference in FBG levels between groups at 3-month follow-up. FBG levels had decreased by 1.26% in the intervention group, and had increased by 2.75% in the control group. These findings differed from the results in other studies. In the study by Brown et al., the intervention group showed significant differences in HbA1c and FBG levels at 6 and 12 months compared to the control group.<sup>184</sup> In the study by Jarab et al., significant improvements in HbA1c and FBG levels between groups were found at 6 months.<sup>313</sup> A meta-analysis of randomised educational and behavioural interventions in T2D demonstrated reduction of FBG level by a mean of 24 mg/dL.<sup>319</sup>

Meanwhile, there was a significant difference in 2-h PPG levels between groups at 3-month follow-up. However, there are no DSME studies with glycaemic control outcome measurement using 2-h PPG level with which these results can be compared. The finding did indicate that the programme led to a significant improvement of glycaemic control as assessed by postprandial glucose measurement.

There was no significant difference in systolic blood pressure between groups at 3-month follow-up. However, a greater reduction in systolic blood pressure was found in the intervention group (4.59%) as compared to the control group (3.85%). There was no significant difference in diastolic blood pressure between groups at 3-month follow-up. Diastolic blood pressure had decreased by 3.29% in the intervention group and increased by 0.8% in the control group. Similarly, no significant differences in systolic and diastolic blood pressure between groups were found in the Diabetes X-PERT and DESMOND studies,<sup>153,157</sup> as well as in the study by Scain et al.<sup>312</sup> The findings of the present study differed from the results reported in the study by Jarab et al. which indicated significant improvements in systolic and diastolic blood pressure between groups at 6 months.<sup>313</sup>

There was no significant difference in body weight between groups at 3-month follow-up. However, a greater reduction in body weight was found in the intervention group (by 1.10% or 0.67 kg) as compared to the control group (0.45% or 0.27 kg). This finding was lower than the result reported in a meta-analysis of randomised educational and behavioural interventions in T2D which demonstrated reduction of body weight by 3 lbs.<sup>319</sup> There was also no significant difference in BMI between groups at 3-month follow-up although a greater reduction in BMI was found in the intervention group (1.15%) as compared to the control group (0.58%). There was a significant difference in waist circumference between groups at 3-month follow-up. Other studies reported varying results. In the Diabetes X-PERT study, there were significant improvements in body weight, BMI and waist circumference between groups at 14 months.<sup>153</sup> In the DESMOND study, there was a significant difference in weight loss between groups at 12 months but not in waist circumference reduction, while BMI was not reported.<sup>157</sup> There was no significant difference in BMI between groups in the study by Scain et al.<sup>312</sup> and Jarab et al.<sup>313</sup> No significant difference in body weight between groups was also reported in the study by Tan et al.<sup>24</sup>

In the scoping discussions, the intervention group participants reported a more detailed implementation of lifestyle modifications as compared to the control group participants. During the four programme sessions, there were a lot of interactive discussions on lifestyle modifications and problem solving of diabetes-related issues to enable the patients develop knowledge, skills and confidence for performing self-care activities. It is possible that this contributed to the greater weight loss and BMI reduction, and significant waist circumference reduction in the intervention group.

There was no significant difference in diabetes health beliefs (the DHBM scores) between groups at 3-month follow-up. The DHBM scores had decreased by 0.02% in the intervention group and increased by 1.79% in the control group. This indicated that the participants in the intervention group did not experience an increase in their belief about their

ability to manage diabetes, although they demonstrated significant improvements of diabetes knowledge and glycaemic control. This unexpected finding might be due to patients having already accepted the condition and exercised resignation towards the consequences of long-term diabetes as suggested by HCPs and patients in the scoping discussions. Additionally, this might be related to the life philosophy of Javanese people – “*Nrimo ing pandum*” (in Javanese local language) which literally means “accepting things wholeheartedly without protesting or rejecting as they have been preordained to happen”. Thus when Javanese people facing life’s ordeals, such as conflicts, poverty, illness, they culturally tend to manage the situation with this philosophy.<sup>270</sup>

Moreover, among the four adapted diabetes-related instruments, the DHBM was considered as the most challenging and time-consuming instrument by the research assistants during patient interviews. The research assistants reported that many participants were confused in their attempts to understand and answer the questions. This is possibly because the DHBM is lengthy with 25 items and comprises long sentences that are similar in format. These factors may have contributed to the unexpected finding. Similar results were found in other studies. No significant differences in DHBM scores were found in the studies by Lujan et al. and by Brown et al.<sup>230,254</sup>. In the former study, DHBM scores decreased in both groups at 3 and 6 months.<sup>230</sup>

There were no significant differences in diabetes self-care behaviours (the SDSCA scores) on the five subscales – general diet, specific diet, exercise, blood sugar testing and foot care – between groups at 3-month follow-up. However, there were improvements in all subscales in both groups. Greater improvements were demonstrated by the intervention group on blood sugar testing and foot care, while the control group showed greater improvements on general diet, specific diet and exercise. Similar results were found in the empowerment-based self-management consultant intervention study by Anerson et al. which demonstrated no significant differences between groups in any of the self-care behaviours at 2 years.<sup>320</sup> The findings of the present study differed from the results reported in the study by Jarab et al. which indicated significant improvements in total diet, exercise, and blood sugar testing between both groups at 6 months, but not in foot care.<sup>313</sup>

There was no significant difference in diabetes self-efficacy (the DES-SF scores) between groups at 3-month follow-up. However, greater improvement in the DES-SF scores was found in the intervention group (2.86%) as compared to the control group (2.57%). This finding was similar to the result reported in the study by Anderson et al. which showed no significant difference in the DES-SF scores between groups at 6 weeks.<sup>259</sup> This finding differed from the result reported in another study by Anderson et al. which demonstrated a

significant improvement in the DES-SF scores in the intervention group as compared to the control group at 2 years.<sup>320</sup>

The findings of the present study support the greater effectiveness of structured diabetes education programmes incorporating principles of diabetes self-management and patient empowerment as compared to the traditional didactic teaching of diabetes seminar. The effectiveness of the programme in this research project may be due to several factors. The programme used group format, face-to-face delivery, a mixture of educational, behavioural and psychological interventions, a mixture of didactic and interactive teaching methods, and had mixed topics (4), more sessions (4), and longer contact hours (10-12 hours) than the diabetes seminar. All of these elements of DSME intervention have been shown to be effective in improving knowledge, metabolic control and self-management behaviour.<sup>288,295</sup>

There is a possibility that the programme was effective solely because of the 10-12 hours of contact time. However, when patients receive the same structured diabetes education either delivered on individual or group basis over the same time period, the group intervention has been shown to be more effective.<sup>153,321</sup> Even if the effectiveness of the programme was due to the length of contact time, it would still be a more cost-effective and realistic strategy as compared to delivering the structured education to patients individually.<sup>153</sup>

Moreover, the programme was a compact programme with sessions closely grouped together. Diabetes education interventions of this type have been shown to be effective.<sup>290</sup> The programme follow-up was conducted at 3 months. Evidence supports the effectiveness of short-term diabetes self-management education (< 6 months).<sup>18,289</sup>

A simple cognitive reframing technique with a short prayer of conveying gratitude to God was incorporated in the programme. A spiritual aspect was included in the programme as a feature of the biopsychosocial approach of empowerment-based intervention.<sup>148</sup> Additionally, religion plays a major role in the everyday life of Indonesian people. The collective influence of religions is significantly manifest in Indonesia's political, economic and cultural life.<sup>284</sup> Diabetes education that employs cognitive reframing teaching method are likely to include more psychosocial interactions and make the patients become more engaged in the process. Such intervention has been shown to improve glycaemic control.<sup>295</sup>

The comprehensive nature of the structured diabetes education programme incorporating practical demonstrations of self-management techniques (including simple weight training and foot exercise) may have contributed to the success of the intervention. In addition to the comprehensive diabetes leaflets distributed to the participants, the diabetes

teaching was supported by large A1-sized diabetes posters with colourful graphics. Diabetes education which is comprehensive and includes a physical activity component has been shown to improve glycaemic control.<sup>18,295</sup>

Throughout the programme sessions, there were interactive discussions on biopsychosocial issues faced by the patients in living with diabetes, with relevant problem solving solutions. The programme was patient-centred with a biopsychosocial approach thus recognising each patient as a whole person since diabetes is a biopsychosocial illness.<sup>148,153</sup> Patient-centred care requires a thorough explanation of the disease process to patients and exploration of patients' affect and cognitions (i.e. feelings, beliefs, and expectations).<sup>105,322</sup> A study on a patient-centred approach by Little et al. indicated that patients in primary care strongly want a patient-centred approach with three important elements: communication with patients, partnership and health promotion. This study also showed that fewer patients wanted an examination (63%), and only a quarter wanted a prescription.<sup>105,323</sup>

In contrast, there was a low recognition of the importance of patient-centred elements among the HCPs in the CHCs in their diabetes care provision. The common practice was that the HCPs focused more on giving prescriptions, and this element was the main part of each patient-provider encounter. There was also a low recognition among the HCPs that diabetes is a biopsychosocial illness. The HCPs focused their diabetes care more on the patients' physical aspect, while psychosocial issues were rarely addressed. The HCPs failed to recognise that poor adherence may be due to physical, psychological, social and socioeconomic issues, and each needs to be explored and addressed.<sup>105</sup>

There was inadequate provision of traditional diabetes education at CHCs due to underlying problems associated with constrained resources and, according to the HCPs, patient characteristics. As indicated by both the HCPs and patients, the biggest problem was lack of human resources to provide services to the many patients using the publicly funded CHCs prompting time constraint in each patient-provider encounter. This finding was similar with the results of a previous study by Agarwal et al. which found that the main problems experienced by the GPs in providing good quality diabetes care included difficulty in effecting lifestyle modifications and lack of time with individual patients.<sup>70</sup>

There was a substantial menace of such practice. It was apparent from the scoping discussions with the HCPs and patients that there were many beliefs and misconceptions about T2D in the communities, as well as prevalent use of herbal and alternative treatments practices – without supportive evidence. During the course of research activities, the GP researcher received many queries from research participants regarding these issues. When

not properly addressed and corrected through adequate diabetes education, such misconceptions and practices will become more deeply entrenched in the community.

When patients did not receive adequate diabetes education from their HCPs, patients were more likely to turn to herbal and alternative treatments. Herbal and alternative healers tend to provide misleading information promoting their treatments for chronic diseases with bombastic testimonials. Patients reported that many herbal and alternative treatments gave promises to cure T2D after only a few treatments. Patients with low education level, low socioeconomic status or old age are more likely to be prone to such enticing promotions. Until recently, advertisements for herbal and alternative treatments with irrational and unwarranted testimonials were common on Indonesian national television channels. After protests from health professional associations and the Ministry of Health, these advertisements are now under scrutiny and may be banned.<sup>324,325</sup>

The HCPs at the CHCs expected that the diabetic patients would eventually gain adequate diabetes knowledge by themselves through living with diabetes, learning about diabetes from other sources including the internet, or sharing illness experiences with other patients. HCPs also expected the patients to follow the HCPs' simple medical advice on diabetes management, particularly with respect to regular medication taking, monthly blood sugar testing, and reducing intake of sweet drink and food. The HCPs identified patients as noncompliant when patients continuously had very high blood sugar level, decreased or increased the medication dosage by themselves or had difficulty controlling their diet when attending wedding parties. Without an adequately detailed explanation of diabetes management, it is unreasonable to expect patients to comply with the diabetes regimen successfully and achieve good glycaemic control. The patients at CHCs complained that during patient-provider encounters, the HCPs talked very little, only asking about presenting complaints and writing prescriptions without providing diabetes information. A previous study by Ciechanowski showed that patients who rated their patient-provider communication as poor had lower adherence rates to oral medications and SMBG.<sup>326</sup> A study by Thorne et al. revealed that the ability of HCPs to engage in effective communication during consultations can reinforce or discourage health actions thereby influencing patients' capacity to live positively with chronic conditions.<sup>108</sup>

In addition, the use of the terms 'compliance' and 'adherence' in diabetes care has been considered as counter-productive because the terms attribute the problem to the patients' personal qualities or behaviours, such as forgetfulness, lack of will power or discipline, or low education level. The concepts of 'non-compliance' and 'non-adherence' can have a corrosive effect in patient-provider relationship because they assume a negative

attitude towards patients and place patients in a passive, unequal role in the relationship.<sup>93,94,327</sup>

Meanwhile, patients with T2D are faced with the complexity of diabetes-related tasks that they are required to perform. This consists of several unrelated behaviours, such as remembering to take medication, reducing sugar intake, increasing physical activity, and checking one's feet. Patients may successfully perform any one of these behaviours but not another, as indicated by the patients in the scoping discussions. In this respect, a patient may be considered to be compliant with one area of diabetes regimen but not with another. Thus, these behaviours are difficult to define, and measure in any meaningful, standardised and objective way.<sup>328,329</sup>

Patients with T2D are fully responsible for the self-management of their diabetes inevitably, due to the three characteristics of the disease: choices, control and consequences. It is the patients with T2D, and not the HCPs, who make the most important day-to-day choices affecting patients' health and well-being. Patients are in control at all times and have the ultimate say over the lifestyle choices they make regarding their diabetes care, despite the providers' recommendations. The consequences of the choices patients make regarding their diabetes care accrue to patients themselves, and cannot be shared with the providers. Therefore, the complexities and realities of patients caring for diabetes are better captured by the terms 'self-management' or 'self-care behaviours', and not 'compliance' or 'adherence'.<sup>93,94,146,327,329</sup>

In the scoping discussions, a few HCPs suggested that diabetic patients should take care of themselves daily and considered this as mandatory because patients do not see HCPs every day. However, the majority of HCPs at the CHCs failed to recognise that diabetes is a self-managed disease. Moreover, many of the HCPs' attitudes and behaviours did not support patients in their diabetes self-management, such as not providing adequate diabetes education, labelling patients who were committed to monitor their blood sugar levels more intensively as 'overreacting', and using scare tactics to warn patients about their high blood sugar level. Furthermore, the HCPs had low expectations about their own capability and felt that they could not manage complicated tasks. This may be related to the lack of additional formal training for GPs which may result in a lack of competence and confidence in disease management. To date, in Indonesia there is no additional vocational training for medical doctor graduates who intend to practice directly in the community; and they are called 'general practitioners'.<sup>81</sup> In addition, diabetes educator training is not available for most HCPs. There was a limited number of diabetes educator training organised by the Yogyakarta City Health Office. Moreover, this training was usually of short duration (half day), consisted of lectures on T2D, and did not involve the practice of diabetes teaching. This



diabetes educator training might not adequately equip the HCPs with competence and confidence to provide adequate diabetes education to patients with T2D.

In contrast, the diabetic patients at the CHCs demonstrated enthusiasm in knowing and understanding about T2D, and commitment to follow the HCPs' advice on diabetes regimens despite their deficiencies. The patients described self-management as "being active in their own care". These patients' attitudes reflected their efforts to self-manage their diabetes. To successfully manage diabetes, patients must be able to set goals and make frequent daily decisions that are both effective and fit their values and lifestyle, while taking into account multiple biopsychosocial factors.<sup>146</sup> During the scoping discussions, some patients described these realities of diabetes care in achieving good glycaemic control. These patients indeed need a lot of support from the HCPs in their diabetes self-management to achieve long-term glycaemic control and live well with their condition.

To be effective, diabetes self-management education intervention needs to be based on a strong theoretical foundation, address psychosocial issues and provide problem-solving skills.<sup>146,330</sup> Empowerment is a patient-centred, collaborative approach that best accommodates the fundamental realities of diabetes care. Patient empowerment is defined as 'helping patients enhance and use their own innate ability to gain mastery over their diabetes', and designed to facilitate self-directed behaviour change. The approach is particularly suitable in diabetes care because the recommended behaviour changes involve the patients' deeply embedded lifestyle. To achieve success, patients should be internally motivated, rather than externally motivated.<sup>130,146</sup>

Despite unfamiliarity with the term patient empowerment, the diabetic patients generally demonstrated motivation and efforts to follow the recommended diabetes regimens, make lifestyle changes, and overcome biopsychosocial problems in their diabetes care. The patients also expected HCPs to be more communicative and provide detailed information about diabetes to help them manage their diabetes better. Moreover, the patients described potential advantages associated with the implementation of diabetes self-management and patient empowerment concepts, i.e. increased motivation and knowledge. Patients' attitudes reflected positive perceptions and preferences towards diabetes self-management and patient empowerment despite patients' unfamiliarity with the concepts.

In contrast, the attitudes of HCPs at the CHCs reflected misconceptions about the empowerment approach in diabetes self-management that commonly occur in diabetes care and education.<sup>130</sup> While questioning the existence of the term patient empowerment, the HCPs gave a specific description which was related to their traditional patient education perspective, i.e. "the independence of diabetic patients in managing their own condition and

applying the recommended diabetes management without the need for HCPs to scare them about diabetes consequences". Towards the notion of the implementation of diabetes self-management and patient empowerment concepts, the HCPs argued that such implementation was not for publicly funded CHCs where many of the regular attendees had low socioeconomic status, low education level, and older age. Instead, the HCPs suggested that implementation should begin with patients with better socioeconomic status and more resources, that is, patients attending hospitals, particularly private hospitals. In addition, surprisingly, the HCPs wondered if the community became independent then the income of HCPs might decrease.

Contrary to the beliefs of the HCPs at the CHCs, many empowerment-based diabetes self-management studies have been conducted among medically underserved minority patients. The fact is, despite having limited resources available to manage diabetes, the patients' ability for assuming responsibility and making informed decisions is not limited.<sup>130,259,320</sup> Empowerment approach is not associated with giving or taking power, and does not involve convincing, persuading, empowering or changing patients. Instead, the empowerment approach focuses on facilitating and supporting patients to reflect on their experience of living with diabetes. This often leads to patients' enhanced awareness and understanding of the consequences of their self-management decisions.<sup>130</sup>

The scoping discussions indicated that patients with T2D at the CHCs were ready and enthusiastic to embrace the implementation of diabetes self-management and patient empowerment concepts with expectations that such implementation would help them achieve long-term glycaemic control and live well with their condition. In contrast, the scoping discussions raised questions about the readiness of HCPs at the CHCs to embrace diabetes self-management education, particularly when there is evidence to suggest that they were reluctant to engage adequately in traditional diabetes education, let alone accommodate the patient empowerment concept. This might be compromised by a lack of competence and confidence as diabetes educators among the HCPs. Being a successful diabetes educator requires teaching and counselling skills, as well as diabetes content expertise.<sup>330</sup>

According to Anderson and Funnel, embracing the empowerment approach involves making a paradigm shift that is often difficult because the traditional approach to care is deeply embedded in the training and socialisation of HCPs. Empowerment begins when HCPs acknowledge that patients are in control of their daily diabetes care. Empowerment approach includes both a process and an outcome. Empowerment is a process when the objective of the intervention is to increase one's ability to think critically and act autonomously. When an enhanced sense of self-efficacy occurs as a result of the process, empowerment is an outcome.<sup>130</sup> The empowerment approach involves the collaboration of

two distinct kinds of expertise, namely diabetes expertise of the HCPs and the equally important expertise of patients about their priorities, goals, concerns, values, traditions, culture and resources.<sup>11,130</sup> Empowerment is primarily a vision that guides each patient-provider encounter and requires both HCPs and patients to adopt new roles. The role of patients is to be well-informed active partners in their own care. Meanwhile, the role of HCPs is to help patients make informed decisions in achieving their goals and overcoming barriers through education, appropriate care recommendations, expert advice, self-reflection, and support.<sup>130,146</sup>

The structured diabetes education programme which incorporated principles of diabetes self-management and patient empowerment for patients with T2D conducted in publicly funded CHCs resulted in significant improvements in diabetes knowledge, glycaemic control (2-h PPG) and waist circumference. The findings of the present study can contribute to the development of diabetes self-management education programmes based on patient empowerment approach in the primary care settings with limited resources, and will provide building blocks for an improved programme of diabetes education and care in Indonesia.

For successful implementation of diabetes self-management and patient empowerment concepts in diabetes education and care, considerable work still needs to be done. This includes advocacy directed towards all Indonesian health care stakeholders – policy makers, health care providers, health academics, health care managers, and communities (patients) – on the importance of such programmes and the fundamental principles underlying the concepts. There is also a strong need for advocacy directed towards the Republic of Indonesia Ministry of Health and local health offices to encourage and fund the development of national and local structured diabetes education programmes incorporating diabetes self-management and patient empowerment concepts, and the provision of free comprehensive diabetes education materials. The development of such programmes can support the establishment of a national diabetes programme (NDP) in Indonesia.<sup>58,89</sup> Additionally, such programmes can be incorporated into the *Prolanis* programme, an integrated chronic disease management programme recently established by *Askes Inc.*,<sup>88</sup> which has not included the provision of structured education in chronic diseases. More importantly, national initiatives should be conducted simultaneously to focus on both supporting patients to engage in self-management and equipping HCPs with the necessary resources to assist the patients.<sup>103</sup>

## 7.6. STRENGTHS AND LIMITATIONS OF THE STUDY

### 7.6.1. Strengths

There were several strengths of the study. The structured diabetes education programme is likely to be generalisable to the majority of patients with T2D attending CHCs. The publicly funded CHCs comprise the majority of primary care health centres in all parts of Indonesia. The study was a pragmatic trial with minimum exclusion criteria and delivered under normal conditions within primary care. The programme provided diabetes structured education on a group basis which was more cost-effective and realistic as compared to diabetes education delivered on an individual basis.

### 7.6.2. Limitations

There were several limitations of the study. The relatively small sample for a cluster randomised controlled trial might affect the generalisability of the findings. The study participants were not entirely representative of the general population due to underrepresentation of male participants, and overrepresentation of participants with low socioeconomic status. Additionally, the research project was conducted among Javanese people residing in Central Java hence the findings may not be applicable to other ethnic/cultures in Indonesia.

The effect of the intervention was assessed at 3-month follow-up, measuring only the short-term effect. The moderate-term and long-term effects to demonstrate sustainability of the impact were not conducted due to time and resource constraints. The group format of programme sessions was relatively large, consisting of 15-25 patients with several family members making up to around 30 participants. This was also due to time and resource constraints. Sessions with smaller groups consisting of 10-12 participants would be more effective.<sup>312</sup>

Furthermore, given the low level of health literacy in the local communities and the scarcity of diabetes information, the provision of comprehensive leaflets to the control group acted as a significant intervention. This overshadowed the impact of the broader structured diabetes education programme in the intervention group such that both groups improved across the board and the difference between the two groups was reduced. Therefore the ability to show a significant difference due to the structured diabetes education programme was impaired and to a large extent this compromised the trial.

The total attrition rate of participants was 17.8% (intervention group = 19.6%; control group = 16%). Although the rates were still below the 20-percent rule,<sup>331</sup> they might affect the validity and overall outcome of the study. The intervention and assessment sessions of the research project were conducted at the community health centres during office hours. This might pose a barrier for working participants to attend the research sessions. For future roll out of similar research interventions, each intervention and assessment session will be conducted at two different times, i.e. morning and afternoon sessions. This will provide a flexibility for participants to choose a convenient time to attend.

Finally, it was not possible with this study design to completely exclude the possibility of a Hawthorn effect – a phenomenon wherein the study subjects' behaviours or study results are altered by the subjects' awareness that they are being studied or receiving additional attention.<sup>332</sup> The effect of the structured diabetes education programme may be influenced by a Hawthorn effect due to the increase attention of the GP researcher on participants in the intervention group.

## **7.7. CONCLUSIONS AND RECOMMENDATIONS**

### **7.7.1. Conclusions**

Several conclusions could be drawn from this chapter as follows:

- 1) The majority of the participants in the cluster randomised controlled trial were females, and had low socioeconomic status. Many participants were elderly, and had low education levels.
- 2) The participants in the intervention and control groups were matched for sociodemographic characteristics, medical history and key outcome variables, except in the case of monthly family income, diet treatment, stroke complication and health insurance coverage, and 2-h PPG level. Such anomalies are not uncommon in a pragmatic cluster randomised controlled trial.
- 3) The Indonesian versions of DKQ-24 and the DHBM had satisfactory internal consistency reliabilities. These instruments are valid and reliable for use in an Indonesian population. Meanwhile, the Indonesian versions of 10-item SDSCA and the DES-SF had adequate internal consistency reliabilities to be used as research instruments for a pilot study. The Indonesian version of the DKQ-24, the DHBM, the 10-item SDSCA and the DES-SF were therefore used to measure diabetes

education interventions in the cluster randomised controlled trial. However, among the four adapted instruments, the DHBM was the most challenging one to use.

- 4) In the main study, both groups received diabetes education interventions, namely a structured diabetes education programme for the intervention group, and a diabetes seminar for the control group. All participants were provided with additional diabetes education and a set of comprehensive diabetes leaflets (9 leaflets and 1 booklet) aside from their usual care at the CHCs. Participants from both groups positively received the interventions and expected the sessions to be continued. These factors thus might have contributed to the improvements in many of the outcome variables in the control group such that changes were comparable to the intervention group.
- 5) Participation in the structured diabetes education programme resulted in significant improvements in diabetes knowledge, 2-hour postprandial plasma glucose level and waist circumference at 3-month follow-up.
- 6) Many outcome variables in the intervention group showed trends of improvement at 3-month follow-up. However, some of these improvements did not significantly differ to the changes in the control group, including: HbA1c (primary outcome), fasting blood glucose, systolic and diastolic blood pressure, body weight, BMI, the SDSCA scores on general diet, specific diet, exercise, blood sugar testing and foot care, and the DES-SF score. For some of these variables, the mean changes in the intervention group were positively greater than in the control group, including: fasting blood glucose, systolic and diastolic blood pressure, body weight, BMI, the SDSCA scores on blood sugar testing and foot care, and the DES-SF score.
- 7) The scoping discussions suggested that there was inadequate provision of traditional diabetes education in the communities studied due to underlying problems at the CHCs, namely constrained resources and patient characteristics. There were prevalent diabetes misconceptions and use of herbal and alternative treatments – without supportive evidence – in the communities. When not properly addressed and corrected through adequate diabetes education, such misconceptions and practices will become more deeply entrenched in the communities.
- 8) The scoping discussions indicated that patients with T2D at the CHCs were ready and enthusiastic to embrace the implementation of diabetes self-management and patient empowerment concepts with expectations that such implementation would help them achieve long-term glycaemic control and live well with their condition.

- 9) In contrast, the scoping discussions raised questions about the readiness of HCPs at the CHCs to embrace diabetes self-management education, particularly when there is evidence to suggest that they were reluctant to engage adequately in traditional diabetes education, let alone accommodate the patient empowerment concept. This might be compromised by a lack of competence and confidence as diabetes educators among the HCPs.
- 10) The findings of the present study can contribute to the development of diabetes self-management education programmes based on patient empowerment approach in the primary care settings with limited resources, and will provide building blocks for an improved programme of diabetes education and care in Indonesia.

### **7.7.2. Recommendations**

Several recommendations that emerged from this chapter are as follows:

- 1) Dissemination and training provision for health care providers at primary care clinics or community health centres should be offered to facilitate self-management and patient empowerment through structured diabetes education programmes for patients with T2D. A starting point for this will be available September 2014 in the Yogyakarta Meeting in Family Medicine where a national seminar on the topic will be conducted by the researcher through the Universitas Muhammadiyah University Centre for Family Medicine Studies and the Association of Indonesian Family Doctors Yogyakarta Branch.
- 2) There is a strong need for advocacy, on the part of the Universitas Muhammadiyah University Centre for Family Medicine Studies and the Association of Indonesian Family Doctors, directed towards all Indonesian health care stakeholders – policy makers, health care providers, health academics, health care managers, and communities (patients) – on the importance of implementing self-management and patient empowerment in diabetes education and care through structured diabetes education programmes.
- 3) There is also a strong need for advocacy directed towards the Republic of Indonesia Ministry of Health and local health offices to encourage and fund the development of national and local structured diabetes education programmes incorporating self-management and patient empowerment concepts, and the provision of free comprehensive diabetes education materials. The development of such programmes can support the establishment of a national diabetes programme (NDP) in Indonesia. More importantly, national initiatives should be conducted

simultaneously to focus on both supporting patients to engage in self-management and equipping HCPs with the necessary resources to assist the patients.

- 4) The Republic of Indonesia Ministry of Health and local health offices and/ or universal health coverage organisation (BPJS) should provide funds for the training as well as incentives for health care providers at primary care clinics or community health centres to facilitate self-management and patient empowerment in structured diabetes education programmes.
- 5) Structured diabetes education programmes incorporating self-management and patient empowerment should be developed at the researcher's home university medical centre, primary care clinics, community settings or other Indonesian institutions to be offered to the general public. Participants should be universally provided with comprehensive diabetes leaflets. This will require funding from governments or aid agencies.
- 6) Similar studies with bigger samples and of longer duration involving more heterogeneous participants with T2D are needed in the Indonesian context. Similar studies extended to other chronic illnesses, such as hypertension, osteoarthritis, heart disease, and obesity, are needed as well.
- 7) Similar structured group education programmes extended to other chronic diseases, such as hypertension, osteoarthritis, heart disease, and obesity, should be developed at the researcher's home university medical centre, primary care clinics, community settings or other Indonesian institutions to be offered to the general public. Such programmes can be incorporated into the *Prolanis* programme, an integrated chronic disease management programme recently established by *Askes Inc.*, which has not included the provision of structured education in chronic diseases.
- 8) This will require networking and collaboration with local, national, regional and international relevant organisations in order to obtain broader support for these initiatives. International financial support for these initiatives should also be sought.
- 9) In future studies, it would be also valuable to explore the efficacy and effectiveness of traditional medicines currently used in the community for the treatment of diabetes and other chronic diseases since little is known about them. In addition, it would be similarly valuable to explore the nature and extent of community perceptions of the use of these medicines.



## **7.8. SUMMARY**

In summary, this chapter is the largest and most important chapter in this thesis. This chapter not only describes the main study, that is the cluster randomised controlled trial of a structured diabetes education programme, but also reports the reassessment of internal consistency reliability of the four adapted diabetes-related instruments, and the scoping discussions as informal evaluation. The latter served to enrich the findings of the pilot cluster randomised controlled trial.

This chapter has outlined the research methods, results and discussion about the reassessment of internal consistency reliability of the four adapted diabetes-related instruments, the pilot cluster randomised controlled trial of a structured diabetes education programme, and the scoping discussions. The next chapter, Chapter 8, will discuss the overall conclusions and recommendations emerging from this research project.

# **CHAPTER 8 – Overall Conclusions and Recommendations**

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**A Structured Diabetes Education Programme  
in Indonesia**

## **8.1. INTRODUCTION**

This research project was initiated out of the researcher's concern for the alarming increasing prevalence of type 2 diabetes in Indonesia. Indonesia has been consistently listed in the fourth place amongst the top ten countries with the highest numbers of estimated diabetes cases in 2000 and projected diabetes cases for 2030.<sup>6</sup> A large number of problems have been identified by the WHO (2002) within health care systems in countries worldwide in addressing chronic conditions.<sup>2</sup> However, this research project only focused on the problem at patient interaction level, namely 'the failure to empower patients to improve health outcomes' and 'the lack of emphasis on quality interactions with the health care personnel', particularly in the primary care setting in Indonesia

Considerable evidence from developed and Western countries has demonstrated the effectiveness of empowerment-based chronic disease self-management and diabetes self-management education interventions in improving health outcomes. These interventions have increasingly been introduced in Asian countries. However, in Indonesia, there is a limited awareness and availability of diabetes structured patient education based on diabetes self-management and patient empowerment concepts in the health care service. In order to achieve better health outcomes in this area, it was therefore considered useful to pilot a programme for diabetes structured patient education, promoting diabetes self-management and patient empowerment, for patients with type 2 diabetes in the primary care setting.

This research project was divided into two studies: (1) a cross-cultural adaptation of existing validated diabetes-related instruments; and (2) a pilot cluster randomised controlled trial of a structured diabetes education programme (main study) which was enriched by several scoping discussions on perceptions towards diabetes education among people with type 2 diabetes and their family members, and health care providers. The research project sought to answer the following questions, respectively: (1) "Are the existing validated diabetes-related instruments valid and reliable for an Indonesian population?"; (2) "Is a structured diabetes education programme promoting self-management and patient empowerment effective in improving clinical outcomes and diabetes related scores of knowledge, health beliefs, self-care behaviours, and self-efficacy in adult patients with type 2 diabetes in primary care setting in Indonesia?"; and (3) "What are the perceptions of people with type 2 diabetes and their family members regarding the current diabetes education that they receive?"; and "What are the perceptions of health care providers regarding the current diabetes education that they provide to patients with type 2 diabetes?".

The two studies were completed and have answered the three research questions. These two studies were described in two chapters, namely Chapter 5 – the cross-cultural

adaptation of diabetes-related instruments; and Chapter 7 – the cluster randomised controlled trial of a structured diabetes education programme and scoping discussions. Meanwhile, an overview of the study designs employed in this research project was described in Chapter 4; and an overview of the development of diabetes education materials used in the research interventions was reported in Chapter 6.

## **8.2. OVERALL CONCLUSIONS AND RECOMMENDATIONS**

This PhD research project set out to introduce and promote self-management and patient empowerment concepts through a structured diabetes education programme among patients with type 2 diabetes (T2D) in primary care settings with limited resources, i.e. publicly funded community health centres (CHCs). These centres are generic primary health care facilities found in each subdistrict in all 33 provinces in Indonesia.

Structured diabetes education programmes, promoting self-management and patient empowerment, are completely new in Indonesia. Patient education in T2D commonly found in Indonesia is traditional diabetes education conducted in hospitals and community health centres. This patient education is mostly didactic teaching, neither structured nor comprehensive, and usually conducted by a nutritionist focusing primarily on diabetes meal planning to an individual patient with T2D. Other common forms of traditional diabetes education are carried out in groups, including: diabetes public education conducted in the communities within the working areas of CHCs, and diabetes seminars conducted in hospitals.

Introducing the structured diabetes education programme, with its overlay of Western concepts and culture, into the local communities with completely different characteristics is very difficult and complex. As in many other South East Asian communities, the local communities in which this research project was conducted are characterised by low socioeconomic status (SES), low level of education, low literacy, and consequent low health literacy. Most of the population in these communities have only a primary school education and limited exposure to public health education. Health education would be provided through the community health centres but these publically funded programs depend on available funds which are usually very limited. Furthermore, these local communities have little exposure to research, and present with different cultural context and health beliefs. Therefore it was necessary to undertake a preliminary study in the area in order to understand the issues such a programme would face if implemented in Indonesia.

Conducting this preliminary study required a number of adaptations to the Western models including adapting the research tools, adapting and developing the programme, and

developing the diabetes patient education materials. There was a potential mismatch between the research interventions with the population studied. Given the low SES, low level of health literacy in the local communities and the scarcity of diabetes information, the provision of a three-hour diabetes seminar and comprehensive leaflets to the control group acted as a significant intervention. This overshadowed the impact of the broader structured diabetes education programme in the intervention group such that both groups improved across the board and the difference between the two groups was reduced. Therefore the ability to show a significant difference due to the structured diabetes education programme was impaired and to a large extent this compromised the trial.

Furthermore, there were different expectations of patients with T2D and their health care providers (HCPs) regarding the current diabetes education. Patients with T2D at the CHCs were ready and enthusiastic to embrace the implementation of diabetes self-management and patient empowerment concepts with expectations that such implementation would help them achieve long-term glycaemic control and live well with their condition. In contrast, the readiness of HCPs at the CHCs to embrace diabetes self-management education is questionable, particularly when there is evidence to suggest that they were reluctant to engage adequately in traditional diabetes education, let alone accommodate the patient empowerment concept. Their willingness to engage with the programme might be compromised by a lack of competence and confidence as diabetes educators among the HCPs. Therefore, dissemination and training provision for health care providers at primary care clinics or community health centres should be offered to facilitate self-management and patient empowerment through structured diabetes education programmes for patients with T2D. In addition, appropriate relevant training programmes should be incorporated into the medical and nursing education curriculum. Training would encompass health promotion and disease prevention through lifestyle modification in chronic diseases and through opportunistic intervention for the wider family unit.

