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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Discipline of General Practice and Discipline of Public Health
School of Population Health
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The University of Adelaide
# 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

## 1 CHAPTER 1 – Introduction ............................................................................................................................. 1

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

## 2 CHAPTER 2 – Literature Review .................................................................................................................. 12

2.1 INTRODUCTION ........................................................................................................................................... 13
2.2 TYPE 2 DIABETES ....................................................................................................................................... 13

\[2.2.1\] Definition, Classification and Diagnosis of Diabetes Mellitus ............................................................. 13

\[2.2.2\] Symptoms and Complications of Diabetes Mellitus ........................................................................... 14

\[2.2.3\] Management of Type 2 Diabetes ......................................................................................................... 15

2.3 DIABETES CARE AND NATIONAL PROGRAMMES ............................................................................. 19

\[2.3.1\] Evolution in Diabetes Care .................................................................................................................. 19

\[2.3.2\] Shifting Diabetes Care: Secondary to Primary Care ......................................................................... 21

\[2.3.3\] Diabetes Care in Indonesia .................................................................................................................. 23

\[2.3.4\] National Diabetes Programmes (NDPs) ............................................................................................. 26

2.4 CHRONIC DISEASE SELF-MANAGEMENT .................................................................................................. 27

\[2.4.1\] Chronic Disease Care ........................................................................................................................ 27
2.4.2 Collaborative Care and Self-Management Education .............................. 28
2.4.3 The Chronic Care Model .......................................................................... 30
2.4.4 Self-Management Support of the Chronic Care Model ......................... 31
2.4.5 Chronic Disease Self-management Education ........................................... 33

2.5 THE ROLE OF CHRONIC DISEASE SELF-MANAGEMENT IN DIABETES
EDUCATION ........................................................................................................ 36
2.5.1 Patient Education in Type 2 Diabetes ....................................................... 36
2.5.2 Diabetes Self-Management Education (DSME) ....................................... 38
2.5.3 Diabetes Self-Care Behaviours ................................................................. 40
2.5.4 Underlying Philosophy and Theories for DSME .................................... 41
2.5.5 Patient Empowerment in the Self-Management of Diabetes .................. 44
2.5.6 Diabetes Self-Management Support for Patient Empowerment ............. 47

2.6 MODELS OF STRUCTURED PATIENT EDUCATION IN TYPE 2 DIABETES .... 49
2.6.1 The Diabetes X-PERT Programme ........................................................... 49
2.6.2 The DESMOND Structured Group Education Programme .................... 50

2.7 SUMMARY ..................................................................................................... 51

CHAPTER 3 – Country Setting: Geography, Population, Government, and Health Care
System of Indonesia ............................................................................................ 53

3.1. INTRODUCTION ......................................................................................... 54
3.2. GEOGRAPHY AND POPULATION OF INDONESIA .................................... 54
3.3. STATISTICS OF INDONESIA ..................................................................... 55
3.4. INDOONESIAN GOVERNMENT AND DECENTRALISATION POLICY .......... 58
3.5. HEALTH CARE SYSTEM OF INDONESIA .................................................... 59

3.6. SUMMARY .................................................................................................... 64

CHAPTER 4 – Research Methods ......................................................................... 65

4.1. INTRODUCTION .......................................................................................... 66
4.2. RESEARCH OVERVIEW AND CONCEPTUAL FRAMEWORK .................. 66
4.2.1. Research Overview .................................................................................. 66
4.2.2. Research Conceptual Framework ............................................................ 69
4.3. RESEARCH SETTING .................................................................................. 70
4.4. OPERATIONAL TERMS AND OUTCOME MEASUREMENTS ............... 71
4.4.1. Definitions of Operational Terms ............................................................. 71
4.4.2. Description of Outcome Measurements ................................................. 83
4.5. RESEARCH ETHICS ...................................................................................... 85
4.6. SUMMARY ............................................................................................................. 85

CHAPTER 5 – Cross-Cultural Adaptation of Diabetes-Related Instruments .......... 86

