THE ROLE OF GOAL SETTING IN THE DIABETES CASE MANAGEMENT OF ABORIGINAL AND NON-ABORIGINAL POPULATIONS IN RURAL SOUTH AUSTRALIA

MD THESIS
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ABSTRACT

This thesis examines goal setting in people with diabetes as part of chronic disease management in a rural setting. Good quality diabetes care includes a team approach, regular follow-up, patient education and patient centred interventions. Shared goal setting and written management plans are central to this. Rural general practitioners work closely with their own health services, however there is little published work on case management and goal setting in these communities.

This work seeks to answer two hypotheses around goal setting in General Practice. Firstly that: Goal setting when used by patients with diabetes type 2 in a rural setting will result in improved clinical outcomes and improved social/emotional outcomes. Secondly that: Goal setting can be successfully performed in rural Australian General Practice as part of case management of diabetes.

The studies were performed in a rural setting (Eyre Peninsula) with a significant (10-20%) Aboriginal population. A randomised controlled trial (Trial 1) used goal setting alone, and two observational trials (Trials 2 and 3) used goal setting in conjunction with a service coordinator to plan diabetes care. These two observational trials were part of the larger Coordinated Care Trials in South Australia (HealthPlus). A fourth observational trial incorporated self-management strategies (Trial 4) with goal setting in an Aboriginal community. Outcomes included physical and biochemical indices, quality of life data (SF36), prescribing costs, service costs and hospital admissions.

Goal setting consistently identified problems related to social, emotional, health maintenance and medical issues. Patients were able to formulate their own solutions to these problems with help in each trial. Goal achievement was 60% in non-Aboriginal trials despite limited resources to address social issues. In Trial 1 goal setting was associated with reduced disability ratings but not improved SF36 scores. HbA1c improved from 7.7 to 7.4 with both intervention (goal setting) and control (structured care) groups.

Goal setting identified significant service gaps that were needed to fulfill ideal care. Case management (Trials 2 and 3) therefore required considerable structural reform at a clinical and practice level to be satisfactorily implemented. The interactions between providers,
Abstract

particularly allied health workers and general practitioners, needed to be formalised. Service coordinators in these trials and Aboriginal Health Workers in the Aboriginal trials provided care where this was otherwise not available, and in doing so created new and valuable linkages.

The Aboriginal Trials (Trials 3 and 4) identified social and family issues as primary problems affecting diabetes care. Goal setting was less successful partly because community and family issues took precedence over personal problems, and partly because it was impossible to address the social problems in the trial context. Goal setting in Trial 4 was associated with 26% goal achievement, 46% improvement in diabetes knowledge and a fall in HbA1c from 7.8 to 7.4.

General practitioners found goal setting time consuming and were frustrated by inadequate service provision. They tended to concentrate on medication issues at reviews. Accurate hand held records were favoured by local specialists and hospital services. Patients and carers enjoyed the additional time spent exploring issues.

Goal setting alone was not associated with improved health outcomes beyond those provided by structured care. Goal setting assisted by service coordinators was associated with small reductions in prescribing costs and hospital admissions, so that savings did not offset the costs of the service coordinators. Chronic Disease Self Management (CDSM) strategies were an alternative model to incorporate goal setting into care for Aboriginal people with diabetes.

Care planning was incorporated into the Medical Benefit Schedule under the Enhanced Primary Care package in November 1999 and includes a requirement to set goals by General Practitioners. Service coordinators may be better placed to set goals that are patient generated in view of the time required. Future research should explore this role as a way of enhancing delivery of diabetes and other chronic disease care in general practice.
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.

I consent to this copy of my thesis, when deposited in the University Library, being for loan and photocopying.

Dr David Mills

April 2005
I want to thank the following people who have helped support, encourage and inspire my work over the past seven years. Through their guidance in formulating this work, I have been able to translate ideas into clinical practice and learning opportunities.

**Professor Justin Bellby**  
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Justin has been my supervisor and mentor during the preparation of this thesis, spending endless hours reading my drafts and offering the much needed constructive criticism that has helped refine and develop my ideas and arguments. His help has been invaluable. He succeeded Professor John Marley who inspired me to start this work, but moved to the University of Newcastle as Vice Chancellor early in my work.

**Dr Peter Harvey**  
*Division of Health Sciences, University of South Australia*

Peter has provided me with constant ideological support in Port Lincoln for this work. He has encouraged me to write and research my work. His energy, ideas and visions for ongoing research in this area have been constant. His background in education and health management were essential to the Health Plus trials that he managed on Eyre Peninsula.

**Dr Malcolm Battersby**  
*Department of Psychiatry, Flinders University*

Malcolm and I spent many hours discussing, reformulating and designing interventions in behaviour change that related to chronic disease management, and how these could be applied in general practice. Malcolm has worked tirelessly to integrate these with chronic disease management processes at a national level.

I am indebted to the Nawu, Wirunga, and Banggarla Aboriginal peoples who are the traditional owners of the land where I have carried out this work. They have supported and assisted me through many of the difficult processes around working in Aboriginal communities.
I would also like to thank the Professor Peter McDonald, Di Quintel, the Eyre Peninsula Division of General Practice, Port Lincoln Aboriginal Health Service, Jim Collins, Peter Morton, and Pat Phillips who have worked with me and supported this work for the past 7 years.
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<td>AHW</td>
<td>Aboriginal Health Worker</td>
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<td>CDSM</td>
<td>Chronic Disease Self Management</td>
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<td>CCT</td>
<td>Coordinated care trial</td>
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<td>CKAHS</td>
<td>Ceduna Koonibba Aboriginal Health Service</td>
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<td>COAG</td>
<td>Council of Australian Governments</td>
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<td>EPDGP</td>
<td>Eyre Peninsula Division of General Practice</td>
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<td>ERHS</td>
<td>Eyre Regional Health Service</td>
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<tr>
<td>GP</td>
<td>General Practitioner</td>
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<tr>
<td>HIC</td>
<td>Health Insurance Commission</td>
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<td>LET</td>
<td>Local Evaluation Team</td>
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<td>MBS</td>
<td>Medical Benefit Schedule</td>
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<td>MCS</td>
<td>Mental Component Score</td>
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<td>NER</td>
<td>National Evaluation Report</td>
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<tr>
<td>NHMRC</td>
<td>National Health and Medical Research Council</td>
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<tr>
<td>PBS</td>
<td>Pharmaceutical Benefit Scheme</td>
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<tr>
<td>PCS</td>
<td>Physical Component Score</td>
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<tr>
<td>PLAHS</td>
<td>Port Lincoln Aboriginal Health Service</td>
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<td>QOL</td>
<td>Quality Of Life</td>
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<td>RDNS</td>
<td>Royal District Nursing Service</td>
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<td>SC</td>
<td>Service Coordinator</td>
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<td>SD</td>
<td>Standard Deviation</td>
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<td>SF-36</td>
<td>Short Form 36 Health Survey</td>
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<td>Work and Social Adjustment Scale</td>
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Four trials are described in this thesis. My involvement in each of these is as follows:

**Trial 1 A Randomised Control Trial of Goal Setting**

January 1997-January 1999. This trial was designed and completed by myself in conjunction with a diabetes educator. One hundred and ninety eight patients with diabetes were allocated to routine care with or without goal setting and followed for 2 years. Analysis of the data was performed by the University of Adelaide in the Department of General Practice, under my supervision.

**Trial 2 The Eyre Diabetes Coordinated Care Trial**

December 1997-December 1999. In this trial I was a chief investigator and local mentor to the trials. The Coordinated Care Trials were funded by the Commonwealth and State Governments in South Australia. These observational trials used geographical controls, and sought to improve the quality of care of patients with complex conditions such as diabetes. Three hundred and ninety eight patients with diabetes were allocated to case management provided by GPs and service coordinators for 2 years. Goal setting was part of case management for all patients and performed by the service coordinators. Data was collected by service coordinators and the primary data analysis performed by Flinders University; the National Evaluation Report [1] outlining the findings was published in March 2001. Much of the data was aggregated and I have performed secondary analyses from the raw data to extract outcomes relating specifically to diabetes patients on Eyre Peninsula.

One hundred and one of these patients were Aboriginal and their experience of goal setting and case management is described in **Trial 3 The Eyre Aboriginal diabetes Coordinated Care Trial**. This work is not related to the National Aboriginal and Torres Strait Islander Coordinated Care Trials [2] which involved care planning but not goal setting. I was chief investigator and local mentor to this trial. Data was collected by the service coordinators and Aboriginal Health Workers. I have drawn conclusions from the final reports, provider feedback and consumer experiences.
Trial 4 The Aboriginal Diabetes Chronic Disease Self Management Program

June 2001-June 2002. This trial was funded by the South Australian Government and I was a chief investigator. The costs of coordination in the CCTs precluded its adoption, although goal setting was accepted by Aboriginal people because of its narrative approach. This observational trial incorporated goal setting by Aboriginal Health Workers into self-management strategies and was tested over one year. Sixty Aboriginal people with diabetes participated in the trial. The data was collected by myself and the Aboriginal Health Workers. The primary data analysis was performed by Flinders University Coordinated Care Training Unit, and secondary analysis by myself.
This work began as a practical problem I faced in General Practice. In 1996 I signed death certificates for two people with diabetes, one an Aboriginal man in his forties and the other a 60 year former cook at our hospital. Both had attended my diabetic clinic for 5 years, ignoring my attempts to persuade them that diabetes was a deadly disease. Central to their treatments were a number of self-management and behaviour strategies and at each review I would revisit their importance. Neither of the health systems they used reinforced behaviour change as part of systematic care outside my clinic. In isolation my traditional diabetic model seemed to be a complicated way of documenting their demise.

A few days later I met Malcolm Battersby, a psychiatrist from Adelaide, and we discussed a cognitive approach to this problem and reviewed a model used to treat anxiety disorders in a London clinic. The model measured change on a linear analogue scale and seemed flexible enough to adapt to a wide variety of problems. After several attempts we refined it enough to use in assessing the problems or barriers to overall diabetes management. In doing so solutions were also generated; the process we called problems and goals, although this was essentially goal setting. The problem was how to incorporate such a process into the busy schedule of GPs struggling against patient expectations and demands.

General practitioners must be good organisers, good communicators and good clinicians. The quality of their work is determined by personal and organisational factors, and by external processes such as peer review and audit, and importantly, patient consultations or feedback. This latter process is a daily exchange that leads to refinements and alterations to treatment and future care. Any deficiencies in that information can lead us to incorrect conclusions and management. Patients withhold information for many reasons, sometimes only revealing important personal details after many consultations. The practical information we gather may tell us the opposite of what our patients tell us, yet patients may be telling us what they think we want to hear. GPs are also familiar with patients seeking out practitioners who will only ask them questions to which they can confidently reply, while avoiding potentially distressing areas.
The consequences of incomplete patient interactions become apparent when we move from acute care to chronic care management. Incorrect information leads to a train of invalid management decisions. If we make decisions based on all the factors impacting on care, then the outcomes are likely to be better. However the quality of our consultation is very dependent on our relationship with patients, and in particular how much they want to contribute to the interaction. The key question is how best to nurture that relationship over a period of years, and how to draw out all the important and relevant information that we need, particularly when we plan complicated and extended care.

The ability of GPs to spend time developing these relationships has become more difficult for a number of reasons. Over the last 20 years there has been the explosion of clinical knowledge. The Human Genome Project has allowed us to believe that many of our problems are genetically based and likely to be amenable to scientific intervention in the future. Patients eagerly await their arrival. Numerous trials are published on every aspect of diabetes care, and there is an assumption that we can remember these details and integrate them into individual cases as clinical judgment. This is clearly not possible and we have become more reliant on specialist help. This in turn has diluted the effectiveness of GPs as patient managers. In some European and American centres the managerial role has been delegated to junior staff that coordinate specialist opinions. It is not known whether professional non-medical managers would perform this role any better.

Unfortunately patients are not always so obliging as to separate their illnesses into compartments for us to analyse, and an understanding of the links between compartments is also necessary. Patients have been persistent in their desire for holistic approaches to health and disease management. The increasing tendency of medicine to reduce problems to diseased organs or biochemistry has not always been to the patient’s benefit. This reductionist approach overlooks the impact disease has on their lives, as well as the impact their lives have on the disease process.