Despite the compromised research findings, this preliminary study was a useful learning process and provided substantial understanding of the strengths and weaknesses in the programme of work. This will be beneficial for future research and for implementation of diabetes self-management programmes in Indonesia. The findings of this preliminary study can contribute to the development of diabetes self-management education programmes based on patient empowerment approach in the primary care settings with limited resources, and will provide building blocks for an improved programme of diabetes education and care in Indonesia. Future research projects with a larger cohort over a longer time period would allow us to test more effectively the benefits or otherwise of the program. However, given a beneficial effect was shown in both arms of the project we would anticipate that a longer and

larger research programme would demonstrate the benefits of a diabetes self-management education programme based on patient empowerment approach in Indonesian settings. Additionally, the learnings are transferable to other chronic disease self-management programmes.

Furthermore, multi-level strategies would be required in order to change the current practice and embed diabetes self-management education programmes based on patient empowerment approach into health care delivery in Indonesia. This might occur through a number of avenues involving various health care stakeholders – policy makers, health care providers, health academics, health care managers, and communities (patients). The strategies might include seminars for doctors, nurses and patients, workshops at local and national levels, discussions with relevant organisations such as the Association of Indonesian Family Doctors; and ultimately developing patient education materials and protocols for use in primary care clinics. Such programmes would require support and substantial funding from the Republic of Indonesia Ministry of Health and local health offices and/ or the universal health coverage organisation (BPJS) and other privately funded medical institutions, particularly for the training as well as incentives for health care providers at primary care clinics to facilitate self-management and patient empowerment in structured diabetes education programmes. Therefore this would require significant advocacy efforts on the part of the researcher through her private medical institution i.e. the Universitas Muhammadiyah University Centre for Family Medicine Studies. The advocacy efforts would include a number of avenues including paper presentations at primary care and specialist physician conferences, scientific publications and editorials in relevant medical journals, deputations and policy briefs to the Government; and in appealing to the broader population through newspaper and magazine articles, and TV and radio appearances.

Currently, the researcher is in charge of two relevant task forces at her home private medical school, the Universitas Muhammadiyah University Faculty of Medicine and Health Sciences, i.e. Task Force for Primary Care Clinics and Task Force for Postgraduate Training for Primary Care Physicians. The first task force aims to establish two new university primary care clinics to replace the existing clinic in the next year which provide holistic and comprehensive health care services emphasising on health promotion and disease prevention. These new clinics are expected to become a prototype model for developing other primary care clinics within the health institution network of Muhammadiyah Islamic organisation as well as for other primary care clinics in Indonesia. These clinics will offer structured education programmes incorporating self-management and patient empowerment approach in type 2 diabetes, hypertension, obesity and other chronic diseases. Pilot programmes for the general public will be offered starting September 2014 held in the

existing university clinic. Diabetes self-management education and chronic disease self-management education will be incorporated into the primary care postgraduate training curriculum.

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# **APPENDIX A – Research Ethics Approval**

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RESEARCH BRANCH  
RESEARCH ETHICS AND COMPLIANCE UNIT

SABINE SCHREIBER  
SECRETARY  
HUMAN RESEARCH ETHICS COMMITTEE

THE UNIVERSITY OF ADELAIDE  
SA 5005  
AUSTRALIA

TELEPHONE +61 8 8303 6028  
FACSIMILE +61 8 8303 7325  
email: sabine.schreiber@adelaide.edu.au  
CRICOS Provider Number 00123M

17 September 2009

Professor JJ Beilby  
Faculty of Health Sciences

Dear Professor Beilby

**PROJECT NO:** *Patient empowerment promoting self-management for adult patients with type 2 diabetes in primary care setting in Indonesia*  
**H-075-2009**

I write to advise you that the Human Research Ethics Committee has approved the above project. Please refer to the enclosed endorsement sheet for further details and conditions that may be applicable to this approval.


Approval is current for one year. The expiry date for this project is: 30 September 2010

Where possible, participants taking part in the study should be given a copy of the Information Sheet and the signed Consent Form to retain.

Please note that any changes to the project which might affect its continued ethical acceptability will invalidate the project's approval. In such cases an amended protocol must be submitted to the Committee for further approval. It is a condition of approval that you immediately report anything which might warrant review of ethical approval including (a) serious or unexpected adverse effects on participants (b) proposed changes in the protocol; and (c) unforeseen events that might affect continued ethical acceptability of the project. It is also a condition of approval that you inform the Committee, giving reasons, if the project is discontinued before the expected date of completion.

A reporting form is available from the Committee's website. This may be used to renew ethical approval or report on project status including completion.

Yours sincerely .

 Professor Garrett Cullity  
Convenor  
Human Research Ethics Committee



RESEARCH BRANCH  
RESEARCH ETHICS AND COMPLIANCE UNIT

SABINE SCHREIBER  
SECRETARY  
HUMAN RESEARCH ETHICS COMMITTEE

THE UNIVERSITY OF ADELAIDE  
SA 5005  
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TELEPHONE +61 8 8303 6028  
FACSIMILE +61 8 8303 7325  
email: sabine.schreiber@adelaide.edu.au  
CRICOS Provider Number 00123M

Applicant: Professor JJ Beilby

Department: Faculty of Health Sciences

Project Title: *Patient empowerment promoting self-management for adult patients with type 2 diabetes in primary care setting in Indonesia*

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THE UNIVERSITY OF ADELAIDE HUMAN RESEARCH ETHICS COMMITTEE

**Project No:**

**H-075-2009**

RM No: 0000009251

APPROVED for the period until: 30 September 2010

Thank you for the detailed response dated 11.9.09 to the matters raised by the Committee. It is noted that this study will be conducted by Oryzati Hilman Agrimon, PhD candidate.

Refer also to the accompanying letter setting out requirements applying to approval.

Professor Garrett Cullity  
Convenor  
Human Research Ethics Committee

Date: 17 SEP 2009



RESEARCH BRANCH  
RESEARCH ETHICS AND COMPLIANCE UNIT

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CRICOS Provider Number 00123M

11 October 2010

Professor JJ Beilby  
Faculty of Health Sciences

Dear Professor Beilby

**PROJECT NO:** *Patient empowerment promoting self-management for adult patients with type 2 diabetes in primary care setting in Indonesia*  
**H-075-2009**

Thank you for your report on the above project. I write to advise you that I have endorsed renewal of ethical approval for the study on behalf of the Human Research Ethics Committee.


The expiry date for this project is: 30 September 2011

Where possible, participants taking part in the study should be given a copy of the Information Sheet and the signed Consent Form to retain.

Please note that any changes to the project which might affect its continued ethical acceptability will invalidate the project's approval. In such cases an amended protocol must be submitted to the Committee for further approval. It is a condition of approval that you immediately report anything which might warrant review of ethical approval including (a) serious or unexpected adverse effects on participants (b) proposed changes in the protocol; and (c) unforeseen events that might affect continued ethical acceptability of the project. It is also a condition of approval that you inform the Committee, giving reasons, if the project is discontinued before the expected date of completion.

A reporting form is available from the Committee's website. This may be used to renew ethical approval or report on project status including completion.

Yours sincerely

 Professor Garrett Cullity  
Convenor  
Human Research Ethics Committee

5 OCT 2010

**THE UNIVERSITY OF ADELAIDE HUMAN RESEARCH ETHICS COMMITTEE  
APPLICATION TO RENEW ETHICAL APPROVAL OR REPORT ON PROJECT STATUS**

<b>Project No:</b>	<b>H-075-2009</b>	<b>Rm Code:</b> 0000009251
<b>Title:</b>	<b>Patient Empowerment Programme Promoting Self-Management for Adult Patients with Type 2 Diabetes in Primary Care Setting in Indonesia</b>	
<b>Applicant:</b>	<b>Professor Justin Beilby, MD, MPH, MBBS, FRACGP, DRACOG, DA</b> Executive Dean, Faculty of Health Sciences, University of Adelaide	
<b>Department:</b>	Faculty of Health Sciences, University of Adelaide Adelaide, South Australia 5005, Australia	
<b>Telephone:</b>		
<b>Email:</b>		
<b>Others Involved:</b>	<ul style="list-style-type: none"> <li>• <b>Jackie Street PhD, BSc (Hons), Grad.Dip.Primary Health Care</b> Lecturer, Discipline of Public Health, School of Population Health &amp; Clinical Practice, Faculty of Health Sciences, University of Adelaide Mail Drop DX650 545, Room 3.20 (Level 3), 122 Frome St , Adelaide, SA 5005, Australia</li>   <li>• <b>Oryzati Hilman Agrimon, MD, MSc.CMFM</b> PhD Student, Discipline of General Practice, School of Population Health &amp; Clinical Practice, Faculty of Health Sciences, University of Adelaide</li> </ul>	
<b>Date first approved:</b>	17 September 2009	<b>Annual expiry date:</b> 30 September 2010

<b>STATUS OF PROJECT</b>	<b>COMMENCED</b> /NOT COMMENCED/CONTINUING/COMPLETE?
Reason if project has not commenced?	
Expected completion date? <b>August 2011</b>	
Have there been any changes to the project in the last year which may affect its ethical approval? <b>NO</b>	
Are there likely to be any changes to the project in the next twelve months which may affect its ethical approval? <b>NO</b>	
If yes, give details of changes (if insufficient space, please attach a separate sheet):	
Have any participants withdrawn from the study? <b>NO</b>	
If yes, give number of participants who have withdrawn and reasons if known?	





RESEARCH BRANCH  
RESEARCH ETHICS AND COMPLIANCE UNIT

SABINE SCHREIBER  
SECRETARY  
HUMAN RESEARCH ETHICS COMMITTEE  
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CRICOS Provider Number 00123M

21 October 2011

Professor J Beilby  
Faculty of Health Sciences

Dear Professor Beilby

**PROJECT NO: H-075-2009**  
*Patient empowerment promoting self-management for adult patients with type 2 diabetes in primary care setting in Indonesia*

Thank you for your report on the above project. I write to advise you that I have endorsed renewal of ethical approval for the study on behalf of the Human Research Ethics Committee.

**The expiry date for this project is: 30 September 2012**

Where possible, participants taking part in the study should be given a copy of the Information Sheet and the signed Consent Form to retain.

Please note that any changes to the project which might affect its continued ethical acceptability will invalidate the project's approval. In such cases an amended protocol must be submitted to the Committee for further approval. It is a condition of approval that you immediately report anything which might warrant review of ethical approval including (a) serious or unexpected adverse effects on participants (b) proposed changes in the protocol; and (c) unforeseen events that might affect continued ethical acceptability of the project. It is also a condition of approval that you inform the Committee, giving reasons, if the project is discontinued before the expected date of completion.

A reporting form is available from the Committee's website. This may be used to renew ethical approval or report on project status including completion.

Yours sincerely

 **PROFESSOR GARRETT CULLITY**  
Convenor  
Human Research Ethics Committee

1107 130 8 1

**THE UNIVERSITY OF ADELAIDE HUMAN RESEARCH ETHICS COMMITTEE  
APPLICATION TO RENEW ETHICAL APPROVAL OR REPORT ON PROJECT STATUS**

<b>Project No:</b>	<b>H-075-2009</b>	Rm Code: 0000009251
<b>Title:</b>	<b>Patient Empowerment Programme Promoting Self-Management for Adult Patients with Type 2 Diabetes in Primary Care Setting in Indonesia</b>	
<b>Applicant:</b>	<b>Professor Justin Beilby, MD, MPH, MBBS, FRACGP, DRACOG, DA</b> Executive Dean, Faculty of Health Sciences, University of Adelaide	
<b>Department:</b>	Faculty of Health Sciences, University of Adelaide Adelaide, South Australia 5005, Australia	
<b>Telephone:</b>		
<b>Email:</b>		
<b>Others Involved:</b>	<ul style="list-style-type: none"> <li>• <b>Jackie Street PhD</b>, BSc (Hons), Grad.Dip.Primary Health Care Lecturer, Discipline of Public Health, School of Population Health &amp; Clinical Practice, Faculty of Health Sciences, University of Adelaide</li>   <li>• <b>Oryzati Hilman Agrimon, MD, MSc.CMFM</b> PhD Student, Discipline of General Practice, School of Population Health &amp; Clinical Practice, Faculty of Health Sciences, University of Adelaide</li> </ul>	
<b>Date first approved:</b>	17 September 2009	<b>Annual expiry date:</b> 30 September 2010

<b>STATUS OF PROJECT</b>	COMMENCED/NOT COMMENCED/ <b>CONTINUING</b> /COMPLETE?
Reason if project has not commenced?	
Expected completion date? <b>March 2012</b>	
Have there been any changes to the project in the last year which may affect its ethical approval? <b>NO</b>	
Are there likely to be any changes to the project in the next twelve months which may affect its ethical approval? <b>NO</b>	
If yes, give details of changes (if insufficient space, please attach a separate sheet):	

Have any participants withdrawn from the study? <b>YES</b>
If yes, give number of participants who have withdrawn and reasons if known?
A total number of 107 adult patients with type 2 diabetes were recruited and interviewed using a diabetes self-management questionnaire, and only 101 of them completed the baseline clinical measurement. <b>Six</b> participants withdrew from the study because they could not attend the clinical measurement session due to other commitments.

Have any adverse reactions or events occurred (including reactions to the administration of drugs) in the progress of the project in the last twelve months? **NO**

If yes, give details below (or in an attachment)

Please provide a brief report on the project's progress:

1. Cross-cultural adaptation of diabetes self-management instruments was completed in September 2010
2. Patient recruitment was completed in February 2011.  
A total number of 107 adult patients with type 2 diabetes were recruited and randomized into control group (n=53) and intervention group (n=54). They were interviewed using a diabetes self-management questionnaire.
3. Baseline clinical measurement was completed in March 2011.  
This included blood pressure, body weight, height, waist circumference, hip circumference, body fat percentage and blood tests (HbA1C, fasting blood sugar and 2-hour postprandial blood glucose), completed by 101 participants (control group= 50, intervention group=51).
4. Pre-intervention focus group interviews were completed in August 2011.  
Three separate focus group interviews were done i.e. control group, intervention group and a group of health care providers (general practitioners and nurses at community health centres)
5. Research interventions were completed in August 2011  
The intervention for control group was a diabetes seminar (didactic-teaching), while intervention group was given a four-week structured patient education on diabetes self-management
6. Three-month follow-up clinical measurement will be done in November 2011.  
This will include blood pressure, body weight, height, waist circumference, hip circumference, body fat percentage and blood tests (HbA1C, fasting blood sugar and 2-hour postprandial blood sugar)
7. Post-intervention focus group interviews will be done in November 2011.  
Two separate focus group interviews will be done i.e. control group and intervention group

Applicant's signature

Date: 17 October 2011

Please return to the Secretary, Human Research Ethics Committee,  
Research Ethics and Compliance Unit, Research Branch, Level 7, 115 Grenfell St, The University of Adelaide, SA 5005

The University of Adelaide Human Research Ethics Committee  
Renewal of Approval – Approved by the Convenor on behalf of the Committee

Date: 20/10/11

Project No:

Approval is current for the period until:

# **APPENDIX B – Participant Consent Form**

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**THE UNIVERSITY OF ADELAIDE  
HUMAN RESEARCH ETHICS COMMITTEE**

**CONSENT FORM**

FOR PEOPLE WHO ARE PARTICIPANTS IN A RESEARCH PROJECT:  
**“The Effectiveness of A Structured Diabetes Education Programme Promoting Diabetes Self-Management and Patient Empowerment in Primary Care Setting in Yogyakarta City, Indonesia”**

**Supervisors : Professor Justin Beilby and Dr. Jackie Street**  
**Investigator : Dr. Oryzati Hilman Agrimon**

1. I, ..... *(please print name)*  
consent to take part in the research project entitled:  
**“The Effectiveness of A Structured Diabetes Education Programme Promoting Diabetes Self-Management and Patient Empowerment in Primary Care Setting in Yogyakarta City Indonesia”**

2. I acknowledge that I have read the attached Information Sheet entitled:  
**“Better Care for Patients with Type 2 Diabetes”**

3. I have had the project, so far as it affects me, fully explained to my satisfaction by the research worker. My consent is given freely.

4. Although I understand that the purpose of this research project is to improve the quality of medical care, it has also been explained that my involvement may not be of any benefit to me.

5. I have been given the opportunity to have a member of my family or a friend present while the project was explained to me.

6. I have been informed that, while information gained during the study may be published, I will not be identified and my personal results will not be divulged.

7. I understand that I am free to withdraw from the project at any time and that this will not affect medical advice in the management of my health, now or in the future.

8. I am aware that I should retain a copy of this Consent Form, when completed, and the attached Information Sheet.

.....  
*(signature)* *(date)*

**WITNESS**

I have described to ..... *(name of subject)*  
the nature of the research to be carried out. In my opinion she/he understood the explanation.

Status in Project: .....

Name: .....

.....  
*(signature)* *(date)*

**THE UNIVERSITY OF ADELAIDE  
HUMAN RESEARCH ETHICS COMMITTEE  
(KOMITE ETIK PENELITIAN MANUSIA)**

**FORMULIR PERSETUJUAN**

BAGI ORANG YANG MENJADI PESERTA PROYEK PENELITIAN:  
**“Efektivitas Program Edukasi Diabetes Terstruktur yang Mendorong  
Pengelolaan Mandiri Diabetes dan Pemberdayaan Pasien  
di Pelayanan Kesehatan Primer di Kota Yogyakarta Indonesia”**

**Pembimbing : Professor Justin Beilby and Dr. Jackie Street**

**Peneliti : Dr. Oryzati Hilman Agrimon**

1.	Saya, ..... (tulis nama) setuju untuk berpartisipasi dalam proyek penelitian yang berjudul: <b>“Efektivitas Program Edukasi Diabetes Terstruktur yang Mendorong Pengelolaan Mandiri Diabetes dan Pemberdayaan Pasien in Pelayanan Kesehatan Primer di Kota Yogyakarta Indonesia”</b>
2.	Saya menyatakan bahwa saya telah membaca Lembar Informasi terlampir yang berjudul: <b>“Perawatan yang Lebih Baik untuk Pasien Diabetes Tipe 2”</b>
3.	Bagaimana pengaruh penelitian ini bagi saya sudah dijelaskan sepenuhnya oleh pekerja penelitian sampai saya puas. Saya memberikan persetujuan tanpa tekanan.
4.	Walaupun saya memahami bahwa tujuan proyek penelitian ini adalah untuk memperbaiki kualitas perawatan medis, telah dijelaskan bahwa keterlibatan saya mungkin tidak membawa manfaat bagi saya.
5.	Saya telah diberikan kesempatan ditemani anggota keluarga atau seorang teman saat penelitian ini dijelaskan kepada saya.
6.	Saya telah diberitahu bahwa, ketika informasi yang diperoleh selama penelitian mungkin dipublikasikan, nama saya tidak akan diidentifikasi dan hasil penelitian terkait pribadi saya tidak akan dibocorkan.
7.	Saya memahami bahwa saya bebas untuk mengundurkan diri dari penelitian ini kapan saja dan hal ini tidak akan berpengaruh pada nasihat medis dalam pengelolaan kesehatan saya, saat ini atau di waktu mendatang.
8.	Saya sadar bahwa saya harus menyimpan salinan dari Formulir Persetujuan ini jika sudah lengkap, dan lampiran Lembar Informasi.
	..... (tanda tangan) (tanggal)

<b>SAKSI</b>
Saya telah menjelaskan kepada ..... (nama responden) gambaran penelitian yang akan dilakukan. Menurut pendapat saya, dia memahami penjelasan tersebut. Status dalam penelitian: ..... Nama: .....
..... (tanda tangan) (tanggal)

# **APPENDIX C – Participant Complaint Sheet**

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**THE UNIVERSITY OF ADELAIDE  
HUMAN RESEARCH ETHICS COMMITTEE**

*Document for people who are participants in a research project*

**CONTACTS FOR INFORMATION ON PROJECT AND INDEPENDENT COMPLAINTS PROCEDURE**

The Human Research Ethics Committee is obliged to monitor approved research projects. In conjunction with other forms of monitoring it is necessary to provide an independent and confidential reporting mechanism to assure quality assurance of the institutional ethics committee system. This is done by providing research participants with an additional avenue for raising concerns regarding the conduct of any research in which they are involved.

The following study has been reviewed and approved by the University of Adelaide Human Research Ethics Committee:

**“Patient Empowerment Promoting Self-Management for Adult Patients  
with Type 2 Diabetes in Primary Care Setting in Indonesia”**

1. If you have questions or problems associated with the practical aspects of your participation in the project, or wish to raise a concern or complaint about the project, then you should consult the project co-ordinator:

Name: **Professor Justin Beilby**

Executive Dean, Faculty of Health Sciences, the University of Adelaide

Adelaide, South Australia 5005, Australia

Phone: +61 8 8303 5193

2. If you wish to discuss with an independent person matters related to:

- making a complaint, or
- raising concerns on the conduct of the project, or
- the University policy on research involving human participants, or
- your rights as a participant

contact **the Human Research Ethics Committee’s Secretary** on phone + 61 8 8303 6028



**THE UNIVERSITY OF ADELAIDE  
HUMAN RESEARCH ETHICS COMMITTEE  
(KOMITE ETIK PENELITIAN MANUSIA)**

***Dokumen untuk orang yang menjadi peserta proyek penelitian***

**KONTAK UNTUK INFORMASI TENTANG PENELITIAN DAN PROSEDUR PENGADUAN  
INDEPENDEN**

*The Human Research Ethics Committee* berkewajiban untuk mengawasi proyek penelitian yang disetujui. Bersamaan dengan bentuk pengawasan lainnya, perlu untuk memberikan suatu mekanisme pelaporan rahasia dan independen untuk memastikan jaminan kualitas dari sistem komite etik kelembagaan. Hal ini dilakukan dengan memberikan kepada para peserta penelitian suatu jalan tambahan untuk mengajukan kekhawatiran terkait pelaksanaan penelitian yang melibatkan mereka.

Penelitian berikut ini telah dikaji dan disetujui oleh *the University of Adelaide Human Research Ethics Committee*:

**“Pemberdayaan Pasien yang Mendorong Pengelolaan Mandiri bagi Pasien Dewasa  
dengan Diabetes Tipe 2 di Pelayanan Kesehatan Primer di Indonesia”**

1. Jika Anda mempunyai pertanyaan atau masalah yang berhubungan dengan aspek praktis keterlibatan Anda dalam penelitian ini, atau ingin mengajukan suatu kekhawatiran atau pengaduan tentang penelitian ini, maka Anda sebaiknya berkonsultasi kepada koordinator penelitian ini.

Nama : **Professor Justin Beilby**

Dekan Eksekutif, Fakultas Ilmu Kesehatan, the University of Adelaide  
Adelaide, South Australia 5005, Australia

Telepon: +61 8 8303 5193

2. Jika Anda ingin membahas dengan seseorang independen terkait dengan:

- membuat pengaduan, atau
- mengajukan kekhawatiran terkait pelaksanaan penelitian, atau
- kebijakan universitas tentang penelitian yang melibatkan peserta manusia, atau
- hak-hak Anda sebagai peserta penelitian

hubungi **Sekretariat Komite Etik Penelitian Manusia** (*the Human Research Ethics Committee's*

**Secretary**) di telepon: + 61 8 8303 6028

# **APPENDIX D – Participant Information Sheet**

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Approval No: H-075-2009

## PARTICIPANT INFORMATION STATEMENT

### “Better Care for Patients with Type 2 Diabetes” (Diabetic Patients in the Intervention Group)

The University of Adelaide in cooperation with Universitas Muhammadiyah Yogyakarta are conducting a research project looking at how a structured diabetes education programme promoting diabetes self-management and patient empowerment for adult patients with type 2 diabetes can improve their health outcomes in Yogyakarta City, Indonesia. We believe that your views and your participation in the project are important for helping us to improve diabetes care in primary care setting in Indonesia and therefore we would like to ask you to participate in the research project.

Thank you for your interest to participate in the research project. You are invited to attend a **free diabetes structured group education programme**. You are strongly encouraged to attend the program **accompanied by one family member**. This will enable your family member to provide a beneficial family support for you for living with this chronic condition.

We will conduct **patient interviews** regarding your diabetes-related issues and ask you to come for **free health check-ups for diabetes** at the beginning of the research and at 3 months after the diabetes education programme completed. The physical measurements will be conducted by community nurses. The blood tests will be carried out by an accredited clinical pathology laboratory in Yogyakarta City. All required blood samples from diabetic patients (10 ml for each blood test) will be taken by laboratory personnel trained in phlebotomy.

At the beginning of the study, some of you will also be invited to a group meeting to discuss about your experiences and expectations towards the current diabetes education you receive at the community health centres. We estimate that it will take the group about two hours to discuss all issues. At three months after the diabetes education programme completed, a similar group meeting will be conducted with the same group members previously selected to discuss about the diabetes education programme administered. The session will be taped and typed up to ensure that we do not miss any of the discussion. Only the researchers involved in the study will be allowed to listen to the tapes or look at the transcripts.

The structured diabetes education programme involves four weekly sessions, each lasting 2.5 - 3 hours, held in community health centre venues. The programme will generally be carried out through interactive and collaborative approach focusing on different topics as follows:

- Week 1 : Understanding type 2 diabetes and goal setting introduction
- Week 2 : Type 2 diabetes prevention and lifestyle modification
- Week 3 : Meal planning and physical activity
- Week 4 : Diabetes self-management and evaluation

The timetable and venue of the research activities are to be advised. Generally, there will be 7-9 research activities; each lasts for 2-3 hours with the following agenda:

- Activity 1: Patient interview 1 on diabetes-related issues
- Activity 2: Focus group interview 1 on the current diabetes education received (only for some participants)

- Activity 3: Free health check-up 1 at the first month
- Activity 4: Diabetes structured group education session 1
- Activity 5: Diabetes structured group education session 2
- Activity 6: Diabetes structured group education session 3
- Activity 7: Diabetes structured group education session 4
- Activity 8: Free health check-up 2 and patient interview 2 on diabetes-related issues at 3 months after activity 7 completed
- Activity 9: Focus group interview 2 on the diabetes education programme (only for some participants, the same group members as previously)

For your participation in the research project, we will provide:

- Meals and/ or refreshments during the course of research activities
- Travel compensation for each attendance at an arranged research activity

The research activities will be photographed and videotaped. Any information obtained through this study will remain confidential except as required by law. We plan to publish the findings so that other people working in diabetes care can better understand about a structured diabetes education programme which incorporates diabetes self-management and patient empowerment concepts, and improve the diabetes care by adopting such programme. In the publication, information will be provided in such a way that you cannot be identified. A summary of the research findings will be reported and presented in a public seminar to which all participants will be invited.

Complaints may be sent to The University of Adelaide, Human Research Ethics Committee's Secretary on Tel: +61 8 8303 6028. Any complaint you make will be treated with confidentiality and investigated, and you will be informed of the outcome. Your decision whether or not to participate will not affect in any way your future relations with The University of Adelaide or Universitas Muhammadiyah Yogyakarta or any individual or institution involved in your care. If you decide to participate, you are free to withdraw at any time without any consequences.

If you have any questions, please contact the program manager, Professor Justin Beilby (Tel: +61 8 8303 5913; Email: [justin.beilby@adelaide.edu.au](mailto:justin.beilby@adelaide.edu.au)), or Dr. Jackie Street (Tel: +61 8 8303 6498; Email: [jackie.street@adelaide.edu.au](mailto:jackie.street@adelaide.edu.au)), or Dr. Oryzati Hilman Agrimon (Tel: +61 43 0393716 and +62 274 387656; Email: [oryzati.agrimon@adelaide.edu.au](mailto:oryzati.agrimon@adelaide.edu.au)) who will be happy to address them.



Approval No: H-075-2009

## PERNYATAAN INFORMASI PESERTA “Perawatan yang Lebih Baik untuk Pasien dengan Diabetes Tipe 2” (Pasien Diabetes dalam Kelompok Intervensi)

The University of Adelaide bekerja sama dengan Universitas Muhammadiyah Yogyakarta sedang mengadakan suatu proyek penelitian untuk melihat bagaimana suatu program edukasi diabetes terstruktur untuk mempromosikan pengelolaan diabetes mandiri dan pemberdayaan pasien bagi pasien dewasa dengan diabetes tipe 2 dapat memperbaiki tingkat kesehatan mereka di Kota Yogyakarta, Indonesia. Kami percaya bahwa pandangan dan partisipasi Anda dalam penelitian ini sangat penting dalam membantu kami untuk memperbaiki perawatan diabetes di pelayanan kesehatan primer di Indonesia dan oleh karenanya kami meminta Anda untuk berpartisipasi dalam penelitian ini.

Terima kasih atas minat Anda untuk berpartisipasi dalam penelitian ini. Anda diundang untuk menghadiri **program edukasi diabetes terstruktur secara gratis**. Anda sangat dianjurkan untuk menghadiri acara tersebut dengan ditemani oleh satu orang anggota keluarga. Hal ini akan memungkinkan bagi anggota keluarga Anda untuk memberikan dukungan keluarga yang menguntungkan bagi Anda untuk hidup dengan penyakit kronis ini.

Kami akan melakukan **wawancara pasien** mengenai beberapa hal terkait dengan penyakit diabetes Anda dan meminta Anda untuk datang pada acara **pemeriksaan kesehatan untuk diabetes secara gratis** pada awal penelitian dan 3 bulan setelah program edukasi diabetes selesai. Pengukuran fisik akan dilakukan oleh perawat komunitas. Tes darah akan dilakukan oleh suatu laboratorium patologi klini terakreditasi di Kota Yogyakarta. Semua sampel darah yang dibutuhkan dari pasien diabetes (10 ml untuk setiap tes darah) akan diambil oleh teknisi laboratorium yang terlatih dalam proses mengeluarkan darah.

Pada awal penelitian, beberapa dari Anda juga akan diundang ke pertemuan diskusi kelompok untuk membahas tentang pengalaman dan harapan Anda terhadap edukasi pasien yang saat ini Anda terima di puskesmas. Kami memperkirakan bahwa kelompok ini perlu waktu sekitar 2 jam untuk membahas semua masalah yang ada. Pada 3 bulan setelah program edukasi diabetes selesai, pertemuan diskusi kelompok serupa akan dilakukan dengan anggota kelompok yang sama dengan sebelumnya untuk membahas tentang program edukasi diabetes yang diberikan. Diskusi tersebut akan direkam dan diketik untuk memastikan tidak ada yang terlewat dalam diskusi tersebut. Hanya para peneliti yang terlibat dalam penelitian yang diijinkan untuk mendengar rekaman atau melihat transkrip rekaman tersebut.

Program edukasi diabetes terstruktur ini terdiri atas empat sesi mingguan, masing-masing berlangsung sekitar 2,5-3 jam, diadakan di tempat pusat kesehatan masyarakat. Program ini umumnya akan dilakukan melalui pendekatan yang interaktif dan kolaboratif dengan fokus pada topik yang berbeda-beda:

- Minggu 1: Memahami diabetes tipe 2 dan pengenalan penetapan tujuan
- Minggu 2: Pencegahan diabetes tipe 2 dan modifikasi gaya hidup
- Minggu 3: Pengaturan makan dan aktivitas fisik
- Minggu 4: Pengelolaan mandiri diabetes dan evaluasi

Jadwal dan tempat kegiatan penelitian ini akan diberitahukan lebih lanjut. Secara umum, akan ada 7-9 kegiatan penelitian, masing-masing berlangsung selama 2-3 jam dengan agenda berikut:

- Kegiatan 1: Wawancara pasien 1 tentang hal-hal terkait diabetes
- Kegiatan 2: Diskusi kelompok terarah 1 tentang edukasi diabetes yang diterima saat ini

(hanya untuk beberapa peserta)

- Kegiatan 3: Pemeriksaan kesehatan gratis 1 pada bulan pertama
- Kegiatan 4: Sesi 1 edukasi diabetes berkelompok yang terstruktur
- Kegiatan 5: Sesi 2 edukasi diabetes berkelompok yang terstruktur
- Kegiatan 6: Sesi 3 edukasi diabetes berkelompok yang terstruktur
- Kegiatan 7: Sesi 4 edukasi diabetes berkelompok yang terstruktur
- Kegiatan 8: Pemeriksaan kesehatan gratis 2 dan wawancara pasien 2 tentang hal-hal terkait diabetes pada 3 bulan setelah kegiatan 7 selesai
- Kegiatan 9: Diskusi kelompok terarah 2 tentang program edukasi diabetes yang diberikan (hanya untuk beberapa peserta, dengan anggota kelompok yang sama dengan sebelumnya)

Untuk partisipasi Anda dalam penelitian ini, kami akan memberikan:

- Makanan dan/ atau makanan kecil serta minuman selama kegiatan penelitian
- Kompensasi uang perjalanan untuk setiap kehadiran Anda dalam kegiatan penelitian

Semua kegiatan penelitian akan diambil fotonya dan direkam dalam bentuk video. Setiap informasi yang diperoleh melalui penelitian ini akan tetap rahasia kecuali sebagaimana diharuskan oleh hukum. Kami berencana untuk mempublikasikan temuan penelitian sehingga orang lain yang bekerja dalam perawatan diabetes dapat lebih memahami tentang program edukasi diabetes terstruktur yang memasukkan konsep pengelolaan mandiri diabetes dan pemberdayaan pasien, dan meningkatkan perawatan diabetes dengan mengadopsi program tersebut. Dalam publikasi, informasi akan diberikan sedemikian rupa sehingga Anda tidak dapat diidentifikasi. Ringkasan dari temuan penelitian akan dilaporkan dan disajikan dalam seminar publik yang semua peserta akan diundang.

Pengaduan dapat dikirimkan ke Sekretariat Komite Etik Penelitian Manusia, *The University of Adelaide Human Research Ethics Committee's Secretary*, di telepon +61 8 8303 6028. Setiap pengaduan yang Anda buat akan diperlakukan dengan kerahasiaan dan diselidiki, dan Anda akan diberitahu hasilnya. Keputusan Anda apakah berpartisipasi atau tidak, tidak akan mempengaruhi apapun terhadap hubungan Anda dengan The University of Adelaide atau Universitas Muhammadiyah Yogyakarta atau individu atau lembaga yang terlibat dalam perawatan Anda di masa mendatang. Jika Anda memutuskan untuk berpartisipasi, Anda bebas untuk mengundurkan diri setiap saat tanpa konsekuensi.

Jika Anda memiliki pertanyaan, silakan hubungi manajer program, Profesor Justin Beilby (Tel: +61 8 8303 5913; Email: [justin.beilby@adelaide.edu.au](mailto:justin.beilby@adelaide.edu.au)), atau Dr. Jackie Street (Tel: +61 8 8303 6498; Email: [jackie.street@adelaide.edu.au](mailto:jackie.street@adelaide.edu.au)), atau Dr. Oryzati Hilman Agrimon (Tel: +61 43 0393716 dan +62 274 38765; Email: [oryzati.agrimon@adelaide.edu.au](mailto:oryzati.agrimon@adelaide.edu.au)) yang dengan senang hati akan membahas hal tersebut.



Approval No: H-075-2009

## PARTICIPANT INFORMATION STATEMENT

### “Better Care for Patients with Type 2 Diabetes” (Diabetic Patients in the Control Group)

The University of Adelaide in cooperation with Universitas Muhammadiyah Yogyakarta are conducting a research project looking at how a diabetes education programme for adult patients with type 2 diabetes can improve their health outcomes in Yogyakarta City, Indonesia. We believe that your views and your participation in the project are important for helping us to improve diabetes care in primary care setting in Indonesia and therefore we would like to ask you to participate in the research project.