5.1. INTRODUCTION ................................................................................................. 87
5.2. BACKGROUND .................................................................................................... 87
5.3. AIMS ................................................................................................................... 89
5.4. METHODS .......................................................................................................... 89
  5.4.1. Procedure of Cross-Cultural Adaptation ...................................................... 89
  5.4.2. Research Design ........................................................................................... 95
  5.4.3. Sample Size ................................................................................................ 95
  5.4.4. Preparation .................................................................................................. 96
5.5. Participants ....................................................................................................... 96
5.6. Instruments and Data Analysis ....................................................................... 98
5.7. RESULTS .......................................................................................................... 102
  5.7.1. Sociodemographic Characteristics and Medical History ......................... 102
  5.7.2. The 24-item Diabetes Knowledge Questionnaire (DKQ-24) ..................... 104
  5.7.3. The Diabetes Health Belief Measure (DHBM) ............................................. 106
  5.7.4. The Summary of Diabetes Self-Care Activities (SDSCA) ......................... 108
  5.7.5. The Diabetes Empowerment Scale – Short Form (DES-SF) ...................... 110
5.8. DISCUSSION .................................................................................................... 111
5.9. LIMITATIONS .................................................................................................. 118
5.10. CONCLUSIONS AND RECOMMENDATIONS ............................................ 119
   5.10.1. Conclusions .............................................................................................. 119
   5.10.2. Recommendations ................................................................................... 120
5.11. SUMMARY ...................................................................................................... 120

CHAPTER 6 – Development of Diabetes Education Materials ............................. 121

6.1. INTRODUCTION ............................................................................................... 122
6.2. EXISTING DIABETES EDUCATION MATERIALS .......................................... 122
6.3. DEVELOPMENT OF NEW DIABETES EDUCATION MATERIALS ............ 124
   6.3.1. Leaflet 1: “Recognise Diabetes Mellitus and Act on it” ............................ 130
   6.3.2. Leaflet 2, 3 and 4: “Meal Planning for Diabetics 1, 2, 3” ....................... 130
   6.3.3. Leaflet 5 and 6: “Physical Activity for Diabetics 1, 2” ........................... 131
   6.3.4. Leaflet 7: “Foot Care and Foot Exercise for Diabetics” ............................ 132
   6.3.5. Leaflet 8: “Target for Management of Diabetes Mellitus” ........................ 132
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

CHAPTER 8 – Overall Conclusions and Recommendations ...................................................224

8.1. INTRODUCTION ...............................................................................................................225

8.2. OVERALL CONCLUSIONS AND RECOMMENDATIONS ........................................226

REFERENCE LIST ..................................................................................................................230

APPENDIX A – Research Ethics Approval ............................................................................250

APPENDIX B – Participant Consent Form ...........................................................................258

APPENDIX C – Participant Complaint Sheet ........................................................................261

APPENDIX D – Participant Information Sheet .....................................................................264

APPENDIX E – Research Questionnaire in English ...............................................................275

APPENDIX F – Research Questionnaire in Indonesian Language ........................................283

APPENDIX G – List of Open-Ended Questions for Scoping discussions .............................292

APPENDIX H – Full Key Findings of Scoping discussions ..................................................295

APPENDIX I – Frameworks of Management of Type-2 Diabetes .......................................313

APPENDIX J – Frameworks of Diabetes Self-Management Education ...............................316

APPENDIX K – Frameworks of Patient Empowerment .........................................................323

APPENDIX L – Conference Presentation Abstracts ..............................................................329

APPENDIX M – Diabetes Leaflets .........................................................................................334
APPENDIX N – Diabetes Posters ................................................................................................. 361
APPENDIX O – Pictures of Research Activities ........................................................................... 376
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
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 (α = 0.723) and the DHBM (α = 0.718) demonstrated satisfactory internal consistency reliabilities. The Indonesian versions of 10-item SDSCA (α = 0.605) and the DES-SF (α = 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.
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
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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I also give permission for the digital version of my thesis to be made available on the web, via the University’s digital research repository, the Library catalogue and also through web search engines, unless permission has been granted by the University to restrict access for a period of time.

Signed: __________________________

Date: __________________________
Conference Presentations Resulting from This Thesis