Many GPs have remained expert in the past at integrating the psycho-social aspects of a patient’s problems into clinical decision making by involving their families, by spending
more time with their patients, and visiting them in their homes and after hours. These GPs engage their patients by involving themselves in their patient’s own environment. Patient experiences of GPs managing care in a family based model have been generally positive, although the days of GPs as the pastor, friend and counsellor may be past.

The impact of social class on health outcomes was confirmed in the Whitehall study in the 1960’s and its association with diabetes outcomes in the follow-up study [3] in 1997. Family dynamics and behaviour change on a daily basis, affecting a patient’s ability to manage their diabetes problems. This combination of psychological, social and family determinants is a dynamic process unlike the certainty of knowledge that we build our clinical management on. Our genes and environment also interact, and two individuals with similar genetic makeup may respond very differently to the same pathology. Lastly and inextricably, our patients’ own perceptions of these problems and their response to them, also shape their interactions with us.

This lack of predictability in human responses and behaviour, against the background of family and social circumstances, and in the context of physical and biochemical pathology, is ultimately the art of practicing medicine. The threads of clinical care, particularly the psychological aspects, and organisation of care (including who organises it) are central themes in this thesis. Goal setting is a process that engages patients to fully disclose the barriers and problems to good diabetes care. Care plans are the outcomes that combine patient priorities with organised care. The GPs and the nurses are the interface that engages the two.

Goal setting was imbedded in this thesis into what we called a care plan. Care planning (or case management) was drawn from the same process that Nursing and Allied health teams had used for many years as part of their daily work, and therefore a familiar process if they were to be part if it. I began testing goal setting in my diabetic clinic with interesting results, as clients confessed that a whole range of issues other than the medical perspectives I thought were important. By 1996 there were also greater opportunities as the Commonwealth Government released significant funding for the Coordinated Care Trials.
The South Australian Government’s Coordinated Care Trial was called Healthplus and involved three hundred general practitioners and four thousand six hundred patients in eight trials. The central platform was a Care Plan that wove patients and providers together using nurse practitioners in varying roles. I have focused on the diabetes components of the Eyre HealthPlus trial.

Goal setting was not a familiar process to GPs, although setting goals and contracts with patients based on desired outcomes are comparable. For most GPs it would require dedicated time and training to learn; it would also needed to be easy to perform, and provide useful outcomes. None of these were true at the outset of my studies and much refinement was necessary. There was some scepticism amongst my colleagues that GPs would be willing to learn these skills, and risk losing control of parts of the interaction between patients and themselves. I took the view that GPs would engage any process that made their job easier and improve outcomes for their patients. Goal setting offered a method to deal with complex medical problems with their associated psychological components. It also offered some solutions.

An important theme in all these trials was whether GPs or a third party such as nurses, would be better at engaging patients through the goal setting process. The outcome would determine a likely future role in organising chronic care. The model depended on available resources and services, as well as the patients own systems of learning and ability to deal with change. By determining a set of patient directed goals, it was anticipated that patients would also embrace the system of clinical care that has been shown to minimise progression to diabetes complications.

Goal setting on its own is explored in a RCT in chapter 2 (trial 1), with systematic care and goal setting working in parallel. The work was detailed and time consuming. Social disability, quality of life, personality effects, adjustment to diabetes, and clinical diabetes parameters were measured over 2 years. As such work is impracticable in routine care, both from a human resource point of view and from a time management perspective, a generic model was developed and used in the HeathPlus trials (trials 2 & 3). Nurses were
used to perform goal setting in an observational trial over 2 years. They also developed care plans and negotiated with GPs and services (chapter 3). This process was much more representative of general practice care and likely models for the future.

The application of this model to Aboriginal communities was more challenging but far more urgent. A survey of diabetes in 1997 in the Port Lincoln Aboriginal community showed a prevalence of nearly 20% with little adherence to management plans, regular admissions and poor outcomes. A small subgroup of 100 Aboriginal people with diabetes were involved in the HealthPlus trial, and performed goal setting and care planning in much the same way as non-Aboriginal diabetic group. Some of these people formed a focus group at the end of the HealthPlus trial looking at Aboriginal experiences of living with diabetes. This latter study not only became the subject of an NHMRC trial but also the basis for a funding community diabetes management programs (Appendix 1).

The care planning model proved impractical for Aboriginal people as negotiated by non-Aboriginal workers acting as coordinators, and the responsibility for goal setting was shifted to the Aboriginal Health Workers (AHW). The two Aboriginal trials (chapter 4) explore this shift and its progression to more self-management strategies. Although only part of the CDSM trial, new methods of self-assessment were explored and have become part of our current research. This approach may be better at engaging Aboriginal people, increasing their sense of control and pacing their progress.

The principle themes of the Coordinated Care trials were around financial models of delivery and shifting money from the acute care sector to the chronic care sector, however much more emerged. The research itself precipitated a process of change within the Eyre Regional Health service that ultimately altered methods of service delivery, the way it was planned, and created an infrastructure that allowed that change to continue. The leadership around the change process also allowed those structural changes to become platforms for further change to occur over the next 5 years.
The first Healthplus trial began on Eyre Peninsula 1997 and included 398 people with diabetes. The Coordinated Care Trial results are discussed in chapter 3 however the final result in 1999 was the adoption of a Care Planning item number for General Practitioners in the Medical Benefit Schedule. Item numbers for Case Conferencing and Age Health Assessments were also introduced, beginning a long-term commitment to chronic disease management. Goal setting remains part of that process today, although the evidence from this thesis would suggest that it is likely to be successful in a different framework.
TRIAL HYPOTHESES

The central theme around these trials has been that although health professionals are expert at managing diseases, patients are experts at managing their own lives. Care of diabetes (and other chronic illnesses) involves a shared approach, with health professionals acting more as advisors than teachers. This implies a shared responsibility for solving problems associated with good diabetes care and achieving satisfactory outcomes. The new relationship is additionally challenging to care providers because they retain responsibility to provide, to inform and to motivate. For patients, this involves a substantial step because they also need training, support and guidance.

Solving problems that are part of diabetes care requires a shift in emphasis for motivation from external direction by care providers such as GPs, to internal control by patients themselves. Motivation has been viewed to be more effective if driven internally, particularly for life-style behaviours [4, 5]. Cognitive psychology research on problem solving indicates that reaching a solution requires a sequence of mental processes that are active [6] as an information processing model [7, 8]. In these trials this problem solving process is called goal setting, and is applied to medical, emotional and social problems.

The first hypothesis in these trials seeks to clarify the usefulness of goal setting and states that:

Goal setting when used by patients with diabetes type 2 in a rural setting will result in improved clinical outcomes and improved social/emotional outcomes.

To be useful to GPs, this process must also become incorporated into a model that uses goal setting as part of regular care, specifically diabetes care in general practice. In these trials case management is the framework of regular care. Systems that support the model of diabetes care are essential if this newly shared responsibility is to achieve its aims. Any support must be for both General Practitioners and patients.
The second hypothesis seeks to confirm this, and states that:

Goal setting can be successfully performed in rural Australian General Practice as part of case management of diabetes.

The thesis trials have set out to confirm these hypotheses in three different trial settings, all based in general practice. Success implies not only a clinical benefit in solving problems and improving self-efficacy around diabetes; it also means that the model is viable in a financial and practical sense. Lastly, the model should be transferable to other populations, and has been tested with Aboriginal people who also have diabetes.
Defining the problem

Diabetes mellitus is a metabolic disorder characterised by hyperglycaemia, and results from defects in insulin action, insulin secretion or both. It results in significant morbidity and mortality as a result of micro-vascular and macro-vascular complications, and currently presents enormous public health challenges to most industrialised and developing countries [9, 10].

Two types occur principally in our community. Type 1 diabetes results from beta cell destruction of the pancreas by an undefined auto-immune mechanism, and necessitates exogenous insulin administration for further survival. The rate of beta cell destruction varies and may be quite rapid in children who present acutely with ketoacidosis as their first manifestation of the disease [11]. In others, mainly adults, the rate of progression may be quite slow with residual function for many years. Autoimmune antibodies to islet cells, insulin, glutamic acid decarboxylase (GAD) and tyrosine phosphatases (IA-2) act as markers to this complex process which sees multiple genetic predispositions interact with environmental factors in a poorly understood manner. This group comprises approximately 15% of diabetics and in Australia they are often treated in specialised diabetes clinics in tertiary institutions. These conditions present significant challenges to both families and carers alike.

Type 2 diabetes, previously called NIDDM or adult onset diabetes, is characterised by insulin resistance and relative (rather than absolute) insulin deficiency and represents the predominant form of diabetes seen in general practice [11]. It has a strong genetic component, and is generally associated with increasing obesity, more sedentary lifestyle and high energy diets. Insulin resistance is associated with obesity and may improve with exercise, weight loss and medication, but how this occurs is unclear. Insulin secretion is defective at high blood glucose levels when compared with non-diabetics, and beta cell function gradually reduces with time compounding the problem. Hyperglycaemia may be present for years with no symptoms and diagnosis often occurs at times of inter-current illness or stress. Microvascular and macrovascular complications have commonly developed by diagnosis with macrovascular complications accounting for most diabetes related deaths [10].
Prevalence of diabetes

Estimates of the prevalence of diabetes in different countries vary, in part due to different nutritional standards but also as a result of individual ethnic susceptibilities. Highest rates are seen in Pima Indians 50% and lowest rates in Mapuche Indians 1%, however there is considerable variability even within local populations [9]. This is seen in developing countries where lower rates in rural communities compared with urban ones presumably reflect dietary and exercise differences.

In Australia the accepted prevalence of diabetes has been close to 3.5% in Caucasians (similar to European and American counterparts) but the recent AusDiab study [12] demonstrated a much higher rate of 7%, which included undetected cases. This confirmed that only half the diabetes cases are known within the community under current conditions. The prevalence is 9.9% in Aboriginal populations, and likely to be at least twice that in many Aboriginal communities [13-15] with considerable variation amongst immigrant communities.

Prevalence rates correlate strongly with age, with relatively low rates until the age of 45, but thereafter increasing to 9% by age 65 years. This latter trend is a reflection of deteriorating islet cell function and may be a normal degenerative process.

The incidence of type 1 diabetes in Australia is about 14 per 100,000 [10] which is high in a world context, with most countries other than Northern European ones having rates below 10 per 100,000. The incidence is also increasing worldwide [10]. The incidence of type 2 diabetes is harder to estimate, as many people remain undiagnosed for long periods of time. Of the few studies performed, rates vary from 11 to 58 per 100,000 [11] with considerable age variation.

Size of the problem

Global estimates of the number of people suffering from diabetes are staggering with world numbers likely to double [16] from 98 million in 1994 to 215 million in 2010. In Australia the absolute numbers remain unknown, but the 350,000 known diabetics probably represent
half of the actual number based on a prevalence rate of 4%. The number is likely to rise to over 1 million people by 2010, prompting both national and state governments to draft policy documents in the late 1990s including the National Diabetes Strategy 2000-2004.

The costs accrued in managing diabetics are significant and in 1995 were approximately Aus$2700 per year per person with diabetes [9]. This is less than the Aus$10,000 per diabetic in the USA and lends credence to the belief that we may be underestimating the real cost to our community. Even at that low figure, the impact on health budgets is important, particularly as absolute numbers continue to rise. Many of the complications are preventable or at least, controllable with good diabetic care, and hence their associated costs.

**Complications**

Macrovascular complications (Ischaemic Heart Disease, Peripheral Vascular Disease or both) occur in 50% of diabetics, while microvascular complications (neuropathy, nephropathy or both) occur in 60% of diabetics after 20 years [12]. Retinopathy may affect up to 20% of diabetics however it remains the most common but preventable cause of adult blindness. The United Kingdom Prospective Study (UKPDS) found much higher rates of retinopathy at diagnosis (36%) perhaps indicating that retinal assessment may not be part of routine baseline assessments in general practice [17].

The UKPDS also showed that 8% of diabetics had evidence of macrovascular damage at diagnosis, which became 23% at 10 years, despite their best efforts to control hyperglycaemia. This finding was in keeping with other trials, including the DCCT [18], which so far have failed to show that reducing glycemia is associated with reduced cardiovascular mortality. As macrovascular disease accounts for 50% of diabetes related deaths, this apparent incongruence leaves many clinicians pondering the need to weigh the detrimental effects of treatment regimes, including hypoglycaemia, against its benefits. Although cardiovascular complications are twice as common in diabetics, future efforts are likely to focus on other risk factor management such as blood pressure control, lipids and smoking cessation.
Overall, mortality is likely to be twice that of someone who does not have diabetes, and they are especially likely to die prematurely between the ages of 50 and 70 years [10].