Thank you for your interest to participate in the research project. You are invited to attend a **free diabetes seminar**. We will conduct **patient interviews** regarding your diabetes-related issues and ask you to come for **free health check-ups for diabetes** at the beginning of the research and at 3 months after the diabetes seminar completed. The physical measurements will be conducted by community nurses. The blood tests will be carried out by an accredited clinical pathology laboratory in Yogyakarta City. All required blood samples from diabetic patients (10 ml for each blood test) will be taken by laboratory personnel trained in phlebotomy.

At the beginning of the study, some of you will also be invited to a group meeting to discuss about your experiences and expectations towards the current diabetes education you receive at the community health centres. We estimate that it will take the group about two hours to discuss all issues. At three months after the diabetes seminar completed, a similar group meeting will be conducted with the same group members previously selected to discuss about the diabetes seminar administered. The session will be taped and typed up to ensure that we do not miss any of the discussion. Only the researchers involved in the study will be allowed to listen to the tapes or look at the transcripts.

The timetable and venue of the research activities are to be advised. Generally, there will be 4-6 research activities; each lasts for 2-3 hours with the following agenda:

- Activity 1: Patient interview 1 on diabetes-related issues
- Activity 2: Focus group interview 1 on the current diabetes education received (only for some people)
- Activity 3: Free health check up 1 at the first month
- Activity 4: Diabetes seminar
- Activity 5: Free health check up 2 and patient interview 2 on diabetes-related issues at 3 months after activity 4 completed
- Activity 6: Focus group interview 2 on the diabetes seminar administered (only for some people, the same group members as previously)

For your participation in the research project, we will provide:

- Refreshments during the course of research activities
- Travel compensation for each attendance at an arranged research activity

The research activities will be photographed and videotaped. Any information obtained through this study will remain confidential except as required by law. We plan to publish the findings so that other people working in diabetes care can better understand about a diabetes education programme, and improve the diabetes care by adopting such programme. In the publication, information will be provided in such a way that you cannot be identified. A summary of the research findings will be reported and presented in a public seminar to which all participants will be invited.

Complaints may be sent to The University of Adelaide, Human Research Ethics Committee's Secretary on Tel: +61 8 8303 6028. Any complaint you make will be treated with confidentiality and investigated, and you will be informed of the outcome. Your decision whether or not to participate will not affect in any way your future relations with The University of Adelaide or Universitas Muhammadiyah Yogyakarta or any individual or institution involved in your care. If you decide to participate, you are free to withdraw at any time without any consequences.

If you have any questions, please contact the program manager, Professor Justin Beilby (Tel: +61 8 8303 5913; Email: [justin.beilby@adelaide.edu.au](mailto:justin.beilby@adelaide.edu.au)), or Dr. Jackie Street (Tel: +61 8 8303 6498; Email: [jackie.street@adelaide.edu.au](mailto:jackie.street@adelaide.edu.au)), or Dr. Oryzati Hilman Agrimon (Tel: +61 43 0393716 and +62 274 387656; Email: [oryzati.agrimon@adelaide.edu.au](mailto:oryzati.agrimon@adelaide.edu.au)) who will be happy to address them.





Approval No: H-075-2009

## PERNYATAAN INFORMASI PESERTA “Perawatan yang Lebih Baik untuk Pasien dengan Diabetes Tipe 2” (Pasien Diabetes dalam Kelompok Kontrol)

The University of Adelaide bekerja sama dengan Universitas Muhammadiyah Yogyakarta sedang mengadakan suatu proyek penelitian untuk melihat bagaimana suatu program edukasi diabetes bagi pasien dewasa dengan diabetes tipe 2 dapat memperbaiki tingkat kesehatan mereka di Kota Yogyakarta, Indonesia. Kami percaya bahwa pandangan dan partisipasi Anda dalam penelitian ini sangat penting dalam membantu kami untuk memperbaiki perawatan diabetes di pelayanan kesehatan primer di Indonesia dan oleh karenanya kami meminta Anda untuk berpartisipasi dalam penelitian ini.

Terima kasih atas minat Anda untuk berpartisipasi dalam penelitian ini. Anda diundang untuk menghadiri **diabetes seminar secara gratis**. Kami akan melakukan **wawancara pasien** mengenai beberapa hal terkait dengan penyakit diabetes Anda dan meminta Anda untuk datang pada acara **pemeriksaan kesehatan untuk diabetes secara gratis** pada awal penelitian dan 3 bulan setelah program edukasi diabetes selesai. Pengukuran fisik akan dilakukan oleh perawat komunitas. Tes darah akan dilakukan oleh suatu laboratorium patologi klini terakreditasi di Kota Yogyakarta. Semua sampel darah yang dibutuhkan dari pasien diabetes (10 ml untuk setiap tes darah) akan diambil oleh teknisi laboratorium yang terlatih dalam proses mengeluarkan darah.

Pada awal penelitian, beberapa dari Anda juga akan diundang ke pertemuan diskusi kelompok untuk membahas tentang pengalaman dan harapan Anda terhadap edukasi pasien yang saat ini Anda terima di puskesmas. Kami memperkirakan bahwa kelompok ini perlu waktu sekitar 2 jam untuk membahas semua masalah yang ada. Pada 3 bulan setelah program edukasi diabetes selesai, pertemuan diskusi kelompok serupa akan dilakukan dengan anggota kelompok yang sama dengan sebelumnya untuk membahas tentang program edukasi diabetes yang diberikan. Diskusi tersebut akan direkam dan diketik untuk memastikan tidak ada yang terlewat dalam diskusi tersebut. Hanya para peneliti yang terlibat dalam penelitian yang diijinkan untuk mendengar rekaman atau melihat transkrip rekaman tersebut.

Jadwal dan tempat kegiatan penelitian ini akan diberitahukan lebih lanjut. Secara umum, akan ada 4-6 kegiatan penelitian, masing-masing berlangsung selama 2-3 jam dengan agenda berikut:

- Kegiatan 1: Wawancara pasien 1 tentang hal-hal terkait diabetes
- Kegiatan 2: Diskusi kelompok terarah 1 tentang edukasi diabetes yang diterima saat ini (hanya untuk beberapa peserta)
- Kegiatan 3: Pemeriksaan kesehatan gratis 1 pada bulan pertama
- Kegiatan 4: Seminar diabetes
- Kegiatan 5: Pemeriksaan kesehatan gratis 2 dan wawancara pasien 2 tentang hal-hal terkait diabetes pada 3 bulan setelah kegiatan 4 selesai
- Kegiatan 6: Diskusi kelompok terarah 2 tentang program edukasi diabetes yang diberikan (hanya untuk beberapa peserta, dengan anggota kelompok yang sama dengan sebelumnya)

Untuk partisipasi Anda dalam penelitian ini, kami akan memberikan:

- Makanan dan/ atau makanan kecil serta minuman selama kegiatan penelitian
- Kompensasi uang perjalanan untuk setiap kehadiran Anda dalam kegiatan penelitian

Semua kegiatan penelitian akan diambil fotonya dan direkam dalam bentuk video. Setiap informasi yang diperoleh melalui penelitian ini akan tetap rahasia kecuali sebagaimana diharuskan oleh hukum. Kami berencana untuk mempublikasikan temuan penelitian sehingga orang lain yang bekerja dalam perawatan diabetes dapat lebih memahami tentang program edukasi diabetes dan meningkatkan perawatan diabetes dengan mengadopsi program tersebut. Dalam publikasi, informasi akan diberikan sedemikian rupa sehingga Anda tidak dapat diidentifikasi. Ringkasan dari temuan penelitian akan dilaporkan dan disajikan dalam seminar publik yang semua peserta akan diundang.

Pengaduan dapat dikirimkan ke Sekretariat Komite Etik Penelitian Manusia, *The University of Adelaide Human Research Ethics Committee's Secretary*, di telepon +61 8 8303 6028. Setiap pengaduan yang Anda buat akan diperlakukan dengan kerahasiaan dan diselidiki, dan Anda akan diberitahu hasilnya. Keputusan Anda apakah berpartisipasi atau tidak, tidak akan mempengaruhi apapun terhadap hubungan Anda dengan The University of Adelaide atau Universitas Muhammadiyah Yogyakarta atau individu atau lembaga yang terlibat dalam perawatan Anda di masa mendatang. Jika Anda memutuskan untuk berpartisipasi, Anda bebas untuk mengundurkan diri setiap saat tanpa konsekuensi.

Jika Anda memiliki pertanyaan, silakan hubungi manajer program, Profesor Justin Beilby (Tel: +61 8 8303 5913; Email: [justin.beilby@adelaide.edu.au](mailto:justin.beilby@adelaide.edu.au)), atau Dr. Jackie Street (Tel: +61 8 8303 6498; Email: [jackie.street@adelaide.edu.au](mailto:jackie.street@adelaide.edu.au)), atau Dr. Oryzati Hilman Agrimon (Tel: +61 43 0393716 dan +62 274 387656; Email: [oryzati.agrimon@adelaide.edu.au](mailto:oryzati.agrimon@adelaide.edu.au)) yang dengan senang hati akan membahas hal tersebut.



Approval No: H-075-2009

## PARTICIPANT INFORMATION STATEMENT

### “Better Care for Patients with Type 2 Diabetes” (Health Care Providers)

The University of Adelaide in cooperation with Universitas Muhammadiyah Yogyakarta are conducting a research project looking at how a structured diabetes education programme promoting diabetes self-management and patient empowerment for adult patients with type 2 diabetes can improve their health outcomes in Yogyakarta City, Indonesia. We believe that your views and your participation in the project are important for helping us to improve diabetes care in primary care setting in Indonesia and therefore we would like to ask you to participate in the research project.

If you agree to participate, we will invite you to attend a **focus group interview** on relevant issues to the research topic, particularly about the diabetes education you currently provide to patients with type 2 diabetes. We estimate that it will take the group about two hours to discuss all the issues. The session will be taped and typed up to ensure that we do not miss any of the discussion. Only the researchers involved in the study will be allowed to listen to the tapes or look at the transcripts.

The timetable and venue of the research activities are to be advised. For your participation in the research project, we will provide:

- Refreshments during the course of research activities
- Travel compensation for each attendance at an arranged research activity

The research activity will be photographed and videotaped. Any information obtained through this study will remain confidential except as required by law. We plan to publish the findings so that other people working in diabetes care can better understand about a structured diabetes education programme which incorporates diabetes self-management and patient empowerment concepts, and improve the diabetes care by adopting such programme. In the publication, information will be provided in such a way that you cannot be identified. A summary of the research findings will be reported and presented in a public seminar to which all participants will be invited.

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Approval No: H-075-2009

## PERNYATAAN INFORMASI PESERTA “Perawatan yang Lebih Baik untuk Pasien dengan Diabetes Tipe 2” (Pemberi Pelayanan Kesehatan)

The University of Adelaide bekerja sama dengan Universitas Muhammadiyah Yogyakarta sedang mengadakan suatu proyek penelitian untuk melihat bagaimana suatu program edukasi diabetes yang terstruktur untuk mempromosikan pengelolaan diabetes mandiri dan pemberdayaan pasien bagi pasien dewasa dengan diabetes tipe 2 dapat memperbaiki tingkat kesehatan mereka di Kota Yogyakarta, Indonesia. Kami percaya bahwa pandangan dan partisipasi Anda dalam penelitian ini sangat penting dalam membantu kami untuk memperbaiki perawatan diabetes di pelayanan kesehatan primer di Indonesia dan oleh karenanya kami meminta Anda untuk berpartisipasi dalam penelitian ini.

Jika Anda setuju untuk berpartisipasi, kami akan mengundang Anda mengikuti diskusi kelompok terarah tentang hal-hal terkait penelitian ini, khususnya tentang edukasi diabetes yang Anda berikan kepada pasien dengan diabetes tipe 2. Kami memperkirakan bahwa kelompok ini perlu waktu sekitar 2 jam untuk membahas semua masalah yang ada. Diskusi tersebut akan direkam dan diketik untuk memastikan tidak ada yang terlewat dalam diskusi tersebut. Hanya para peneliti yang terlibat dalam penelitian yang diijinkan untuk mendengar rekaman atau melihat transkrip rekaman tersebut

Jadwal dan tempat kegiatan penelitian ini akan diberitahukan lebih lanjut. Untuk partisipasi Anda dalam penelitian ini, kami akan memberikan:

- Makanan dan/ atau makanan kecil serta minuman selama kegiatan penelitian
- Kompensasi uang perjalanan untuk setiap kehadiran Anda dalam kegiatan penelitian

Kegiatan penelitian akan diambil fotonya dan direkam dalam bentuk video. Setiap informasi yang diperoleh melalui penelitian ini akan tetap rahasia kecuali sebagaimana diharuskan oleh hukum. Kami berencana untuk mempublikasikan temuan penelitian sehingga orang lain yang bekerja dalam perawatan diabetes dapat lebih memahami tentang program edukasi diabetes yang terstruktur yang memasukkan konsep pengelolaan mandiri diabetes dan pemberdayaan pasien, dan meningkatkan perawatan diabetes dengan mengadopsi program tersebut. Dalam publikasi, informasi akan diberikan sedemikian rupa sehingga Anda tidak dapat diidentifikasi. Ringkasan dari temuan penelitian akan dilaporkan dan disajikan dalam seminar publik yang semua peserta akan diundang.

Pengaduan dapat dikirimkan ke Sekretariat Komite Etik Penelitian Manusia, *The University of Adelaide Human Research Ethics Committee's Secretary*, di telepon +61 8 8303 6028. Setiap pengaduan yang Anda buat akan diperlakukan dengan kerahasiaan dan diselidiki, dan Anda akan diberitahu hasilnya. Keputusan Anda apakah berpartisipasi atau tidak, tidak akan mempengaruhi apapun terhadap hubungan Anda dengan The University of Adelaide atau Universitas Muhammadiyah Yogyakarta atau individu atau lembaga yang terlibat dalam perawatan Anda di masa mendatang. Jika Anda memutuskan untuk berpartisipasi, Anda bebas untuk mengundurkan diri setiap saat tanpa konsekuensi.

Jika Anda memiliki pertanyaan, silakan hubungi manajer program, Profesor Justin Beilby (Tel: +61 8 8303 5913; Email: [justin.beilby@adelaide.edu.au](mailto:justin.beilby@adelaide.edu.au)), atau Dr. Jackie Street (Tel: +61 8 8303 6498; Email: [jackie.street@adelaide.edu.au](mailto:jackie.street@adelaide.edu.au)), atau Dr. Oryzati Hilman Agrimon (Tel: +61 43 0393716 dan +62 274 387656; Email: [oryzati.agrimon@adelaide.edu.au](mailto:oryzati.agrimon@adelaide.edu.au)) yang dengan senang hati akan membahas hal tersebut.

# **APPENDIX E – Research Questionnaire in English**

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## RESEARCH QUESTIONNAIRE: EMPOWERMENT-BASED DIABETES SELF-MANAGEMENT

ID Number :
Name :
Address :
Phone/ Mobile ph:
Phase : VS/ I / II
Date completed : dd / mm / yy

### A. SOCIODEMOGRAPHIC CHARACTERISTICS

1.	Age (years) Date of Birth	.....years old dd / mm / yy
2.	Gender <i>[Check ✓ only one]</i>	<input type="checkbox"/> Male <input type="checkbox"/> Female
3.	Marital status <i>[Check ✓ only one]</i>	<input type="checkbox"/> Unmarried <input type="checkbox"/> Married <input type="checkbox"/> Separated <input type="checkbox"/> Divorced <input type="checkbox"/> Widowed
4.	Highest educational qualification (formal education completed) <i>[Check ✓ only one]</i>	<input type="checkbox"/> None <input type="checkbox"/> Elementary school <input type="checkbox"/> Junior and senior high school <input type="checkbox"/> College and university
5.	Employment <i>[Check ✓ only one]</i>	<input type="checkbox"/> Home duties (housewives) <input type="checkbox"/> Self-employed and informal sector job <input type="checkbox"/> Government employee, military force and police <input type="checkbox"/> Private company employee <input type="checkbox"/> Professional occupation <input type="checkbox"/> Retired
6.	Estimated monthly family income (joint income of husband and wife) <i>[Check ✓ only one]</i> Note: 1 AUD = IDR 9,000-10,000	<input type="checkbox"/> < IDR 1,000,000 (< AUD 100) <input type="checkbox"/> IDR 1,000,000 – 2,999,999 (AUD 100 – 299.99) <input type="checkbox"/> IDR 3,000,000 – 10,000,000 (AUD 300 – 1,000) <input type="checkbox"/> > IDR 10,000,000 (> AUD 1,000)

**NOTE:**

Questions about type 2 diabetes from participants will be addressed after the interview is completed

## B. MEDICAL HISTORY

1.	Known duration of T2D (years)	.....years
2.	Patient education in T2D (individual or group session)	<input type="checkbox"/> No <input type="checkbox"/> Yes
3.	Family history of diabetes	<input type="checkbox"/> No <input type="checkbox"/> Yes      Who? .....
4.	Self-monitoring blood glucose (using glucometer)	<input type="checkbox"/> No <input type="checkbox"/> Yes      Frequency per week: .....
5.	Hypertension (raised blood pressure)	<input type="checkbox"/> No <input type="checkbox"/> Yes
6.	Smoking	<input type="checkbox"/> No <input type="checkbox"/> Yes
7.	Diabetic treatment [check ✓ as many as apply]	<input type="checkbox"/> Diet <input type="checkbox"/> Exercise <input type="checkbox"/> Oral antidiabetics: Name.....; dosage..... Name.....; dosage..... Name.....; dosage..... <input type="checkbox"/> Insulin: Name.....; dosage..... Name.....; dosage..... <input type="checkbox"/> Herbal/ traditional remedies: ..... .....
8.	Diabetes complications [check ✓ only one for each complication type]	<ul style="list-style-type: none"> <li>• Neuropathy (nerve damage):      <input type="checkbox"/> No      <input type="checkbox"/> Yes</li> <li>• Vision disorders: (retinopathy/ glaucoma/ cataract/ corneal disease)      <input type="checkbox"/> No      <input type="checkbox"/> Yes</li> <li>• Nephropathy (kidney disease):      <input type="checkbox"/> No      <input type="checkbox"/> Yes</li> <li>• Erectile dysfunction (impotence):      <input type="checkbox"/> No      <input type="checkbox"/> Yes</li> <li>• Heart disease:      <input type="checkbox"/> No      <input type="checkbox"/> Yes</li> <li>• Stroke:      <input type="checkbox"/> No      <input type="checkbox"/> Yes</li> <li>• Peripheral vascular disease: (foot ulcers/gangrene)      <input type="checkbox"/> No      <input type="checkbox"/> Yes</li> </ul>
9.	Is there anyone in your family or social circle who provides you support in managing your diabetes?	<input type="checkbox"/> No <input type="checkbox"/> Yes      Who? .....
10.	Are you covered by a health insurance?	<input type="checkbox"/> No <input type="checkbox"/> Yes      What is it? ..... <input type="checkbox"/> Government health security programme for poor people (Jamkesmas) <input type="checkbox"/> Government health insurance for civil servants (Askes) <input type="checkbox"/> Work forces social security (Jamsostek) <input type="checkbox"/> Private health insurance <input type="checkbox"/> Company/ office health coverage

### C. DIABETES KNOWLEDGE (THE DIABETES KNOWLEDGE QUESTIONNAIRE - 24)

NO.	QUESTIONS	YES	NO	DON'T KNOW
1.	Eating too much sugar and other sweet foods is a cause of diabetes.		√	
2.	The usual cause of diabetes is lack of effective insulin in the body.	√		
3.	Diabetes is caused by failure of the kidneys to keep sugar out of the urine.		√	
4.	Kidneys produce insulin.		√	
5.	In untreated diabetes, the amount of sugar in the blood usually increases.	√		
6.	If I am diabetic, my children have a higher chance of being diabetic.	√		
7.	Diabetes can be cured.		√	
8.	A fasting blood sugar level of 210 is too high.	√		
9.	The best way to check my diabetes is by testing my urine.		√	
10.	Regular exercise will increase the need for insulin or other diabetic medication.		√	
11.	There are two main types of diabetes: Type 1 (insulin-dependent) and Type 2 (non-insulin dependent).	√		
12.	An insulin reaction is caused by too much food.		√	
13.	Medication is more important than diet and exercise to control my diabetes.		√	
14.	Diabetes often causes poor circulation.	√		
15.	Cuts and abrasions on diabetes heal more slowly.	√		
16.	Diabetics should take extra care when cutting their toenails.	√		
17.	A person with diabetes should cleanse a cut with iodine and alcohol.		√	
18.	The way I prepare my food is as important as the foods I eat.	√		
19.	Diabetes can damage my kidneys.	√		
20.	Diabetes can cause loss of feeling in my hands, fingers and feet.	√		
21.	Shaking and sweating are signs of high blood sugar.		√	
22.	Frequent urination and thirst are signs of low blood sugar.		√	
23.	Tight elastic hose or socks are not bad for diabetics.		√	
24.	A diabetic diet consists mostly of special foods		√	



**D. DIABETES HEALTH BELIEFS  
(THE DIABETES HEALTH BELIEF MEASURE)**

NO.	STATEMENTS	ANSWERS [Check <input checked="" type="checkbox"/> only one]				
		<input type="checkbox"/> 1 Strongly Disagree	<input type="checkbox"/> 2 Disagree	<input type="checkbox"/> 3 Not Sure	<input type="checkbox"/> 4 Agree	<input type="checkbox"/> 5 Strongly Agree
1.	My diabetes is well controlled					
2.	I would have to change too many habits to follow my diet (diabetic foods)					
3.	It has been difficult following the diet (diabetic foods) the doctor ordered for me					
4.	I am confused by all the medication the doctor has given me					
5.	I would have to change too many habits to take my medication					
6.	Taking my medication interferes with my normal daily activities					
7.	I have others around me who remind me to eat the right foods					
8.	I can count on my family when I need help following my diet (diabetic foods)					
9.	My husband/wife helps me follow my diet (diabetic foods)					
10.	If I changed 'jobs' I would be easier to follow my diet (diabetic foods)					
11.	My work makes me so tired that it's hard to follow my diet (diabetic foods)					
12.	I could control my weight if the pressures of my job weren't so great					
13.	If I changed 'jobs', it would be easier to take my medication					
14.	I worry so much about my job that I can't take my medication					
15.	I believe that my diet (diabetic foods) will help prevent diseases (complications) related to diabetes					
16.	Following a prescribed diet (diabetic foods) is something a person must do no matter how hard it is					
17.	I believe that my diet (diabetic foods) will control my diabetes					
18.	I must follow my diet (diabetic foods) even if I don't think I am getting better					
19.	In general, I believe that my diet (diabetic foods) for diabetes will help me to feel better					
20.	Controlling weight is something one must do no matter how hard it is					
21.	I believe that my medication will help prevent diseases (complications) related to diabetes					
22.	Taking medication is something one must do no matter how hard it is					
23.	I believe that my medication will control my diabetes					
24.	I must take my diabetes medication even if I don't think I am getting better					
25.	I believe that my medication for diabetes will help me to feel better					

**E. DIABETES SELF-CARE BEHAVIOURS  
(THE SUMMARY OF DIABETES SELF-CARE ACTIVITIES)**

The questions below ask you about your diabetes self-care activities during the past 7 days. If you were sick during the past 7 days, please think back to the last 7 days that you were not sick.

NO.	QUESTIONS	ANSWERS [Circle only one]
<b>A. Diet</b>		
1.	How many of the last SEVEN DAYS have you followed a healthful eating plan?	0 1 2 3 4 5 6 7
2.	On average, over the past month, how many DAYS PER WEEK have you followed your eating plan?	0 1 2 3 4 5 6 7
3.	On how many of the last SEVEN DAYS did you eat five or more servings of fruits and vegetables?	0 1 2 3 4 5 6 7
4.	On how many of the last SEVEN DAYS did you eat high fat foods such as red meat or full-fat dairy products?	0 1 2 3 4 5 6 7
<b>B. Exercise</b>		
5.	On how many of the last SEVEN DAYS did you participate in at least 30 minutes of physical activity? (Total minutes of continuous activity, including walking).	0 1 2 3 4 5 6 7
6.	On how many of the last SEVEN DAYS did you participate in a specific exercise session (such as swimming, walking, biking) other than what you do around the house or as part of your work?	0 1 2 3 4 5 6 7
<b>C. Blood Sugar Testing</b>		
7.	On how many of the last SEVEN DAYS did you test your blood sugar?	0 1 2 3 4 5 6 7
8.	On how many of the last SEVEN DAYS did you test your blood sugar the number of times recommended by your health care provider?	0 1 2 3 4 5 6 7
7A.	Have you had your blood sugar tested in the last MONTH?	0. No 1. Yes. <i>If yes</i> , how many times? Number of blood tests: ...../ month
8A.	How many times in the past MONTH did your health care providers recommend you to have your blood sugar tested?	0. Not recommended 1. Recommended: Number of blood tests recommended: ...../ month
<b>D. Foot Care</b>		
9.	On how many of the last SEVEN DAYS did you check your feet?	0 1 2 3 4 5 6 7
10.	On how many of the last SEVEN DAYS did you inspect the inside of your shoes?	0 1 2 3 4 5 6 7
<b>E. Smoking</b>		
11.	Have you smoked a cigarette—even one puff—during the past SEVEN DAYS?	0. No 1. Yes. <i>If yes</i> , how many cigarettes did you smoke on an average day? Number of cigarettes: ...../ day

**F. DIABETES SELF-EFFICACY  
(THE DIABETES EMPOWERMENT SCALE – SHORT FORM)**

NO.	STATEMENTS	ANSWERS [Check <input type="checkbox"/> only one]				
		<input type="checkbox"/> 1 Strongly Disagree	<input type="checkbox"/> 2 Disagree	<input type="checkbox"/> 3 Not Sure	<input type="checkbox"/> 4 Agree	<input type="checkbox"/> 5 Strongly Agree
	<b>In general, I believe that:</b>					
1.	I know what part(s) of taking care of my diabetes that I am dissatisfied with.					
2.	I am able to turn my diabetes goals into a workable plan.					
3.	I can try out different ways of overcoming barriers to my diabetes goals.					
4.	I can find ways to feel better about having diabetes.					
5.	I know the positive ways I cope with diabetes-related stress.					
6.	I can ask for support for having and caring for my diabetes when I need it.					
7.	I know what helps me stay motivated to care for my diabetes.					
8.	I know enough about myself as a person to make diabetes care choices that are right for me.					

**G. CLINICAL MEASUREMENT**

No.	Clinical Measurement	Results			
1.	HbA1c (%)				
2.	Fasting plasma glucose (FPG) (mg/dL)				
	Fasting plasma glucose (FPG) (mmol/L)				
3.	2-hour postprandial plasma glucose (2-h PPG) (mg/dL)				
	2-hour postprandial plasma glucose (2-h PPG) (mmol/L)				
4.	Systolic and diastolic blood pressure (mmHg)	1	2	3	Average
5.	Body weight (kg)				
6.	Height (cm)				
7.	Body mass index (BMI) (kg/m <sup>2</sup> )				
8.	Waist circumference (cm)				



**Thank you very much for your participation..!**

**APPENDIX F – Research  
Questionnaire in Indonesian  
Language**

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## KUESIONER PENELITIAN: PENGELOLAAN MANDIRI DIABETES BERBASIS PEMBERDAYAAN PASIEN

Nama	:	.....
Alamat (Kelurahan,RT/RW)	:	..... .....
No.Telp/HP	:	.....
Tanda Tangan Responden	:	.....
No. Responden (Diisi peneliti)	:	.....
Tanggal Pengisian	:	.....
Fase	:	VS/ CRCT EVAL I/ II (Lingkari salah satu)
Nama Pewawancara	:	.....
Tanda Tangan Pewawancara	:	.....

**Catatan:**

Tolong disampaikan kepada pasien bahwa jika ada pertanyaan dari pasien akan dijawab setelah wawancara selesai

## A. KARAKTERISTIK DEMOGRAFI SOSIAL

1.	Usia (tahun) Tanggal Lahir	.....tahun ...../...../.....
2.	Jenis Kelamin <i>[Beri tanda ✓ hanya satu]</i>	<input type="checkbox"/> Laki-laki <input type="checkbox"/> Perempuan
3.	Status Pernikahan <i>[Beri tanda ✓ hanya satu]</i>	<input type="checkbox"/> Tidak kawin <input type="checkbox"/> Kawin <input type="checkbox"/> Berpisah <input type="checkbox"/> Cerai <input type="checkbox"/> Cerai mati
4.	Pendidikan tertinggi (pendidikan formal yang diselesaikan) <i>[Beri tanda ✓ hanya satu]</i>	<input type="checkbox"/> Tidak pernah sekolah <input type="checkbox"/> Sekolah Dasar <input type="checkbox"/> Sekolah Menengah Pertama dan Atas <input type="checkbox"/> Akademi dan Universitas
5.	Pekerjaan <i>[Beri tanda ✓ hanya satu]</i>	<input type="checkbox"/> Pekerjaan rumah tangga (ibu rumah tangga) <input type="checkbox"/> Wiraswasta dan pekerjaan sektor informal <input type="checkbox"/> Pegawai negeri sipil (PNS), TNI dan Polisi <input type="checkbox"/> Pegawai perusahaan swasta <input type="checkbox"/> Pekerja profesional <input type="checkbox"/> Pensiunan
6.	Perkiraan penghasilan per bulan (gabungan penghasilan suami & istri) <i>[Beri tanda ✓ hanya satu]</i>	<input type="checkbox"/> < Rp 1.000.000 <input type="checkbox"/> Rp 1.000.000 – 2.999.999 <input type="checkbox"/> Rp 3.000.000 – 9.999.999 <input type="checkbox"/> > Rp 10.000.000

**B. RIWAYAT MEDIS**

1.	Lama menderita diabetes yang diketahui (tahun)	.....tahun
2.	Edukasi pasien tentang diabetes tipe 2 (individual atau kelompok)	<input type="checkbox"/> Tidak <input type="checkbox"/> Ya
3.	Riwayat keluarga penderita diabetes	<input type="checkbox"/> Tidak <input type="checkbox"/> Ya      Siapa? .....
4.	Pengawasan/ pemeriksaan sendiri gula darah (dengan alat <i>glucometer</i> )	<input type="checkbox"/> Tidak <input type="checkbox"/> Ya      Frekuensi per minggu: .....
5.	Hipertensi (penyakit darah tinggi)	<input type="checkbox"/> Tidak <input type="checkbox"/> Ya
6.	Merokok	<input type="checkbox"/> Tidak <input type="checkbox"/> Ya
7.	Pengobatan diabetes [Beri tanda ✓ sebanyak yang berlaku]	<input type="checkbox"/> Diet <input type="checkbox"/> Olah raga <input type="checkbox"/> Obat penurun kadar gula darah: Nama: .....; dosis;..... Nama: .....; dosis;..... Nama: .....; dosis;..... <input type="checkbox"/> Insulin: Nama: .....; dosis;..... Nama: .....; dosis;..... <input type="checkbox"/> Pengobatan traditional/ herbal: ..... .....
8.	Komplikasi diabetes yang pernah dialami [Beri tanda ✓ hanya satu untuk setiap jenis komplikasi]	<ul style="list-style-type: none"> <li>• Kelainan syaraf tepi (neuropati): <input type="checkbox"/> Tidak    <input type="checkbox"/> Ya</li> <li>• Kelainan penglihatan: (retinopati/ glukoma/ katarak/ penyakit kornea)    <input type="checkbox"/> Tidak    <input type="checkbox"/> Ya</li> <li>• Penyakit ginjal (nefropati):    <input type="checkbox"/> Tidak    <input type="checkbox"/> Ya</li> <li>• Kelainan ereksi (impoten):    <input type="checkbox"/> Tidak    <input type="checkbox"/> Ya</li> <li>• Penyakit jantung koroner:    <input type="checkbox"/> Tidak    <input type="checkbox"/> Ya</li> <li>• Stroke:    <input type="checkbox"/> Tidak    <input type="checkbox"/> Ya</li> <li>• Penyakit pembuluh darah tepi: (ulkus kaki/gangren):    <input type="checkbox"/> Tidak    <input type="checkbox"/> Ya</li> </ul>
9.	Adakah di keluarga atau lingkungan sosial yang memberikan dukungan dalam mengelola penyakit diabetes Anda?	<input type="checkbox"/> Tidak <input type="checkbox"/> Ya      Siapa? .....
10.	Apakah Anda mempunyai atau dilindungi asuransi kesehatan?	<input type="checkbox"/> Tidak <input type="checkbox"/> Ya      Apakah itu? ..... <input type="checkbox"/> Jamkesmas/ Jamkesda untuk keluarga miskin <input type="checkbox"/> Askes <input type="checkbox"/> Jamsostek <input type="checkbox"/> Asuransi kesehatan swasta <input type="checkbox"/> Tanggungan perusahaan/ kantor



**C. PENGETAHUAN TENTANG DIABETES**  
**(THE DIABETES KNOWLEDGE QUESTIONNAIRE - 24)**

NO.	PERTANYAAN	YA	TIDAK	TIDAK TAHU
1.	Makan terlalu banyak gula dan makanan manis lainnya merupakan penyebab diabetes			
2.	Penyebab umum diabetes adalah kurangnya insulin yang efektif dalam tubuh.			
3.	Diabetes disebabkan karena kegagalan ginjal mencegah gula masuk ke dalam kencing			
4.	Ginjal memproduksi insulin			
5.	Pada diabetes yang tidak diobati, jumlah gula dalam darah biasanya meningkat			
6.	Jika saya menderita diabetes, anak-anak saya berpeluang lebih besar menderita diabetes juga			
7.	Diabetes dapat disembuhkan			
8.	Kadar gula darah puasa 210 adalah terlalu tinggi.			
9.	Cara terbaik untuk memeriksa diabetes adalah dengan tes kencing			
10.	Olah raga teratur akan meningkatkan kebutuhan atas insulin atau obat diabetes lainnya.			
11.	Ada dua jenis utama diabetes: Tipe 1 (tergantung pada insulin) dan Tipe 2 (tidak tergantung pada insulin)			
12.	Insulin bekerja disebabkan karena makan terlalu banyak			
13.	Obat lebih penting daripada diet dan olah raga untuk mengendalikan diabetes			
14.	Diabetes sering menyebabkan peredaran darah yang tidak baik			
15.	Luka dan lecet pada penderita diabetes sembuhnya lebih lama			
16.	Penderita diabetes harus sangat berhati-hati saat memotong kuku kaki			
17.	Penderita diabetes harus membersihkan luka dengan yodium (betadine) dan alkohol			
18.	Cara memasak makanan sama pentingnya dengan makanan yang dimakan oleh penderita diabetes			
19.	Diabetes dapat merusak ginjal			
20.	Diabetes dapat menyebabkan mati rasa pada tangan, jari-jari dan kaki			
21.	Gemetaran dan berkeringat merupakan tanda tingginya kadar gula darah			
22.	Sering kencing dan haus merupakan tanda rendahnya kadar gula darah			
23.	Kaos kaki yang ketat boleh dipakai oleh penderita diabetes			
24.	Diet diabetes sebagian besar terdiri dari makanan-makanan khusus			

#### D. KEPERCAYAAN KESEHATAN TERKAIT DIABETES (THE DIABETES HEALTH BELIEF MEASURE)

NO.	PERNYATAAN	JAWABAN [Beri tanda $\surd$ hanya satu]				
		<input type="checkbox"/> 1 Sangat Tidak Setuju	<input type="checkbox"/> 2 Tidak Setuju	<input type="checkbox"/> 3 Ragu- ragu	<input type="checkbox"/> 4 Setuju	<input type="checkbox"/> 5 Sangat Setuju
1.	Diabetes saya terkontrol dengan baik (Hasil tes gula darah saya terjaga dengan baik)					
2.	<b>Saya harus mengubah banyak sekali kebiasaan makan untuk mengikuti diet diabetes</b>					
3.	Selama ini sulit bagi saya untuk mengikuti diet diabetes yang disuruh dokter					
4.	Saya bingung dengan semua pengobatan yang diberikan dokter kepada saya					
5.	<b>Saya harus mengubah banyak sekali kebiasaan (sehari-hari) untuk minum obat</b>					
6.	Pengobatan saya mengganggu aktivitas keseharian saya					
7.	Saya memiliki orang-orang di sekitar saya yang mengingatkan saya untuk makan makanan yang tepat					
8.	Saya bisa mengandalkan keluarga ketika saya perlu bantuan untuk menjalankan diet diabetes					
9.	Suami/ istri/ keluarga saya membantu saya menjalankan diet diabetes					
10.	<b>Jika saya ganti 'pekerjaan', akan lebih mudah menjalankan diet diabetes</b>					
11.	Pekerjaan saya membuat saya sangat capek sehingga sulit untuk menjalankan diet diabetes					
12.	Saya bisa mengendalikan berat badan jika tekanan dari pekerjaan saya tidak terlalu berat					
13.	<b>Jika saya ganti 'pekerjaan', akan lebih mudah untuk minum obat</b>					
14.	Saya sangat khawatir dengan pekerjaan saya sehingga tidak bisa minum obat					
15.	Saya percaya bahwa diet diabetes saya akan membantu mencegah penyakit dan komplikasi akibat diabetes					
16.	Mengikuti diet diabetes yang ditentukan merupakan sesuatu yang harus dilakukan meskipun berat					
17.	Saya percaya bahwa diet diabetes akan <b>mengendalikan</b> diabetes saya (mengendalikan= membuat tidak menjadi parah; membuat gula darah tidak tinggi)					
18.	<b>Saya harus menjalankan diet diabetes meskipun saya pikir tidak tambah membaik</b>					
19.	Secara umum, saya percaya bahwa diet diabetes akan membantu saya merasa lebih sehat					
20.	Mengendalikan berat badan harus dilakukan meskipun berat					
21.	Saya percaya bahwa pengobatan akan membantu mencegah penyakit dan komplikasi akibat diabetes					
22.	Minum obat harus dilakukan meskipun berat					
23.	Saya percaya bahwa pengobatan akan mengendalikan diabetes saya					
24.	<b>Saya harus minum obat diabetes meskipun saya pikir tidak tambah membaik</b>					
25.	Saya percaya bahwa pengobatan diabetes akan membantu saya merasa lebih sehat					

## E. PERILAKU PERAWATAN MANDIRI DIABETES (THE SUMMARY OF DIABETES SELF-CARE ACTIVITIES)

Pertanyaan-pertanyaan di bawah ini menanyakan tentang kegiatan perawatan diri diabetes Anda selama 7 hari terakhir. Jika Anda sakit selama 7 hari yang lalu, silahkan mengingat ke belakang 7 hari terakhir yang Anda tidak sakit.