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List of Tables

Table 2-1  The Standford Chronic Disease Self-Management Program\textsuperscript{114} and the Flinders Program\textsuperscript{115} .............................................................................................................. 35
Table 3-1  Regional comparison of health performance indicators among Asian countries.\textsuperscript{158} .............................................................................................................. 57
Table 3-0-2  The trends of Indonesia’s HDI in 1980, 1990, 2000, 2010 and 2011.\textsuperscript{163}. .................................................................................................................. 58
Table 3-0-3  The comparison of HDI ranks and values among ASEAN countries in 2011.\textsuperscript{164} .............................................................................................................. 58
Table 4-0-1  AADE \textsuperscript{TM} Self-Care Behaviors\textsuperscript{124} and the Principles of Self-Management of the Flinders Program\textsuperscript{TM115} .................................................................................. 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 (n = 83)....... 102
Table 5-0-4  Medical history of the participants (n = 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 SDSCSA 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
Table 6-0-1  Summary of the Guidelines for Developing Effective Print Materials for Low-Literate Readers .................................124
Table 6-0-2  Quick tips for writing low literacy materials .............................127
Table 6-0-3  The most helpful written materials for all users, especially poor readers .................................................................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 \((n = 42)\) ..........................................................................136
Table 6-0-6  Results of the evaluation of diabetes leaflets in the intervention group \((n = 46)\) .................................................................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 \((n = 101)\) ......................164
Table 7-0-2a Comparison of medical history of the intervention and control group participants at baseline \((n = 101)\) .................................165
Table 7-3  Psychometric properties of the Indonesian version of the DKQ-24 instrument \((n=101)\) ...............................................................168
Table 7-4  Psychometric properties of the Indonesian version of the DHBM instrument \((n=101)\) .................................................................169
Table 7-5  Psychometric properties of the Indonesian version of the SDCSA instrument \((n=101)\) .................................................................170
Table 7-6  Psychometric properties of the Indonesian version of the DES-SF instrument \((n=101)\) .................................................................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 \((n=101)\) .....................................................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
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^2) ................ 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
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
List of Boxes

Box 2-1 Preventing complications of type 2 diabetes\textsuperscript{38} ........................................ 16

Box 2-2 Goals for optimum diabetes management from guidelines of type 2 diabetes\textsuperscript{46} ........................................................................................................... 18
# List of Terms