A problem for General Practitioners

Despite the overwhelming amount of data available, the translation of research into practice has been slow because the problem is complex [19]. Patient behaviour is not predictable and mainly determined by factors external to the health system; eating behaviour and obesity are good examples. Powerful media images control the purchasing of food in all socio-economic groups, despite an understanding of the consequences of overeating. Even those well versed in healthy eating behaviour will have trouble maintaining this over long periods of time [20]. The source of our over-eating has social, financial, psychological, biochemical and genetic components, and the answers are likely to be as multidimensional.

Many patients eventually seek help when they develop problems. General practitioners remain well placed to find solutions as the point of first contact, however they urgently need help to manage the behavioural aspects of obesity and diabetes. The numbers of people are now too great too be managed in hospital clinics. Tools that can be successfully used by GPs in their 15 minute consultations are needed. This is a practical problem that faces nearly all GPs and has brought me to the research that culminates in this thesis.

In searching for solutions, it is clear that a combination of external and internal barriers must be addressed, and both are interdependent. Factors beyond the GP surgery (social, organisational and political) are as important as factors that can be influenced within it (psychology, behaviour and medical). The influences that affect GPs individually have not been explored in this thesis. These include personal attitudes to behaviour, motivation, self-efficacy, cognitive modelling, learning and practice styles. Implicit in much of this work is the theme that we may be best served by applying the knowledge that we already have more effectively, rather than seeking totally new models [21, 22].

This work therefore follows two themes. Firstly patient behaviour and the complex influences that affect how patients respond to their diabetes management are explored
using goal setting. This concentrates on the process of prioritising diabetes related problems and barriers, and seeking practical solutions to them. It is hypothesised that goal setting will improve clinical outcomes by overcoming barriers to care, and increase patient engagement by using their own priorities.

Secondly the organisational aspects of care are directed by the patient’s own preferences in consultation with those who provide the services. A system approach to care is used that is practical in general practice. This is based on current practice guidelines. The interface between the two systems changes between trials, shifting from general practitioner to nurse practitioner to Aboriginal Health Worker. Each model seeks better engagement using goal setting.

The place of goal setting in overall diabetes care is shown in figure 1. Goal setting based on patient priorities is part of the self-management process rather than clinical management where goals are more likely to be GP directed.

![Figure 1: Goal setting and diabetes management](image)

For overall care to be successful, both the goal setting and the management structure must be functional as many of the goals are based on system performance. In an ideal world successful integration will result in greater patient ownership and responsibility for their care. Implicit in this is that greater participation will improve diabetes outcomes and greater self-efficacy.
Background to Eyre diabetes trials

The Eyre Peninsula is a predominantly agricultural region lying approximately 200km west of Adelaide. The population in 1997 (Australian Bureau of Statistics) was 60,000 (4% SA population) with just over a third of those people (24000) living in a major centre, Whyalla [23]. The main industry, ship building, had been in recession for ten years resulting in a large clustering of socio-economically disadvantaged people. The other main population centre on Eyre Peninsula is Port Lincoln, a more affluent fishing and farming base with a population of 13,000. There are specialist surgical and medical services based in both Port Lincoln and Whyalla, although it is 200km between the two and they tend to operate separately. They are also funded independently by the state government, with a regional health authority supervising all services outside Whyalla. There are in addition, 8 other smaller towns within the region with small hospitals that are run by local general practitioners. In general their populations are less than 2000 people.

Diabetes services over the region vary considerably, depending on local interest and funding availability. Historically dieticians and occasionally diabetes educators have provided information and education to diabetics, however type 1 diabetics or those on insulin have been the main recipients of such services. Physicians have consequently found themselves treating complications, while diabetic surveillance has been a nonentity. In the
remoter parts of the region, allied health services have provided a limited outreach service, with the bulk of diabetes care still falling to general practitioners. In 1996 there only 2 diabetes educators for Eyre Peninsula [23].

Over the last ten years as public awareness of the number of people suffering from diabetes has increased, with its associated morbidity, GPs too have become more organised in their approach. Services however have continued to work independently of each other. In 1993 a general practice based diabetes clinic was established in Port Lincoln Hospital with help from the Commonwealth via the Divisions of General Practice. It fostered a multidiscipline approach to diabetes care, and remains the only diabetic clinic in the region.

Almost no data concerning hospital admissions, presentations to accident and emergency departments, or consultations in general practice was available in 1996 for the region. Only limited hospital separation data for diabetes admissions was known, and this was inaccurate with only primary diagnoses being coded for funding (case-mix) purposes.

In 1995, the CEO of the SA Health Commission indicated at the COAG meeting [24] that he anticipated a large increases in costs of care for an aging population, and the State’s inability to cover forecasts of acute care costs in the short term. This was compounded by the government’s State Bank crisis. The outcome was reduced budget lines on all aspects of health spending in all regions. Actual costs during the thesis trials are shown in table 1.
<table>
<thead>
<tr>
<th>Year</th>
<th>Public Hospital</th>
<th>Age care</th>
<th>Medical Services</th>
<th>PBS</th>
<th>Public Health</th>
<th>Dental</th>
<th>Total Cost</th>
</tr>
</thead>
<tbody>
<tr>
<td>2000-01</td>
<td>788</td>
<td>184</td>
<td>442</td>
<td>254</td>
<td>228</td>
<td>43</td>
<td>2,352</td>
</tr>
<tr>
<td>1999-00</td>
<td>766</td>
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<td>376</td>
<td>172</td>
<td>117</td>
<td>28</td>
<td>1,923</td>
</tr>
<tr>
<td>1997-98</td>
<td>669</td>
<td>168</td>
<td>360</td>
<td>156</td>
<td>71</td>
<td>26</td>
<td>1,782</td>
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<tr>
<td>1996-97</td>
<td>607</td>
<td>160</td>
<td>349</td>
<td>154</td>
<td>72</td>
<td>24</td>
<td>1,654</td>
</tr>
</tbody>
</table>

Table 1 Health expenditure $ per person in South Australia (source AIHW)
For a region that was spread over large distances, this was difficult to achieve given that there were minimum funding levels for the majority of small hospitals within the region. The small towns with populations of under 1000 people continued to provide care through their local hospital, which usually had low bed occupancy rates. The service was maintained despite this inefficiency at a cost of about $1 million per hospital per year (ERHS budget 2003). This meant that most small health units needed to receive additional funding each year, above that provided under the Casemix calculations.

The government looked at solutions such as service reduction, as well as some newer ones, including capitation models, service utilisation models and a combination of both adjusted for age, sex, demographics and Aboriginality, and population based health care funding. Ultimately however, fundamental structural change was required if rural communities were to preserve access to high quality health care.

There were further problems that compounded the situation on Eyre Peninsula. These included an aging population, an aging nursing and medical work force, an inability to recruit allied health staff, nursing staff or medical practitioners and a steady population shift to the larger centres [23]. For many smaller communities, the loss of the hospital and its associated workload was a matter of deepest concern. It ultimately placed communities in the vulnerable position of potentially losing their doctor and having to travel long distances in the event of emergencies. They consequently clung tenaciously to what they had, and fought bitterly in the political arena to maintain it. This was even at the cost of looking at longer-term change and different models of service provision.

The politics around change continue to trouble the implementation of service redistribution even in 2004. Local communities chose to pressure their politicians to continue funding their local hospitals. Each hospital was therefore duplicated across the region and valuable resources spent maintaining them. The Regional Health Service proposed efficiencies that were to allow acute services to be concentrated in one centre, and funds redirected to developing chronic care facilities. It has only been a combination of capital maintenance
costs and falling nursing staff numbers that have caused the local hospital boards to consider redefining their service provision.

This failure of local population to accept or be fully informed about health delivery change was a lesson that was carried into the current round of service delivery arrangements. It was a central theme in the WHO paper on chronic care management strategies published in 2001 [25]. The WHO believed that healthcare systems must be redesigned to manage long-term health problems more effectively. It proposed a framework centred on the “healthcare triad,” a partnership between patients and their families, healthcare teams, and supporters in the community. Because managing chronic conditions involves behavioural and lifestyle changes, patients must be empowered to take a central role in their own care. Healthcare staff will need to be skilled in counselling and behavioural change techniques.

The coordinated care trials

In February 1994 the Council of Australian Governments (COAG) discussed health reform and established a Task Force. Poor communication at the State and Federal level had generated large numbers of separate services with their own funding. Often these services acted independently, resulting in much unnecessary duplication and waste of valuable resources. The paths of funding were complicated [24] and often encouraged intergovernmental conflict.

The background to the COAG discussion paper was both consumer and fiscally driven [26, 27]. On one hand, patients were demanding more input into the provision and planning of health care. Patient advocate groups argued that medical agendas had favoured expenditure in the acute sector, ignoring health maintenance and disease prevention. The profession maintained a strong influence within health planning and generally resisted on attempts to change this. On the other hand, medical costs were likely to increase. Australia’s universal funding system (Medicare) offered high quality care at a relatively low percentage of GDP. Diagnostic and treatment costs, an aging population and falling private health rates contributed to this. Cost shifting between state and federal services obscured the central issues, and distracted planners away from urgent need to provide solutions.
The Task Force argued that although the system often worked well, some key reforms were necessary, highlighting the following key elements [24]:

- reorganisation of services into general care, acute care and coordinated care
- restructuring on the basis of care outcomes
- new funding arrangements to reflect care and support needs
- improved continuity of care
- service reform
- an improved nationally consistent database

The Task Force’s Discussion Paper was endorsed by COAG in April 1995, and expressions of interest sought in September 1995 to explore possible solutions. Ultimately twelve coordinated care trials Australia wide commenced design and tracking phases in 1996. One of these was the HealthPlus trial in South Australia in which 4600 patients enrolled, although funding was not agreed until June 1997. The trials covered chronic cardiac, respiratory and mental health disorders, as well as diabetes. The live phases of the trial ran between June 1997 and December 1999. Several trials such as health care for the homeless, and antenatal and postnatal care in socially deprived areas were unable to commence by the start date.

**The HealthPlus Model**

In 1996 the CEO of the South Australian Health Commission (SAHC) already actively supported shifts in the emphasis of care toward the primary care sector. He had much support from sections of the allied health fields and ideological support from parts of the medical community. The combination of budget pressure and the opportunity provided by the CCTs were perceived to be a window of opportunity for large-scale system change. He hoped to create greater integration by pooling all resources, financial and clinical, into a new model that joined State and Commonwealth funded providers. He believed that savings in the acute sector could provide long-term sustainability.
In a broader context, this provided not only a mechanism for change, but also the opportunity to demonstrate that primary care could indeed be cost effective on a large scale. Unfortunately this latter emphasis on financial outcome ultimately was to replace the original desired clinical and patient outcomes that inspired the SA HealthPlus trial [28, 29]. Whether this was always an unwritten requirement on behalf of the Commonwealth that was withheld for fear of losing clinical support will never be known. The year 1997 – 98 was also a time of considerable change in the SA political system. The formation of the Department of Human Services, and changes in Health Minister and executive level personnel in the SA bureaucracy, resulted in a fundamental change to support for the objectives of the trial. By September 1998 the trial focus was on incremental rather than transformational change [30]. Change would not necessarily depend on cash pooling by both Commonwealth and State, and the trial managers focused on which components of the model were most effective/essential.

SA HealthPlus looked in some detail at several existing models of care, including the Port Lincoln diabetes service. A review of historical Health Insurance Commission (HIC) data, including Medical Benefits Schedule (MBS), Pharmaceutical Benefits Schedule (PBS) and hospital separation data, suggested lower costs incurred in funding this type of model [27]. The subsequent Anderson report [26] commissioned by the SAHC examined a broader population in SA, and looked at several chronic diseases including diabetes. Average length of hospital stay (1993-96) was higher in SA country areas compared with the city, as was the number of hospital separations. The report outlined a number of structural and financial models to deliver the trial, based in part on best practice models used in the United States. The implied message was that savings could be made in the acute sector, which in turn could be used to fund long-term preventive care.