NO.	PERTANYAAN	JAWABAN (Lingkari hanya salah satu)
<b>A. Diet/ Makanan</b>		
1.	Dalam TUJUH HARI (SEMINGGU) terakhir, berapa hari Anda mengikuti pola makan yang sehat? [4 sehat 5 sempurna]	0 1 2 3 4 5 6 7
2.	Dalam SEBULAN INI, rata-rata, berapa HARI PER MINGGU Anda mengikuti pola makan tersebut?	0 1 2 3 4 5 6 7
3.	Dalam TUJUH HARI (SEMINGGU) terakhir, pada berapa hari Anda makan lima takaran/sediaan atau lebih buah dan sayuran dalam per-hari-nya?	0 1 2 3 4 5 6 7
4.	Dalam TUJUH HARI (SEMINGGU) terakhir, pada berapa hari Anda makan makanan tinggi lemak seperti daging merah, produk susu tinggi lemak atau santan?	0 1 2 3 4 5 6 7
<b>B. Olah Raga</b>		
5.	Dalam TUJUH HARI (SEMINGGU) terakhir, pada berapa hari Anda melakukan aktivitas fisik selama paling tidak 30 menit? (Jumlah total menit dari aktivitas kontinyu, termasuk berjalan, aktivitas membersihkan rumah, dll)	0 1 2 3 4 5 6 7
6.	Dalam TUJUH HARI (SEMINGGU) terakhir, pada berapa hari Anda melakukan olah raga khusus (seperti berenang, berjalan, bersepeda) selain kegiatan yang Anda lakukan di rumah atau kegiatan yang merupakan bagian dari pekerjaan Anda?	0 1 2 3 4 5 6 7
<b>C. Tes Gula Darah</b>		
7.	Dalam TUJUH HARI (SEMINGGU) terakhir, pada berapa hari Anda melakukan pemeriksakan gula darah?	0 1 2 3 4 5 6 7
8.	Dalam TUJUH HARI (SEMINGGU) terakhir, pada berapa hari Anda melakukan pemeriksaan gula darah sejumlah yang disarankan oleh petugas kesehatan (dokter/perawat)?	0 1 2 3 4 5 6 7
7A.	Dalam SEBULAN terakhir, apakah Anda melakukan pemeriksaan gula darah?	0. Tidak 1. Ya. Jika ya, berapa kali? Jumlah tes gula darah: ...../ bulan
8A.	Dalam SEBULAN terakhir, berapa kali petugas kesehatan (dokter/ perawat) menyarankan kepada Anda untuk melakukan pemeriksaaan gula darah?	0. Tidak disarankan 1. Disarankan. Jumlah tes gula darah yang disarankan: ...../ bulan
<b>D. Perawatan Kaki</b>		
9.	Dalam TUJUH HARI (SEMINGGU) terakhir, pada berapa hari Anda memeriksa sendiri kaki Anda?	0 1 2 3 4 5 6 7
10.	Dalam TUJUH HARI (SEMINGGU) terakhir, pada berapa hari Anda memeriksa sendiri bagian dalam sepatu Anda?	0 1 2 3 4 5 6 7
<b>E. Merokok</b>		
11.	Apakah Anda menghisap rokok – meskipun sekali hisap – dalam TUJUH HARI terakhir?	0. Tidak 1. Ya. Jika ya, berapa batang rokok Anda hisap rata-rata per hari? Jumlah rokok: ..... / hari

**F. EFIKASI DIRI TERKAIT DIABETES  
(THE DIABETES EMPOWERMENT SCALE – SHORT FORM)**

NO.	PERNYATAAN	JAWABAN				
		[Beri tanda ✓ hanya satu]				
		<input type="checkbox"/> 1 Sangat Tidak Setuju	<input type="checkbox"/> 2 Tidak Setuju	<input type="checkbox"/> 3 Ragu- ragu	<input type="checkbox"/> 4 Setuju	<input type="checkbox"/> 5 Sangat Setuju
	<b>Secara umum, saya percaya bahwa:</b>					
1.	Saya tahu bagian mana dari perawatan diabetes yang saya merasa tidak puas. <b>*Ricek:</b> Apa yang dirasa belum memuaskan?					
2.	Saya mampu mengubah tujuan penanganan diabetes menjadi rencana yang bisa diwujudkan <b>*Ricek:</b> Apa contohnya?					
3.	Saya bisa mencoba berbagai cara untuk mengatasi hambatan pada tujuan penanganan diabetes saya. <b>*Ricek:</b> Apa contoh hambatannya? Bagaimana cara mengatasinya?					
4.	Saya bisa menemukan cara untuk merasa lebih baik saat menderita diabetes <b>*Ricek:</b> Apa contohnya?					
5.	Saya tahu cara positif untuk mengatasi stress akibat diabetes. <b>*Ricek:</b> Apa contohnya?					
6.	Saya bisa minta dukungan selama menderita dan merawat diabetes ketika membutuhkan. <b>*Ricek:</b> Kepada siapa?					
7.	Saya tahu apa yang membantu saya tetap termotivasi/ bersemangat dalam merawat diabetes <b>*Ricek:</b> Apakah itu?					
8.	Saya cukup tahu tentang diri sendiri untuk memilih perawatan diabetes yang tepat <b>*Ricek:</b> Apa contohnya?					

**G. PEMERIKSAAN KLINIS**

No.	Pemeriksaan Klinis	Hasil			
1.	HbA1c (%)				
2.	Gula darah puasa (GDP) (mg/dL)				
	Gula darah puasa (GDP) (mmol/L)				
3.	Gula darah 2 jam postprandial (GDPP) (mg/dL)				
	Gula darah 2 jam postprandial (GDPP) (mmol/L)				
4.	Tekanan darah sistolik dan diastolik (mmHg)	1	2	3	Rerata
5.	Berat badan (kg)				
6.	Tinggi badan (cm)				
7.	Index massa tubuh (IMT) (kg/m <sup>2</sup> )				
8.	Lingkar pinggang (cm)				



**Terima Kasih Atas Partisipasinya...!**

## **APPENDIX G – List of Open-Ended Questions for Scoping discussions**

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## List of Open-Ended Questions for Scoping discussions

### A. Scoping discussions before the administration of the research interventions

Group of Patients with Type 2 Diabetes and Their Family Members		Group of Health Care Providers	
No.	Questions	No.	Questions
1.	<ul style="list-style-type: none"> <li>• What do you think about the diabetes care provided by your HCPs?</li> <li>• How do you feel about it?</li> </ul>	1	<ul style="list-style-type: none"> <li>• What do you think about the diabetes care that you provide to your patients?</li> <li>• Is it adequate? Is it based on the current guidelines?</li> </ul>
2.	<ul style="list-style-type: none"> <li>• I would like all of you to look back at your experiences when you were newly diagnosed to have T2D by HCPs at the CHCs, did you receive sufficient information about the disease?</li> </ul>	2.	<ul style="list-style-type: none"> <li>• I would like all of you to look back at your practice experiences. When you encounter patients newly diagnosed with T2D, do you provide sufficient information about the disease?</li> </ul>
3	<ul style="list-style-type: none"> <li>• What kind of diabetes information should your HCPS provide to you?</li> </ul>	3.	<ul style="list-style-type: none"> <li>• What kind of diabetes information should you provide to patients with T2D?</li> </ul>
4.	<ul style="list-style-type: none"> <li>• What do you understand about T2D?</li> <li>• Is your knowledge and understanding about T2D sufficient to be able to live well?</li> </ul>	4.	<ul style="list-style-type: none"> <li>• In general, what do you think about the diabetes knowledge level of your patients with T2D?</li> <li>• Is your patients' knowledge and understanding about T2D sufficient to be able to live well?</li> </ul>
5.	<ul style="list-style-type: none"> <li>• What kind of support do you need related to your diabetes?</li> </ul>	5.	<ul style="list-style-type: none"> <li>• What kind of support do you think patients with T2D need?</li> </ul>
6.	<ul style="list-style-type: none"> <li>• What do you expect from the HCPs regarding the diabetes care they provide?</li> </ul>	6.	<ul style="list-style-type: none"> <li>• What do you think about your patients' expectations regarding the diabetes care you provide?</li> </ul>
7.	<ul style="list-style-type: none"> <li>• What do you expect from your family regarding your diabetes?</li> </ul>	7.	<ul style="list-style-type: none"> <li>• What do you think about the patients' expectation from their family regarding their diabetes?</li> </ul>
8.	<ul style="list-style-type: none"> <li>• How has diabetes affected your life and family?</li> </ul>	8.	<ul style="list-style-type: none"> <li>• How would diabetes affect your patients' life and family?</li> </ul>
9.	<ul style="list-style-type: none"> <li>• What do you understand about the term "diabetes self-management"?</li> <li>• What do you think about it?</li> <li>• What do you understand about the term "patient empowerment"?</li> <li>• What do you think about it?</li> </ul>	9.	<ul style="list-style-type: none"> <li>• What do you understand about the term "diabetes self-management"?</li> <li>• What do you think about it?</li> <li>• What do you understand about the term "patient empowerment"?</li> <li>• What do you think about it?</li> </ul>
10.	<ul style="list-style-type: none"> <li>• What do you think if concepts of "patient empowerment" and "self-management" are applied to your diabetes care?</li> <li>• Are we ready to implement patient empowerment program, as in a structured patient education program promoting self-management for diabetic patients?</li> <li>• What do you think about the enablers and barriers for their implementation?</li> </ul>	11.	<ul style="list-style-type: none"> <li>• What do you think if concepts of "patient empowerment" and "self-management" are applied to your diabetes care provision?</li> <li>• Are we ready to implement patient empowerment program, as in a structured patient education program promoting self-management for diabetic patients?</li> <li>• What are the enablers and barriers for their implementation?</li> </ul>

**B. Scoping discussions after the administration of the research interventions**

No.	Questions
1.	<ul style="list-style-type: none"> <li>• Last time all of you have learned about T2D in the diabetes seminar/ diabetes structured patient education sessions, and you have received a set of diabetes leaflets...How were the sessions and the leaflets?</li> <li>• Did you learn new things different from what you had known before?</li> <li>• Was the information provided adequate?</li> <li>• Is there any other diabetes information you still need to obtain?</li> </ul>
2.	<ul style="list-style-type: none"> <li>• After receiving such diabetes information, how do you implement the information in your daily life?</li> <li>• What are your experiences in implementing the information (positive and negative)?</li> <li>• What are the enablers and barriers for such implementation?</li> </ul>
3.	<ul style="list-style-type: none"> <li>• What do you think about your:               <ul style="list-style-type: none"> <li>- diabetes knowledge?</li> <li>- ability to perform diabetes self-care activities?</li> <li>- motivation to perform diabetes self-care activities?</li> <li>- compliance to perform diabetes self-care activities?</li> <li>- family and social support to perform diabetes self-care activities ?</li> </ul> </li> </ul>
4.	<ul style="list-style-type: none"> <li>• What are your further expectations from the HCPs for the diabetes care provision?</li> <li>• What still needs to be improved?</li> </ul>



# **APPENDIX H – Full Key Findings of Scoping discussions**

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## FULL KEY FINDINGS OF SCOPING DISCUSSIONS

Six scoping discussions were carried out in this research project (See **Section 6.3.1**). The full key findings are presented in the following sections based on the themes that emerged within similar topics. The key findings of four scoping discussions for exploring the perceptions of HCPs and patients with T2D towards the current provision of diabetes care and education at the CHCs are presented in Section 1 to Section 9. Meanwhile, the key findings of two scoping discussions for exploring the perceptions of patients with T2D towards the diabetes education intervention administered are presented in Section 10 to Section 13.

### **1. The Perceptions of HCPs and Patients with T2D on Diabetes Care Provided by the HCPs**

In general, the HCPs believed that the diabetes care they provided at the CHCs was adequate based on the Guidelines of Basic Treatment at Community Health Centre developed by the Ministry of Health<sup>311</sup>, and the CHC's local protocol. The diagnosis of T2D was confirmed both with random blood sugar test or fasting blood sugar, and 2-hour postprandial plasma glucose tests; and not with HbA1c. The HCPs advised all diabetic patients to measure their blood sugar monthly, particularly with random blood sugar test. In cases where a patient's blood sugar level was very high, a fortnightly blood sugar testing was recommended. The HCPs provided regular prescribing of diabetes medicines to be dispensed at the CHCs for a period of 3-5 days, depending on the local protocol. The HCPs indicated that there were only three oral diabetes medications available at the CHCs: metformin, glibenclamide, and glimepiride. The diabetes education was provided particularly on diabetes meal planning by a nutritionist working at the CHC. Newly diagnosed patients with T2D were offered a referral to the nutritionist with an additional fee (IDR 5,250 or Australian 52.5 cents for patients having Yogyakarta City identity card and IDR 7,000 or Australian 70 cents for patients living outside Yogyakarta City). This referral was optional, not a mandatory protocol for all patients newly diagnosed with T2D.

Meanwhile, the diabetic patients provided various responses with respect to the diabetes care provided, ranging from 'not satisfying', 'quite adequate' to 'satisfying'. Two patients who stated 'satisfying', however, were referring to the diabetes care provided by specialist doctors at a tertiary public hospital, particularly because of the more detailed diabetes education provided. These participants went to both CHC and public hospital for their diabetes care. They further revealed that GPs at the CHCs spoke little during patient-provider encounters, and were not as proactive in asking questions as the hospital specialist doctors.

Many diabetic patients who were dissatisfied with the diabetes care provided at the CHCs related their dissatisfaction to the inadequate provision of diabetes education. The patients complained that during encounters, the HCPs usually only asked about presenting complaints and prescribed medicines, without further investigation or provision of diabetes information unless the patients were proactive in asking questions. The patients speculated that the HCPs might think that the patients already knew about T2D.

Nevertheless, several patients indicated that such practice at the CHCs was understandable because of time constraints in providing services to the many patients in public funded CHCs. The participants also reported that some HCPs were more communicative and approachable than others. One patient complained that HCPs should be more communicative, providing relevant diabetes information to patients without waiting to be asked. However, another patient who was an administrative staff at one CHC argued that a long consultation with one patient would cause complaints from other waiting patients. To overcome the problem, another participant suggested that CHC staff could conduct diabetes public education sessions in each neighbourhood.

Several patients were dissatisfied with the recommended frequency of blood sugar testing (once a month), and wished for more frequent testing. A few patients questioned the recent advice for less frequency, i.e. once in 2 months, particularly for patients covered by *Jamkesmas* (the government social security programme for poor people).

## **2. The Perceptions of HCPs and Patients with T2D on Diabetes Education Provided by the HCPs**

Many HCPs acknowledged that the diabetes information they provided to patients with T2D was not sufficient, detailed or clear as it should be. Several HCPs indicated that not all diabetic patients were treated equally in the provision of diabetes education. Diabetes education was primarily provided to patients newly diagnosed with T2D because they were perceived as keen and curious to know about the disease. A few HCPs considered ongoing patients with T2D as already knowing a lot about the disease since they had been living with it and had already received information about diabetes from various sources (e.g. diabetes seminars, leaflets, magazines), so less education was provided. One GP pointed out that communication during patient-provider encounters was only for sharing and reminding the diabetic patients about the diabetes management, and assessing their presenting problems related to their diabetes management.

The HCPs indicated that inadequate provision of diabetes education was particularly due to underlying problems at CHCs associated with constrained resources and patient characteristics. As indicated, the biggest problem was lack of human resources to provide services to the many patients using the publicly funded CHCs prompting time constraint in each encounter. The HCPs illustrated that a CHC was the health care of choice for many people in Yogyakarta City because the medical fee was very inexpensive cheap (IDR 2,000 or Australian 20 cents including medications and blood tests needed), and the location was convenient (found in each sub-district), thus a lot of patients attended CHCs. Every day the CHCs catered to 100-150 patients in the general clinic at the centre and sub-centre usually with only 3-4 HCPs on duty (within effective clinic hours from 8 to 12 am). The HCPs acknowledged that a typical patient-provider encounter was limited to focusing on the presenting complaints of the patients and provision of required prescriptions. One GP indicated that it was unethical to provide a long patient education session while there were many patients waiting to be seen. There was an additional pressure on HCPs in one CHC which had applied the ISO Standard

with a standardised maximal duration for a medical consultation, i.e. 15 minutes for a new patient, and 10 minutes for a follow-up patient.

The HCPs indicated that most general clinics at CHCs were manned by 3 GPs and 3 nurses who also had other administrative and field duties. Due to the shortage of GPs, sometimes nurses also saw and examined patients independently. One participating CHC was better staffed with 5 GPs and 6 nurses because the CHC had an in-patient care facility. Even so, the HCPs indicated that the number of HCPs was still insufficient to meet the clinical demands. This made it difficult for them to provide diabetes education properly. Moreover, each CHC usually only had one nutritionist with various administrative and field duties, thus the nutritionist was not available everyday to provide nutritional consultation to diabetic patients. Accordingly, the HCPs admitted that many diabetic patients failed to get the recommended nutritional consultation.

The HCPs also revealed that funds were inadequate to provide effective diabetes education materials and public education in the community. In order to provide systematic diabetes education, the HCPs indicated that they needed teaching aids such as diabetes leaflets and/ or desk flip charts otherwise they would forget what information should be provided and the diabetes information would be inconsistently provided. Sometimes diabetes leaflets were provided by the district health office, but the number of leaflets received was very limited, such that they were compelled to photocopy the leaflets. This was not always possible because of lack of funding for photocopying. Furthermore, the HCPs indicated that there were requests from diabetes groups in the community for public education sessions during their group activities. However, since these were scheduled for late afternoons, after the opening hours of CHCs (8 am – 2 pm), the requests could not be fulfilled because no funds were allocated for such activities.

The HCPs believed that several patient characteristics contributed to the inadequate provision of diabetes education, including: low socioeconomic status, low education level, old age and language barriers. The HCPs indicated that patients attending the CHCs mostly had low socioeconomic status and low education level. Many of CHC patients were covered by Jamkesmas (the government social security programme for poor people). The HCPs suggested that many diabetic patients refused to obtain a consultation from a nutritionist as recommended because of the additional fee charged.

The HCPs indicated that many diabetic patients at CHCs were elderly with impaired hearing which resulted in poor communication. In addition, many elderly diabetic patients spoke Javanese, not *Bahasa Indonesia* (the national language). For HCPs whose background was not Javanese, the language acted as a barrier for providing diabetes information.

Several HCPs revealed that if diabetes information conveyed to patients with a low education level was too detailed and complicated, the patients would be overwhelmed and fearful. The HCPs thus suggested that when dealing with such patients, they had to use a 'different' language, which was a simpler language and included jokes. One GP suggested that conveying the diabetes information should not be conducted rigidly which could make the patients feel hopeless, but in such a way as to provide support.

Meanwhile, in one patient focus group, a diabetic patient who was an administrative staff member at a CHC also explained that patients newly diagnosed with T2D were referred to the nutritionist working at the CHC for a consultation on diabetes meal planning. However, several diabetic patients disclosed that they were not referred to a nutritionist by the GPs when newly diagnosed with T2D. The researcher then asked all participating diabetic patients whether they had ever taken part in consultation with a nutritionist. In one group, of nine diabetic patients only four had done so, and one of the four had attended the consultation at a tertiary public hospital. In another group, of eight diabetic patients only two had done so, with one attending the consultation at a tertiary public hospital. Several participants reasoned that the nutritionist at the CHC was very busy and often unavailable for the consultation.

The diabetic patients provided a range of responses towards the diabetes education provided, ranging from 'not sufficient' or 'not complete' or 'not understandable' to 'sufficient'. The patients who stated that the information received was sufficient were generally patients with longer diabetes duration, i.e. above 10 years. However, these patients also indicated that they wished to know more about diabetes. These patients described obtaining diabetes information not only from their HCPs but also from other sources, including: diabetes leaflets, magazines, internet, and other diabetic patients' experiences. One participant indicated that the diabetes information from various HCPs was similar, but the information conveyed by HCPs at a tertiary public hospital was more complete. One participant stated that the diabetes information was sufficient, but his problem lay in his attempts to follow what had been advised by the doctors. The diabetes advice provided by HCPs included: diabetes meal planning, regular exercise, regular medication taking, regular blood sugar testing, and the need for precaution in cutting finger nails.

The patients who stated that the information received was not sufficient or not complete were generally patients with shorter diabetes duration, i.e. less than 2 years. These patients revealed that they did not receive information on certain issues they believed were essential, including: frequency of follow-up consultations, explanation about diabetes medications prescribed, how long patients should take diabetes medications, and which foods to eat and avoid. These patients stated that every time they saw an HCP, the HCP only gave a prescription and did not attempt to explain about these issues. One patient described attending a group diabetes education delivered by a nutritionist who mostly instructed patients to reduce the amount of food eaten, while which foods to avoid were not explained. Another participant indicated that much of the information provided was not understandable by lay people because of the medical terms used, and suggested that the diabetes information should be explained in lay language.

In contrast with the perceptions of the HCPs, the diabetic patients generally described only two underlying factors for the insufficient diabetes information. Firstly, there was time constraint in providing services to the many patients at the publicly funded health centres; and secondly, the CHC doctors had limited knowledge about the disease. Diabetes educator training sessions for HCPs organised by the Yogyakarta City Health Office were usually held in half day and provided minimal

information. This finding was provided by a diabetic patient who was a CHC administrative staff member.

### 3. The Perceptions of HCPs and Patients with T2D on Diabetes Education That Should be Provided by the HCPs

Several HCPs acknowledged that a lot of diabetes information should be provided to diabetic patients. However, due to several underlying factors (as indicated previously), these HCPs revealed that they had to be selective, and therefore only limited information was conveyed.

Several HCPs described the content of diabetes information as primarily diabetes definition, symptoms, complications, and management, and considered this to be the minimal information which should be conveyed to patients. The information on diabetes management conveyed to diabetic patients was called 'the four pillars of diabetes management', namely education, meal planning, physical activity and medication. However, these HCPs acknowledged that the information on diabetes management was mostly limited to regular medication taking and diabetes meal planning; with the latter was mostly provided by a nutritionist.

Detailed information on medication and physical activity was not provided, but might be discussed in the context of presenting complaints or symptoms raised by the patients. Several HCPs acknowledged that diabetic patients were not informed about the mechanism of diabetes because the topic was deemed too complex. However, the information might be conveyed in response to a patient's direct question on diabetes medicines.

Several HCPs described issues which were most frequently asked about by diabetic patients, including queries about: (1) foods to eat and avoid; (2) the side effects of taking diabetes medications for a long time; (3) high blood sugar level despite patients' efforts to control it; (4) the effectiveness of herbal plants or alternative treatments for diabetes commonly used in the community; and (5) community beliefs about diabetes. Herbal and alternative treatments for diabetes commonly used in the community including: *jamu Jawa* (Javanese medicinal herbs), insulin plant (*Costus igneus*) leaves, *dhandang gendis* leaves (*Clinacanthus nutans*), antlion or *undur-undur* (*Myrmeleon Sp*) eaten alive, *binahong* leaves, squash leaves, pumpkin leaves, red betel leaves, hot chillies, boiled bamboo shoot water, massage, and drinking one own's early morning urine. Meanwhile, erroneous community beliefs about diabetes were frequently presented to the HCPs, including: that rice cooked several days previously contains less carbohydrate and calorie; that bitter food, such as bitter melon, neutralises high blood sugar level; and that there are two types of diabetes, i.e. dry and wet diabetes, with wet diabetes having delayed wound healing causing amputation.

Meanwhile, patients described several topics of diabetes information that should be provided, including: (1) detailed explanation about diabetes medications and their side effects, including during Ramadhan fasting; (2) detailed explanation about the recommended blood sugar tests: fasting and 2-hour-after-meal blood sugar; (3) healthy lifestyle: diet, exercise and sleep, including during Ramadhan fasting; (4) the difference between 'hypo' and 'hyper' (hypoglycaemia and hyperglycaemia); (5) the

effect of T2D on the body; (6) the age at which T2D begins; (7) how to overcome weakness; (8) precautions to take when undertaking a tooth extraction; (9) herbal and alternative treatments for T2D; and (10) type of diabetes, particularly 'wet' and 'dry' diabetes.

#### **4. The Perceptions of HCPs and Patients with T2D on the Patients' Diabetes Knowledge Level to Live Well**

Several HCPs indicated that the diabetes knowledge level of diabetic patients at CHCs varied. There were patients who did not care about their diabetes management even though they had been repeatedly informed and warned about the risks of poor glucose control. In contrast, the HCPs believed that some patients were 'overreacting' with their diabetes care, such as testing blood sugar more frequently than the recommended once-a-month practice and keeping notes of all results of blood sugar tests. Some patients reported that they read about diabetes from various sources including the internet.

Generally the HCPs considered that the patients' basic knowledge of diabetes management was sufficient for the patients to manage their diabetes successfully. One GP referred this basic knowledge as "I have T2D, which cannot be cured, and I have to take medications for the rest of my life". However, contradictory to this supposition, they also suggested that where instruction in diabetes management was not sufficient, this deficiency was addressed by diabetic patients sharing their illness experiences with other patients and by regular monthly encounters with HCPs.

Nevertheless, several HCPs indicated that sometimes the fact that "T2D cannot be cured and diabetic patients have to take medications for the rest of their life" might not be well understood. In particular, sometimes on getting a normal result of blood sugar test, patients would stop their medication, eat inappropriately or change to herbal or alternative treatment. The elderly diabetic patients were least knowledgeable particularly due to impaired hearing. In such cases, the HCPs would usually ask a family member to accompany the patient during the encounter and they would convey the diabetes information to the family member.

Moreover, several HCPs suggested that occasionally even when patients already had good diabetes knowledge, patients had difficulty controlling their diet, particularly when attending social gatherings such as wedding parties. The HCPs also suggested that many patients, particularly the elderly ones, had accepted the condition and exercised resignation towards the consequences of long-term diabetes.

Meanwhile, when the diabetic patients were asked about their diabetes knowledge to live well, their responses ranged from 'not sufficient at all', 'only a little' to 'sufficient'. As previously, the participants who stated 'sufficient' were generally patients with longer diabetes duration (above 10 years), and the participants who stated 'not sufficient at all' or 'only a little' were patients with shorter diabetes duration (less than 2 years).

The general understanding about T2D as described by diabetic patients included that it is a chronic disease which cannot be cured but can be controlled. Indicators for the disease understood by

the patients included higher blood sugar than normal and abnormal blood circulation. One patient suggested an easy way to know whether someone had T2D or not was by checking the morning urine: when the urine attracts ants, the person has T2D.

The patients described several causes of T2D, including: genetic factors, eating a lot of sweet food, lack of physical activity, pancreatic defect, and pancreas not producing insulin normally. The patients also described the components required for effective diabetes management, including: good meal planning, regular exercise, regular medication and blood sugar testing.

Furthermore, several patients suggested that accepting the condition with a big heart, not taking it as a burden, and just enjoying life had helped them in managing T2D. One family member suggested that diabetic patients need to be given motivation in order not to get discouraged. Several patients admitted that along with taking the diabetes medication, they also tried various herbal and alternative treatments recommended by relatives and friends.

### **5. The Perceptions of HCPs and Patients with T2D on the Support Needed by Diabetic Patients**

The HCPs suggested that diabetic patients needed a range of support including: provider, family, peer and community supports. Several HCPs suggested that diabetic patients primarily needed support, motivation and encouragement from the HCPs for continuous treatment, because sometimes patients became demotivated due to the long-term nature of diabetes treatment. The motivation required patients to accept, live and 'make a friend with diabetes', while maintaining a good quality of life, so that the patients live longer. The HCPs also encouraged patients with the thought that they could live normally as long as their blood sugar was controlled. The HCPs frequently praised patients with good blood sugar test results and encouraged them to maintain their efforts.

Many HCPs indicated that family support was very important, particularly in reminding the patients to take diabetes medication, supporting good meal planning, escorting patients to attend CHCs, and on-going care including wound management and giving insulin injections. A few HCPs suggested that sometimes the patients expected their family members to cook food separately for the patients or even follow the patients' diabetes diet. However, one GP was concerned about caregiver fatigue due to the long-standing nature of the condition, particularly since taking care of a diabetic patient or not seemingly made little outward difference.

Several HCPs indicated that diabetic patients often shared their illness experiences with other diabetic patients which could help them gain more understanding about T2D. Several HCPs also revealed that the CHCs had attempted to organise group meetings for patients with T2D using a fund provided by the district health office as a part of the Caring-for-Diabetes Community Programme. However, due to the limited funds available, the meetings were discontinued after the second meeting. The HCPs reported that diabetes groups were established in a few neighbourhoods with weekly diabetes exercise, and a diabetes club was established at the Yogyakarta City district hospital to facilitate diabetes group activities.



Meanwhile, when the diabetic patients were asked about the support they needed, they described a similar range of support sources as indicated by the HCPs (i.e. provider, family, peer, and community), with an additional support, i.e. self-awareness. However, in contrast with the HCPs' responses, some of patients' responses reflected not only needed support they were getting, but also support they expected to get.

Several participants indicated that diabetic patients need self-awareness on life motivation for living with T2D. One patient suggested diabetic patients should neither fear nor underestimate the condition. One family member suggested several ways in which patients could cope with the condition: to be thankful for the things that the patients could still do, to ask HCPs questions as to what steps the patients could take in order to manage their condition, and to control their own eating habits.

Several participants described the provider support needed including: reminders about what foods to eat and avoid, and motivation in order not to become discouraged. However, these participants indicated that during encounters, the HCPs' advice to patients was primarily limited to recommendations to reduce sugar consumption.

The participants described the family support needed, including: motivating patients to manage the condition; showing patience about the demands of the disease; reminding patients to take their medications, control eating, do exercise and attend follow-up consultations; escorting patients to attend CHCs; preparing meals based on diabetes diet; and advising herbal and alternative treatments for T2D. However, one participant questioned how diabetic patients would expect family support when their family members did not know about T2D and suggested that diabetes public education should be conducted door-to-door to include family members.

Several patients indicated that they received support from other diabetic patients in the neighbourhood, including advice on herbal and alternative treatments for T2D. Several patients described how during regular village gatherings, they were not served with sweet snacks or drinks because other people knew and cared about their condition. Several participants suggested that regular diabetes meetings and exercise should be facilitated by the CHCs.

## **6. The Perceptions of HCPs and Patients with T2D on the Expectations of Diabetic Patients from Their HCPs Regarding Their Diabetes Care**

Several HCPs revealed that there were many requests from diabetic patients to increase the amount of oral diabetes medications dispensed to at least 10 days or even to 30 days (as practiced at the district hospital), rather than the usual 3-5 days. However, these HCPs indicated that it was impossible to fulfil the requests, because that was the treatment protocol applied at the CHCs. Meanwhile a few patients requested the provision of insulin injections at the CHCs, a practice occurring at the neighbouring district CHCs.

Several HCPs acknowledged that many patients requested blood sugar testing to be performed more frequently than monthly and free of charge. They indicated that the general patients who paid out-of-pocket for medical fees at the CHCs could have more frequent blood sugar tests,

however this was not possible for patients covered by *Jamkesmas* (the government health security programme for poor people) or *Askes* (the government health insurance for civil servants). One GP revealed that most diabetic patients preferred blood sugar tests using finger-prick sampling rather than venous blood sampling, because the former was quicker than the latter.

Several HCPs indicated that many diabetic patients requested ongoing CHC facilitated diabetes group meetings which would permit diabetic patients to obtain peer support and further diabetes education. These HCPs expected that the initial group meetings organised by the CHC should serve as a stimulant for diabetic patients to set up their own diabetes group independently. However, these HCPs indicated that mostly it did not work that way. Even when the diabetes group was established, there were no activities. Meanwhile, there were a few neighbourhoods that had established diabetes groups independently with regular activities, such as weekly exercise classes.

In contrast to the HCPs' responses, the expectations of diabetic patients were primarily related to the inadequate provision of diabetes education. Many participants suggested that the HCPs should provide more detailed diabetes education, not only giving prescriptions. The participants also expected the HCPs to remind them about diabetes management, particularly about food choices, during their patient-provider encounters.

Many patients expected the HCPs to increase the amount of diabetes medications prescribed and dispensed, from 3 days to at least 7 days but preferably enough for 30 days (as was the practice at the district hospital). This would mean that the patients would not need to attend the CHCs too frequently or buy the medication from pharmacies outside the CHCs. Two patients believed that subsidised insulin injections should be available at the CHCs, particularly because CHC patients mostly came from lower socioeconomic groups. Two patients indicated that they had requested prescriptions for vitamins, but these had been refused, and the patients had to purchase the vitamins themselves at a pharmacy.

Several patients suggested that regular diabetes meetings and exercise should be facilitated by the CHCs. One patient requested that the participants of the scoping discussions who were not covered by *Jamkesmas* be assisted to obtain a *Jamkesmas* card so that their diabetes care could be subsidised.

### **7. The Perceptions of HCPs and Patients with T2D on the Impact of T2D on the Patients' Life and Family**

The initial descriptions by HCPs about the impact of T2D on patients mostly focused on physical impact. Only after further prompting by the researcher, did the HCPs describe psychological and financial impacts. HCPs primarily described the physical implications of the disease, including: easily getting sick, decreased vision, diabetic foot, and erectile dysfunction. A few HCPs also indicated that the diabetic patients had to make life adjustments regarding changes to their diet, work, and lifestyle. They also noted that patients needed to attend CHCs more frequently post diagnosis.