<table>
<thead>
<tr>
<th>Abbreviation</th>
<th>Definition</th>
</tr>
</thead>
<tbody>
<tr>
<td>AADE</td>
<td>American Association of Diabetes Educators</td>
</tr>
<tr>
<td>ADA</td>
<td>American Diabetes Association</td>
</tr>
<tr>
<td>ASEAN</td>
<td>Association of South East Asian Nations</td>
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<tr>
<td>Askes</td>
<td><em>Asuransi Kesehatan</em> (Government mandatory health insurance for civil servants)</td>
</tr>
<tr>
<td>Askeskin</td>
<td><em>Asuransi Kesehatan Keluarga Miskin</em> (Government subsidised social health insurance programme for poor families)</td>
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<tr>
<td>BMI</td>
<td>Body Mass Index</td>
</tr>
<tr>
<td>CBIA-DM</td>
<td>Community-Based Interactive Approach - Diabetes Mellitus</td>
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<tr>
<td>CDSME</td>
<td>Chronic Disease Self-Management Education</td>
</tr>
<tr>
<td>CDSMP</td>
<td>Chronic Disease Self-Management Programme</td>
</tr>
<tr>
<td>CHCs</td>
<td>Community Health Centres (<em>Puskesmas</em>)</td>
</tr>
<tr>
<td>CVI</td>
<td>Content Validity Index</td>
</tr>
<tr>
<td>DAWN</td>
<td>The Diabetes Attitudes Wishes and Needs study</td>
</tr>
<tr>
<td>DCCT</td>
<td>Diabetes Control and Complications Trial</td>
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<tr>
<td>DES-SF</td>
<td>The Diabetes Empowerment Scale – Short Form</td>
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<tr>
<td>DHBM</td>
<td>The Diabetes Health Belief Measure</td>
</tr>
<tr>
<td>DKQ-24</td>
<td>The 24-item Diabetes Knowledge Questionnaire</td>
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<td>DSME</td>
<td>Diabetes Self-Management Education</td>
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<td>DSMS</td>
<td>Diabetes Self-Management Support</td>
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<tr>
<td>DSMT</td>
<td>Diabetes Self-Management Training</td>
</tr>
<tr>
<td>FBG</td>
<td>Fasting Blood Glucose</td>
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<td>FPG</td>
<td>Fasting Plasma Glucose</td>
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<td>GDM</td>
<td>Gestational Diabetes Mellitus</td>
</tr>
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<td>GLP-1</td>
<td>Glucagon-Like Peptide</td>
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<tr>
<td>GMS</td>
<td>General Medical Services</td>
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<td>Acronym</td>
<td>Description</td>
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<td>---------</td>
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<tr>
<td>GNI</td>
<td>Gross National Income</td>
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<td>GPs</td>
<td>General Practitioners</td>
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<td>GSM</td>
<td>Grams per Square Metre</td>
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<td>HCPs</td>
<td>Health Care Providers</td>
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<td>HDI</td>
<td>Human Development Index</td>
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<tr>
<td>IDI</td>
<td><em>Ikatan Dokter Indonesia</em> (Indonesian Medical Association)</td>
</tr>
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<td>IDF</td>
<td>International Diabetes Federation</td>
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<td>IDR</td>
<td>Indonesian Rupiah (AUD 1 = IDR 9,600-10,600)</td>
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<tr>
<td>IMR</td>
<td>Infant Mortality Rate</td>
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<tr>
<td>Jamkesmas</td>
<td><em>Jaminan Kesehatan Masyarakat</em> (Government subsidised public health security programme for poor people)</td>
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<td>Jamkesos</td>
<td><em>Jaminan Kesehatan Sosial</em> (Government social security programme)</td>
</tr>
<tr>
<td>Jamsostek</td>
<td><em>Jaminan Sosial Tenaga Kerja</em> (Social security insurance for work forces)</td>
</tr>
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<td>LM</td>
<td>The Lifelong Management programme</td>
</tr>
<tr>
<td>MKDT</td>
<td>Michigan Diabetes Knowledge Test</td>
</tr>
<tr>
<td>MMR</td>
<td>Maternal Mortality Rate</td>
</tr>
<tr>
<td>NCDs</td>
<td>Non-Communicable Diseases</td>
</tr>
<tr>
<td>NCI</td>
<td>National Cancer Institute</td>
</tr>
<tr>
<td>NDPs</td>
<td>National Diabetes Programmes</td>
</tr>
<tr>
<td>NGSP</td>
<td>National Glycohemoglobin Standardization Program</td>
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<tr>
<td>NHS</td>
<td>National Health Service</td>
</tr>
<tr>
<td>NICE</td>
<td>National Institute for Clinical Excellence</td>
</tr>
<tr>
<td>NSF</td>
<td>National Service Framework</td>
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<tr>
<td>OGT TT</td>
<td>Oral Glucose Tolerance Test</td>
</tr>
<tr>
<td>PCO</td>
<td>Primary Care Organisation</td>
</tr>
<tr>
<td>PEDI</td>
<td><em>Perhimpunan Diabetes Edukator Indonesia</em> (Indonesian Diabetes Educator Association)</td>
</tr>
<tr>
<td>PERKENI</td>
<td><em>Perhimpunan Endokrinologi Indonesia</em> (Indonesian Society of Endocrinology)</td>
</tr>
<tr>
<td>Acronym</td>
<td>Description</td>
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<tr>
<td>PERSADIA</td>
<td><em>Persatuan Diabetes Indonesia</em> (Indonesian Diabetes Association)</td>
</tr>
<tr>
<td>Prolanis</td>
<td><em>Program Pengelolaan Penyakit Kronis</em> (Integrated chronic disease management programme based on self-management initiatives developed by Askes Inc.)</td>
</tr>
<tr>
<td>QOF</td>
<td>Quality and Outcome Framework</td>
</tr>
<tr>
<td>RCT</td>
<td>Randomised Controlled Trial</td>
</tr>
<tr>
<td>SDSCA</td>
<td>The Summary of Diabetes Self-Care Activities</td>
</tr>
<tr>
<td>SEEIP</td>
<td>The Self-Efficacy Enhancing Intervention Programme</td>
</tr>
<tr>
<td>SMART</td>
<td>Specific – Measurable – Achievable – Realistic – Time line</td>
</tr>
<tr>
<td>SMBG</td>
<td>Self-Monitoring of Blood Glucose</td>
</tr>
<tr>
<td>STR</td>
<td><em>Surat Tanda Registrasi</em> (Certificate of registration for new medical doctors, one of prerequisites to practice)</td>
</tr>
<tr>
<td>TPB</td>
<td>The Theory of Planned Behaviour</td>
</tr>
<tr>
<td>T2ARDIS</td>
<td>The Type 2 Diabetes Accounting for a Major Resource Demand in Society study</td>
</tr>
<tr>
<td>2-h PBG</td>
<td>Two-hour Postprandial Blood Glucose</td>
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<tr>
<td>2-h PPG</td>
<td>Two-hour Postprandial Plasma Glucose</td>
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<tr>
<td>T1D</td>
<td>Type 1 Diabetes</td>
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<tr>
<td>T2D</td>
<td>Type 2 Diabetes</td>
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<tr>
<td>UKDI</td>
<td><em>Uji Kompetensi Dokter Indonesia</em> (National competency examination for newly graduated medical doctors)</td>
</tr>
<tr>
<td>UKPDS</td>
<td>The United Kingdom Prospective Diabetes Study</td>
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<tr>
<td>WHO SEARO</td>
<td>World Health Organisation South-East Asia Regional Office</td>
</tr>
</tbody>
</table>
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 Gadja 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
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.