The organisational aspects of this trial were additionally challenging to all health care providers. Because of perceived conflicts in state and federally funded services, a new tier of management, the Regional Development Units (RDUs), were established to draw together all providers with consumers. This group directed funding and prioritised issues within the trial [31]. It was anticipated that if these arrangements were to continue beyond the trial completion into a real and ongoing funding pooling arrangement, then the regional
health authority would undertake this task. (Fund pooling envisaged sharing of Commonwealth and State funds as already occurred, within a common budget. Duplication of supporting administrative arrangements could be avoided and the additional funds redirected into care.) Much effort went into the RDU as many salaried care providers found the financial models both threatening and complex. The inability to convince providers that funding based on need and outcomes was more appropriate, led to many structural delays and lost opportunities within the trial.

**Aboriginal health perspectives**

**Background**

The vast majority of Aboriginal people (who participated in trials) live either in Ceduna or Port Lincoln. Ceduna is situated at the head of the Great Australian Bight and has a population of 3500. A high proportion are Aboriginal (about 700) and are mobile, travelling to other communities in Yalata, Oak Valley, Coober Pedy, Port Augusta, Western Australia and Port Lincoln. The Ceduna and Koonibba Aboriginal Health Service (CKAHS) was established in 1986 and provides basic health services in addition to specific ones such as dog control, drug and alcohol counselling, trachoma and lice programs. They employ Aboriginal Health Workers (AHW) for much of their community work and employ a full time medical practitioner.

By contrast Port Lincoln’s Aboriginal population (1200) represents 10% of the overall population. The Port Lincoln Aboriginal Health Service (PLAHS) was established in 1992 and provide similar services although they lack a full time medical practitioner, relying on local GPs to provide clinic services.

Diabetes services have until recently, been provided by non-Aboriginal health workers working out of hospitals. Few indigenous diabetes educators have been available, and little culturally appropriate information is available. Some Aboriginal health workers with diabetes have taken a greater interest in diabetes and used their own experiences to educate others, however there was little continuity.

The experience of Aboriginal Health Workers is noteworthy. Required to advocate both medically and politically on behalf of their clients, these young motivated people could be
at work all of the time. Community expectations were such that a request for help was not to be ignored. During the day they were required to assess, transport, treat, find money for medication, and support family members. At night they might be called upon to mediate in crises, find accommodation or transport clients to hospital. Not surprisingly many AHWs often only lasted 12 months and the difficult task of retraining would begin again.

Diabetes prevalence rates in 1996 in Ceduna were 25% based on CKAHS medical record review, and 18% in Port Lincoln based on a screening program of 500 Aboriginal people over 20 years age. The diagnosis was based on Glucose Tolerance testing within each health service. Little or no diabetes specific funding was available despite these extraordinary rates. Nationally, Aboriginal life expectancy was 20 years less than the rest of the Australian population, and coronary heart disease rates four times higher [10, 32].

The social circumstances of many of the indigenous patients in these areas are unsatisfactory by Western standards, and are typified by a combination of factors. Patients often lived in and shifted between poor and overcrowded housing, many had no phone or transport, levels of education were often low, and unemployment was common [33]. Low self esteem and confidence that influenced how individual patients coped within the trial was also common, and there was a high incidence of denial of their disease, which was linked to low self-esteem.

In addition, there were the indigenous patient cultural obligations of sharing of material items such as money, obtaining and shared foods and medications (usually but not always with family members) and caring for multiple family members and relations. The important aspects of illness, its effects on family and community roles, spiritual linkage with the land, and ownership of land were generally lost on the non-Aboriginal population.

Furthermore, the Wangka Wilurrara Aboriginal Regional Council in its 'Regional Plan 1996 – 1999' [34] highlighted issues such as:

- a life expectancy for Aboriginal people of 15 to 18 years less than the normal for white Australian (males 57 & females 65 years)
• a higher than normal rate of smoking (53.6% of people)
• a consensus that alcohol was a problem in the community (some 78.7% compared with national figures of 58.8% of people indicating that alcohol was a concern)
• a high incidence of illness such as asthma, ear and hearing problems and diabetes among Aboriginal people
• a need for greater autonomy for Aboriginal community programs and for the people concerned to be much more involved in framing strategies to deal with health problems
• a need for more data collection and quantification of health problems in Aboriginal communities as a means of securing funding and new program initiatives
• a need for funding for specific programs for remote communities in the areas of dialysis support, mental health, aged care, substance abuse, rehabilitation, domestic violence and transport services
• a need for education and awareness programs for Aboriginal people to begin to address the unacceptably high levels of poor health facing people in the Region
• a need for improvements in housing and basic family security and comfort
• a need for increased awareness among mainstream and Aboriginal communities of the degree to which poor housing and living conditions contribute to disease and poor health prospects for indigenous people

Consequently at the time these trials were formulated, the Aboriginal communities were actively seeking solutions to these important problems, and showed great interest in becoming involved.

Delivering better diabetes services
The Coordinated Care Trials offered many new funding opportunities to Aboriginal communities who were incorporated into the mainstream CCT on Eyre Peninsula, rather than the National Aboriginal CCTs [2]. The themes of story telling (as part of goal setting) and more personal approaches were additionally appealing. It also made good sense to be part of local changes in service delivery as they occurred rather than being incorporated later.
Following several approaches to both health services, 59 people from Ceduna and 42 from Port Lincoln were enrolled in the Healthplus Coordinated Care Trial and a similar number in the follow-up Chronic Disease Self Management trial. The politics of enrolling clients were not difficult although the importance of trusted and established relationships were critical in reassuring both populations. Both health services were very clear that there needed to be tangible benefits to the community, not just to the patients and the AHWs through their employment. Far from being naïve, they (and many other Aboriginal organisations) understood the underlying national political agenda of health reform and empowerment. This was to remain a constant theme throughout the trials.

**Overview of thesis trials**

It was in this context that these trials have sought to answer questions around goal setting, and barriers to diabetes management and planning. A summary is set out in figure 2. Goal setting on its own identified many problems and some answers. The solutions required health service intervention so that the goals could be implemented, and in many cases services were inadequate. Overcoming barriers using goal setting therefore required a review of how services could provide solutions to meet patient demand. It has also required a review of how care can be planned and delivered in general practice.

![Diagram](image-url)

**Figure 2**: Overview of the changes required to support goal setting and case management of people with diabetes.
New models of service delivery based on patient rather than provider demand, were required as part of health service reform. General practice also had to respond by organising chronic care and use new information technology. Care planning required recall and review systems to be implemented, and for information to be shared across systems. Ultimately the hospitals, on behalf of their communities, had to decide on how to best respond to the needs of the diabetic population in a long-term commitment. The choices were challenging because they had to involve patients (community engagement) more than ever before. For GPs the model needed to be sustainable and workable for themselves, in this case with the assistance of nurse coordinators. Engaging patients in managing their diabetes as much as possible was a key issue, and goal setting sought to do this by overcoming barriers. It did however require the rest of the system to be functional to be successful.

Goal setting as an independent intervention is explored in chapter 2. The ability of the health system to incorporate case management (and goal setting) as a financial model is explored in chapter 3. The application of care planning and goal setting under current financial conditions for local Aboriginal people with diabetes is explored in chapter 4. The use of goal setting in this diabetes model ultimately seeks better patient engagement and self-management skills. From a goal setting perspective this means better problem solving skills. Most of the changes required to support goal setting only evolved dynamically over the course of the trials. Sustainable support in General Practices is still lacking, and in this model would be best achieved with nurses based in practices. Current funding favours the model outlined in fig.2 with community based care, community engagement and self-management strategies although it is work in progress.
CHAPTER ONE

Literature Review

Introduction

Clear evidence now is available from the UK Prospective Diabetes Study (UKPDS) and the Diabetes Control and Complications Trial (DCCT) that close to normal glycaemic control is associated with reduced micro-vascular complication rates [17, 18]. Evidence is also available that tight blood pressure control [35], lipid management [36], aspirin [37], regular foot examinations [38], and smoking cessation [39] are associated with reduced complication rates.

Lifestyle interventions, particularly diet and exercise, are effective both in the treatment of diabetes [40], and the prevention of diabetes [41-43]. Although many GPs recommend diet and exercise changes, many patients also find such changes too hard, compounding the psychological impact of their disease.

The professional recommendations of the American Diabetes Association and Royal Australian College of General Practitioners reflect the importance of following these clinical guidelines, however achieving them remains more difficult. Attainment rates vary with 20-30% of Australian diabetics having HbA1c or microalbumin testing annually, only 10% having HbA1c results less than 7%, and 50% having high cholesterol levels (≥ 5.5) or BP >140/90 [10]. Overseas outcomes are no better. Unfortunately many GPs are unaware of the multiple guidelines available [45] and find them hard to integrate into day to day care. Current prescribing software fails to incorporate such guidelines, particularly as they are updated, compounding the problem [46, 47].
Patients with diabetes additionally rate their health status as poorer compared with non-diabetics [12]. Little data is available comparing differences between people with diabetes in the city and those in rural areas. Knuiman reported no difference in cardiovascular prevalence, hospital use and self-assessed health status [48]. Rural populations do not differ in self-assessed health status compared with city populations [49].

Barriers to high quality diabetes care may be placed by policymakers, healthcare professionals, or patients themselves and emphasise the need for multifaceted approaches to care. Solutions must overcome provider failure (actual delivery or bias discussed in section one of this chapter), and patient problems (personal or supporting environment discussed in section two). Provider adherence may be improved by systematic approaches.

**Financial implications**

The incentive to efficiently manage diabetes care is the escalating cost with increasing complications and complexity of care. Currently there are 350,000 diabetics in Australia, half the number predicted by the AusDiab study[12]. The last Australian estimate of costs was in 1996 [9] and was $2774 per patient per year (dollar values are in Australian dollars unless otherwise stated). This compared favourably with Canada ($2978) and the USA ($8980). The current minimum cost for a diabetic patient with no complications in the USA is $2600: few such patients exist. The costs of care increase 10-30% with drug treatment, micro-vascular and macro-vascular complications. Insulin treatment, angina and MI increase costs by 60-90%, and renal dialysis by a factor of ten [50].

The costs associated with intensive glycaemic control however, are not insignificant. The UKPDS found that costs increased by $1700 per patient over 10 years, but decreased the cost of complications by $2300[51]. Much of this additional cost is drug related and may be unsustainable as greater numbers of patients are identified [52]. The number needed to treat intensively over 10 years to prevent one micro-vascular complication was 196, and to prevent one diabetes related death was 15; by contrast 6 patients need to have hypertension treated to target over 10 years to prevent one complication. The actual cost
savings under intensive glycaemic control (principally in shorter hospital stays) may not be sustainable and may be translated into prescription costs [53] eventually anyway.

The likelihood of hospital admission and the number of admissions for short term complications increases with increasing HbA1c[54-56]. Risk stratification processes have been developed in the USA but not Australia [57]. The dilemma for governments will be whether to spend resources on diabetes prevention (lifestyle intervention cost $1600 per year in the Diabetes Prevention Program[58]) with no immediate benefits, or concentrate on complicated patients with poor glycaemic control where potential gains are greatest.

SECTION ONE - Current diabetes systems

1.1 Primary care

In primary health care the central concept is the application of particular models of care at the point of first contact; it implies that such systems should reach all members of a community and be able to involve them in health programs (WHO 1978). This latter component, particular patient involvement in strategies to address determinants of their health (including those outside the health sector), is likely to challenge current structures over the next 5 years. Politics rather than health is likely to dominate this process [59].

1.1.1 General Practice

In Australia diabetes care is provided mainly by its 17000 [14] practicing GPs [44]; diabetes problems account for 1.9% of all problems and is the seventh most common problem in general practice [15](BEACH study). Only 3% of diabetes problems are referred to allied health providers and 2% to medical specialists [10]. Specialist care is provided in private practice, hospital outpatient clinics and diabetes centres in some parts of Australia. Specialist services are generally only available in remote and rural areas as visiting services. This places great demand on GP services in those areas.

Incentives for GPs were introduced in 2001 under the National Integrated Diabetes Program. The budget allocation for this program was $43 million. The incentives were to
develop systems of care within general practice, funding to support networks around
general practice and improve access to care, and resources for diabetics for education and
support.