Several HCPs indicated that many diabetic patients became bored with the long-term nature of diabetes treatment, particularly when the patients' blood sugar level did not decrease despite dieting and regular diabetes medication. In such cases, sometimes patients increased or decreased their medication dosage by themselves or changed to herbal or alternative treatments.

Several HCPs suggested that since diabetic patients easily became sick and had decreased vision, their work productivity might decrease which consequently would decrease their usual income as craftsmen or tradespersons. Several HCPs described how patients had to spend more money on diabetes medication and blood sugar testing. Even if the diabetes medication and blood sugar testing were free, the patients still had to spend money for transportation to attend CHCs every week. Many elderly patients took pedicels. Sometimes, patients also had to buy artificial sweetener which was more expensive than sugar.

Meanwhile, the responses of patients described larger range of issues, including the physical, psychological, financial and social impact of diabetes. Many participants described the physical implications of diabetes, including: feeling weak, sluggish, tired, easily getting sick, decreased vision, diabetic foot, and erectile dysfunction. However, several diabetic patients suggested that developing the condition had made them more careful in eating and more diligent in doing physical activity.

A few patients described the distress and shock they experienced when newly diagnosed with T2D. Several patients revealed that over time they became bored over with the condition and the ongoing diabetes treatment. It was particularly difficult to be required to restrict their diet at social gatherings, particularly wedding parties. A few patients also revealed that they easily became emotional and angry with family members over small things and they attributed this behaviour to their illness.

Several patients described how their physical symptoms interfered with their capacity to work, their work productivity decreased, and, as tradespersons, this affected their income. Some also described this meant that they had to buy more supplements which were costly.

Several patients indicated that they were sometimes reluctant to attend social gatherings knowing that they could not eat the foods served during the events. One patient described how his need to urinate frequently limited his mobility. In particular, he often had to rethink travelling plans to visit relatives in another city because of this problem.

## **8. The Perceptions of HCPs and Patients with T2D on the Concepts of Diabetes Self-Management and Patient Empowerment**

All HCPs indicated that they had not heard about the concept of diabetes self-management. One GP argued that the common term is only 'diabetes management', not 'diabetes self-management'. However, they made several assumptions about the concept, including:

- The concept is complex, involving not only knowledge but also awareness.
- People with T2D should be proactive, actively learning about T2D by themselves, so as to be in control of the condition.

- People with T2D should 'make friends with diabetes' so that they can structure diet and exercise into their daily life to maintain good glycaemic control, and have a good quality of life.
- People with T2D should take care of themselves daily. The HCPs felt that this was mandatory, because patients do not see HCPs every day, and this may be particularly important where there is a hypoglycaemic condition or a diabetic wound.

All HCPs indicated that they had not heard about the concept of patient empowerment. One GP argued that the term did not exist, but indicated that while presently diabetic patients depended heavily on the HCPs, in the future, the practice should be to work towards patient empowerment.

Nevertheless, the HCPs made several assumptions about the concept, including:

- It is about the independence of diabetic patients in managing their own condition after they are provided with diabetes education. The patients are aware of the disease and the management, no need to be scared by HCPs in applying the recommended diabetes management.
- Diabetic patients should understand about the disease and be able to manage their condition, and strengthen each other with peer support.
- Diabetic patients should be able to manage their own daily life, but follow-up encounters with HCPs are still needed.
- Establishing a diabetes group in the community wherein the members could share experiences with each other would be useful, particularly in enabling new diabetic patients to learn from other patients with longer diabetes duration.

As anticipated, all diabetic patients also stated that they had not heard about the concept of diabetes self-management. Several participants explained that their health information was primarily sourced from the CHCs and the HCPs at the CHCs had not mentioned it. However, they described several aspects which might be seen to be diabetes self-management, including:

- Understanding that diabetic patients need to contribute to the diabetes management
- Actively sourcing and implementing diabetes-related information including knowledge about herbal and alternative treatments
- Implementing healthy lifestyle changes, such as using diabetes diet based on food portions
- Being active in one's own diabetes care, including taking diabetes medication regularly without being reminded by family members, and managing hypoglycaemic symptoms by drinking sweet tea.

Moreover, all diabetic patients stated that they had not heard about the concept of patient empowerment. However, they described several aspects which might be considered to support the patient empowerment notion, including:

- People with T2D are gathered and given public education about T2D and informed to be careful with the condition
- People with T2D are instructed to be motivated and not pessimistic
- Establishing a diabetes group in the community

- Sharing diabetes information in the community
- Conducting diabetes prevention

## **9. The Perceptions of HCPs and Patients with T2D on the Implementation of Diabetes Self-Management and Patient Empowerment Concepts**

Very few HCPs contributed to this discussion topic since few understood the issues sufficiently to comment. Several HCPs suggested that the implementation of the concepts would rely on patient and provider factors. These HCPs described patient characteristics that would influence the implementation include: socioeconomic status, education level, age of the diabetic patients, and patients' priorities. This was particularly because many diabetic patients at CHCs having low socioeconomic status struggled to meet daily living costs, and therefore were more preoccupied with earning enough to buy food rather than managing their diabetes. For many patients, diabetes was considered unimportant compared with other issues in their lives and was ignored except for restricting sweet foods and drinks.

A few HCPs suggested that the most influential factor for successful implementation was the political will and support from the head of district health office or CHC. To support the implementation, the HCPs also suggested that diabetes educators at the CHCs should update their knowledge through diabetes educator training.

Two HCPs suggested that the CHCs were not ready for such implementation due to the existing problems at CHCs. They reasoned that many diabetic patients attending CHCs were elderly and mostly had low socioeconomic status and low education levels. With such backgrounds, HCPs indicated that it would be very difficult to help patients to understand about the underlying concepts, let alone their implementation. The HCPs argued that the concepts would be more suitable for communities with better socioeconomic status and more resources. Thus if the concepts should be implemented, they suggested that it must begin with diabetic patients who attend hospitals, particularly private hospitals, because these patients cared more about their health and had T2D as a priority; or begin with only a few patients with better resources, who could then share their knowledge with other patients.

Two HCPs suggested that the concepts could be implemented, but implementation would require additional funding from the district health office. These HCPs associated the implementation of the concepts to the development of diabetes groups in the communities with a referral system, just like the existing 'health posts' (called *posyandu*) for under-five children and elderly people managed by health cadres in the hamlets and villages. They indicated that when a case occurred, the coordinator of the health post would refer the affected person to the CHCs.

One GP acknowledged that despite the lack of knowledge and existing resources, patients and their families should be empowered by giving education and trust. Patient empowerment would reduce dependency on the HCPs. This GP indicated that the implementation of the concepts was appropriate because if the community was not involved and empowered with respect to T2D, the number of T2D

cases in Indonesia would increase drastically. When the community knew about diabetes and its management, people could give examples of good diet, and then the children and grandchildren may be prevented from developing T2D.

Several HCPs admitted that actually there may be many advantages associated with implementation. Diabetic patients could be knowledgeable and independent. Thus it would be more favourable for the HCPs as HCPs would not need to exert effort in providing diabetes care as was the current practice. Awareness about diabetes in the community would increase, and this would improve diabetes screening.

However, several HCPs also described a few potential disadvantages of such implementation. The HCPs have to be very careful in teaching the right techniques of blood sugar self-testing, otherwise potential risks could occur. Patient to patient education may give rise to errors in patient understanding if it is not adequately supported, and once erroneous knowledge is embedded in the community it would be difficult to change. Finally, a few HCPs wondered if the community became independent then the income of HCPs might decrease.

The HCPs suggested several enablers for implementation. The HCPs at CHCs might be ready to enact this programme because they were already conducting home care to teach diabetic patients and their family members to take care of the patients themselves at home. However, the question was: Would the diabetic patients and their family members be willing to be taught and to apply what was taught? Diabetes group meetings had been initiated by the CHCs and therefore need to be continued. In the last two years the Ministry of Health, the Yogyakarta Provincial Health Office, and Yogyakarta City Health Office had been developing more programmes for non-communicable diseases including for diabetes, such as Caring-for-DM Community Programme.

However, the HCPs also described several barriers to implementation. CHCs were understaffed, particularly for HCPs. The HCPs had low expectations of what the CHCs could do as they stated that HCPs at CHCs could only manage easy tasks and not the complicated ones. There was regular rotation of human resources at CHCs within one district, thus the persons in charge of diabetes programmes were frequently replaced. Poor training of diabetes educators at the CHCs was also considered a barrier to implementation. There was a limited number of diabetes educator training provided by the Yogyakarta City Health Office, and the training only consisted of lectures and did not include teaching practice for diabetes information sessions.

Meanwhile, during the focus group of diabetic patients and their family members, only a few participants commented on this topic, particularly about the advantages of such implementation. A few participants thought that implementation of these concepts would motivate diabetic patients to manage the condition better and would provide hope to patients, provide improved knowledge about the condition and thereby prevent family members from getting T2D, and increase the ability of diabetic patients to disseminate the information to other people thereby preventing others from getting T2D.

## 10. The Perceptions of Patients with T2D on the Research Interventions Administered and the Diabetes Leaflets Provided

The majority of the participants from the control group indicated that the diabetes seminar was very beneficial. The benefits of the diabetes seminar as indicated by the diabetic patients included:

- Increasing the participants' knowledge of T2D, particularly about diabetes meal planning: the right foods to eat and the right time to eat the foods.
- Motivating and enabling the patients to manage their diabetes.
- Serving as a reminder about diabetes management for people with T2D.
- Enabling family members to learn about T2D by reading the diabetes leaflets provided, so that they were better able to support diabetic patients.

One diabetic patient expressed:

*“Although there were already many reading materials on diabetes, this seminar made us feel more determined to manage the condition, because the information about diabetes management was real. So we did not only learn it from reading materials.. It was like a reminder for us.”*

Another diabetic patient said:

*“The benefit of the diabetes seminar was that it increased our diabetes knowledge. Previously 90-100% I did not know about diabetes. In the seminar I learned a lot about diabetes, particularly from the diabetes leaflets provided. I asked my wife and children to read the leaflets so that they could learn about which foods I should eat and help me control what I eat.”*

The majority of the participants from the intervention group indicated that there were many benefits to the diabetes structured patient education sessions, including:

- Increasing the participants' knowledge of T2D.
- Enabling the participants to learn a lot T2D, including: diabetes meal planning, exercise (particularly foot exercise), and how to handle diabetes-related problems.
- Maintaining improved blood sugar level and feeling physically healthier after implementing what had been learned from the sessions and leaflets, e.g.: daily foot exercise, regular physical activity, eating meals with regular schedule, eating more vegetables, and swapping white rice for red or black rice.

One diabetic patient said:

*“My daughter could not attend the sessions with me. I put the diabetes leaflets on the table and they were then read by my daughter. Then she was the one who disciplined my meals. She said that I have to eat this and that; I have to finish eating my veggies and fruits... And I have followed the advice to eat red rice. Now I don't feel like eating white rice anymore.”*

Another diabetic patient said:

*“I also swapped to red rice, and now my children are also eating red rice, following me...”*

Several participants from the control group suggested that the diabetes seminar should be held more frequently. Many participants from the intervention group suggested that the structured diabetes education programme should be continued and not stop after four sessions. A few participants from the intervention group gave additional suggestions, including incorporating the technique for administering insulin injections, and improving intimacy among the participants of the diabetes sessions. One patient suggested incorporating the aspect of cheerfulness into the diabetes leaflets, although this aspect had been addressed during the sessions. This patient reasoned that her emotions and thoughts greatly influenced her blood sugar levels.

### **11. The Experiences of Patients with T2D in Implementing the Recommended Diabetes Management**

Positive experiences and enablers for implementing the recommended diabetes management as indicated by the diabetic patients included:

- Several patients indicated that through controlling food intake, without increasing physical activity, they had greatly improved their blood sugar level.
- Several patients suggested that by following the doctor's advice, particularly with respect to undertaking regular exercise and through good meal planning (e.g.: reducing intake of sweet foods and drinks), they were maintaining a stable blood sugar level.
- Several patients suggested that the motivation to live a long life raising the children and grandchildren was a powerful force to support giving up sweet tea and smoking.
- A few patients indicated that they maintained the habits that had brought their diabetes under control, such as having 2 big meals with snacks and regular exercise (e.g.: daily walking and Tai Chi exercise 3 times a week).
- Several patients suggested that they tried various herbal and alternative treatments to help decrease blood sugar levels.
- Two patients indicated that symptoms of a urinary tract infection were a strong motivator to stop drinking sweet tea and change to water.

Barriers to implementing the recommended diabetes management as indicated by the participants (some of them with corresponding solutions), included:

- Easily getting tired and sleepy during midday while working was overcome by taking over-the-counter energy supplements.
- Difficulty in controlling eating when attending wedding parties, which was a big temptation. The solutions offered to overcome the situation by other participants included: exercising self-control, only choosing foods they were allowed to eat, eating fruits first and reducing the intake of rice, eating protein food only, avoiding the buffet table and focusing on meals served in individual stalls, and tasting various foods in small quantities.
- Becoming distressed because of the lifelong nature of diabetes was overcome by realising that there were problems in life, doing prayers and reciting God's holy names.



- Becoming desperate and bored with the condition because despite complying with the doctors' recommendations the blood sugar level did not decrease. The solutions offered to overcome the situation by other participants included: controlling one's thoughts, accepting the existing situation and not thinking of the situation as a problem, and eliminating the stress.
- Having other life problems (such as financial and family problems). The solutions offered to overcome the situation by other participants included: being open and sharing the problem with other people, praying to God, and making efforts to find a solution.
- Difficulty in implementing the recommended diabetes management because of constant sickness.
- Difficulty in undertaking exercise.
- Difficulty in reducing intake of sweet foods and drinks, particularly when they were served during visits to relatives or friends.
- Difficulty in losing weight, even though already eating less food and drinking water instead of sweet tea.
- Difficulty in gaining weight, even though already following the doctor's recommendations.
- Difficulty in swapping white rice for red rice because red rice was less pleasant and required longer time to cook.
- Difficulty with sleeping (elderly patients).

## **12. The Perceptions of Patients with T2D on Their Own Diabetes Knowledge, Ability, Motivation, Compliance, Family and Social Support to Perform Diabetes Self-care Activities**

Many diabetic patients indicated that their diabetes knowledge had increased. However, some patients felt that they still needed to know more. Several patients suggested that through gaining diabetes knowledge, they could inform other people about diabetes.

Patient responses about changes in their ability to perform diabetes self-care activities such as meal planning and regular exercise varied, from patients who indicated that they had already been comfortable in performing these tasks to others who indicated that their ability to perform these tasks had improved greatly. Some patients found their ability to perform one of these tasks – but not the other – had improved. In addition, patients indicated that their care had improved in the following ways: combining diabetes medication with herbal and alternative treatments, taking smaller amount and fewer type of diabetes medication than before, eating more green vegetables and fruits, and losing weight.

Several patients described their motivation for performing diabetes self-care activities, including: wishing to live a long life to raise their children and/ or grandchildren, learning from the experiences of other patients who developed severe complications, and gaining motivation and hopes from prayers. Several patients suggested that they had tried their best to follow the doctors' recommendations for regular diabetes medication taking, meal planning and exercise, and considered their compliance as

good and in some cases better than before. However, a few patients described difficulty following the recommended diabetes management when they were sick.

Several diabetic patients described good family and social support for performing diabetes self-care activities, such as reminding them about diabetes management, particularly with respect to diet. One patient described problems with family support: although the patient was living with family, the family members did not support the patient's ability to manage his diet.

### **13. Further Expectations and Suggestions of Patients With T2D for the Diabetes Care Provided by HCPs**

Generally many participants described the same expectations and suggestions as previously. In addition, several patients suggested that the diabetes care could be improved by HCPs through:

- Having a more friendly and smiling attitude during patient-provider encounters because sick patients need cheerfulness.
- Becoming more communicative and informative.
- Adjusting the dosage of the diabetes medications when getting different blood sugar testing results (decreasing or increasing), rather than maintaining the same dosage as was the current practice.
- Distributing the diabetes leaflets to other diabetic patients at other CHCs and hospitals.

# **APPENDIX I – Frameworks of Management of Type-2 Diabetes**

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## FRAMEWORKS OF MANAGEMENT OF TYPE 2 DIABETES

The Summary of Initial Management from Guidelines of Type 2 Diabetes developed by Diabetes Australia and the Royal Australian College of General Practitioners<sup>46</sup> is summarised and presented in **Box 1**.

**Box 1: The Summary of Initial Management from Guidelines of Type 2 Diabetes developed by Diabetes Australia and the Royal Australian College of General Practitioners.**<sup>46</sup>

### Initial Management of Type 2 Diabetes

#### 1. Nutrition

- Carbohydrates:
  - It is recommended that carbohydrate foods contribute up to 50% of total energy intake and are spread evenly through the day
  - Recommended foods are high in fibre and have a low glycaemic index
  - A small amount of sugar can be included
- Dietary fat:
  - It is recommended that fat contributes to less than 30% of total energy intake
  - The main thrust of management is to lower total fat intake and to find substitutes for saturated fats.
  - Saturated fats (i.e. meat, dairy products) and fried foods should be avoided.
  - Recommended foods which have lowering effects on cholesterol and triglyceride levels are omega-9 monounsaturated fats (i.e. olive and canola oils), omega-6 polyunsaturated fats (i.e. nuts, seeds), and omega-3 fish oils
- Dietary protein:
  - It is recommended that protein contribute 10-20% of total energy intake.
- Alcohol:
  - Alcohol should be minimised, i.e.  $\leq 2$  standard drinks (20 g) per day for men and women
- Salt:
  - Added salt in cooking and in foods needs to be minimised
  - The use of 'low salt' or 'no salt' products are recommended
- Alternative sweeteners:
  - Sweeteners may have a role in management i.e.: aspartame, sucralose, acesulphame K, alitame, saccharin and cyclamates

#### 2. Physical activity

- Low level aerobic exercise and physical resistance training have the following benefits:
  - Improved glucose tolerance as insulin sensitivity increases
  - Increased energy expenditure resulting in weight loss
  - Increased feeling of well being
  - Increased work capacity
  - Improved blood pressure and lipid profiles
- Recommendation:
  - Aerobic training, i.e. brisk walking, for a minimum of 30 minutes 3 or 4 times a week
  - Aerobic training which brings the heart rate up to 60-70% of maximum ( $220 - \text{age (in years)}$  beats per minute) establishes and maintains fitness and aerobic capacity
  - Active Australia recommends > 150 minutes per week of moderate intensity physical activity, e.g. walking
- A careful history should be taken when prescribing a physical activity programme:
  - Special attention needs to be paid to exertion-induced symptoms, e.g. chest or abdominal discomfort, syncope
  - Diabetics frequently have silent macrovascular disease
  - Consider second yearly ECG if a patient is over 50 years old and has at least one vascular risk factor
  - Screening with a stress ECG is not indicated in asymptomatic individuals, but specific symptoms need to be actively investigated
- Resistance programmes using moderate weights and high repetition can be part of an exercise programme for diabetics
- Patients on insulin sulphonylureas or repaglinide many need to take special precautions to prevent hypoglycaemia
- Appropriate care of feet during physical activity is important

The management of type 2 diabetes based on the clinical guideline developed by National Institute for Health and Clinical Excellence<sup>40</sup> is summarised in **Box 2**.

**Box 2: Summary of Clinical Guideline for Management of Type 2 Diabetes developed by National Institute for Health and Clinical Excellence<sup>40</sup>**

**The Management of Type 2 Diabetes:**

1. Patient education:  
Structured education to every diabetic and/or their carer at and around the time of diagnosis, with annual reinforcement and review
2. Lifestyle management/ non-pharmacological management:
  - Dietary advice include healthy balanced eating, high-fibre, low-glycaemic carbohydrates, and low fat foods
  - Increasing physical activity
  - Losing weight for overweight people
  - Smoking cessation
3. Management of depression
4. Glucose control levels: Target level of HbA1c  $\leq$  6.5%
5. Self-monitoring of plasma glucose
6. Oral glucose control therapies (1): Metformin, insulin secretagogues and acarbose
7. Oral glucose control therapies (2): Other oral agents and exenatide
8. Blood pressure therapy
9. Cardiovascular risk estimation
10. Management of blood lipid levels: Statins and ezetimibe, fibrates, nicotinic acid, omega-3 fish oils
11. Anti-thrombotic therapy: Low-dose aspirin, i.e. 75 mg daily
12. Kidney damage assessment
13. Eye damage assessment
14. Nerve damage assessment

# **APPENDIX J – Frameworks of Diabetes Self-Management Education**

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## FRAMEWORKS OF DIABETES SELF-MANAGEMENT EDUCATION

There are key differences between acute disease and chronic disease as described by Lorig et al. in the book entitled “Living a Healthy Life with Chronic Conditions”,<sup>90</sup> as presented in **Table 1**.

**Table 1: Differences between acute and chronic disease<sup>90</sup>**

Feature	Acute Disease	Chronic Disease
Beginning	Rapid	Gradual
Cause	Usually one	Many
Duration	Short	Indefinite
Diagnosis	Commonly accurate	Often uncertain, especially early on
Diagnostic Tests	Often decisive	Often of limited value
Treatment	Cure common	Cure rare
Role of Professional	Select and conduct therapy	Teacher and partner
Role of Patient	Follow orders	Partner of health professionals, responsible for daily management

There are key differences between traditional and collaborative care as described by Bodenheimer et al.,<sup>11</sup> presented in **Table 2**.

**Table 2: Comparison of traditional and collaborative care in chronic disease<sup>11</sup>**

Issue	Traditional Care	Collaborative Care
What is the relationship between patient & physician?	Professionals are the experts who tell patients what to do. Patients are passive.	Shared expertise with active patients. Professionals are experts about the disease and the patients are experts about their lives
Who is the principal caregiver and the problem solver?	The professional	The patient and professionals are the principal caregivers; they share responsibility for solving problems and outcomes
What is the goal?	Compliance with instructions. Noncompliance is a personal deficit of the patient	The patient sets goals and the professional helps the patient make informed choices. Lack of goal achievement is a problem to be solved by modifying strategies
How is behaviour changed?	External motivation	Internal motivation. Patients gain understanding and confidence to accomplish new behaviours
How are problems identified?	By the professional, e.g. changing unhealthy behaviours	By the patient, e.g., pain or inability to function; and by the professional
How are problems solved?	Professionals solve problems for patients	Professionals teach problem-solving skills and help patients in solving problems

There are major differences between self-management education and traditional patient education as described by Bodenheimer et al.,<sup>11</sup> as presented in **Table 3**.

**Table 3: Comparison of traditional patient education and self-management education<sup>11</sup>**

Issue	Traditional Patient Education	Self-Management Education
What is taught?	Information and technical skills about the disease	Skills on how to act on problems
How are problems formulated?	Problems reflect inadequate control of the disease	The patient identifies problems he/she experiences that may or may not be related to the disease
Relation of education to the disease	Education is disease-specific and teaches information and technical skills related to the disease	Education provides problem-solving skills that are relevant to the consequences of chronic conditions in general
What is the theory underlying the education?	Disease-specific knowledge creates behaviour change which in turn produces better clinical outcomes	Greater patient confidence in his/her capacity to make life-improving changes (self-efficacy) yields better clinical outcomes
What is the goal?	Compliance with the behaviour changes taught to the patient to improve clinical outcomes	Increased self-efficacy to improve clinical outcomes
Who is the educator?	A health professional	A health professional, peer leader, or other patients, often in group settings

Skelton outlines the comparison of the traditional medical-centred model and the patient centred model,<sup>120,123</sup> as presented in **Table 4**.

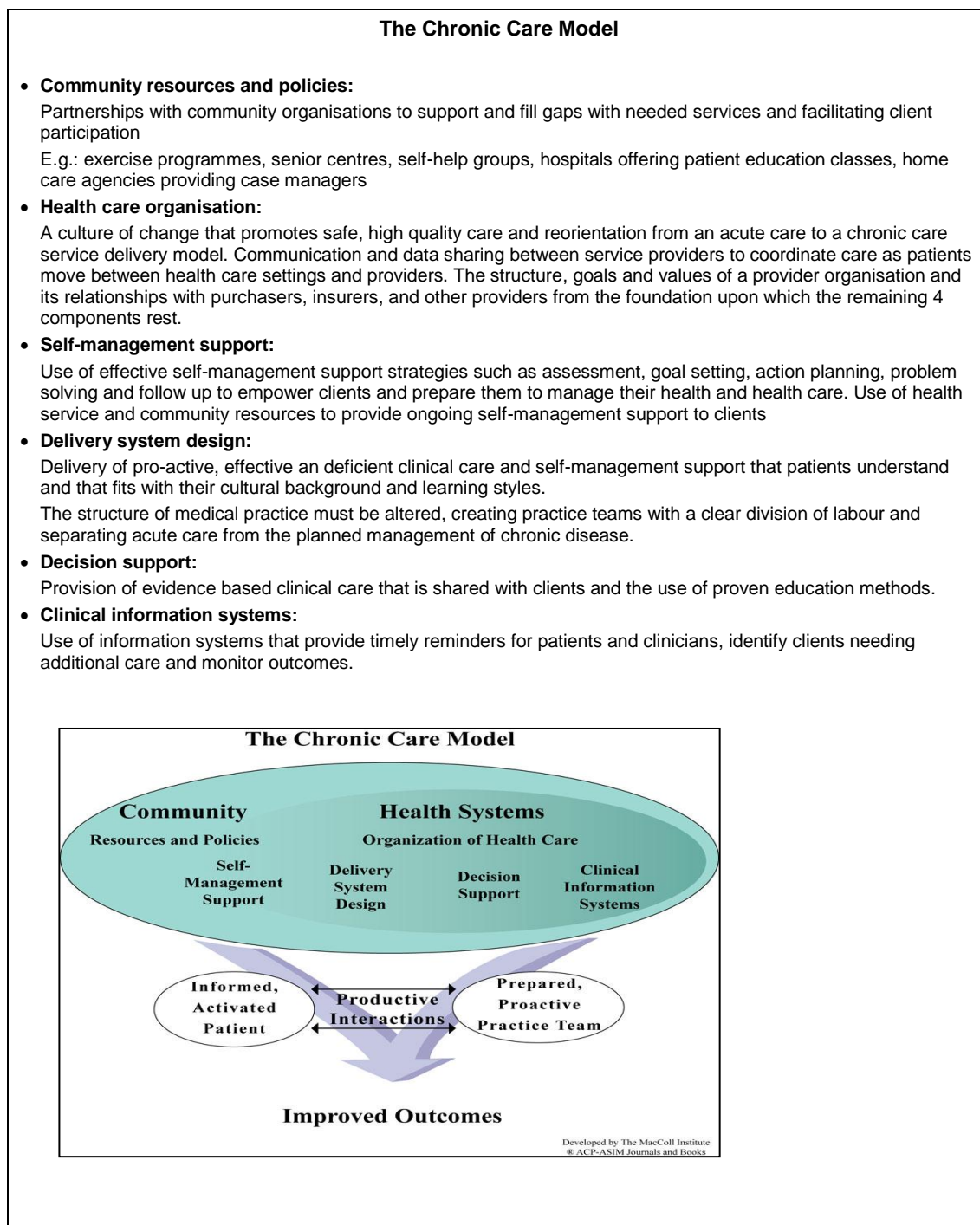
**Table 4: Comparison of traditional medical-centred and patient-centred models<sup>120,123</sup>**

Medical-centred model	Patient-centred model
Compliance	Autonomy
Adherence	Patient participation
Planning for patients	Planning with patients
Behaviour change	Empowerment
Passive patient	Active patient
Dependence	Independence
Professionals determine needs	Patients define needs
Patient	Client



The Chronic Care Model developed by Wagner<sup>101</sup> is presented in **Box 1**.

**Box 1: The Chronic Care Model<sup>101</sup>**



The National Standards for Diabetes Self-management Education 2007 developed by a task force jointly convened by the American Association of Diabetes Educators and the American Diabetes Association<sup>122</sup> is presented in **Table 5**.

**Table 5: The National Standards for Diabetes Self-Management Education 2007<sup>122</sup>**

Guiding Principles	Standards
<p>1. Diabetes education is effective for improving clinical outcomes and quality of life, at least in the short term</p> <p>2. DSME has evolved from primarily didactic presentations to more theoretically based empowerment models</p> <p>3. There is no “best” education programme or approach; however, programmes incorporating behavioural and psycho-social strategies demonstrate improved outcomes. Additional studies show that culturally and age-appropriate programmes improve outcomes and that group education is effective</p> <p>4. Ongoing support is critical to sustain progress made by participants during the DSME programme</p> <p>5. Behavioural goal-setting is an effective strategy to support self-management behaviours</p>	<p><b>Standard 1:</b> <i>The DSME entity will have documentation of its organisational structure, mission statement, and goals and will recognise and support quality DSME as an integral component of diabetes care.</i></p> <p><b>Standard 2:</b> <i>The DSME entity shall appoint an advisory group to promote quality. This group shall include representatives from the health professions, people with diabetes, the community, and other stakeholders.</i></p> <p><b>Standard 3:</b> <i>The DSME entity will determine the diabetes educational needs of the target population(s) and identify resources necessary to meet these needs.</i></p> <p><b>Standard 4:</b> <i>A coordinator will be designated to oversee the planning, implementation, and evaluation of DSME. The coordinator will have academic or experiential preparation in chronic disease care and in programme management</i></p> <p><b>Standard 5:</b> <i>DSME will be provided by one or more instructors. The instructors will have recent educational and experiential preparation in education and diabetes management or will be a certified diabetes educator.</i></p> <p><b>Standard 6:</b> <i>A written curriculum reflecting current evidence and practice guidelines, with criteria for evaluating outcomes, will serve as the framework for the DSME entity. Assessed needs of the individual with pre-diabetes and diabetes will determine which of the content areas listed below are to be provided:</i></p> <ul style="list-style-type: none"> <li>• Describing the diabetes disease process and treatment options</li> <li>• Incorporating nutritional management into lifestyle</li> <li>• Incorporating physical activity into lifestyle</li> <li>• Using medication(s) safely and for maximum therapeutic effectiveness</li> <li>• Monitoring blood glucose and other parameters and interpreting and using the results for self-management decision making</li> <li>• Preventing, detecting, and treating acute complications</li> <li>• Preventing, detecting, and treating chronic complications</li> <li>• Developing personal strategies to address psychosocial issues and concerns</li> <li>• Developing personal strategies to promote health and behaviour change</li> </ul> <p><b>Standard 7:</b> <i>An individual assessment and education plan will be developed collaboratively by the participant and instructor(s) to direct the selection of appropriate educational interventions and self-management support strategies. This assessment and education plan and the intervention and outcomes will be documented in the education record.</i></p> <p><b>Standard 8:</b> <i>A personalised follow-up plan for ongoing self-management support will be developed collaboratively by the participant and instructor(s). The patient’s outcomes and goals and the plan for ongoing self-management support will be communicated to the referring provider.</i></p> <p><b>Standard 9:</b> <i>The DSME entity will measure attainment of patient-defined goals and patient outcomes at regular intervals using appropriate measurement techniques to evaluate the effectiveness of the educational intervention.</i></p> <p><b>Standard 10:</b> <i>The DSME entity will measure the effectiveness of the education process and determine opportunities for improvement using a written continuous quality improvement plan that describes and documents a systematic review of the entities’ process and outcome data</i></p>

The details of the AADE 7 Self-Care Behaviors<sup>TM126</sup> are presented in **Table 6**.

**Table 6: The AADE 7 Self-Care Behaviors<sup>TM126</sup>**

<p><b>1. Healthy eating</b></p>	<ul style="list-style-type: none"> <li>• Making healthy food choices, understanding portion sizes, and learning the best times to eat are central to managing diabetes</li> <li>• By controlling their weight and achieving optimal blood glucose levels, many adults may be able to manage their condition for a time without medications</li> <li>• Diabetes education classes provide information about the effect of food on blood glucose, source of carbohydrates and fat, appropriate meal planning and resources to assist in making food choices</li> <li>• Skills taught include reading labels, planning and preparing meals, measuring food for portion control, fat control and carbohydrate counting</li> <li>• Issues discussed include barriers, e.g. environmental triggers; emotional, financial and cultural factors</li> </ul>
<p><b>2. Being active</b></p>	<ul style="list-style-type: none"> <li>• Regular activity is important for overall fitness, weight management and blood glucose control</li> <li>• With appropriate levels of exercise, those at risk for type 2 diabetes can reduce the risk, and those with diabetes can improve glycaemic control</li> <li>• Being active can also help improve body mass index, enhance weight loss, help control lipids and blood pressure and reduce stress</li> <li>• Diabetes educators and patients collaborate to address barriers, e.g. physical, environmental, psychological and time limitations.</li> <li>• They also work together to develop an appropriate activity plan that balances food and medication with the activity level</li> </ul>
<p><b>3. Monitoring</b></p>	<ul style="list-style-type: none"> <li>• Daily self-monitoring of blood glucose provides people with type 2 diabetes the information they need to assess how food, physical activity and medications affect their blood glucose levels.</li> <li>• Monitoring also includes checking their blood pressure, urine ketones and weight regularly</li> <li>• Diabetes education classes provide information about equipment choices and selection, timing and frequency of testing, target values, and interpretation and use of results</li> </ul>
<p><b>4. Taking medication</b></p>	<ul style="list-style-type: none"> <li>• The health care team will determine which medications people with type 2 diabetes should be taking and help them understand how the medications work</li> <li>• The goal is for the patients to be knowledgeable about each medication, including its action, side effects, efficacy, toxicity, prescribed dosage, appropriate timing and frequency of administration, effect of missed and delayed doses and instructions for storage, travel and safety</li> <li>• Effective drug therapy in combination with healthy lifestyle choices, can lower blood glucose levels, reduce the risk for diabetes complications and produce other clinical benefits.</li> </ul>
<p><b>5. Problem solving</b></p>	<ul style="list-style-type: none"> <li>• People with type 2 diabetes must keep their problem-solving skill sharp because on any given day, a high or low blood glucose episode or a sick day will require them to make rapid, informed decisions about food, activity and medications.</li> <li>• This skill is continuously put to use because even after decades of living with the disease, stability is never fully attained; the disease is progressive, chronic complications emerge, life situations change, and the patient is aging.</li> <li>• Diabetes educators and patients collaborate to address barriers, such as physical, emotional, cognitive, and financial obstacles and develop coping strategies</li> </ul>
<p><b>6. Reducing risks</b></p>	<ul style="list-style-type: none"> <li>• Effective risk reduction behaviours such as smoking cessation, and regular eye, foot and dental examinations reduce diabetes complications and maximise health and quality of life.</li> <li>• An important part of self-care is learning to understand, seek and regularly obtain an array of preventive services to decrease risks.</li> <li>• Skills taught include smoking cessation, foot inspections, blood pressure monitoring, self-monitoring of blood glucose, aspirin use and maintenance of personal care records.</li> </ul>
<p><b>7. Healthy coping</b></p>	<ul style="list-style-type: none"> <li>• Health status and quality of life are affected by psychological and social factors.</li> <li>• Psychological distress directly affects health and indirectly influences a person's motivation to keep their diabetes in control.</li> <li>• When motivation is dampened, the commitments required for effective self-care are difficult to maintain.</li> <li>• When barriers seem insurmountable, good intentions alone cannot sustain the behaviour.</li> <li>• Coping becomes difficult, and a person's ability to self-manage their diabetes deteriorates</li> <li>• An important part of the diabetes educator's work is identifying the individual's motivation to change behaviour, then helping set achievable behavioural goals and guiding the patient through multiple obstacles</li> <li>• They can provide support by encouraging the patients to talk about concerns and fears and can help them learn what they can control and offer ways for them to cope with.</li> </ul>

The Royal Australian College of General Practitioners outlined key aspects relating to the clients' ability to take on a self-management role,<sup>129</sup> as presented in **Table 7**.