More general support for GPs became available through the Enhanced Primary Care
initiatives however GP uptake of these incentives has been slow without significant
infrastructure funding.

The Aged Health Assessment has been the most widely adopted item with 18% of eligible
patients over 75 years having an assessment in the first two years, but only 45% of these
having a second assessment one year later. Care plans have peaked at 19,000 per month
(April 2002) and currently are claimed at about 11,000 per month; diabetes annual reviews
are performed at 6000 per month [62]. Despite 74% of GPs having used any of the EPC
item numbers, only 30% regularly claim one number per month or more. Interestingly this
figure is 36% higher in rural areas.

1.1.2 Community health care teams

Health expenditure in 2001-02 on allied health was $2521 million (4% of health budget)
compared with medical services $11,187 million (17%) and the global General Practice
budget of $3.41 billion (AIHW01-02). Most allied health services are funded by State
governments, and operate in community health centres independent of general practices.
Diabetes teams provide local and outreach services but are limited in their ability to provide
medication and pathology services. There is increasing interaction between general
practice and community health services through the Divisions of General Practice to
improve GP involvement in these teams. Their leadership may be important in determining
funded models.

Models substituting nurses [63, 64] or pharmacists [65] for physician roles have been
successful, as have models working with physicians [66-69]. Diabetes centres have
become more common in parts of Australia since 1994, combining allied health teams with
endocrinologists. They provide limited outreach services within cities.
1.1.3 Community based programs

Diabetes Australia was established in 1937 and is the principal consumer body with roles in patient advocacy, service provision, research and the National Diabetes Strategy. They currently support local diabetes networks, but are not involved in patient led management programs.

There much interest in Chronic Disease Self-Management (CDSM) strategies with several government funded trials in Australia awaiting evaluation. Self-management strategies have been promoted in Australia by Battersby [70] and overseas by Lorig[71]; considerable interest shown by governments in adopting these lower cost programs. In general however, patients who are more engaged with their care process have better outcomes [72, 73].

Available evidence suggests that CDSM systems are financially viable and improve health outcomes[74-76]. Whether this transfer of self-efficacy can be translated into financial savings in the long term is uncertain. Morbidity compression has been used to describe the potential delay in health costs [77].

In the UK, the Expert Patient program [78] has been developed in over 100 centres and has been incorporated into NHS policy for the next 10 years. Little evidence has been published on outcomes.

1.2 Secondary care systems

Specialist services

No estimate has been made of specialist shortages in rural Australia [60] because the provision of outreach services distorts figures, and requirements for sustainable practice in many areas are not met. These include inadequate pathology and radiology services, specialist nursing, equipment and specialist beds, or on-call cover. Endocrinologists, ophthalmologists, renal physicians and vascular surgeons all provide varying degrees of outreach service. They provide services to patients and train GPs in some circumstances to provide specialised services. The Commonwealth has funded this program since 2001 through the More Specialists Outreach Assistance Program (MSOAP).
Diabetes outreach services combining allied health teams with endocrinologists have been shown to be effective in rural areas [68] as well as larger centres [79]. Nurse practitioners provide a further degree of service substitution and in some states prescribe and refer to specialists.

Telemedicine has been used to provide both specialist medical and specialist allied health services in rural communities. Its cost effectiveness has not been proven [80]. Diabetes education by telemedicine can be as effective as face to face education [81].

**Hospital outpatient services**

The quality of diabetes care is similar in hospital outpatient and community settings [82]. There is considerable variation in hospital services [83] just as there is in primary care. Intensive hospital based treatment programs although successful are also expensive [84], and whether care is provided by generalists or sub-specialists does not affect outcomes [85, 86].

### 1.3 Overseas models of diabetes care

#### The US experience

Wagner and colleagues have developed a chronic care model that has been widely adopted in the USA in a variety of settings. The key elements of his system are organisational support, information systems, practice design, decision support, self-management and community resourcing. They have been associated with improved processes of care, lower rates of specialist use[87] and costs[88].

His model includes audit systems, patient tracking systems and disease registries. He argues that the quality of care relates to the design of the care system rather than the physician capabilities[89].

Managed care is responsible for health provision of 62% of the US market. Traditional fears about managed care relate to cost containment at the expense of quality care, however these have not been realised [90, 91]. Increasingly care within the managed care organisations is being shared with nurse practitioners and physician assistants, and
specialists are being replaced by GPs. Access to high quality care is however not guaranteed in the US where 14% of patients are uninsured and another third underinsured. Compared with their Canadian counterparts, diabetics in the US are more likely not to receive recommended care, despite higher costs (US$4178 compared with US$2285) [92].

The application of structured programs has also been successful in primary care settings in the USA [79, 87]. Unfortunately GPs only comprise 13% of the medical workforce, and rural US GPs face similar problems to those in Australia (high patient numbers, social and academic isolation, limited access to services). Their numbers have also been supplemented by nurse practitioners and physician assistants, who face the same pressures as GPs. Generally, successful interventions in rural populations have not proved easy to sustain [93].

The UK experience
Diabetes care is traditionally performed by GPs working in community settings, with support from large teaching hospital outpatient systems. Nearly two thirds of diabetes care occurs in general practice. Diabetes care is more likely to occur in training practices, those with good nursing support, and those with a high prevalence of diabetes (especially diet or tablet controlled) [94]. Better compliance with care by contrast was not associated with any of these factors, including attending hospital outpatient clinics, but more likely in small fund-holding practices with recall systems [95]. Socioeconomic status was also related outcomes.

In 2002 the government released its National service framework for diabetes [96]. It plans to invest in primary care, including the development of specialist general practitioners, to develop national registers by 2006, and improve patient care through information technology and direct patient participation in local diabetes networks.

1.4 Factors affecting the quality of diabetes care systems
Renders reviewed the effectiveness of interventions targeting professionals and health care structures in primary care [97]. Multiple professional interventions including postgraduate education, in conjunction with patient education, nurse support, and/or computerised
tracking systems, were most likely to lead to improved patient outcomes and process of care. Nurses were identified as important in most areas of diabetes care, particularly self-management, behaviour change and follow-up. No studies of nurse physician collaboration have been done [98].

Case management (care planning in Australia) similarly is most effective in conjunction with disease management, patient education, reminder and support systems [99, 100]. This is not true for preventive services [101]. Influencing policy makers to implement these findings may not be easy [102] as their agendas are political. This may or may not be progressed by local opinion leaders [103].

Interventions to change provider behaviour must also be multifaceted [104]. Apart from improving knowledge and skills, individual provider motivation and organisational motivation need to be addressed. Audit and feed-back is effective [105] at changing practice behaviour, however targeted payments [106] and payment method [107, 108] are not. Media interventions in contrast are effective at influencing patients and health professionals use of health services [109]. Software technology to assist clinical decision making is likely to help [110].

Affordability, accessibility and efficiency of care were identified by patients as deficiencies in primary care settings [111]. Evidence that involving patients in changing services, effects quality of life, satisfaction and outcomes is not available [112].

SECTION TWO - Patient behaviour and goal setting in diabetes care
The previous section covered provider issues that impact on the quality of diabetes care. In this section, patient behaviour is reviewed with particular reference to the barriers that influence patient behaviour, and how goal setting may help.

1.5 Psychological impact of diabetes
The expectation that patients can achieve goals directed by their doctors requires persistence and determination in the face of declining beta cell function. Medications frequently become ineffective over time and are replaced by exogenous insulin. Multiple
medications for complications or coexisting disease increase the increased risk of depression and anxiety disorders [113, 114]. Good self-care behaviour can become obsessional behaviour and may enhance this risk.

Depression although twice as common in diabetes [115] has been regarded as a consequence of diabetes, but may predict the later occurrence of diabetes [116, 117]. It adversely affects microvascular outcomes [118], and may accelerate the presentation of coronary heart disease [119]. Treatment of depression and anxiety may reverse some of these adverse outcomes [120-122].

Hyperglycaemia has its own psychomotor effects [123] although learning, memory and problem solving are spared.

1.6 Evolution of goal setting

Most research has concentrated on the system of care or its providers, despite 95% of care being performed by the patients themselves. How patients respond to the system, in their social and cultural environment determines the outcomes as much as the system itself. The importance of illness behaviour was raised by Balint [124] in the 1950’s. He felt that the doctor’s behaviour influenced the presentation of symptoms by operant conditioning. Reinforcing healthy behaviour and ignoring other symptoms should result in fewer symptoms. Improvements in an individual’s confidence in his or her ability to undertake specific self-management behaviour, or self-efficacy, are associated with good doctor-patient relationships [125].

Patient education approaches evolved in the 1970’s, and more systematic approaches in the 1980’s that acknowledged the social and psychological aspects of chronic disease [126]. Stress, habits and personality were thought to cause non-compliance but remain unproven [127-129]. Patient responses were grouped into emotional (depression, phobias), cognitive (denial, maladaptive coping) or behavioural, and were further determined by family and the supporting structures. Compliance with treatment was effected by these same factors, as well as poor understanding (cognitive hypothesis Ley 1977 [130]) and the context in which treatment was provided (health belief model Becker and Maiman 1975.
In this latter model perceived seriousness, perceived outcome and cost (psychological, physical and financial) determined treatment adherence.

More recent research techniques have focused on patient behaviour following a review of personal attitudes and experiences of diabetes. These include empowerment training [132], autonomy support [133], and activation counselling [134] where management is negotiated and associated with improved physiological outcomes. In motivational interviewing [135], patients are encouraged to explore their feelings and conflicts about behaviour change, and in doing so resolve those conflicts.

The method of achieving such change usually involves definition of the problem, solutions and strategies. It can be done individually or in groups. Participatory Action Research is a group technique that explores these issues in a cultural and social framework, a model that is applicable to Aboriginal research. Other group approaches have been successful [136-139].

Patient generated solutions have been described differently depending who and where they were being used. Goal setting has been used by dieticians and diabetes educators in weight management programs [140, 141], and to a lesser extent by physicians [142]. Problem solving describes a similar process developed in the 1970's by diabetes educators to assist management of type 1 diabetics, but extended to type 2 management [7, 136, 143-147]. Negotiation describes a similar process but has not been widely adopted [148, 149].

The underlying themes of these interventions relate to health beliefs, autonomy and self-efficacy. The intended outcomes are greater patient empowerment and better coping behaviour. Strong self-efficacy beliefs are associated with better coping behaviour and in turn HbA1c results [125]. A multitude of psychological outcome measures are available to assist physicians and patients with behaviour change [150] however few are easily used in routine clinical practice. GPs remain in a prime position to influence patient behaviour, albeit in a short interview.
1.7 Psychological theory of goal setting

Goal setting theory is based on final causality (Aristotle [151]), that is, action is caused by a purpose. It assumes that personal reflections provide accurate information on which to formulate psychological concepts and measure behaviour. Consciousness, volition (free will) and introspection are central themes. Twentieth century interpretations of behaviour externalised causes, and followed accepted principles of the time, determining that man has no control over his beliefs, actions or thinking. Cognitive psychology in the 1970’s and 1980’s challenged this, however much work was done on sub-conscious motivation.

Locke’s work in the 1960’s followed conscious motivation. He considered that all living organisms engage in goal directed action as a necessity to survive, however many functions became automated (digestion, cell repair). In man, goals are set volitionally, and may cover a lifetime but can be chosen incorrectly. He and Latham performed over 500 studies on goal setting [152].

A goal is the aim of an action, and has internal aspects that are ideas, and external aspects such as performance level. Goals also include some content (the actual object being sought) and varying degrees of intensity (complexity of choice process). Locke’s research showed that the more difficult the goal the greater the achievement, and that both specific and difficult goals lead to the highest achievement. High commitment to goals was attained when the individual was convinced the goal was important and was achievable (or at least progress is being made toward it). Self-efficacy was a key influence in the difficulty of goals chosen, commitment to goals, response to failure and choice of strategies.

He also noted that goals stimulate planning in general, often at a higher level than would occur otherwise. He assumed that positive learning becomes automatic, and incorporated into regular problem solving behaviour. Goal setting however, on complex tasks is least effective if people have no prior experience, and/or there is high pressure to perform. Goal setting also mediates the effects of past performance on subsequent performance; this in turn affects the degree of effort, the direction and persistence of any strategies.
Locke's work is heavily tied to social-cognitive theory and cognitive behavioural models. His studies were in industrial and organisational settings but applicable to a wide range of audiences, including self-management. He left many aspects of goal setting unexplored, such as goal setting in dynamic environments, goals and problem solving, and self-commitment techniques.