**Table 7: Key aspects relating to the clients' ability to take on a self-management role<sup>129</sup>**

<b>Factors Affecting Self-management</b>	<b>How Can These Factors be Modified</b>	<b>Practical Points to Consider</b>
<b>Motivation</b>	This will be effected by the stage of change currently experienced by the client	<ul style="list-style-type: none"> <li>• What stage of change is the client in?</li> <li>• Is the client concerned about lifestyle behaviours?</li> <li>• Does the client recognise the benefits that may come with the change?</li> <li>• Does the client know what action is needed to change?</li> </ul>
<b>Knowledge of condition</b>	Knowledge helps the client in their decision making process. However, it is generally accepted that programme which seek to improve health by increasing client knowledge alone are rarely successful	<ul style="list-style-type: none"> <li>• Does the client want information related to their illness?</li> <li>• Does the client understand the rationale behind treatment?</li> </ul>
<b>Knowledge of symptom management plan</b>	Information on managing a crisis, emergency or symptoms is important for both client or carer (s)	<ul style="list-style-type: none"> <li>• Does the client have a symptom management plan?</li> <li>• Is there a need to consider the management capacity of carers and others in the immediate social environment as well?</li> </ul>
<b>Co-morbidities</b>	Consideration of other conditions that may affect self-management, e.g. sensory or cognitive impairments (hearing or visual loss, dementia)	<ul style="list-style-type: none"> <li>• Are there sensory or cognitive impairments that may affect the client's ability to self-manage?</li> </ul>
<b>Health beliefs</b>	Understanding the religious, cultural and familial beliefs that may influence the effect of management interventions	<ul style="list-style-type: none"> <li>• What effect do these beliefs have on the client's thoughts about self-management?</li> </ul>
<b>Self-efficacy</b>	The extent of the client's confidence in their capacity to self-manage, the extent to which the client values him/herself and the extent to which they feel they have some control over their ability and desire to assume a self-management role	<ul style="list-style-type: none"> <li>• Is the client confident in his/her ability to self-manage?</li> <li>• Does the client feel that he/she has the skills to make changes and control the illness?</li> </ul>
<b>Social context</b>	Consideration of such things as access to services and cultural aspects of the client's life	<ul style="list-style-type: none"> <li>• What aspects of life, e.g. family, friends, literacy, access, employment, culture, roles need to be considered?</li> </ul>

# **APPENDIX K – Frameworks of Patient Empowerment**

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## FRAMEWORKS OF EMPOWERMENT APPROACH

Anderson and Funnel integrates the key concepts of empowerment into the design of their educational programmes emphasising on the whole person and personal strengths,<sup>148</sup> as presented in **Box 1**.

### Box 1: Outline of integrated self-management education<sup>148</sup>

#### Outline of Integrated Self-Management Education

1. **Educator** elicits the primary concern of the patient:
  - a) Identify the area of greatest dissatisfaction with current situations
  - b) Patient and educator agree to focus efforts on this area
2. **Educator** discusses nature of patient-provider relationship in the treatment of diabetes:
  - a) Diabetes is a self-managed disease
  - b) Educator will act as expert consultant
  - c) Educational process is intended to help patients make informed choices in diabetes self-management
3. **Educator** assesses current status (physical, psychosocial, cognitive, etc.) of patient's diabetes knowledge and self-management practices:
  - a) Assists patient to identify self-management problems
  - b) Assists patient to identify feelings related to diabetes and diabetes care
4. **Educator** acknowledges patient's responsibilities for self-management;
  - a) Helps patient explore, reflect on, and clarify personal values specific to diabetes
  - b) Helps patient identify desired outcomes
5. **Educator** provides relevant diabetes information based on patient-identified concerns and educator's assessment:
  - a) Describes diabetes and various treatment options
  - b) Reviews costs and benefits for each option
  - c) Helps patient identify personal costs and benefits for each option
6. **Patient** selects goals and identifies barriers and strengths related to achieving self-management goals
7. **Patient** assumes problem-solving responsibility:
  - a) Develops skills to optimise support (e.g. develops communication and assertiveness skills to enhance support from family and friends, increases support networks)
  - b) Identifies potential barriers/ supports
  - c) Learns strategies skills to overcome barriers (e.g. negotiation, self-care agreements and plans, conflict resolution to maximise support)
8. **Patient** identifies options to try and establishes plan in collaboration with educator
9. **Patient** carries out plan
10. **Patient** and educator evaluate, review and revise plan.

The problem solving process conducted in empowerment-based DSME group programmes follows the five-step empowerment model using the Behaviour Change Protocol as outlined by Anderson and Funnel,<sup>148</sup> as presented in **Box 2**.

**Box 2: Empowerment-based problem solving model using the Behaviour Change Protocol.<sup>148</sup>**

<b>Behaviour Change Protocol</b>
<p><b>Step 1: Explore the problem or issue (past)</b></p> <ul style="list-style-type: none"><li>• What is the hardest thing about caring for diabetes for you?</li><li>• Please tell me more about that.</li><li>• Are there some specific examples you can give me?</li></ul> <p><b>Step 2: Clarify feelings and meaning (present)</b></p> <ul style="list-style-type: none"><li>• What are your thoughts about this?</li><li>• Are you feeling [insert] because [insert meaning]?</li></ul> <p><b>Step 3: Develop a plan (future)</b></p> <ul style="list-style-type: none"><li>• What do you want?</li><li>• How would this situation have to change for you to feel better about it?</li></ul> <p><b>Step 4: Commit to action (future)</b></p> <ul style="list-style-type: none"><li>• Where would you like to be regarding this situation in [specific time, e.g., 1 month, 3 months, and 1 year]?</li><li>• What are your options?</li><li>• What are barriers for you?</li><li>• What could help you?</li><li>• What are the cost and benefits for each of your choices?</li><li>• What would happen if you do not anything about it?</li><li>• How important is it, on a scale of 1 to 10, for you to do something about this?</li><li>• Let's develop a plan.</li></ul> <p><b>Step 5: Experience and evaluate the plan (future)</b></p> <ul style="list-style-type: none"><li>• How did it go?</li><li>• What did you learn?</li><li>• What barriers did you encounter?</li><li>• What, if anything, would you do differently next time?</li><li>• What will you do when you leave here today?</li></ul>

Funnel and Anderson outlined strategies for promoting patient empowerment that can be used by HCPs and implemented within a practice,<sup>146</sup> as summarised and presented in **Box 3**.

**Box 3: Summary of the strategies for promoting patient empowerment<sup>146</sup>**

**The Strategies for Promoting Patient Empowerment  
Used by Health Care Providers and Implemented within a Practice**

**During patient visits, providers can:**

- Stress the importance of patients' role in self-management and daily decision making. Describe our role as coach or partner in the care process. Acknowledge the patient's right and responsibility to make self-care choices and to be the primary decision makers.
- Begin each visit with an assessment of patients' concerns, questions, and progress towards metabolic and behavioural goals. Some providers ask patients to complete a short, open-ended one- to three- question form to ascertain any questions or concerns they would like to be addressed during the visit.
- Listen to patient-identified fears and concerns.
- Ascertain patients' opinions about home blood glucose monitoring results and other laboratory and outcome measures.
- Review and revise diabetes care plans as needed based on patients and providers' assessment of its effectiveness.
- Provide ongoing information about the costs and benefits of therapeutic and behavioural options. Acknowledge that there are many options for treating diabetes, and determine patients' interests in or concerns about each option.
- Take advantage of teachable moments that occur during each visit.
- Establish a partnership with patients and their families to develop collaborative goals.
- Provide information about behaviour change and problem solving strategies
- Assist patients in solving problems and overcoming barriers to self-management.
- Support and facilitate patients in their role as self-management decision-makers.
- Offer referrals to a diabetes education programme and a registered dietician

**Within the practice, professionals can:**

- Link patient self-management support with provider support (e.g. system changes, patient flow, logistics)
- Supplement self-management support with information technology
- Incorporate self-management support into practical interventions, coordinated by nurse case managers or other staff members
- Create a team with other health care professionals in your system or area who have additional experience or training in the clinical, educational, and behavioural or psychosocial aspects of diabetes care
- Replace individual visits with group or cluster visits to provide efficient and effective self-management support
- Assist patients in selecting one area of self-management on which to concentrate that can be reinforced by all team members
- Create a patient-centred environment that incorporates self-management support from all practice personnel and is integrated into the flow of the visit



The empowerment model was used throughout the Lifelong Management (LM) sessions,<sup>16,31</sup> as presented in **Table 1**. Helpful hints for diabetes educators for facilitating empowerment-based DSMS programmes<sup>16,31</sup> are listed in **Table 2**.

**Table 1: Structure of the DSMS intervention using empowerment model<sup>16,31</sup>**

<b>Structure of the Weekly Problem-Based Group Sessions of DSMS Intervention</b>
<p><b>Component 1: Reflecting on Relevant Experiences (~ 10 minutes)</b></p> <p>Purpose: At the end of the sessions, group patients have identified a goal and action plan related to their self-management. At the beginning of the subsequent session, patients are invited to reflect on their experience of working on their self-selected goals.</p> <ul style="list-style-type: none"> <li>• Invite group patients to comment on goals identified and implemented (plan of action) since the last session.</li> <li>• Do the patients view their experiences as positive or negative?</li> <li>• What did patients learn from this experience?</li> <li>• What did patients learn about their diabetes self-management?</li> <li>• Can they incorporate what they learned into their overall self-management plans</li> </ul>
<p><b>Component 2: Discussing the Role of Emotion (~ 10 minutes)</b></p> <p>Purpose: Living with diabetes raises emotional issues related to relationships, work, family, economic circumstances, overall health, physical functioning, and other life events. We provide this time to have group patients discuss important events that have occurred since the previous meeting and how these events have affected their self-management.</p> <ul style="list-style-type: none"> <li>• Invite group patients to talk about something that happened since the last session and what feelings it raised for them</li> <li>• How can these feelings influence self-management decisions?</li> </ul>
<p><b>Component 3: Engaging in Systematic Problem-Solving (~ 30 minutes)</b></p> <p>Purpose: The problem-solving component is based on the fundamental principle that patients' concerns and needs are the highest priority. Topics and issues discussed are ones patients have self-identified or generated. The problems addressed include interacting with health care providers as well as self-management and psycho-social issues. The flexibility of the group structure is guided directly by patients' needs.</p> <ul style="list-style-type: none"> <li>• Invite a group patient to raise a problem or concern he or she is encountering</li> <li>• Generate possible solutions to the problem</li> <li>• Identify facilitators and barriers to implementing possible solutions</li> <li>• The individual patient determines the "goodness of fit" of the solution based on his or her experience</li> <li>• The individual patient outlines a plan of action based on the identified problem and goals for self-management</li> <li>• Each week, patients will be invited to conduct a self-care experiment by trying to achieve a self-selected short-term goal. However, patients will not be pressured to set a goal if they do not wish to do so.</li> </ul>
<p><b>Component 4: Answering Clinical Questions (~ 20 minutes)</b></p> <p>Purpose: This component provides the opportunity for patients to inquire about diabetes self-management related issues. We have identified topic about which people can ask questions. These general topic areas are drawn from the National Standards for Diabetes Self-Management education listing of required content areas:</p> <ul style="list-style-type: none"> <li>• Address diabetes-related clinical and health inquiries raised</li> <li>• Participants share and exchange knowledge among the group</li> <li>• Participants are encouraged to seek consultations from health care providers when necessary</li> <li>• Psychosocial and behavioural aspects are addressed for each of the clinical areas identified as a way to integrate content with the patients' behaviour and life experiences</li> </ul>
<p><b>Component 5: Providing Feedback (~ 20 minutes)</b></p> <p>Purpose: We actively solicit feedback from patients at the end of each session so the community-based group interventions can be tailored and modified to the needs of the patients.</p> <ul style="list-style-type: none"> <li>• What are some things you found helpful about this session?</li> <li>• Is there anything we can do to make future sessions better?</li> <li>• What are future discussions or topics you would like to raise for next week?</li> </ul>

**Table 2: Helpful Hints for Facilitating Empowerment-Based DSMS Programmes<sup>16,31</sup>**

<b>Helpful Hints for Facilitating Empowerment-Based DSMS Programmes</b>
<p><b>DO:</b></p> <ul style="list-style-type: none"> <li>• Actively look for opportunities to turn the question back to the group. If it is a purely clinical question, then answer it. If not, ask the group to respond</li> <li>• Actively look for opportunities to ask questions that will help integrate psychosocial and behavioural aspects with clinical content</li> <li>• Clarify that you have been understood</li> <li>• Ask questions to stimulate discussions rather than just starting to lecture.</li> <li>• For example, "What do you think of the sodium content of this food?" rather than telling the group it is too high in sodium.</li> <li>• Provide positive feedback for effort, not results. Use experiences to help the group: "What is different about your exercise plan this time that is helping you to follow through? How were you able to get past your feelings of denial?"</li> <li>• Listen. Allow a few minutes of quiet before responding unless it is clear that a question has been posed that requires a response</li> <li>• Include participants' words in your response based on the advice you want to give. Respond to what the patient has said.. Respond to what the patient has said.</li> <li>• Refrain from formulating your response based on the advice you want to give</li> <li>• Redefine patient's statements by putting it back to them: "What do you think?" or "How can you make that better?" or "What have you done in the past that has worked?"</li> <li>• Be patient</li> </ul>
<p><b>AVOID:</b></p> <ul style="list-style-type: none"> <li>• Giving a 20-minute lecture in response to a question. Answer the question and then wait for the response. Think of it as an interview.</li> <li>• Making judgements, including positive judgements.</li> <li>• Using judgment words (e.g. good, bad, great, positive, negative, better, success, failure, control, out-of-control, must, should)</li> <li>• Trying to direct the conversation. Remember that non-diabetes-related conversations help the group get to know each other and bond</li> </ul>

# **APPENDIX L – Conference Presentation Abstracts**

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## 2009 STATE POPULATION HEALTH CONFERENCE: “Challenges and Successes in Public Health”

31 October 2009, Adelaide, Australia

### Patient Empowerment Programme Promoting Self-Management for Adult Patients with Type 2 Diabetes in Primary Care Setting in Indonesia\*

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**Background:** Diabetes is a global public health problem which can cause serious disabling complications. Indonesia has been among the top four countries with the highest numbers of diabetes. Diabetes self-management education is widely recognized as an essential element of diabetes care. However, self-management program which entails patient empowerment is an entirely new concept in Indonesia.

**Aims:** To evaluate the effectiveness of patient empowerment program promoting self-management in improving knowledge of diabetes, lifestyle behaviours, self-care skills, psychosocial self-efficacy, quality of life, and clinical outcomes in adult patients with type 2 diabetes in primary care setting in Indonesia.

**Methods:** An RCT of 100 adult diabetic patients who will be randomly allocated to either intervention or control group. The intervention group will receive a six-week structured patient education promoting diabetes self-management with family involvement (one family member for each patient), while the control group will be given a two-hour didactic teaching on diabetes. Prospective surveys using a questionnaire on diabetes related aspects and measurements of clinical outcomes (blood pressure, fasting blood glucose, HbA1c, lipid profile) will be done at baseline, 3 month and 6 month follow up. Focus group interviews will be carried out with patients, family members, general practitioners and nurses.

**Expected Outcomes:** Improvements of health outcomes of diabetic patients: 20% increase of diabetes knowledge score, 20% increase of lifestyle behaviours score, 20% increase of self-care skills score, 20% increase of psychosocial self-efficacy score, 10% increase of quality of life score, and 10-20% increase of clinical outcomes.

\*Oral presentation

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The 18<sup>TH</sup> WONCA ASIA PACIFIC REGIONAL CONFERENCE 2011:  
“Paradigms of Family Medicine:  
Bridging Old Traditions with New Concepts”

21-24 February 2011, Cebu, Philippines

**Cross Cultural Adaptation of Diabetes-related Health Belief Instrument  
for Patients with Type 2 Diabetes in Indonesia\***

Oryzati Hilman-Agrimon<sup>1,2</sup>, Justin Beilby<sup>2</sup>, Jackie Street<sup>3</sup>, Yayi Suryo Prabandari<sup>4</sup>

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**Background:** Diabetes is a global public health problem which can cause serious disabling complications. Indonesia has been among the top four countries with the highest numbers of diabetes. Although there are various diabetes instruments to evaluate diabetes care in international literature, adequate Indonesian language instruments are scarce. Therefore, suitable diabetes-related Indonesian language instruments need to be developed or adapted for Indonesian population.

**Aims:** To adapt an English/ Spanish version of the Diabetes-related Health Belief instrument consisting of 25 items for use with an Indonesian population.

**Methods:** The first two steps of the study included translation and back-translation of the English/ Spanish version, and content validation through expert panel. The Indonesian version instrument was then distributed to a convenience sample of 83 adult patients with type 2 diabetes at two community health centres in Yogyakarta City, Indonesia. Third step was reliability testing of the adapted instrument for internal consistency using Cronbach's Alpha.

**Results:** The internal consistency reliability of the total scales showed coefficient  $\alpha = 0.737$  (acceptable).

**Conclusion:** The Diabetes-related Health Belief instrument for patients with type 2 diabetes was determined to be valid and reliable for use in the Indonesian population. However, some cultural factors affected the applicability of some items of the instrument.

\*Oral presentation

## The 2<sup>ND</sup> ASEAN REGIONAL PRIMARY CARE CONFERENCE 2011: “Achieving Millennium Development Goals through Primary Care”

24-26 November 2011, Jakarta, Indonesia

### Patient Empowerment Program Promoting Diabetes Self-Management in Community Health Centres (*Puskesmas*) in Yogyakarta City, Indonesia\*

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**Background:** Diabetes is a global public health problem which can cause serious disabling complications. Indonesia has been among the top four countries with the highest numbers of diabetes. Self-management is important in chronic disease management including type 2 diabetes (T2D); and diabetes patient education is a key factor for a successful diabetes care. All patients with T2D are recommended to be referred to structured patient education. Diabetes self-management education should involve “empowering patients” and include multifaceted interventions providing knowledge, management skills, coping skills and attitudes. However, diabetes self-management is not widely known in Indonesia.

**Aims:** To pilot a “patient empowerment program promoting diabetes self-management” in Community Health Centres (CHCs) or *Puskesmas* in Yogyakarta City. The program aims to develop skills, build confidence, and enable diabetic patients to make informed decisions regarding their diabetes self-care.

**Methods:** Two CHCs in Yogyakarta City were chosen as the setting of the pilot program. Adult patients with T2D registered in the two CHCs were invited to attend the program. The pilot program was a four-week structured patient education, with different topics discussed each week: (1) Understanding T2D and Setting Goals; (2) Prevention & Life Style Modification; (3) Meal Planning & Physical Activity; and (4) Diabetes Self-Management & Evaluation. It was designed as small group and interactive sessions (20-25 people) involving one family member for each patient. All diabetic patients were given a set of 10 diabetes education leaflets. After completing the program, all participants were asked to fill out an evaluation form of the pilot program.

**Results:** A total of 49 diabetic patients attended two small groups of four-week structured diabetes patient education held in two CHCs. Generally, all participants were very satisfied with the pilot program and requested to have follow-up diabetes education sessions because they could learn a lot on diabetes knowledge and skills as well as meet and share experiences with other diabetic patients.

**Conclusion:** The patient empowerment program promoting diabetes self-management should be introduced and applied in community health centres in Indonesia to develop skills, build confidence, and enable diabetic patients to make informed decisions regarding their diabetes self-care.

\*Oral presentation

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**The 19<sup>TH</sup> WONCA ASIA PACIFIC REGIONAL CONFERENCE 2012:  
“Clinical Excellence in Family Medicine:  
Evidence-Based Approach in Primary Care”**

**24-27 May 2012, Jeju, Korea**

**Patient Empowerment Programme Promoting Diabetes Self-Management  
in Primary Care Setting in Yogyakarta City, Indonesia\***

Oryzati Hilman-Agrimon<sup>1,2</sup>, Justin Beilby<sup>2</sup>, Jackie Street<sup>3</sup>, Yayi Suryo Prabandari<sup>4</sup>

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<sup>4</sup> Department of Public Health, Faculty of Medicine, the University of Gadjah Mada, Yogyakarta, Indonesia

**Background:** Indonesia has been among the top four countries with the highest numbers of diabetes. Self-management is important in chronic disease management including type 2 diabetes (T2D); and diabetes patient education is a key factor for a successful diabetes care. All patients with T2D are recommended to be referred to structured patient education. Diabetes self-management education should involve “empowering patients” and include multifaceted interventions providing knowledge, management skills and coping skills.

**Aims:** To develop a patient empowerment program promoting diabetes self-management and assess its effectiveness on diabetes knowledge, self-care behaviours, and clinical outcomes.

**Methods:** Adults with type 2 diabetes [T2D] (n=101) registered in four community health centres in Yogyakarta City, Indonesia were randomized to either diabetes seminar [control group] (n=50) or structured patient education on diabetes self-management [intervention group] (n=51). Intervention group participants were invited to attend four weekly 2-3 hour sessions with different topics discussed each week. It was patient-centred and interactive group sessions involving one family member for each patient. All participants were given a set of 10 diabetes education leaflets. Outcomes were assessed at baseline and 3 month.

**Results:** Forty-nine participants (96.1%) attended the patient empowerment programme (1-4 sessions). After 3 months, the intervention group showed significant improvements compared to the control group in the scores of diabetes knowledge [Diabetes Knowledge Questionnaire] and self-care behaviours (Summary of Diabetes Self-Care Activities), means of 2-hour postprandial blood glucose, systolic blood pressure, body fat, waist and hip circumferences. Although the primary outcome of HbA1C of the intervention group did not show statistically significant improvement compared to the control group (p=0.081), there was a decrease of the mean (8.612 to 8.380) which showed a positive trend. This might be due to the short time of the assessment.

**Conclusion:** The patient empowerment program promoting diabetes self-management could be useful in improving diabetes knowledge, self-care behaviours, glycaemic control, systolic blood pressure, body fat, waist and hip circumferences. However, longer time of assessment should be done to allow for the behaviour change process to take place which may make significant improvements.


**Key words:** patient empowerment, diabetes self-management, randomized controlled trial, structured patient education


\*Oral presentation

## **APPENDIX M – Diabetes Leaflets**

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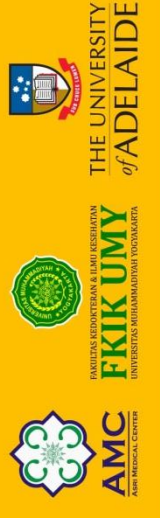



  
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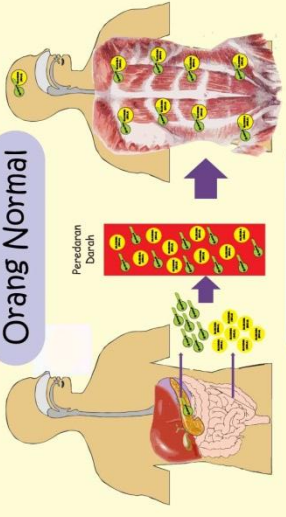
# Kenali Diabetes Mellitus dan Bertindaklah!

**“Pengetahuan adalah Kekuatan”**  
 Mengenal diabetes adalah kunci  
 untuk **bersahabat** dan **hidup sehat**  
 bersama diabetes seumur hidup!


  
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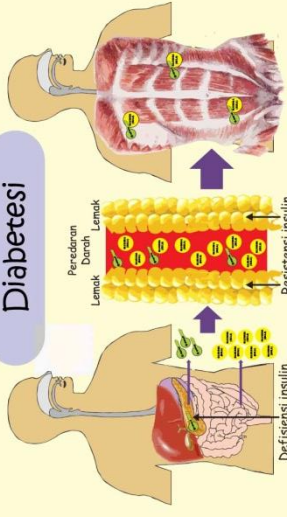
## Mekanisme Kerja Insulin

**Orang Normal**



Persediaan Darah

**Diabetesi**



Defisiensi insulin  
= **GLUKOSA (GULA)**  
= **INSULIN**

Resistensi insulin

Penderitaan Darah Lemak

Reprinted with permission from Effrie Kopsaffris (Certified Diabetes Educator, SA, Australia) via personal communication

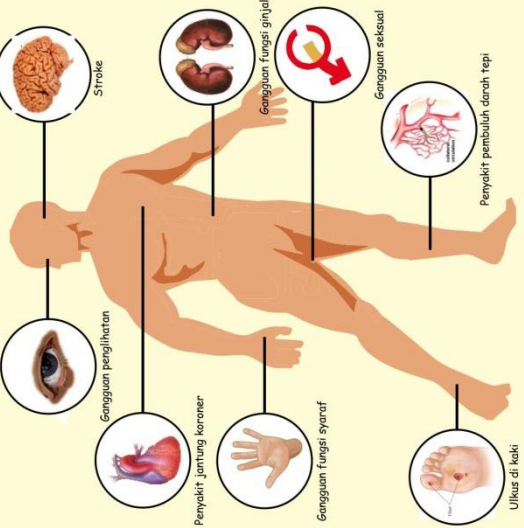
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## Komplikasi Kronik




**Pengelolaan Diabetes Mellitus:**  
**4 Sehat 5 Teratur**


Edukasi Diabetes meningkatkan:

- Pengetahuan tentang diabetes mellitus
- Perubahan sikap & perilaku gaya hidup sehat
- Penyesuaian psikologis & kualitas hidup yang lebih baik

**Edukasi Berkelanjutan**




**Pengobatan**




- Obat oral  
- Insulin

**Pengaturan Makanan**




- Tambah kalori  
- Tambah protein  
- Tambah lemak

**Aktivitas Fisik/ Olahraga Teratur**



Minimal 30 menit setiap hari

**Cek Kadar Gula Darah**



- Gula darah puasa  
- Gula darah 2 jam setelah makan  
- HbA1c

### Pengertian Diabetes Mellitus

**DIABETES MELLITUS (DM)** atau penyakit gula/ kencing manis merupakan suatu kelompok penyakit metabolik yang ditandai dengan kadar glukosa darah yang melebihi normal (hiperglikemia) yang terjadi karena kelainan sekresi insulin, kerja insulin, atau keduanya.

(Sumber: American Diabetes Association, 2005)

**DIABETESI** adalah penderita diabetes mellitus.

### Klasifikasi

1. Diabetes mellitus tipe 1
2. Diabetes mellitus tipe 2
3. Diabetes mellitus gestasional
4. Diabetes tipe lain (Diabetes sekunder)

(Sumber: American Diabetes Association, 2005)

### Faktor Risiko

- Riwayat keluarga (faktor keturunan)
- Usia: bertambahnya usia
- Ras/ suku bangsa: orang Asia/ Afrika
- Aktivitas fisik kurang
- Kegemukan

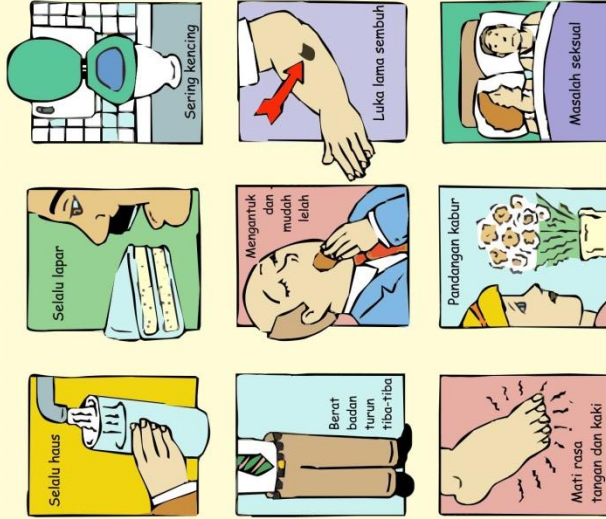


### Kriteria Diagnosis

	Bukan DM	Belum pasti DM	DM
<b>GDS</b> (Gula Darah Sewaktu)	Vena < 100 Kapiler < 90	100–199 90–199	≥200 ≥200
<b>GDP</b> (Gula Darah Puasa)	Vena < 100 kapiler < 90	100–125 90–99	≥126 ≥100

(Sumber: Konsensus PERKENI, 2006)

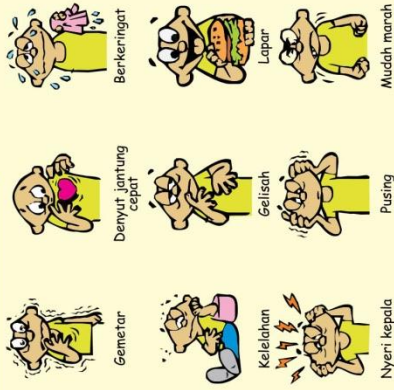
### Gejala-Gejala



Sumber : Eli Lilly & Company in collaboration with Boehringer Mannheim Corporation

### Komplikasi Akut

#### Hipoglikemia

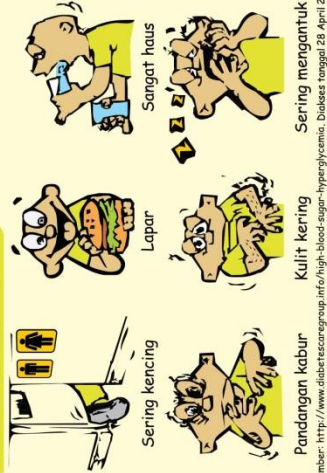


Sumber: <http://www.diabetescaregroup.info/hipoglykemia-low-blood-sugar>. Diakses tanggal 28 April 2011.

**Kadar Gula Darah < 60 mg/dl**

**Yang harus dilakukan:**  
1. Segera hentikan aktivitas  
2. Segera minum teh manis/permen  
3. Bila pringsan, segera dibawa ke RS

#### Hiperglikemia




**Kadar Gula Darah > 200 mg/dl**

**Yang harus dilakukan:**  
Bila ada nafas cepat dan adihan, badan lemas, akhirnya pringsan, segera dibawa ke RS. Keadaan ini (KOMA KETOASIDOSIS) sangat berbahaya, dapat menyebabkan KEMATIAN!


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# Pengaturan Makanan



untuk

# DIABETESI 1

**“We are what we eat”**  
*(Kita seperti apa yang kita makan)*

### Lemak

- Lemak membantu penyerapan nutrisi, transmisi saraf, menjaga integritas membran sel, dll.
- Jika berlebihan, lemak menyebabkan kenaikan berat badan, penyakit jantung dan jenis kanker tertentu.
- Komposisi lemak = 20-25% x total kalori harian, tidak > 30% kalori harian.

Apakah semua lemak tidak baik?

Jawabannya lihat di brosur  
**Pengaturan Makanan untuk Diabetesi 2**

### Komposisi Makanan

#### Karbohidrat

- Komposisi karbohidrat = 45 - 65% x total kalori harian.
- Sumber karbohidrat diutamakan berupa karbohidrat kompleks/berserat tinggi.
- Gula pasir tidak >5% total kalori harian.
- Frekuensi makan 3 x/hari ditambah makanan selingan 2-3 x/hari untuk mendistribusikan asupan karbohidrat dalam sehari.

**Sumber karbohidrat:**

- Pasta, nasi, sereal
- Umbi atau sayuran berzat tepung, seperti kentang dan jagung.
- Roti, biskuit, kue, makanan manis (snack)

#### Protein

- Komposisi protein = 10-20% x total kalori harian.
- Pada pasien diabetes dengan gangguan ginjal (nefropati diabetik): asupan protein dibatasi menjadi 0,8 gr/kg BB perhari atau 10% dari kebutuhan total kalori, dan 65% hendaknya berkualitas baik dengan nilai biologik tinggi.

**Sumber protein yang dianjurkan:**

- Ikan, daging tanpa lemak, ayam tanpa kulit, produk susu rendah lemak, kacang-kacangan, tahu, tempe.

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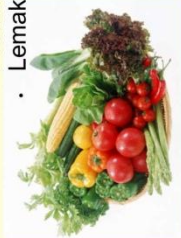
## Panduan Diet Sederhana



### Jumlah kalori

Asupan makanan sesuai kebutuhan kalori (BB kurang/BB normal/BB lebih).

- Karbohidrat : 45-65%
- Protein : 10-20%
- Lemak : 20-25% (<7% Lemak jenuh, <10% Lemak tidak jenuh)



- Serat : ganda, sisanya lemak tidak jenuh (tinggal)
- Gula pasir : ± 25 gram/hari
- : 5% (dari total kalori)
- Kolesterol : <300 mg/hari
- Natrium : 3.000 mg/hari

### Jadwal makan

Makan teratur 5-6 kali/hari (3 kali makan besar, 2-3 kali makan kecil, dengan selang waktu 2-3 jam) : **"Sedikit-sedikit tapi sering."**



### Jenis makanan

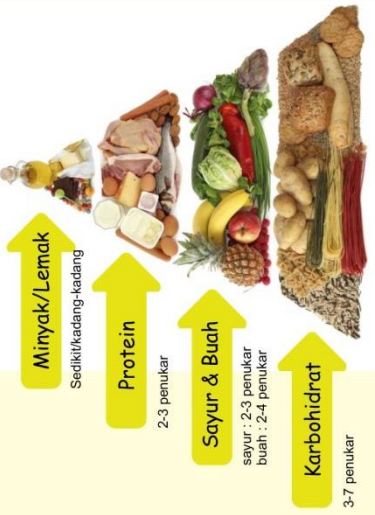
- Pilih makanan yang sehat:
- Karbohidrat kompleks
- Indeks glikemik rendah
- Tinggi serat
- Protein
- Lemak tidak jenuh tunggal dan ganda



Sumber: Pusat Diabetes dan Lipid RSCM/IFK UI, 2009

## Makanan Seimbang untuk Diabetesi

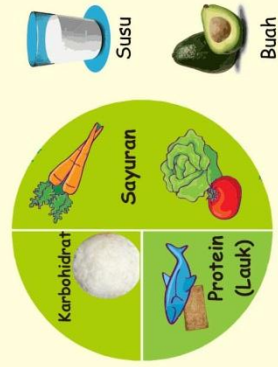
### Piramida Makanan



### BATASI :

- Gula (Gula alternatif diperbolehkan sesuai batas aman [ADI/ Accepted Daily Intake] 4 mg/kg BB)
- Lemak jenuh
- Garam/ natrium

### Proporsi Makanan Seimbang



Sumber: Pusat Diabetes dan Lipid RSCM/IFK UI, 2009

## Pengukuran Porsi Makanan

### Pengukuran Asupan Nutrisi Harian

**Karbohidrat dan Buah**

Sebesar satu genggam tangan

**Lemak**

Batasi lemak seukuran ibu jari

**Protein**

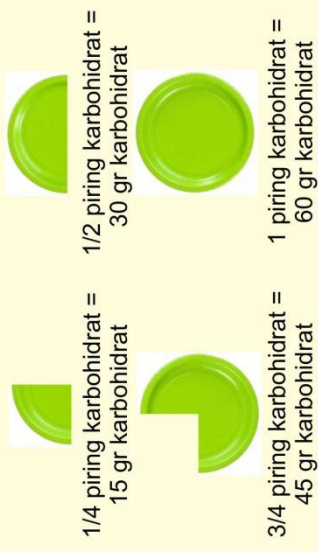
Seukuran dua telapak tangan, dengan ketebalan jari kelingking

**Sayuran**

Seukuran dua telapak tangan, sayuran rendah kalori: selada, kobis, tomat

Sumber : [http://diabetes.ca/files/plan\\_your\\_portions.pdf](http://diabetes.ca/files/plan_your_portions.pdf), Diakses tanggal 28 April 2011.

### Metode Piring Idaho



Sumber : <http://www.platemethod.com/>, Diakses tanggal 28 April 2011.