1.8 Goal setting studies in General Practice

Kinmonth followed 250 newly diagnosed type 2 diabetics the UK for 1 year. Nurses and GPs in the intervention group received training in patient centred care and behaviour change. Patients reported greater satisfaction and well-being, but had lower knowledge scores, higher body mass index and higher triglycerides. Glycaemic control was not affected [153].

Olivarius provided structured care to 870 diabetics in Denmark over 6 years. This included goal setting by the general practitioner of lipids, diastolic blood pressure, HbA1c and in some cases weight reduction. Intervention patients had lower HbA1c by 0.5%, lower systolic blood pressure by 5mmHg and lower total cholesterol by 0.1mmol/l. Intervention doctors arranged more follow-up, referred fewer patients to diabetes clinics, and set more optimistic goals. Both intervention and control groups lost weight (2.6 v 2.0kg) [154].

A search of Medline and PsychInfo databases from 1980 to 2003 failed to identify any other trials in general practice, using goal setting in patients with type 2 diabetes. Key search terms were: goal setting, problem solving, patient centred care, and diabetes. A number of references exist on problem solving in paediatric diabetic populations, relating to diet and treatment adherence. Considerable literature exists on patient provider concordance in General Practice but none specifically on patients with type 2 diabetes.

1.9 Rural based research on diabetes in Australia

Little work has been published on diabetes in non-Aboriginal communities in Australia. Knuiman and Welborn described risk factor prevalence in Western Australia [155, 156] in the 1980’s but little has been described since. His follow-up studies showed excess cardiovascular mortality but no intervention was planned. Rural GPs are more likely to be involved in complex care [157] yet their work is not documented. There are no published
studies of goal setting, problem solving, family and social support interventions in non-Aboriginal rural Australian diabetics.

Much of rural based diabetes data is now incorporated into larger reports; these include AIHW reports such as BEACH and Diabetes Australian Facts 2002, and government reports such as 'The Impact of Diabetes in South Australia 2000'. Broader studies comparing rural and city general practice [49] are published occasionally.

1.10 Barriers to change and future research

Simmons has identified five categories of barriers to diabetes care; they included internal psychological (self efficacy/health beliefs), external psychological (psychosocial environment), internal physical (co-morbidities/side effects of treatment), external physical (finance/access to care), and educational (knowledge of diabetes/services) barriers [158]. External physical, external psychological and internal psychological barriers were associated with less monitoring.

Glasgow's personal models [159] are widely accepted in the USA. He has identified beliefs about treatment effectiveness as the strongest predictor of self-management, ahead of disease seriousness and barriers to care. These in turn were stronger predictors than demographic and medical characteristics. The implication was that exploring personal models and specific self-management barriers may be a short cut to assessment of treatment problems.

A meta-analysis of behavioural interventions has shown only modest improvements in HbA1c of 0.43%, blood sugar reduction of 1.3 mmol/l and weight loss of 1.5kg [160]. A systematic review of psychosocial outcomes following education, self-management and psychological interventions showed improvements in quality of life and depression [161]. Both reviews noted methodological problems and recommended larger controlled studies with better diabetes specific interventions. There is also a need for more longitudinal studies that do not rely on self-reported measures, that include family and social impact, and examine treatment adherence. More work also needs to explore the relation between complexity and/or duration of disease, and its likely responsiveness to multiple interventions.
1.11 Research on the family and social influences in diabetes care

The influence of diabetes on family is most obvious in newly diagnosed children, however this influence also evolves during adolescence and adulthood into self-care. Emotional support, problem solving and cooperative relationships are central to good type 1 care [162]. Personal and social satisfaction is associated with good self-care in type 2 diabetes [163, 164]. Low levels of social and family support are associated with poor adherence and worse outcomes [165].

Few studies have examined the influence of family support on diabetes metabolic outcomes [166, 167]. Women achieve greater weight loss and glycaemic control than men [168] in some studies, and less in others [169]. Navajo Indians show better lipid profiles and HbA1c in families who provide nutritional support, compared with those who cook and shop for themselves [170]. Gender expectations may affect who cooks and the appropriateness of asking for help, whereas ethnicity affects glycaemic control indirectly via social context, disease experience and ultimately support through family networks.

Illness-specific support may also be more predictive than general support [171] of diabetes outcomes. This has not been shown for other chronic diseases other than diabetes, but may represent different self-management behaviour patterns that respond to social support.

Social interactions can have negative impacts on diabetes behaviour, but research is limited to qualitative studies. Frequently noted problems include difficulties at social events, family obligations, family stress and unsupportive behaviour, particularly unwillingness of other family members to change their diet [172].

No studies have been performed of the influence of diabetes on family or carer health, the influence of age on social support, or friends who may offer advice or join in exercise programs.
Contribution of thesis trials

The lack of research of interventions in rural general practice to improve diabetes management, particularly self-management, requires attention. Goal setting offers an opportunity to include patient perspectives into overall case management, to identify barriers and system problems, and to address them. Many of the goals require behavioural change and the support of the diabetes care system. Chapter 2 explores the effectiveness of goal setting as an intervention in primary care. Subsequent chapters explore its sustainability, and application in an Aboriginal setting, with the interface (service coordinator) changing at each step.
A Randomised Controlled Trial of Goal Setting in Diabetes Care (Trial 1)

Introduction

Maintaining tight glycaemic control has not proven easy despite good evidence that microvascular complications are reduced and interventions are cost effective [51, 173]. Quality of life is effected by complications [174] but not by the intensive treatment involved in achieving this. In the four years after the DCCT there was a steady rise in the mean HbA1c from 7.0 to 7.9%. The UKPDS showed a similar trend for fasting glucose, HbA1c and weight for both control and intensively treated groups. To counter this natural trend, patients need regular support and review in sustainable management systems that may span decades [175]. Identifying patient needs early is important [176, 177].

Simmons has identified five categories of barriers to diabetes care [158]. Of these barriers, internal psychological (self efficacy/health beliefs), external psychological (psychosocial environment) and external physical (finance/access to care) factors appear more important. Yet our current systems tend to address the internal physical (co-morbidities/side effects of treatment) and educational (knowledge of diabetes/services) barriers. Self-directed attempts to overcome these barriers include empowerment training, autonomy support, activation counselling and motivational interviewing [132-135]. There is however a continuing need for general practice based psychosocial interventions, especially those
that are cost effective [178, 179]. Patient directed goal setting has not been widely studied in general practice [144], despite being regularly used by diabetes educators and dieticians [142, 145, 180].

Previous studies in general practice have used staff training in a patient centred approach [153] or doctor orientated goal setting [154]. Few studies, prior to 1997 have attempted to use patients own health priorities as a basis for treatment planning [181]. It seems a logical but unproven hypothesis that dealing with a patient's health issues in the order that they choose, will lead to better engagement in their management. This study used patient generated, problem based goal setting to identify diabetes related health issues that were barriers to good management.

The study ultimately sought to determine whether identifying solutions to these problems actually improved clinical and psychosocial outcomes.

2 Research design
2.1 Trial population
Patients were drawn from a diabetes clinic run in Port Lincoln, a small remote fishing town in South Australia, population 13000. The clinic has no visiting or resident endocrinologist and is run by general practitioners in conjunction with a diabetes educator, dietician and podiatrist. Patients are reviewed on an annual basis and further care is carried out by each patients' own general practitioners. One hundred and ninety eight patients were randomised using a table of random numbers, and one hundred and eighty eight completed the trial. Demographics are shown in table 2 and 3. There were 3 deaths and 7 withdrawals from the control group during the trial. The reasons for withdrawing were moving location (4), carer illness (2) and mental illness (1). Patients aged 40 to 75 years were randomised to either usual clinic care or usual care with goal setting. In both cases patients were reviewed at six monthly intervals.
The study design is outlined in Fig3. in accordance with CONSORT statement [182].

**RCT Goal Setting**

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<thead>
<tr>
<th></th>
<th>randomisation</th>
<th>intervention</th>
<th>control</th>
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<td>n=97</td>
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<td>n=1</td>
<td>1 death</td>
<td>9</td>
</tr>
<tr>
<td>analysed</td>
<td>n=100</td>
<td></td>
<td>n=88</td>
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Figure 3: Study design

### 2.2 Data collection

All data collection occurred within the diabetic clinic, and was performed either by a diabetes educator or a medical practitioner for both intervention and control groups. Diabetes diagnosis was based on a 75g oral glucose tolerance (OGTT), and all subjects were GAD (islet cell) antibody negative. HbA1c was measured by high performance liquid chromatography (Pharmacia-MonoS), and lipids by Dimension technique (Dade) in a local state pathology service.

**Clinic visits**

Patients attended a clinic every 6 months for a total of five visits. At each visit HbA1c, lying blood pressure and weight were measured. Fasting serum lipids, creatinine and urine microalbumin were measured annually. Information concerning smoking, alcohol consumption (units per day) and exercise (hours per week) was recorded.

An SF36, ATT39 and WSAS questionnaire was completed at baseline, midpoint and end of the trial for all patients. Problems, problem rating, goal setting and goal rating were undertaken at each visit for all intervention patients.
2.3 Description of intervention and quantitative measurements

Goal setting

The concept of problem statements and goal setting is based on a semi structured interview technique developed for behavioural treatment of anxiety disorders [183]. It was later adapted to other psychiatric disorders. Its adaptation to this and subsequent trials was based on its previous use by nurses in psychiatric clinics in the UK and the likely role nurses would play in goal setting in conjunction with GPs[184]. Their familiarity with goal setting in clinical scenarios allowed them to easily adapt to the psychological and social aspects of goal setting required for these diabetes trials.

Patients were asked to identify problems that might impact on diabetes care that they perceived were important. These need not necessarily be medically related, and may have related to carers or dependents within their family and social structure. Patients were encouraged to formulate the problems in their own words, and to rate the severity of the problem on a linear scale from 0 to 8 using the phrase “this problem upsets me and/or interferes with my normal activities” (where 8 represented the most severe disruption). Patients were then asked to generate solutions that they felt were achievable. These goals were very specific and were modified until they were realistic. An example would be to walk on Monday, Wednesday and Friday from the main street to the jetty for at least 30 minutes, rather than provide the patient with a simple request to increase their exercise.

Patients were also asked to rate their progress towards achieving each goal on a linear scale from 0 to 8 (where 8 represented no success) at each visit. This allowed not only an opportunity to review progress toward problem resolution, but also the opportunity to generate new goals as circumstances changed.
Problem & goal scales

This problem interferes with my daily activities:

![Scale](image)

My progress towards achieving this goal:

![Scale](image)

Problem and goal assessment is outlined in more detail in Appendix 1.

Work and social adjustment scale (WSAS)

The WSAS covers five areas: work, home management, social leisure activities, private leisure activities, and family/social relationships. It is problem based rather than disease focused, and designed to assess the impact of problems on daily lives. It was adapted from the linear scale used to measure problem and goal rating. It is quick and easy to use, however it is not a validated tool and lacks information about sensitivity to change.

The WSAS is measured on a linear analogue scale as follows:

This problem (as per problem statement) interferes with my work/home/social leisure/private leisure/relationships on the following scale...

![Scale](image)

ATT39

The ATT39 is a self-reported measure of psychological adjustment to diabetes [185]. It covers six main areas: diabetes generated stress, ability to cope with these stresses, guilt and embarrassment associated with diabetes, adoption of an independent approach to diabetes management, illness conviction and tolerance for ambiguity. It was developed in
response to the need for more specific measures of psychosocial issues in diabetes [150] by Dunn 1986. It is a validated tool used in outpatient and community settings.

**Statistical methods**

All data was recorded in paper form by either a diabetes educator or medical practitioner. Further analysis was performed in outline below.

- For data which were continuous and normally distributed test were used to compare means.
- Chi-square tests were used to compare proportions.
- Wilcoxon's Rank sum tests were used to compare continuous but non-normally distributed data. All tests were two sided and significance was measured at the 5% level of significance.
- Data were managed in an Access database.
- The SAS statistical package was used for all analyses.

### 2.4 Results

Patient demographics and baseline characteristics are shown in tables 2 and 3. Overall the intervention group were slightly younger and smoked more than the control group.

**Goal setting**

Problems were divided into five main groups as follows:

A. medical issues including complications, glycaemic control, sexual dysfunction
B. behavioural problems such as smoking cessation and alcohol use
C. social and psychological problems especially depression and stress
D. weight change and dietary issues
E. education and self help strategies
<table>
<thead>
<tr>
<th></th>
<th>N</th>
<th>Sex Ratio (M/F)</th>
<th>Age (Yrs) Median</th>
<th>Duration of diabetes (yrs) Median</th>
<th>BMI Mean (SD)</th>
<th>Smokers %</th>
</tr>
</thead>
<tbody>
<tr>
<td>GS Model</td>
<td>100</td>
<td>51/49</td>
<td>62</td>
<td>6</td>
<td>31.4 (5.92)</td>
<td>19.2</td>
</tr>
<tr>
<td>Control</td>
<td>88</td>
<td>50/38</td>
<td>65</td>
<td>7</td>
<td>30.5 (5.44)</td>
<td>8.2</td>
</tr>
<tr>
<td>All</td>
<td>188</td>
<td>101/87</td>
<td>64</td>
<td>6</td>
<td>31.0 (5.70)</td>
<td>14.1</td>
</tr>
</tbody>
</table>

BMI - body mass index  SD - standard deviation

There was a significant difference in the age between the patients in the control group and those in the Goal Setting (GS) model (P = 0.0055). The proportion of smokers was significantly different between the two groups (P = 0.0334)
Table 3 Percentages of the study population with complications

<table>
<thead>
<tr>
<th></th>
<th>N</th>
<th>HT</th>
<th>NP</th>
<th>RT</th>
<th>HL</th>
<th>PVD</th>
<th>IHD</th>
<th>SD</th>
</tr>
</thead>
<tbody>
<tr>
<td>Control</td>
<td>88</td>
<td>63.64</td>
<td>15.91</td>
<td>13.64</td>
<td>51.14</td>
<td>37.50</td>
<td>20.45</td>
<td>5.68</td>
</tr>
<tr>
<td>GS Model</td>
<td>100</td>
<td>59.00</td>
<td>11.00</td>
<td>13.00</td>
<td>50.00</td>
<td>24.00</td>
<td>14.00</td>
<td>13.00</td>
</tr>
<tr>
<td>All</td>
<td>188</td>
<td>61.17</td>
<td>13.29</td>
<td>13.29</td>
<td>50.53</td>
<td>30.32</td>
<td>17.02</td>
<td>9.37</td>
</tr>
</tbody>
</table>

N- number HT- hypertension NP- nephropathy RT- retinopathy HL- hyperlipidaemia

PVD- peripheral vascular disease IHD- ischaemic heart disease SD- sexual dysfunction

There was statistically significant association between the two groups and peripheral vascular disease (p = 0.0445).
The frequency of problems by category and the percentage of goals set against these problems are shown in the following table.

**Table 4  Frequency of problems by category and % of goals**

<table>
<thead>
<tr>
<th>Problem category</th>
<th>Problem frequency (%)</th>
<th>% of all goals set against this problem</th>
</tr>
</thead>
<tbody>
<tr>
<td>A</td>
<td>53</td>
<td>24</td>
</tr>
<tr>
<td>B</td>
<td>7</td>
<td>23</td>
</tr>
<tr>
<td>C</td>
<td>13</td>
<td>12</td>
</tr>
<tr>
<td>D</td>
<td>20</td>
<td>22</td>
</tr>
<tr>
<td>E</td>
<td>7</td>
<td>19</td>
</tr>
</tbody>
</table>

A – Medical  B – Psychosocial  C – Behavioural  D – Diet  E – Education

For those patients in the intervention group the number of goals set over the trial is set out in table 5.

**Table 5  Number and percent of goals set**

<table>
<thead>
<tr>
<th>Number of goals</th>
<th>0</th>
<th>1</th>
<th>2</th>
<th>3</th>
<th>4</th>
<th>5</th>
<th>6</th>
<th>7</th>
<th>8</th>
<th>9</th>
</tr>
</thead>
<tbody>
<tr>
<td>Percent</td>
<td>5.9</td>
<td>10.2</td>
<td>30.9</td>
<td>17.6</td>
<td>15.7</td>
<td>9.5</td>
<td>3.8</td>
<td>2.4</td>
<td>2.8</td>
<td>0.8</td>
</tr>
<tr>
<td>Cumulative percent</td>
<td>5.9</td>
<td>16.1</td>
<td>47.0</td>
<td>64.6</td>
<td>80.3</td>
<td>89.8</td>
<td>94.0</td>
<td>96.4</td>
<td>99.2</td>
<td>100</td>
</tr>
</tbody>
</table>
**Goal rating**

All types of goal improved over the duration of the trial, regardless of type of goal or degree of achievement (figure 4).

**Goal achievement**

This was calculated by subtracting the final visit goal rating from the first visit goal rating. A positive result was a score of 1 or greater. For the different goal types, the following success rates toward goal achievement were noted:

A. Medical issues 85%
B. Behavioural 66%
C. Social 69%
D. Dietary change 77%
E. Education 83%

Goal achievement was not predicted by a disability rating.
Figure 4: Goal rating over time
Disability Rating (WSAS)

The questions relating to work activities were omitted in the analyses, as the majority of patients were not employed. A total score was calculated from the last 4 questions. All questions relate to the amount of interference experienced in each of the 4 daily activities with respect to their problem(s). Self reported responses were rated on a 9 point scale from 0 to 8 (8 represents the highest level of interference). This instrument was administered to all patients at each visit.

Aggregated mean scores for each visit were as follows:

**Table 6 Aggregated Mean WSAS and HbA1c Scores**

<table>
<thead>
<tr>
<th></th>
<th>CONTROL</th>
<th></th>
<th></th>
<th>INTERVENTION</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Disability rating</td>
<td>HbA1c</td>
<td></td>
<td>Disability rating</td>
<td>HbA1c</td>
</tr>
<tr>
<td>1</td>
<td>4.0</td>
<td>7.8</td>
<td></td>
<td>6.0</td>
<td>7.5</td>
</tr>
<tr>
<td>2</td>
<td>3.3</td>
<td>7.9</td>
<td></td>
<td>3.8</td>
<td>7.7</td>
</tr>
<tr>
<td>3</td>
<td>2.1</td>
<td>7.5</td>
<td></td>
<td>4.0</td>
<td>7.3</td>
</tr>
<tr>
<td>4</td>
<td>1.7</td>
<td>7.5</td>
<td></td>
<td>3.5</td>
<td>7.0</td>
</tr>
<tr>
<td>5</td>
<td>1.8</td>
<td>7.5</td>
<td></td>
<td>2.0</td>
<td>7.1</td>
</tr>
</tbody>
</table>

The mean disability rating improved over the course of the study (figure 5) for both the intervention and the control patients, p=0.0001 but there was no difference between the two groups. There was also a significant decrease in HbA1C over the study, but there was no difference in the trend over time between the intervention and control groups.

There was a weak positive correlation between disability rating and HbA1c $r = 0.0856$

There was a significant change ($p=0.0001$) in disability ratings over time however there was no difference between the intervention and control groups.
Figure 5: Disability rating over time

Disability Rating over time

Visit

- **Intervention**
- **Control**
**SF-36 and ATT39 measurements**

No significant difference was observed between the intervention and control groups for 6 domains of the SF36 questionnaire. In the intervention group there was a slight worsening in the domains of Role Physical and Role Emotional, however this was not statistically significant. This implied increased limitation in usual role activities because of physical and emotional health problems respectively.

The SF36 score changes were very small. A sample size of 19828 in each group would have had 80% power to detect a difference in means of 0.6 (the difference between the control group mean of 60.1 and the intervention group mean, of 59.5) assuming that the control group standard deviation of 20.4, and the intervention group standard deviation of 22.2, with a 5% significance level.

On each subscale of the ATT39 the total score analysis of co-variance was used to determine whether the two groups differed at their 2nd ATT39, controlling their baseline score. The ATT39 was analysed using the un-weighted total score and six weighted subscales. There were no statistically significant differences in the responses of the intervention and control groups.

Overall both groups had similar scores at the beginning and end of the trial, with little difference between subscales. The trial population as a whole showed intermediate levels of diabetes related stress, a satisfactory perception of dealing with these stresses, higher levels of guilt associated with having diabetes, a mainly independent approach to diabetes self management, good acceptance of diabetes as a chronic disease and a good tolerance for the uncertainties of diabetes treatment.

**Medical Outcomes**

**Weight change**

There was a small change in BMI over time however there was no significant difference between the intervention and control groups.
Blood pressure

There was no change in systolic or diastolic blood pressure over time and there was no difference between the intervention and control groups.

Exercise

Although there was an increase in time exercising in the intervention group, there was no significant overall difference between the intervention and control groups.
**HbA1c**

There was a downward trend in HbA1c over time however there was no significant difference between the intervention and control groups. This is shown in figure 8. The change in HbA1c between groups was small, and the study underpowered. A sample size of 449 in each group would have been required for 80% power to detect a difference in means of 0.32, assuming a control group standard deviation of 1.860, and an intervention group standard deviation of 1.540, with a 5% significance level.

![Change in HbA1c](image)
Lipid changes

There was no significant difference in the mean values for both groups over time. There was a small increase in HDL from 1.1 to 1.3 that was not statistically significant (figure 9). Mean LDL fell from 3.8 to 3.3 in both groups. Total cholesterol fell from 5.5 to 5.1 in the intervention group but stayed unchanged at 5.4 in the control group.

Figure 9: HDL Changes

2.5 Discussion

2.5.1 Goal setting

In this rural diabetic population, patients used goal setting to identify a range of problems and barriers to diabetes care. Defining problems required an exploration of health beliefs, self-efficacy, family dynamics and professional interactions, usually lasting one hour. With increasing confidence, patients were able to identify resolvable issues that were barriers to care. The distribution of problems was heavily weighted towards medical presentations. Concern about complications, glycaemic control, pain related to mobility, and weight were the commonest stated problems.

Many of the medical problems resulted in behavioural goals such as exercise, diet or self-management strategies. Goals were most likely to be achieved if they were specific and patients could see evidence of progress. The distribution of goals reflected the range of achievable goals within the local health system. Resolution of many goals had secondary effects such as the establishment of walking groups, self help groups and targeted education programs.
A smaller number of goals were set against psychological problems. Emotional issues may be significant barriers to care, however using them as motivators may not be associated with improvements in HbA1c by patients [186]. The low frequency of family and social problems reflected an unwillingness of the investigators to generate insoluble problems that affected the performance of other goals. Social contexts are closely related to diabetes self care behaviour [163]. Those goals generated for family or social issues were often coping strategies such as relaxation or exercise routines, which were achievable.

Motivation and engagement in problem solving, key components of goal setting, were more likely if both the doctor or diabetes educator and the patient perceived the goal as important and attainable. The high goal achievement rates of 66-85% were in keeping with the aim of setting patient orientated, achievable tasks. Specific goals were also more likely to be achieved, and positively affected subsequent choice of goals and goal difficulty. The linear analogue scale was easy to use, demonstrate progress and provide positive feedback. The one notable exception to this was goal setting for weight loss. Many patients, set unrealistic goals for weight loss that perpetuated feelings of failure and helplessness. They were generally encouraged to set goals on dietary and lifestyle change instead.

We found the relationship between the degree of goal difficulty and goal performance to be a stepwise progression based on previous successful goal completion rather than a linear relationship [141]. As patients became comfortable setting goals, they increasingly chose more complex and specific solutions, however this took most of the trial to achieve. Eighty percent of patients set themselves 4 goals or less over the two year trial, with most patients unwilling to attempt more than 2 goals at any one time.

2.5.2 Medical outcomes

Blood pressure was unchanged and lipids improved 10% over the study. This is likely to be related to dietary changes and increased exercise rates. It is notable that after 18 months, exercise began to decline and reflects the difficulties associated with maintaining behaviour change in real life. BMI changes were not statistically significant, and the rise in weight in the intervention group relates to decreasing exercise levels. Alcohol consumption and smoking rates did not alter over the two years.
HbA1c levels fell in both groups 0.3% over the trial although the initial improvement declined over the final 6 months. This goes against the predicted trend of steady yearly HbA1c rises of 0.1% even for intensively treated diabetics [17]. Olivarius found that HbA1c was lower by 0.5%, systolic blood pressure lower by 5mmHg and total cholesterol lower by 0.1mmol/l using structure care and practitioner set goals [154]. Renders also found that behavioural interventions were associated with HbA1c improvements of 0.43% [160]. Kinmonth found no improvement in HbA1c using a patient centred approach [153].