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# Pengaturan Makanan



untuk

# DIABETESI 2





### Sumber Makanan Tinggi Kalsium



1. Susu
2. Keju, yoghurt, es krim
3. Susu kedelai
4. Ikan: salmon, sarden, makarel, belut, kakap, ikan teri
5. Sayuran hijau: buncis, brokoli, kubis, bayam, sawi
6. Buah: jeruk, pepaya
7. Biji-bijian: gandum, nasi, nasi merah, jagung

Sumber:  
• Straub, DA. Calcium Supplementation in Clinical Practice: A Review of Forms, Doses and Indication. *Journal of Nutr. Clin Pract* 2007; 22: 186.  
• Pareira, et.al. Dietary Calcium-Strategies Optimize Intake. *Rev Bras Rheumatol* 2009; 49(2): 164-80

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## Kalsium

### Fungsi Kalsium:

- Membentuk dan mempertahankan tulang dan gigi yang sehat.
- Membantu pembekuan darah dan penyembuhan luka.
- Penghantaran rangsang syaraf.
- Membantu kontraksi otot.
- Membantu transport ion melalui membran sel.
- Komponen penting dalam memproduksi hormon dan enzim yang mengatur proses pencernaan, energi dan metabolisme lemak.

### Kebutuhan Kalsium (Anjuran WHO)

Usia	Kebutuhan Kalsium (mg)
0-6 bulan	300
7-12 bulan	400
1-3 tahun	500
4-8 tahun	800
9-18 tahun	1300
19-50 tahun	1000
50 tahun ke atas	1200
Ibu hamil & menyusui	+400

Dosis penyerapan optimal kalsium : **500 mg/ saji**. Apabila konsumsi lebih dari dosis optimal maka penyerapan kalsium akan menurun.

Jenis Lemak

LEMAK BAIK

A. ASAM LEMAK TIDAK JENUH TUNGGAL (*Mono-unsaturated Fatty Acid/ MUFA*)

- Menurunkan kolesterol total & LDL (kolesterol jahat) dan meningkatkan kolesterol HDL (kolesterol baik).
- **Sumber:** Alpukat, zaitun, kacang tanah, kacang mete, almond, minyak zaitun, minyak canola, minyak kacang.



B. ASAM LEMAK TIDAK JENUH GANDA (*Poly-unsaturated Fatty Acid/ PUFA*)

- Menurunkan kolesterol total & LDL.
- **Sumber:** Minyak kedelai, minyak jagung, minyak bunga matahari, ikan salmon, mackerel, tuna, sarden, kacang-kacangan, biji kenari dan biji bunga matahari.



Dianjurkan makan ikan 2 atau lebih sediaan tiap minggu untuk memenuhi asupan lemak omega 3

LEMAK JAHAT

A. LEMAK JENUH (*Saturated Fatty Acid*)

- Meningkatkan kolesterol darah total dan LDL (kolesterol jahat).
- **Sumber:** Lemak daging (gajih), susu, telur, makanan laut, santan, minyak kelapa dan minyak sawit.

B. LEMAK TRANS (*Trans Fat*)

- Ditemukan dalam proses produksi pangan agar makanan lebih awet. Sebagai hasil dari hidrogenasi, asam lemak trans terbentuk.
- Asam lemak trans ditemukan dalam banyak makanan kemasan komersial (biskuit, kue, *snack*), kentang goreng (*french fries*), *popcorn*, serta minyak sayur.

Sumber: <http://www.healthcastle.com/goodfats-badfats.shtml>. Diakses tanggal 27 April 2011.



Kolesterol

- Anjuran konsumsi kolesterol < 300 mg/hari.
- Kolesterol ditemukan pada telur, makanan laut, dan jerohan.
- Walaupun kolesterol dalam makanan dapat meningkatkan kadar kolesterol darah, tapi lebih penting untuk membatasi makanan yang tinggi lemak jenuh atau lemak trans.

Natrium

- Asupan natrium yang dianjurkan bagi penyandang diabetes tidak >3000 mg atau sama dengan 6-7 gr (1 sendok teh) garam dapur .
- Bagi penderita hipertensi, pembatasan natrium ≤ 2400 mg garam dapur.
- **Sumber natrium:** garam dapur, vetsin, soda.



Pemanis Buatan

A. PEMANIS BERNUTRI BERKALORI (4 kal/ gram)

- Gula alkohol: *Sorbitol, Mannitol, Malitol*, dan *Xylitol*
- Fruktosa: alaminya ditemukan pada buah. Tidak dianjurkan pada diabetesi karena efek samping pada lemak darah.



B. PEMANIS TIDAK BERNUTRISI/ BERKALORI (0 kal/ gram)

- Contoh : aspartam (*Tropicana Slim, Equal, NutraSweet*), asesulfam K, siklamat, sakarin, sukralose (*Nulife, Splenda*), stevia (*Tropicana Slim SteLEAF*)
- Aman digunakan selama tidak melebihi batas aman (*Accepted Daily Intake/ADI*).



Daun Stevia

## Tips Sederhana Diet "Karbohidrat Baik"

- Cobalah untuk mengurangi 'junk food' sebanyak mungkin dari pola makan yang mencakup hampir semua keripik, permen, minuman ringan, dll.
- Hindari/batasi asupan makanan: roti non-gandum utuh, donat, *brownies*, kue, sereal tinggi gula.
- Beli berbagai buah-buahan segar dan sayuran dan mulai untuk menyertakan setidaknya 1 atau 2 porsi setiap jadwal makan besar. Hindari rasa lapar dan makan terlalu banyak, dengan mengemil buah atau sayuran.
- Cobalah untuk makan satu porsi sayuran berdaun hijau min. 2x/hari. Juga makan berbagai sayuran berwarna lain sesering mungkin.
- Gunakan kacang-kacangan dan biji-bijian sebagai *snack* sehat.
- Makan satu porsi kacang atau polong-polongan setidaknya 1-2x/hari.
- Jika membeli produk tepung (roti, sereal, biskuit, pasta, dll) selalu memilih gandum utuh. Pastikan bahwa 'gandum utuh' adalah kata pertama dalam daftar komposisi bahan.
- Bila mungkin, selalu memilih **makanan organik**.



- **LIHATLAH INDEKS GLIKEMIKNYA.** Semakin kecil angka indeks glikemik maka semakin baik bagi (kesehatan) Anda karena karbohidrat tersebut oleh tubuh Anda akan diubah menjadi glukose dalam darah secara lambat (*slow foods*). Dengan demikian hormon insulin akan merespons metaboliseme glukose itu dengan sewajarnya (pankreas tidak memproduksi insulin secara berlebihan).

### SUMBER KARBOHIDRAT BAIK

Nasi merah, ubi, gandum, oatmeal, singkong, pasta, sayur-sayuran dan buah-buahan yang tidak terlalu manis.

Sumber: <http://www.goodcarbs.org/>  
Diakses tanggal 28 April 2011.

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[www.oryzati.com](http://www.oryzati.com)

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# Pengaturan Makanan



untuk

# DIABETESI 3



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THE UNIVERSITY  
of ADELAIDE

### Serat

- Diabetesi dianjurkan mengkonsumsi cukup serat:  $\pm 25 \text{ gr}/1000 \text{ kkal}/ \text{hari}$ .
- Serat dibagi menjadi dua kategori:
  - A. SERAT TIDAK LARUT:**
    - **Manfaat:** melancarkan buang air besar yang teratur dan mencegah sembelit.
    - **Sumber:** sayuran berdaun hijau gelap, gandum utuh, dedak gandum & jagung, kulit buah & akar sayur, kacang-kacangan & biji-bijian.

### B. SERAT LARUT:

- **Manfaat:** menurunkan kolesterol total & kolesterol jahat (LDL), mengurangi risiko penyakit jantung, mengatur gula darah bagi diabetesi.
- **Sumber:** gandum, sereal, polong-polongan kering, kacang-kacangan, buah-buahan (jeruk, apel), sayuran (wortel).

Sumber: <http://www.healthcaastle.com/fiber-soluble-insoluble.shtml>. Diakses tanggal 26 April 2011.

### Indeks Glikemik

- Indeks Glikemik (*Glycemic index/GI*) adalah ranking makanan (0-100) yang menunjukkan seberapa cepat atau lambat suatu makanan karbohidrat dicerna dan diserap, dan mengidentifikasi seberapa banyak makanan menaikkan kadar gula darah (sedikit, sedang atau tinggi).
- Kategori pangan menurut rentang IG:
  - 1) IG tinggi, rentang  $IG > 70$
  - 2) IG sedang, rentang  $IG 55 - 70$
  - 3) IG rendah, rentang  $IG < 55$

### Beban Glikemik

- Beban glikemik (*Glycemic load/GL*) membantu memprediksi efek makanan pada kadar gula darah dengan mempertimbangkan **indeks glikemik makanan dan jumlah karbohidrat** yang dikonsumsi.

$$\text{Beban Glikemik} = \frac{\text{Indeks Glikemik} \times \text{Jml Karbohidrat (gr)}}{100}$$

### Contoh:

1 buah kentang memiliki GI 90, mengandung 20 gram karbohidrat.  $GL = (90 \times 20) / 100 = 18$

### GI vs. GL

- GI dipakai untuk membandingkan makanan sejenis.
- Sedangkan GL untuk membandingkan makanan yang berbeda dengan karbohidrat dan kadar GI yang bervariasi.
- Mempertimbangkan GL bermanfaat ketika membuat perencanaan makan untuk mengendalikan kadar gula darah.

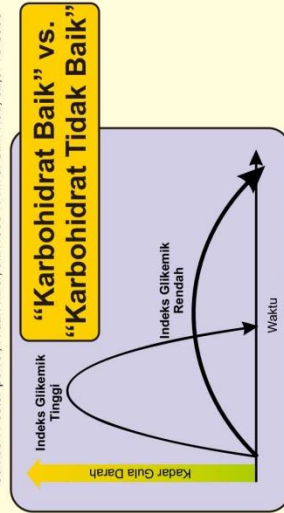
### Efek Karbohidrat, Protein & Lemak pada Kadar Glukosa Plasma

	Kisaran jumlah yang dikonversi menjadi glukosa	Kisaran waktu kadar glukosa tertinggi setelah makan
Karbohidrat	90 – 100%	Gula sederhana: 15-30 menit Karbohidrat kompleks: 1-1,5 jam
Protein	~ 58%	~ 3 – 4 jam
Lemak	< 10%	Beberapa jam

### Indeks Glikemik Beberapa Makanan

No	Jenis Makanan	GI% (Glukosa=100)	Kategori
1	Bubur	92	Tinggi
2	Beras putih, rendah amilosa (pulen, ketan)	88	Tinggi
3	Kentang panggang	85	Tinggi
4	Madu	73	Tinggi
5	Semangka	72	Tinggi
6	Wortel	71	Tinggi
7	Roti (terigu)	69	Sedang
8	Soft drink	68	Sedang
9	Jagung	68	Sedang
10	Nanas	66	Sedang
11	Gula pasir	55	Sedang
12	Es krim	61	Sedang
13	Beras putih, tinggi amilosa	59	Sedang
14	Kentang rebus	56	Sedang
15	Mangga	55	Sedang
16	Kentang goreng	54	Sedang
17	Ketela rambat	54	Sedang
18	Pisang	53	Sedang
19	Jeruk	43	Rendah
20	Apel	36	Rendah
21	Kedelai	18	Rendah
22	Kacang tanah	14	Rendah

Sumber: Foster-powell, K dan miler, J.B.1995-. Am. J. Clin. Nutr. 62:871S-893S





## Tips Mengatasi Hambatan Beraktivitas Fisik

- SAYA TERLALU SIBUK, TIDAK PUNYA WAKTU !**
- Luangkan waktu 3 x 10 menit untuk beraktivitas fisik.
  - Cobalah lakukan aktivitas yang bisa dimasukkan ke dalam rutinitas sehari-hari, seperti berjalan kaki/bersepeda saat bepergian.
- SAYA TIDAK SUKA OLAHRAGA !**
- Lakukan berbagai macam bentuk aktivitas fisik, sampai akhirnya menemukan yang paling disukai.
  - Cari anggota keluarga/teman menjadi "partner aktif" dalam beraktivitas fisik untuk saling memotivasi, berkomitmen, dan menikmati aktivitas bersama.
  - Dengarkan musik sambil beraktivitas.

## SAYA TERLALU CAPEK UNTUK BEROLAHRAGA !

- Beraktivitas secara teratur dapat menimbulkan energi lebih.
- Ingatlah perasaan "segar" sesaat setelah beaktivitas fisik.
- Cobalah untuk beraktivitas fisik di waktu pagi sebelum memulai kesibukan di hari itu.

Sumber: Australian General Practice Network & Baker IDI Heart and Diabetes Institute, 2008.

## Aktivitas Fisik



**30 menit/hari**  
Tetap sehat



**60 menit/hari**

Mencegah kenaikan berat badan



**60-90 menit/hari**  
Mengurangi berat badan



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Pusat Studi Kedokteran Keluarga  
Fakultas Kedokteran dan Ilmu Kesehatan  
Universitas Muhammadiyah Yogyakarta

FAKULTAS KEDOKTERAN KELUARGA  
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UNIVERSITAS MUHAMMADIYAH YOGYAKARTA

# Aktivitas Fisik



untuk

# DIABETESI 1

"Aktivitas fisik  
bukan hanya olahraga saja"

"Aktiflah setiap hari dengan  
berbagai cara yang bisa dilakukan"



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### Manfaat Olahraga/ Aktivitas Fisik

- Meningkatkan aliran oksigen jaringan sehingga meningkatkan sensitivitas insulin
- Membakar kalori dan mengurangi lemak tubuh sehingga meningkatkan kemampuan metabolisme sel dalam menyerap dan menyimpan glukosa
- Meningkatkan mood.
- Mengurangi gejala depresi dan cemas
- Meningkatkan tingkat energi untuk melakukan aktivitas sehari-hari.
- Meningkatkan kualitas hidup
- Memperbaiki kualitas tidur.
- Membantu mengelola berat badan.
- Mengembalikan kehidupan seks.
- Meningkatkan mobilitas dan kekuatan di usia tua.
- Mengurangi risiko penyakit jantung
- Membantu menurunkan tekanan darah tinggi (hipertensi) dan kolesterol tinggi
- Membantu mencegah atau mengendalikan diabetes tipe 2
- Mengurangi resiko radang sendi dan mengurangi gejala terkait
- Membantu mencegah osteoporosis

Sumber:

- <http://www.annecollins.com/health-benefits-of-exercise.htm>. Diakses tanggal 28 April 2011.
- <http://www.mayoclinic.com/health/exercise/HQ01676>. Diakses tanggal 28 April 2011.



### Rekomendasi Aktivitas Fisik

- Aktivitas fisik minimal 30 menit, dengan intensitas sedang dalam beberapa hari per minggu.
- Aktivitas dapat dilakukan 30 menit sekaligus, atau dibagi dalam 10 atau 15 menit.

Sumber: *Physical Activity and Health: A report of the Surgeon General. U.S. Department of Health and Human Services, Centers for Disease Control and Prevention. 1996.*

### Tips Praktis Aktivitas Fisik

- Lakukan pekerjaan rumah dengan bersemangat.
- Saat menonton TV lakukan dengan berdiri atau sambil menyetraka baju.
- Saat iklan di TV, berdiri dan gerakan badan/berjalan keliling ruangan
- Letakkan remote TV di atas TV, bila ingin memindah saluran lebih baik berdiri dan berjalan menuju TV.
- Berpergian lebih baik berjalan kaki/bersepeda, daripada naik bermotor/kendaraan umum (becak, andhong, dll).
- Sebelum berbelanja di pasar, berjalan mengelilingi pasar.
- Naik tangga lebih baik daripada naik lift/ eskalator.
- Saat bekerja, istirahat sebentar untuk berjalan mengelilingi ruangan kerja.

Sumber: Australian General Practice Network & Baker IDI Heart and Diabetes Institute, 2008.

### Membakar Kalori dengan Aktivitas Harian

“Olahraga sebenarnya bukan sesuatu yang sulit dilakukan, karena beberapa pekerjaan rumah yang biasa dilakukan juga merupakan bentuk olahraga”

#### Kalori = METs x BB x waktu

Kalori : Jumlah kalori yang terbakar  
 METs : *Metabolic equivalents* atau banyaknya energi sewaktu melakukan latihan  
 BB : Berat badan (kg)  
 Waktu : Lama latihan  
**Contoh** : Menyikat lantai 30 menit, BB 50 kg.  
 Kalori yang terbakar: 4 x 50 x 30/60= 100 kal

AKTIVITAS	METS
Bersepeda permukaan mendaki	8,5
Lari cepat	8,0
Menaiki tangga	8,0
Jogging	7,0
Lari santai	7,0
Sepakbola	7,0
Jalan cepat permukaan mendaki	6,0
Berenang	6,0
Senam aerobic <i>low impact</i>	5,0
Mencuci mobil	4,5
Jalan cepat permukaan datar	4,0
Bersepeda	4,0
Menyikat lantai	4,0
Menyapu/membersihkan rumah	3,5
Menuruni tangga	3,0
Jalan lambat	2,5
Memasak	2,5
Menyeterika	2,3
Mencuci piring	2,3

Sumber: <https://sites.google.com/site/compendiumpofphysicalactivities>. Diakses tanggal 28 April 2011.

- **Kenakan tanda pengenalan diabetes, agar orang tahu bila terjadi sesuatu dengan Anda.**
- **Hipoglikemi** adalah risiko yang dapat terjadi sewaktu berolah raga.
- Kenaikan penyerapan glukosa oleh otot dapat menurunkan gula darah ke tingkat yang sangat rendah (hipoglikemi).
- Gejala hipoglikemi adalah badan gemetar, jantung berdebar, keringat bertambah, rasa lapar, pusing, lesu, bingung, dan perubahan mood yang cepat.



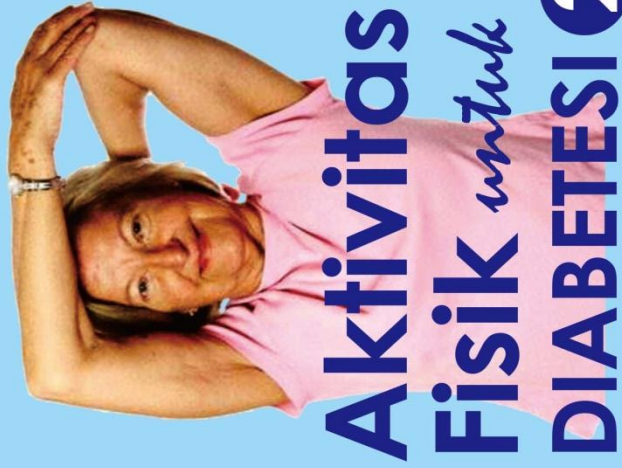
- **Bila terkena gejala hipoglikemi.**

- Cek gula darah Anda.
- Konsumsi makanan atau minuman manis (jus, manis buah). Hindari makanan yang mengandung lemak karena menghalangi penyerapan glukosa oleh tubuh.
- Istirahat 10-15 menit dan lakukan pengecekan lagi sebelum melanjutkan latihan. Jangan meneruskan olah raga bila gula darah di bawah 100 mg/dl.
- Bila melanjutkan olahraga, selalu waspada terhadap munculnya kembali gejala hipoglikemi.
- Setelah selesai olahraga, makanlah makanan yang mengandung karbohidrat kompleks (ubi, roti gandum utuh dan jagung).

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*“Penderita diabetes yang rajin berolah raga secara teratur dapat melepaskan diri dari ketergantungan pada obat.”*



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- Lakukan pengetestan gula darah 12 jam setelah latihan yang agak berat untuk mengecek hipoglikemi yang muncul setelah latihan (*late onset*).
- **Berolahragalah dengan gembira.**
  - Untuk meningkatkan dan mempertahankan motivasi Anda berolah raga, bergabunglah dengan klub-klub olah raga diabetes yang ada di dekat tempat tinggal Anda.

Sumber: <http://indodiabetes.com/11-tips-ber-olah-raga-bagi-penderita-kencing-manis-diabetes.html>. Diakses tanggal 28 April 2011.

*Penurunan berat badan sebesar 5% dari berat awal dapat mengurangi risiko penyakit jantung dan diabetes mellitus tipe 2*

Sumber: American Journal of Cardiology, 2003

Informasi, pengobatan dan perawatan diabetes lebih lanjut  
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## Konsep F.I.T.T.

### FREKUENSI

- Lakukan secara teratur 3-5x/minggu dan berselang-seling atau tidak boleh dalam hari berturut-turut.

### INTENSITAS

- Olahraga aerobik bersifat ringan hingga sedang, yaitu denyut jantung berkisar 60-70% MHR saat olahraga.
- MHR (*Maximum Heart Rate*/Denyut Nadi Maksimal)= 220-Umur

### TIME (WAKTU)

- Durasi latihan antara 30-60 menit

### TIPE

- Olahraga yang bersifat *endurance* (*aerobic*) yang berfungsi untuk meningkatkan kemampuan jantung dan pembuluh darah, misalnya: jalan, jogging, bersepeda, renang.

## Prinsip Olahraga

- Pemanasan (5-10 menit)
- Latihan Inti (20-40 menit)
- Pendinginan
- Peregangan (*stretching*)

Sumber: Pusat Diabetes dan Lipid RSCM/FK UI, 2009

Sesuai dengan latihan olahraga dengan kapasitas tubuh. Jika tubuh jarang melakukan olahraga sebelumnya, pilihlah olahraga ringan (membakar 5 kal/menit); jalan kaki santai, bersepeda santai dan senam (*low impact*).

## Tips Berolahraga bagi Diabetesi

- Konsultasi dengan dokter sebelum menjalani program olah raga.
  - Dokter akan merekomendasikan jenis olah raga apa yang boleh dilakukan sesuai kondisi Anda.
  - Dokter biasanya akan melarang Anda berolah raga bila:
    - Glukosa darah > 250 mg/dl.
    - Memiliki gejala retinopati (kerusakan pembuluh darah pada mata), neuropati (kerusakan syaraf dan sirkulasi darah pada anggota badan), nefropati (kerusakan ginjal) dan gangguan jantung seperti jantung koroner, infark miokard, aritmia, dll.



- Bila tidak ada larangan, mulailah dengan olah raga ringan seperti senam aerobik (*low impact*), berjalan, bersepeda dan berenang.
  - Olah raga aerobik tersebut bermanfaat memperdalam pernafasan dan meningkatkan kerja jantung.
  - Bagi Anda yang tidak pernah berolahraga, awali dengan 10-20 menit setiap kali latihan, beberapa kali seminggu.

- Perhatikan masalah kaki Anda.
  - Sebelum berjalan sehat atau jogging, pastikan kenyamanan dan keamanan sepatu yang dipakai
  - Selalu gunakan kaus kaki yang nyaman.
  - Periksa apakah ada kerikil atau benda lain sebelum mengenakan sepatu.
  - Hindari lecet atau goresan di kaki.
- Bila Anda memiliki masalah di kaki, sebaiknya pilih berenang, senam atau bersepeda yang tidak terlalu membebani kaki.



- Jangan mengangkut beban berat karena dapat meningkatkan tekanan darah secara tiba-tiba.
- Awali dan akhiri latihan dengan pemanasan dan pendinginan selama 5-10 menit untuk mengurangi risiko jantung dan cedera otot.
- Jangan menambah porsi latihan secara drastis.
  - Setiap kali, naikkan hanya satu faktor saja (frekuensi, lama atau intensitas latihan olahraga).

# Perawatan & Senam KAKI DIABETES



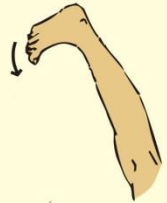
- 10 Gerakan ke-10 (sekali)**
1. Letakkan sehelai koran di lantai.
  2. Bentuk kertas itu menjadi seperti bola dengan kedua belah kaki.
  3. Kemudian, buka bola itu menjadi lembaran seperti semula dengan kedua kaki. Lakukan sekali saja.
  4. Lalu robek koran jadi 2 bagian, pisahkan kedua bagian koran.
  5. Satu bagian koran di sobek-sobek jadi kecil-kecil dengan kedua kaki.
  6. Pindahkan kumpulan sobekan tersebut dengan kedua kaki, lalu letakkan sobekan kertas pada bagian kertas yang utuh.
  7. Bungkus semuanya dengan kedua kaki menjadi bentuk bola.



Informasi, pengobatan dan perawatan diabetes lebih lanjut<sup>TM</sup> silahkan kunjungi:


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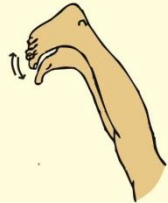
- 6 Gerakan ke-6 (masing-masing kaki 10 kali)**
1. Luruskan salah satu kaki di atas lantai.
  2. Angkat kaki tersebut.
  3. Gerakkan ujung-ujung jari kaki ke arah muka.
  4. Turunkan kembali kaki, bergantian kiri dan kanan.



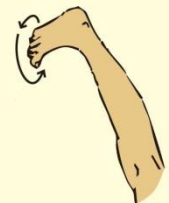
- 7 Gerakan ke-7 (10 kali)**
- Seperti gerakan sebelumnya (gerakan ke-6) tetapi kali ini dengan kedua kaki bersamaan.



- 8 Gerakan ke-8 (10 kali)**
1. Angkat kedua kaki, luruskan dan pertahankan posisi tersebut.
  2. Gerakkan kaki pada pergelangan kaki, ke depan dan belakang.



- 9 Gerakan ke-9 (masing-masing kaki 10 kali)**
1. Luruskan dan angkat salah satu kaki.
  2. Putar kaki pada pergelangan kaki.
  3. Tuliskan angka 0 s.d. 10 di udara dengan kaki.



## Perawatan Kaki



Cuci kaki dengan air hangat tiap hari



Gunakan pelembab (*hand body lotion*)



Bila kaki terluka, tutup dengan pembalut steril




Bersihkan alas kaki dari benda tajam



Hindari air atau benda terlalu dingin atau panas



Keringkan, terutama di antara jari



Periksa kaki setiap hari



Pada orang tua dengan diabetes penyembuhan luka lebih lama



Gunakan sepatu/sandal yang baik, sesuai ukuran, dan enak dipakai



Lakukan Senam kaki diabetes

## Senam Kaki Diabetes

### Tujuan Senam Kaki

- Memperbaiki sirkulasi darah.
- Memperkuat otot-otot kecil kaki.
- Mencegah terjadinya kelainan bentuk kaki.
- Meningkatkan kekuatan otot betis dan paha.
- Mengatasi keterbatasan pergerakan sendi.



### Cara Senam Kaki

#### Senam kaki minimal 3 x/sehari



**Posisi awal:**  
Duduklah tegak di atas kursi (jangan bersandar)

#### 1 Gerakan ke-1 (10 kali)

1. Gerakkan jari-jari kedua kaki seperti cakar.
2. Luruskan kembali



#### 2 Gerakan ke-2 (10 kali)

1. Angkat ujung kaki, tumit tetap diletakkan di atas lantai
2. Turunkan ujung kaki, kemudian angkat tumitnya dan turunkan kembali.



#### 3 Gerakan ke-3 (10 kali)

1. Angkat kedua ujung kaki.
2. Putar pergelangan kaki ke arah samping
3. Turunkan kembali ke lantai dan gerakan ke tengah.



#### 4 Gerakan ke-4 (10 kali)

1. Angkat kedua tumit kaki.
2. Putar kedua tumit ke arah samping.
3. Turunkan kembali ke lantai dan gerakan ke tengah.



#### 5 Gerakan ke-5 (masing-masing kaki 10 kali)

1. Angkat salah satu lutut.
2. Luruskan kaki.
3. Gerakkan jari-jari kaki ke depan.
4. Turunkan kembali kaki, bergantian kiri dan kanan.



Sumber: <http://www.thewig.eu/mediapool/41/419555/data/happyfootscan.jpg>  
Diakses tanggal 28 April 2011.

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# Target Pengelolaan Diabetes Mellitus



## Apa tujuan Anda dalam minggu ini?

- Spesifik = .....
- Diukur = .....
- Dicapai = .....
- Realistis = .....
- Waktu = .....



## Contoh Metode "SMART/SDDRW"

### RUTIN MAKAN SAYURAN & BUAH-BUAHAN

- Spesifik = makan sayuran & buah-buahan 3-5 takaran per hari, minimal 3x/minggu, mulai besok
- Diukur = bisa diukur jumlahnya
- Dicapai = bisa dipilih (sayur & buah cukup murah)
- Realistis = bisa dicapai
- Waktu = mulai besok, dalam 3 bulan bisa kelihatan perbedaannya (badan lebih segar, hasil gula darah membaik)



### RUTIN JALAN KAKI

- Spesifik = rutin jalan kaki 30 menit, 3x/minggu, mulai besok
- Diukur = bisa diukur berapa lama & seringnya
- Dicapai = bisa dipilih (jalan kaki mudah & tidak perlu biaya)
- Realistis = bisa dicapai
- Waktu = mulai besok, dalam 3 bulan bisa kelihatan perbedaannya (badan lebih segar, hasil gula darah membaik)



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## Target Nilai

Glukosa darah puasa

**80-99 mg/dl**

Glukosa darah 2 jam

**80-144 mg/dl**

HbA1c

**<6,5%**

Kolesterol total = <200 mg/dl  
 Kolesterol LDL = <100 mg/dl  
 Kolesterol HDL pria = >40 mg/dl  
 wanita = >50 mg/dl  
 Trigliserida = <150 mg/dl

Tekanan darah = ≤130/80 mmHg

IMT (Indeks Massa Tubuh) = 18,5-<23

\*IMT adalah hasil pembagian berat badan (kilogram) dengan kuadrat tinggi badan (meter)  $[BB/(TB)^2]$ .

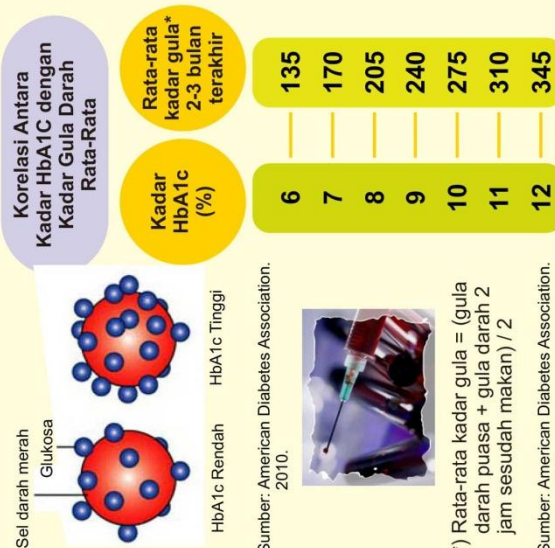
Lingkar pinggang pria = <90 cm  
 wanita = <80 cm

Sumber: Konsensus Pengelolaan dan Pencegahan Diabetes Mellitus Tipe 2 di Indonesia (PERKENI, 2006).

## HbA1C

- HbA1c menggambarkan konsentrasi gula darah rata-rata selama periode 1-3 bulan.
- Jumlah HbA1c yang terbentuk sesuai dengan konsentrasi gula darah.
- Pemeriksaan HbA1c digunakan untuk kontrol gula darah jangka panjang pada penyandang diabetes.
- Pemeriksaan HbA1c dianjurkan untuk dilakukan setiap 3 bulan sekali atau 4 kali dalam setahun.

Sumber : International Expert Committee Report on the Role of the A1C Assay in the Diagnosis of Diabetes. Diabetes Care. 2009.



## Metode "SMART/SDDRW"

<b>S Specific Spesifik</b>	Apa yg akan dilakukan secara detil, seberapa banyak, seberapa sering & kapan
<b>M Measurable Dapat diukur</b>	Bisa diukur perkembangannya
<b>A Achievable Dapat dicapai</b>	Dipilih karena bisa dilakukan
<b>R Realistic Realistis</b>	Percaya bisa mencapainya
<b>T Time line Waktu (jangka waktu)</b>	Tentukan kapan bisa mencapai tujuannya

Seberapa percaya diri Anda bisa mencapai tujuan ini dalam minggu depan?	1	2	3	4	5	6	7	8	9	10
Silapa yang bisa mendukung untuk mencapai tujuan perawatan diabetes Anda?	Tidak percaya diri ← Percaya diri									
Hambatan yang mungkin terjadi...?										
Bagaimana mengatasi hambatan tersebut...?										







# 1

## Makan Sehat

- **Konsep 3J** (Jenis, Jumlah kalori, Jadwal) dengan membuat pilihan makanan sehat, memahami ukuran porsi dan mempelajari waktu terbaik untuk makan adalah kunci utama pengendalian diabetes.
- Dengan mengendalikan berat badan dan mencapai kadar glukosa darah yang optimal, pasien dapat mengelola kondisi mereka selama beberapa saat tanpa obat.



# 2

## Aktivitas Fisik

- Aktivitas fisik yang teratur sangat penting untuk kebugaran secara keseluruhan, manajemen berat badan dan pengendalian gula darah.
- Dengan tingkat aktivitas fisik yang sesuai, bagi yang mempunyai faktor risiko menderita diabetes tipe 2 dapat mengurangi risiko itu, dan bagi diabetesis dapat memperbaiki pengendalian gula darah.
- Banyak manfaat yang diperoleh dari melakukan aktivitas fisik yang teratur.



# 3

## Monitoring

- Pemantauan sendiri kadar gula darah harian memberikan informasi yang dibutuhkan untuk menilai bagaimana makanan, aktivitas fisik dan obat-obatan mempengaruhi kadar glukosa darah.
- Selain itu diabetesis juga harus memeriksa tekanan darah dan berat badan secara teratur.



# 4

## Pengobatan

- Diabetes merupakan kondisi yang progresif. Tergantung jenis diabetes, petugas kesehatan dapat menentukan obat yang dipakai, menjelaskan mekanisme kerja obat/insulin dan kapan harus membawanya, serta mengajarkan cara penyuntikan insulin.
- Pengobatan yang efektif yang dikombinasikan dengan pilihan gaya hidup sehat, dapat menurunkan kadar gula darah, mengurangi risiko komplikasi diabetes dan menghasilkan keuntungan klinis lainnya.



# 5

## Penyelesaian Masalah

- Diabetesis harus mengasah ketajaman keترampilan memecahkan masalah karena setiap saat jika terjadi episode gula darah tinggi/rendah atau sakit, mengharuskan membuat keputusan cepat tentang makanan, aktivitas fisik dan obat-obatan.
- Keterampilan ini secara kontinyu harus terus digunakan karena bahkan setelah puluhan tahun hidup dengan penyakit ini, stabilitas tidak pernah sepenuhnya tercapai karena penyakit ini progresif, komplikasi kronis muncul, situasi kehidupan berubah dan mengalami penuaan.



# 6

## Mengurangi Risiko

- Perilaku pengurangan risiko yang efektif seperti berhenti merokok, dan pemeriksaan mata, kaki dan gigi secara teratur, mengurangi komplikasi diabetes dan memaksimalkan kesehatan dan kualitas hidup.
- Bagian penting dari perawatan mandiri adalah belajar untuk memahami, mencari dan secara teratur memperoleh berbagai layanan pencegahan.





Informasi, pengobatan dan perawatan diabetes lebih lanjut silahkan kunjungi:



**Primary Diabetes Care**  
Klinik Dokter Keluarga

**Asri Medical Center**

Jl. HOS. Cokroaminoto 17 Yogyakarta 55252  
Telp. (0274) 618400 (Hunting)  
Fax. (0274) 618055

[www.asrimedicalcenter.com](http://www.asrimedicalcenter.com)

[www.oryzati.com](http://www.oryzati.com)

Prepared by:

OHA - SA (2011)

**Pusat Studi Kedokteran Keluarga**  
Fakultas Kedokteran dan Ilmu Kesehatan  
Universitas Muhammadiyah Yogyakarta



# Bahan Makanan Penukar & Menu



# DIABETESI



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### Ukuran Rumah Tangga

Untuk memudahkan penggunaan bahan makanan dalam daftar ini dinyatakan dengan alat ukuran yang lazim terdapat di rumah tangga.

Berikut persamaan antara **ukuran rumah tangga (URT)** dengan **gram**.

Ukuran rumah tangga	Ukuran gram
1 sdm gula pasir	8 gr
1 sdm tepung susu	5gr
1 sdm tepung beras, sagu	6 gr
1 sdm terigu, maizena, hunkwe	5 gr
1 sdm minyak goreng, margarine	10 gr
1 sdm = 3 sdt	10 ml
1 gls = 24 sdm	240 ml
1 ckr = 1 gls	240 ml
1 gls nasi = 140 gram = 70 gr beras	
1 ptg pepaya (3 x 15 cm)	100 gr
1 bh sdg pisang (3 x 15 cm)	50 gr
1 ptg sdg tempe (4 x 6 x 1 cm)	25 gr
1 ptg sdg daging (6 x 5 x 2 cm)	50 gr
1 ptg sdg ikan (6 x 5 x 2 cm)	50 gr
1 bj bsr tahu (6 x 6 x 2 1/2cm)	100 gr

#### Arti singkatan:

bh	buah	bsr	besar
bj	biji	ptg	potong
btg	batang	sdm	sendok makan
btr	butir	sdt	sendok teh
bks	bungkus	gls	gelas
kcl	kecil	ckr	cangkir
sdg	sedang		

### Golongan I Karbohidrat

Bahan-bahan ini umumnya digunakan sebagai makanan pokok.

1 satuan penukar = 175 kalori, 4 gr protein dan 40 gr karbohidrat .

Bahan Makanan	Berat (gr)	URT
Nasi	100	¾ gls
Nasi tim	200	1 gls
Bubur beras	400	2 gls
Nasi jagung	100	¾ gls
Kentang	200	2 bj sdg
Singkong	100	1 ptg sdg
Tales	200	1 bj bsr
Ubi	150	1 bj sdg
Roti tawar	80	4 iris
Biskuit	50	5 bh bsr
Tepung maizena	40	8 sdm
Tepung beras	40	8 sdm
Tepung singkong	50	8 sdm
Tepung sagu	40	7 sdm
Tepung terigu	50	8 sdm
Tepung hunkwe	40	8 sdm
Mie basah	100	1 ½ gls
Mie kering	50	1 gls
Bihun	50	1/2 gls
Makaroni	50	1/2 gls
Haverhout	50	6 sdm

## Golongan II Protein Hewani

### 1. RENDAH LEMAK

1 satuan penukar = 50 kal, 7 gr protein, 2 gr lemak

Bahan Makanan	Berat (gr)	URT
Ayam tanpa kulit	40	1 ptg sdg
Babat	40	1 ptg sdg
Daging kerbau	35	1 ptg sdg
Dideh sapi	35	1 ptg sdg
Daging ayam	50	1 ptg sdg
Ikan segar	40	1 ptg sdg
Ikan asin	15	1 ptg kcl
Ikan teri	20	1 sdm
Udang segar	35	5 ekor sdg

### 2. LEMAK SEDANG

1 satuan penukar = 75 kal, 7 gr protein, 5 gr lemak

Bahan Makanan	Berat (gr)	URT
Bakso daging	170	10 bj sdg
Daging kambing	40	1 ptg sdg
Daging sapi	35	1 ptg sdg
Hati ayam	30	1 ptg sdg
Hati sapi	35	1 ptg sdg
Otak	65	1 ptg bsr
Telur ayam	50	1 btr
Usus sapi	50	1 ptg bsr

### 3. TINGGI LEMAK

1 satuan penukar = 150 kal, 7 gr protein, 13 gr lemak

Bahan Makanan	Berat (gr)	URT
Daging babi	50	1 ptg sdg
Corned beef	45	3 sdm
Ayam dg kulit	40	1 ptg sdg
Bebek	45	1 ptg sdg
Sosis	50	½ ptg sdg
Kuning telur ayam	45	4 btr

## Golongan III Protein Nabati

1 satuan penukar = 80 kal, 6 gr protein, 3 gr lemak dan 8 gr karbohidrat.

Bahan Makanan	Berat (gr)	URT
Kacang hijau	20	2 sdm
Kacang kedelai	25	2 ½ sdm
Kacang merah	20	2 sdm
Kacang tanah	15	2 sdm
Keju kacang tanah	15	1 sdm
Kacang tolo	20	2 sdm
Oncom	40	2 ptg kcl
Tahu	100	1 ptg bsr
Tempe	50	2 ptg sdg

## Golongan IV Sayuran

Merupakan sumber vitamin (terutama karotin dan vitamin C) dan mineral (zat kapur, zat besi, zat fosfor).

Satu satuan penukar = 100 gr sayuran mentah (Sayuran ditimbang bersih dan dipotong biasa seperti di rumah tangga) – 1 gelas setelah direbus dan ditiriskan (Sayuran ditakar, setelah dimasak ditiriskan).

Untuk diet diabetes sayuran dibagi dalam 3 kelompok, yakni:

### 1. SAYURAN KELOMPOK A

Mengandung sedikit sekali protein dan karbohidrat. Sayuran ini boleh digunakan sekehendak tanpa diperhitungkan banyaknya.

Beligo	Kembang kol
Lobak	Labu air
Daun koro	Daun kacang panjang
Daun waluh	Pepaya muda
Jamur segar	Pecay (sawi putih)
Oyong (gambas)	Rebung
Kangkung	Sawi
Ketimun	Selada
Tomat	Tauge
Kecipir muda	Terong
Kool	Cabe hijau besar

### 2. SAYURAN KELOMPOK B

Dalam 1 satuan penukar = 25 kal, 1 gr protein, dan 5 gr karbohidrat.

Bayam	Jagung muda
Biet	Jantung pisang
Buncis	Genjer
Brokoli	Kacang panjang
Kol	Kacang kapri
Kangkung	Daun katuk
Daun mangkogan	Labu siam
Daun pakis	Labu waluh
Daun lompong	Nangka muda
Terong	Pare
Rebung	Toge kacang hijau
Kecipir	Wortel

### 3. SAYURAN KELOMPOK C

Dalam 1 satuan penukar = 50 kal, 3 gr protein, dan 10 gr karbohidrat. .

Daun pepaya	Wortel
Daun melinjo	Toge kacang kedelai
Daun singkong	Kluwih
Daun katuk	Melinjo
Daun talas	Nangka muda
Bayam merah	Kacang kapri

## Golongan V Buah-Buahan

Merupakan sumber vitamin terutama karotin, Vitamin B1, B6 dan C, serta sumber mineral. Satu satuan penukar = 50 kalori dan 12 gr karbohidrat.

Bahan Makanan	Berat (gr)	URT
Alpukat	50	1/2 bh bsr
Apel	85	1 bh sdg
Anggur	165	20 bj
Belimbing	125	1 bh bsr
Jambu biji	100	1 bh bsr
Jambu air	100	2 bh sdg
Jambu bol	75	3/4 bh sdg
Duku	75	15 bh
Durian	50	3 bj
Jeruk manis	100	1 bh sdg
Kedondong	100	1 bh bsr
Mangga	50	1/2 bh bsr
Nanas	75	1/6 bh sdg
Nangka masak	50	5 bj
Pepaya	100	1 ptg sdg
Pisang ambon	50	1 bh sdg
Pisang raja sereh	50	2 bh kcl
Rambutan	75	8 bh
Salak	75	1 bh bsr
Sawo	50	1 bh sdg
Sirsak	75	1/2 gls
Semangka	150	1 ptg bsr

## Golongan VI Susu

Merupakan sumber protein, lemak, karbohidrat, vitamin (vitamin A dan Niacin) serta mineral (zat kapur dan fosfor).

### 1. SUSU TANPA LEMAK

1 satuan penukar = 75 kalori, 7 gr protein, 10 gr karbohidrat.

Bahan Makanan	Berat (gr)	URT
Susu skim cair	200	1 gls
Tepung susu skim	20	4 sdm
Yoghurt non-fat	120	2/3 gls

### 2. SUSU RENDAH LEMAK

1 satuan penukar = 125 kalori, 7 gr protein, 10 gr karbohidrat, 6 gr lemak.

Bahan Makanan	Berat (gr)	URT
Susu sapi	200	1 gls
Susu kambing	165	3/4 gls
Yoghurt susu penuh	200	1 gls
Keju	35	1 ptg kcl

### 3. SUSU RENDAH LEMAK

1 satuan penukar = 150 kalori, 7 gr protein, 10 gr karbohidrat, 10 gr lemak.

Bahan Makanan	Berat (gr)	URT
Susu kerbau	100	1/2 gls
Tepung susu penuh	30	6 sdm

### Golongan VII Minyak/Lemak

Bahan makanan ini hampir seluruhnya terdiri dari lemak. 1 satuan penukar = 50 kalori dan 5 gr lemak.

#### 1. LEMAK TIDAK JENUH

Bahan Makanan	Berat (gr)	URT
Alpukat	60	1/2 bh bsr
Kacang almond	25	7 bj
Margarine jagung	5	1/4 sdt
Minyak bunga matahari	5	1 sdt
Minyak jagung	5	1 sdt
Minyak kedelai	5	1 sdt
Minyak kacang tanah	5	1 sdt
Minyak zaitun	5	1 sdt

Bahan Makanan	Berat (gr)	URT
Minyak kelapa	5	1/2 sdt
Minyak inti kelapa sawit	5	1/2 sdt
Mentega	15	1 sdm
Kelapa	15	1 ptg kcl
Santan	40	1/3 gls
Lemak babi	5	1 ptg kcl

### Golongan VIII Makanan Tanpa Kalori

Agar-agar	Gelatin
Air kaldu	Gula alternatif
Air mineral	Kopi
Cuka	Teh

Sumber: Pusat Diabetes dan Lipid RSCM/FK UI, 2007



*Gunakanlah Daftar Penukar Bahan Makanan ini, sehingga Anda dapat memilih bahan makanan yang sesuai dengan menu keluarga*





## Kebutuhan Kalori/ Energi

### 1. KEBUTUHAN KALORI BASAL

25-30 kalori/ kg BB ideal, ditambah dan dikurangi tergantung:

- a. **Jenis kelamin :**
  - W = 25kal/kg BB
  - P = 30kal/kg BB
- b. **Umur :**  
Anak & bayi lebih tinggi; makin tua perlu dikurangi:
  - 40-59th = - 5% tiap 10 tahun
  - 60-69th = - 10%
  - >70th = - 20%
- c. **Aktivitas :**
  - Istirahat = kalori basal + 10%
  - Ringan = + 20%
  - Sedang = + 30%;
  - Berat = + 40%;
  - Sangat berat = + 50%
- d. **Kehamilan/menyusui:**
  - Awal = + 150kal/hr
  - Trimester II-III = + 350kal/hr
  - Menyusui = + 550kal/hr
- e. **Komplikasi/penyakit:**  
Tiap naik suhu 1°C = + 13% kal
- f. **Berat badan:**  
Kegemukan/terlalu kurus = +20-30%

### 2. KEBUTUHAN KALORI SECARA UMUM

Status Gizi	Kalori/kg BB Ideal		
	Kerja Santai	Kerja Sedang	Kerja Berat
Gemuk	25	30	35
Normal	30	35	40
Kurus	35	40	40-50

### 3. PERHITUNGAN BERAT-BADAN IDEAL

#### a. RUMUS BROCCA

$$BB \text{ ideal} = 90\% \times (TB \text{ dlm cm} - 100) \times 1\text{kg}$$

**Bagi Pria <160 cm & Wanita <150 cm:**

$$BB \text{ ideal} = (TB \text{ dlm cm} - 100) \times 1\text{kg}$$

#### b. INDEKS MASSA TUBUH

$$\text{Indeks Massa Tubuh (IMT)} = \frac{\text{berat badan (kg)}}{\text{tinggi badan}^2 (\text{m}^2)}$$

**Kriteria WPRO (2000)**

Kriteria ini merupakan kriteria WHO yang telah disesuaikan untuk pengukuran BMI orang Asia termasuk Indonesia.

- BB kurang : < 18.5
- Normal : 18.5 - 22.9
- BB lebih : 23.0 - 24.9
- Obesitas I : 25-29.9
- Obesitas II : > 30

#### Risiko Kesehatan yang Diasosiasikan dengan Tingkat IMT dan Lingkar Pinggang di Asia

IMT	LINGKAR PINGGANG	
	<90 cm (pria) <80 cm (wanita)	>90 cm (pria) >80 cm (wanita)
<18,5	Risiko rendah*	Risiko sedang
18,5-22,9	Risiko sedang	Risiko meningkat
23-24,9	Risiko meningkat	Risiko agak berat
25-29,9	Risiko agak berat	Risiko berat
>30	Risiko berat	Risiko sangat berat

\*tetapi memiliki risiko dengan masalah kesehatan lainnya

Sumber: Health Communication Australia Pty Limited on Behalf of Steering Committee, 2000.

### Contoh Menu Sehari

#### Contoh Menu dengan Kebutuhan 1.500 Kal.

##### Makan pagi :

- Nasi (1/2 gls)
- Ayam goreng tanpa kulit (1 ptg sdg)
- Tempe goreng (2 ptg sdg)
- Tumis kangkung (1 gls)

##### Selingan pagi :

- Biskuit gandum utuh (5 bh bsr)

##### Makan siang :

- Nasi (3/4 gls)
- Balado ikan (1 ptg sdg)
- Sayur asem (1 gls)
- Pepaya (1 ptg bsr)

##### Selingan sore :

- Alpukat (1 bh)

##### Makan malam :

- Bihun goreng (1/2 gls)
- Orak-arik [telor, wortel, kubis] (1/2 gls)
- Apel (1 bh)

##### Selingan malam

- Susu rendah lemak (1 gls)

### Rencana Pengaturan Makanan Sehari

#### DATA PRIBADI

- Berat badan :..... kg
- Tinggi badan :..... cm
- IMT :..... kg/m<sup>2</sup>
- Aktivitas (ringan/sedang/berat) :..... kalori

#### STANDAR DIET

- Kebutuhan energi :..... kalori
- Karbohidrat :..... gr
- Protein :..... gr
- Lemak :..... gr

#### PEMBAGIAN MAKAN SEHARI

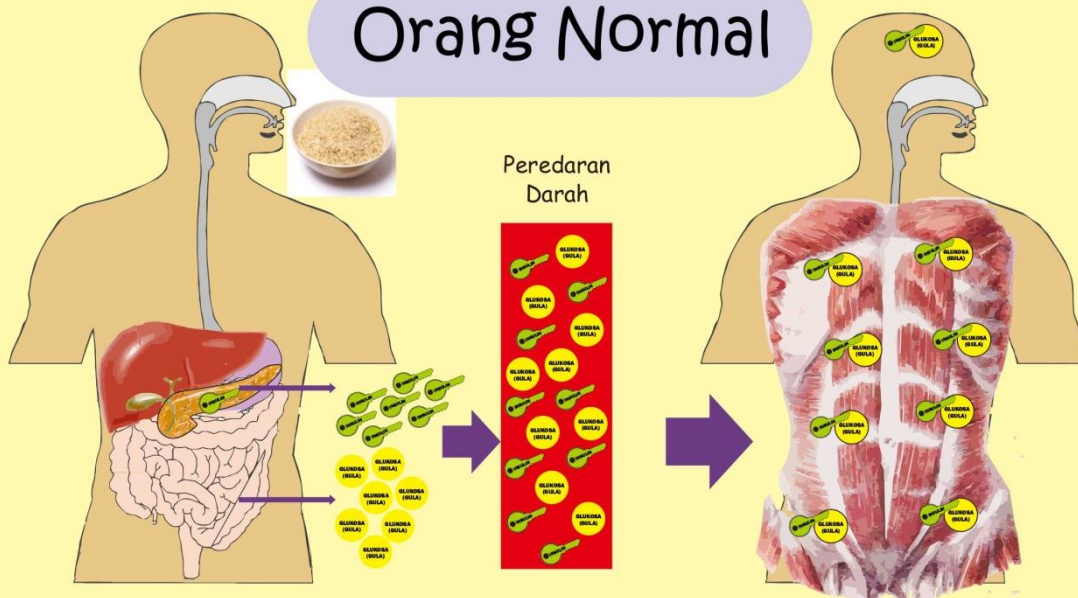
	Menu	URT
<b>Makan Pagi</b>		
• Karbohidrat	.....	.....
• Protein	.....	.....
• Sayuran	.....	.....
• Buah	.....	.....
• Lemak	.....	.....
<b>Selingan pagi</b>		
<b>Makan Siang</b>		
• Karbohidrat	.....	.....
• Protein	.....	.....
• Sayuran	.....	.....
• Buah	.....	.....
• Lemak	.....	.....
<b>Selingan sore</b>		
<b>Makan Malam</b>		
• Karbohidrat	.....	.....
• Protein	.....	.....
• Sayuran	.....	.....
• Buah	.....	.....
• Lemak	.....	.....
<b>Selingan malam</b>		

# **APPENDIX N – Diabetes Posters**

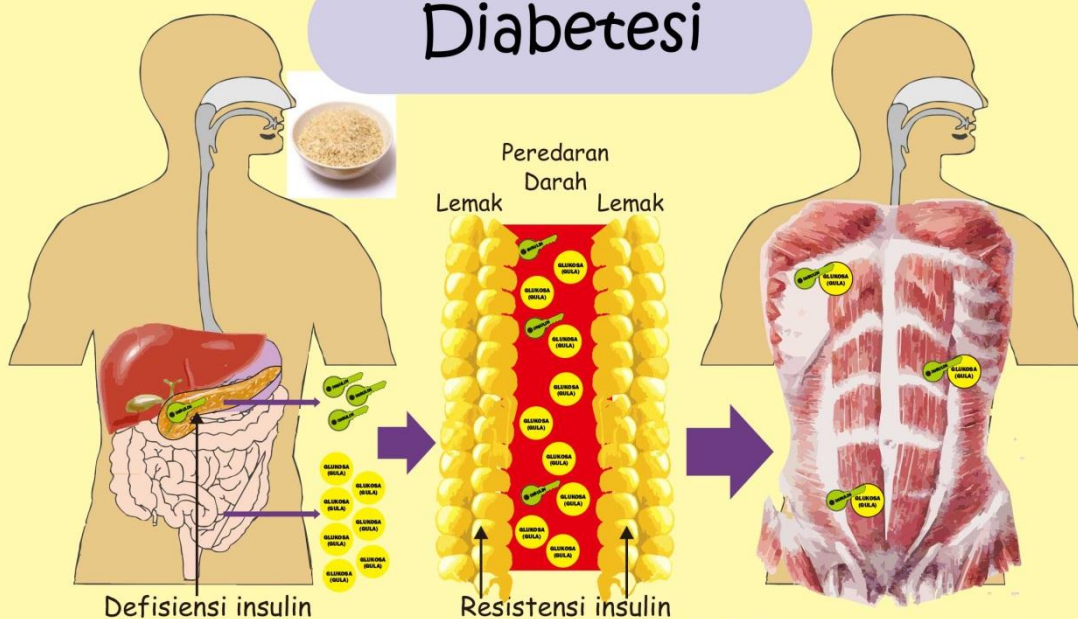
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# Mekanisme Kerja Insulin

## Orang Normal



## Diabetesi



Defisiensi insulin

Resistensi insulin

Reprinted with permission from Effie Kopsaftis (Certified Diabetes Educator, SA, Australia) via personal communication

 = GLUKOSA (GULA)

 = INSULIN

1



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OHA - SA (2011)  
www.oryzati.com

# Faktor Risiko Diabetes

*Kenali risiko diabetes sejak dini...!*



Riwayat keluarga/  
faktor keturunan



Usia:  
bertambahnya usia



Ras/suku bangsa:  
orang Asia/Afrika



Aktivitas fisik  
kurang



Kegemukan



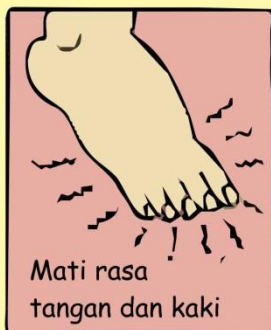
Kehamilan

2



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# Gejala Diabetes Mellitus



Sumber : Eli Lilly & Company in collaboration with Boehringer Mannheim Corporation

3



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www.oryzati.com

## Komplikasi Akut Diabetes Mellitus: Hipoglikemia



Gemetar

Denyut jantung  
cepat

Berkeringat



Kelelahan



Gelisah



Lapar



Nyeri kepala



Pusing



Mudah marah

Sumber: <http://www.diabetescaregroup.info/hypoglycemia-low-blood-sugar>. Diakses tanggal 28 April 2011.

Kadar Gula Darah  
**< 60 mg/dl**

**Yang harus dilakukan:**

1. Segera hentikan aktivitas
2. Segera minum teh manis/permen
3. Bila pingsan, segera dibawa ke RS

4



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## Komplikasi Akut Diabetes Mellitus: Hiperglikemia



Sering kencing



Lapar



Sangat haus



Pandangan kabur



Kulit kering



Sering mengantuk

Sumber: <http://www.diabetescaregroup.info/high-blood-sugar-hyperglycemia>. Diakses tanggal 28 April 2011.

Kadar Gula Darah  
**> 200 mg/dl**

### Yang harus dilakukan:

Bila ada nafas cepat dan dalam, badan lemas, akhirnya pingsan, segera dibawa ke Rumah Sakit. Keadaan ini (KOMA KETOASIDOSIS) sangat berbahaya, dapat menyebabkan KEMATIAN!

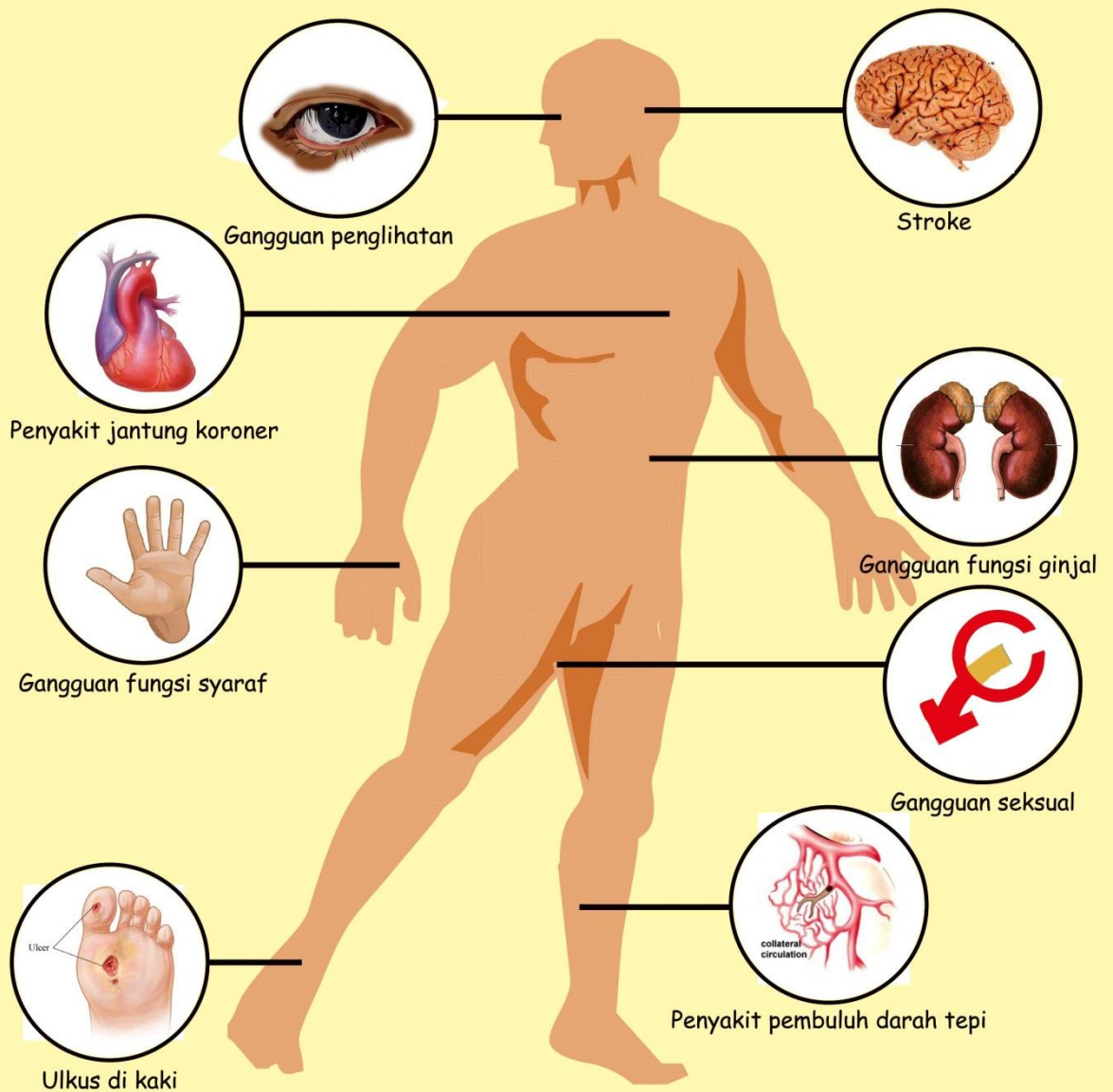
5



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# Komplikasi Kronis Diabetes Mellitus



6



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# Pengelolaan Diabetes Mellitus: 4 Sehat 5 Teratur

Edukasi Diabetes meningkatkan:

- Pengetahuan tentang diabetes mellitus
- Perubahan sikap & perilaku gaya hidup sehat
- Penyesuaian psikologis & kualitas hidup yang lebih baik



7



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# Panduan Diet Sederhana

## 3j

### Jumlah kalori



Asupan makanan sesuai kebutuhan kalori (BB kurang/BB normal/BB lebih).

- Karbohidrat : 45-65%
- Protein : 10-20%
- Lemak : 20-25% (<7% Lemak jenuh, <10% Lemak tidak jenuh ganda, sisanya lemak tidak jenuh tunggal)
- Serat : ± 25 gram/hari
- Gula pasir : 5% (dari total kalori)
- Kolesterol : <300 mg/hari
- Natrium : 3.000 mg/hari



### Jadwal makan

Makan teratur 5-6 kali/hari (3 kali makan besar, 2-3 kali makan kecil, dengan selang waktu 2-3 jam) : *"Sedikit-sedikit tapi sering."*

### Jenis makanan



Pilih makanan yang sehat:

- Karbohidrat kompleks
- Indeks glikemik rendah
- Tinggi serat
- Protein
- Lemak tidak jenuh tunggal dan ganda

Sumber: Pusat Diabetes dan Lipid RSCM/FK UI, 2009

8



FAKULTAS KEDOKTERAN & ILMU KESEHATAN  
FKIK UMY  
UNIVERSITAS MUHAMMADIYAH YOGYAKARTA

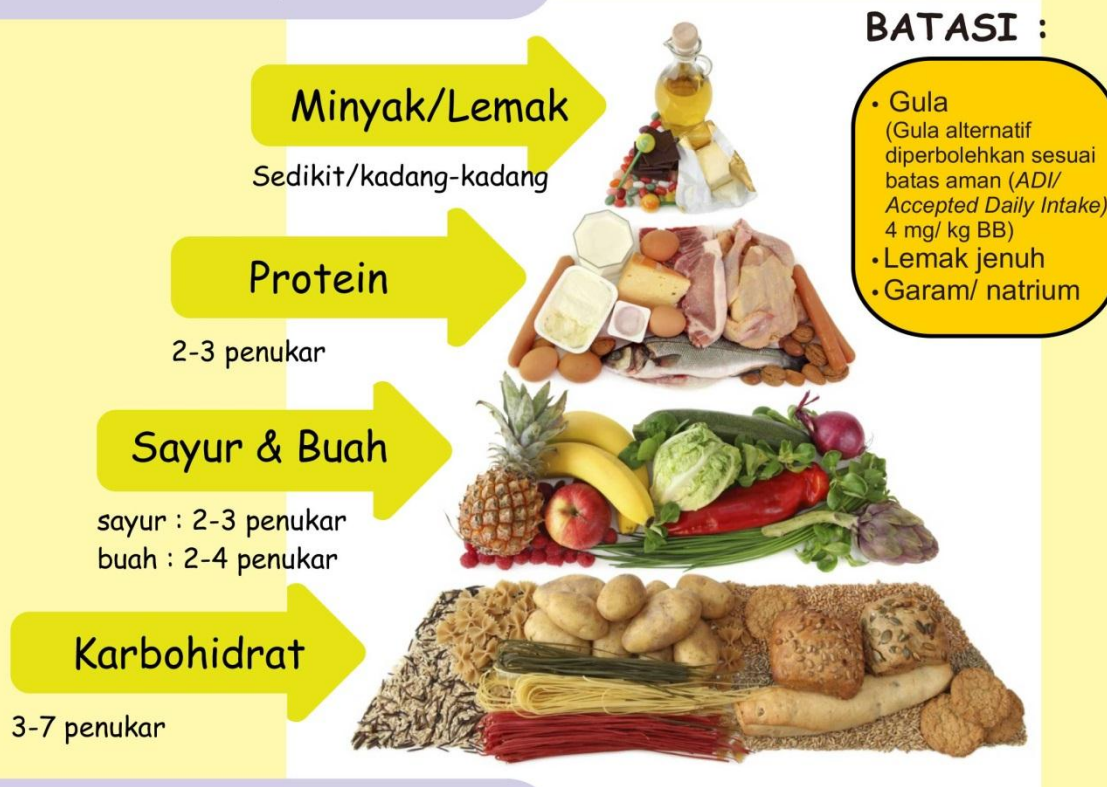


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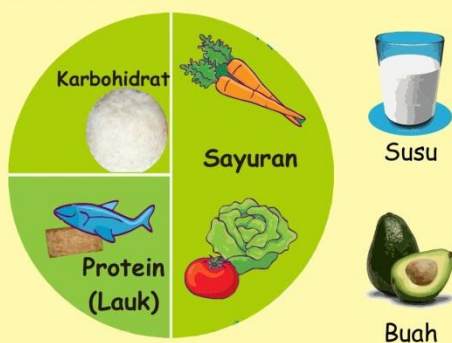
Prepared by:  
OHA - SA (2011)  
www.oryzati.com

# Makanan Seimbang untuk Diabetes

## Piramida Makanan



## Proporsi Makanan Seimbang



Sumber: Pusat Diabetes dan Lipid RSCM/FK UI, 2009

9



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# Pengukuran Porsi Makanan

## Pengukuran Asupan Nutrisi Harian

### Karbohidrat dan Buah



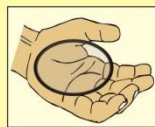
Sebesar satu genggam tangan

### Lemak



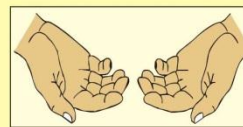
Batasi lemak seukuran ibu jari

### Protein



Seukuran telapak tangan dengan ketebalan jari kelingking

### Sayuran

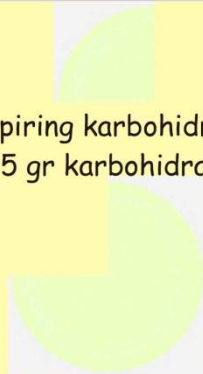


Seukuran dua telapak tangan, untuk sayuran rendah kalori: selada, kobis, tomat

Sumber : [http://diabetes.ca/files/plan\\_your\\_portions.pdf](http://diabetes.ca/files/plan_your_portions.pdf)  
Diakses tanggal 28 April 2011.

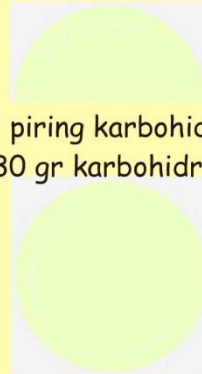
## Metode Piring Idaho

1/4 piring karbohidrat =  
15 gr karbohidrat



3/4 piring karbohidrat =  
45 gr karbohidrat

1/2 piring karbohidrat =  
30 gr karbohidrat



1 piring karbohidrat =  
60 gr karbohidrat

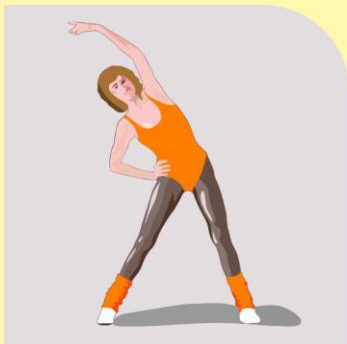
Sumber : <http://www.platemethod.com/>  
Diakses tanggal 28 April 2011.

10



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# Aktivitas Fisik



**30 menit/hari**  
Tetap sehat



**60 menit/hari**  
Mencegah kenaikan berat badan



**60-90 menit/hari**  
Mengurangi berat badan



11



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# Target Nilai Pengelolaan DM

Glukosa darah puasa

**80-99 mg/dl**

Glukosa darah 2 jam

**80-144 mg/dl**

HbA1c

**<6,5%**



Kolesterol total= <200 mg/dl

Kolesterol LDL= <100 mg/dl

Kolesterol HDL pria= >40 mg/dl, wanita = >50 mg/dl

Trigliserida= <150 mg/dl

Tekanan darah=  $\leq$ 130/80 mmHg

IMT (Indeks Massa Tubuh) =  $18,5$ -<23 kg/m<sup>2</sup>

\*IMT adalah hasil pembagian berat badan (kg) dengan kuadrat tinggi badan (meter) [BB/(TB)<sup>2</sup>].

Lingkar pinggang pria= <90 cm, wanita = <80 cm

Sumber: Konsensus Pengelolaan dan Pencegahan Diabetes Melitus Tipe 2 di Indonesia (PERKENI, 2006).

12



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# Perawatan Kaki Diabetes

1



Cuci kaki dengan air hangat tiap hari

2



Keringkan, terutama di antara jari

3



Gunakan pelembab (*hand body lotion*)

4



Periksa kaki setiap hari

5



Bila kaki terluka, tutup dengan pembalut steril

6



Pada orang tua dengan diabetes penyembuhan luka lebih lama

7



Bersihkan alas kaki dari benda tajam

8



Gunakan sepatu/sandal yang baik, sesuai ukuran, dan enak dipakai

9



Hindari air/benda terlalu dingin atau panas

Sumber: <http://www.thewig.eu/mediapool/41/419555/data/happyfootscan.jpg>. Diakses tanggal 28 April 2011.

13



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# 7 Langkah Sukses Perawatan Mandiri (Self-Care) Diabetes

- 1 Makan sehat
- 2 Aktivitas fisik
- 3 Monitoring
- 4 Pengobatan
- 5 Penyelesaian masalah
- 6 Coping (Penanganan stress) yang sehat
- 7 Mengurangi risiko



Sumber: AADE7™ Self-Care Behaviors (<http://www.diabeteseducator.org/ProfessionalResources/AADE7>)  
Diakses tanggal 28 April 2011.

## 7 Prinsip Pengelolaan Mandiri (Self-management) untuk Kondisi Kronik

1. Memiliki pengetahuan tentang kondisi penyakitnya.
2. Mengikuti rencana perawatan yang disetujui bersama tenaga kesehatan.
3. Berperan aktif dalam pengambilan keputusan dengan tenaga kesehatan.
4. Memonitor dan mengelola gejala dan tanda dari kondisi penyakitnya.
5. Mengelola dampak kondisi penyakitnya secara fisik, emosi dan sosial.
6. Mengadopsi gaya hidup sehat.
7. Memiliki kepercayaan diri, akses, dan kemampuan untuk menggunakan layanan pendukung.

Sumber: Flinders Program™ (<http://www.flinders.edu.au/medicine/sites/fhbhru/self-management.cfm>)

14



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# **APPENDIX O – Pictures of Research Activities**

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## Diabetes seminar and diabetes banners

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**Session 1 of Structured Diabetes Education Programme at Wirobrajan and Kraton  
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**Session 4 of Structured Diabetes Education Programme at Wirobrajan and Kraton  
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