The fall in HbA1c was likely to have resulted from standardized clinical care and regular follow-up. This has important implications for diabetes program planning. The disability ratings fell for both groups in parallel with the HbA1c fall suggesting that regular review has more than just biomedical benefits, although this was not reflected in the SF36 results.

2.5.3 Psychological and social outcomes

The SF-36 was chosen ahead of other more diabetes specific quality of life instruments such as the Diabetes Quality of Life Measure (DQOL)[3] for several reasons. Many of these scales were designed to assess patients who were using insulin and therefore suffered considerable disruption as a result of treatment. In this study only 20% were on insulin, rendering parts of the questionnaire inappropriate. Similarly 16% of patients were not on any medication so that questions relating to side effects and hypoglycaemia were not relevant. More importantly however, it was felt that many of the barriers to care were non-medical and a more general client orientated tool should be used. The SF36 provided a measure of health status particularly from a patient viewpoint, and did have one item to measure dynamic changes over the previous year. It was also a validated, reliable and sensitive tool, although it was also recognized that Quality of Life outcomes are may be negative despite satisfaction with treatment [4, 5], as may improvements in mood [6].

The lack of change in the SF36 results may have reflected use of an inappropriate or insensitive measure, insufficient time for goal setting to be effective (especially if it measures effects against complications), no real change from goal setting or changes that occurred in unrelated domains. To be truly effective, goal setting must be able to address
both diabetes specific and social/personal contexts. Although our study was able to identify barriers, it lacked the resources to effectively treat the external physical and psychological barriers to care. The goal setting was therefore around medical problems rather than social or psychological issues.

The more dynamic measure disability rating (WSAS) showed improvements in both groups, again suggesting the system was important in the changes rather than the goal setting. The system of regular reviews, including diet and exercise habits, regular checks of HbA1c, blood pressure and medication, all became regular reminders to patients and providers regarding management and self-management. The system therefore supported both patients and providers in an environment that fostered the positive aspects of self-care when there was only modest feedback on a day-to-day basis from self-management strategies.

More specific measurement around social and economic changes may detect benefits from goal setting [165, 190]. Active coping behaviour has been the only variable shown to be associated with HbA1c outcomes [125] in one complex mathematical model integrating physical and psychosocial factors. This was not measured in this trial although many of the goals were around positive (active) behaviour change rather than maintenance behaviours.

The ATT39 sought to define personal factors and adjustment to diabetes for the diabetes study population, rather than diabetes personality traits [127]. Overall both groups had similar scores at the beginning and end of the trial, with little difference between subscales. The trial population as a whole showed a remarkable adjustment to diabetes and self-management, perhaps implying that improvements would be small. The ATT39 is similar to the SF36 in that it is a static, not dynamic measure, and not applicable to dynamic interventions. Outcomes such as self-management behaviour and life satisfaction may be more appropriate [191, 192]

2.6 Limitations of this study

The trial population represented over half of all patients attending our diabetic clinic and further recruitment to increase the power of this study was not possible. They represented a stable group who were willing to follow treatment, however many diabetics in general practice are not like this. Contamination between study groups was possible in this small
town, however it was not possible to blind patients to the intervention or even keep them apart socially where the merits of the trial were discussed. The patients shared the same allied health providers, hospital resources, and GP surgeries where their intervention status was apparent from the hand held record. Provider behaviours were not measured but were presumed to be unchanged over two years.

On some occasions complex family issues such as marital disharmony or sexual abuse were revealed, and withholding active treatment became counter productive to the relationship. Our rural health services had limited psychological and social work services available, and treatment was sometimes only available from diabetes professionals. In some cases this delayed the goal setting process.

The strengths of this study are that no previous work has been done in this area and new information is available about goal setting. Such work can be learnt by general practitioners and diabetes health workers. The value of regular review was confirmed and consistent with other work [193, 194].

Further work on integrating behavioural, social/personal and disease specific issues into the organisation and delivery of care are needed. Such work has implications for other chronic disease management models. Health funding will need to support integrated models that cross into non-medical areas such as housing.

2.7 Summary

This study has shown that diabetes specific goal setting, has not shown any benefit over structured care alone performed by GPs in a rural primary care setting. There was a trend for HbA1c to decrease over the trial period in both groups, probably as a result of regular review. The category of goal, it's rating by the patient, and the patient's disability rating improved in both groups over the course of the trial. There was a trend for BMI to increase in the intervention group.

Systolic and diastolic blood pressure, smoking, alcohol intake, quality of life rating and psychological adjustment to diabetes were not appreciably different between both groups. Lipids were also unchanged although there was a trend for HDL to rise in both groups.
CHAPTER THREE

The Eyre Diabetes Coordinated Care Trials (Trial 2)

Introduction

Goal setting when performed in isolation, did not alone improve clinical and quality of life measures beyond regular clinical reviews. Systematic care on its own however may not be enough for all patients. Many patients identified a broader range of issues beyond immediate diabetes care that needed to be addressed. In addition the time required performing goal setting, an inability to provide all the services that were needed to help resolve problems, and a failure to integrate problems into the rest of health care, all detracted from the RCT outcomes. These problems were addressed in the HealthPlus Eyre diabetes trial. Although all of the findings described in this chapter are around the diabetes trial on Eyre Peninsula, reference is often made to the other HealthPlus and National trials to place this trial’s findings in the overall context. My interpretation of findings differs in some cases from these reports.

The background to the Coordinated Care Trials (CCTs) have already been outlined in the introduction, however the following key recommendations were made by the COAG Task Force[24] relating to health reform in 1994:

1. reorganisation of services into general care, acute care and coordinated care
2. restructuring on the basis of care outcomes
3. new funding arrangements to reflect care and support needs
4. improved continuity of care
5. service reform

6. an improved nationally consistent database

The SA HealthPlus trial attempted to address all of these points although only a state based database was attempted in the trial. The intervention, care planning (or case management) incorporating patient set goals, was expected to drive system change and funding arrangements through a process of demand.

Some of the lessons from the preceding diabetes trial described in chapter 2 were used to formulate practices in the CCT. The scope of the trial required sufficient training for providers, and the establishment of management protocols before the trials could commence. This training was intended to be uniform across the trial with local variation to suit individual needs. The Eyre trial was based in Port Lincoln and a local training unit was established here; I was one of two GP mentors to this unit.

With the assistance of Malcolm Battersby (Flinders University) and HealthPlus, a training process for GPs and service providers who would undertake goal setting was designed and started. The training process took many months to formalise and complete. Several service coordinators became key trainers and trial advocates.

3 National trial context

In calling for expressions of interest, the Commonwealth set out some of the parameters important to the trials [195]. These included guidance on the role of GPs in the coordination process. Specifically GPs were to remain the principal providers of medical care and were to be involved in care plan preparation. Implicit in this was the condition that patients retain their choice of their own GP and therefore their main advocate in the system. In addition, patients were not expected to pay any extra expense for the process of care planning, even if it entailed additional service use.

General practitioners were also expected to be the primary care coordinators, preparing and managing care plans, although this could be delegated depending on local trial requirements.
Eyre Peninsula sub-trial

Ultimately nine coordinated care trials Australia wide commenced design and tracking phases in 1996. One of these was the HealthPlus trial in South Australia in which 4600 patients enrolled. The trials covered chronic cardiac, respiratory and mental health disorders, as well as diabetes. (Some of the innovative trials that addressed the needs of specific groups such as the homeless were unable to proceed.) The live phases of the trial ran between June 97 and December 99.
Table 7 Outline of the basic design features of the nine coordinated care trials

<table>
<thead>
<tr>
<th>Control Group Trial Design</th>
<th>Target Population</th>
<th>Ratio of intervention to control</th>
</tr>
</thead>
<tbody>
<tr>
<td>Care 21 (SA)</td>
<td>Geographic</td>
<td>1200</td>
</tr>
<tr>
<td>Care Net (NSW)</td>
<td>Randomised</td>
<td>1800</td>
</tr>
<tr>
<td>Careplus (ACT)</td>
<td>Randomised</td>
<td>2400</td>
</tr>
<tr>
<td>Careworks (TAS)</td>
<td>Geographic</td>
<td>1200</td>
</tr>
<tr>
<td>Linked Care (NSW)</td>
<td>Geographic</td>
<td>1500</td>
</tr>
<tr>
<td>North Eastern (VIC)</td>
<td>Randomised</td>
<td>1600</td>
</tr>
<tr>
<td>HealthPlus (SA)</td>
<td>Mixed</td>
<td>6000-8000</td>
</tr>
<tr>
<td>Southern HCN (VIC)</td>
<td>Randomised</td>
<td>4000</td>
</tr>
<tr>
<td>TEAMCare (QLD)</td>
<td>Geographic</td>
<td>3000</td>
</tr>
</tbody>
</table>
### Table 8 Summary of the makeup of the eight HealthPlus sub-trials

<table>
<thead>
<tr>
<th>Project</th>
<th>Type of controls</th>
<th>Intervention Group</th>
<th>Control Group</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>Central Cardiac</td>
<td>Randomised</td>
<td>271</td>
<td>138</td>
<td>409</td>
</tr>
<tr>
<td>Eyre Diabetes</td>
<td>Geographic</td>
<td>398</td>
<td>111</td>
<td>509</td>
</tr>
<tr>
<td>Eyre Chronic &amp; Complex</td>
<td>Geographic</td>
<td>955</td>
<td>402</td>
<td>1357</td>
</tr>
<tr>
<td>Southern COPD</td>
<td>Randomised</td>
<td>165</td>
<td>82</td>
<td>247</td>
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<tr>
<td>Southern Somatization</td>
<td>Randomised</td>
<td>90</td>
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<tr>
<td>Southern aged care</td>
<td>Randomised</td>
<td>632</td>
<td>310</td>
<td>942</td>
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<tr>
<td>Western COPD</td>
<td>Geographic</td>
<td>223</td>
<td>154</td>
<td>377</td>
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<tr>
<td>Western Diabetes</td>
<td>Geographic</td>
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<td>256</td>
<td>637</td>
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<tr>
<td><strong>TOTAL</strong></td>
<td></td>
<td><strong>3115</strong></td>
<td><strong>1488</strong></td>
<td><strong>4603</strong></td>
</tr>
</tbody>
</table>
HealthPlus trial

3.1 Hypotheses

In broad terms the trial sought to answer a series of questions about the sustainability of chronic disease planning using care plans and goal setting as the intervention methods. The key questions related to cost neutrality, the effect of coordination on service use and the effect of more patient centred care. The central aim of the trial was formulated as a primary hypothesis, which stated:

That coordination of care of people with multiple service needs, where care is accessed through individual care plans and funds are pooled from existing Commonwealth, State and joint programs, will result in improved individual client health and wellbeing within existing resources.

A number of secondary hypotheses were also explored in relation to service substitution, the care coordination model, administrative changes and consumer participation. More detail is available in the final report [31].

3.2 Diabetes trial overview

The trial’s focus on the role of the patient, was one of 3 key areas for intervention, which included the patient (goal setting), the clinician (use of evidence based clinical practice) and the system (finances, processes, communication).

The trial had as its core aims:

- to improve health outcomes by empowering patients to change their behaviour towards improved self-management of their illness. This was to be implemented by service coordinators trained in goal setting and behavioural change techniques.
- to have a holistic approach to assessment and provision of care. This had two elements; including and acting on the patient’s perspective and taking a psychosocial approach to complement the medical (biological) approach to assessment and treatment.
- an outcomes based approach to the provision of prospective care to people with chronic illnesses
The consequences of this process were established clinical pathways and best practice guidelines that were defined not only by all service providers, but also the patients themselves via consumer participation groups.

**System changes**

Considerable effort was put into developing clinical and research teams locally, negotiating financial arrangements with regional hospitals (who were already under financial pressure), developing clinical guidelines, assessment and evaluation protocols, and seeking ethics approval. A Regional Development Unit was established to oversee financial and clinical responsibilities of the trial, and had representation from service providers, GPs and patient groups. Clinical guidelines were based on National guidelines and were developed by a GP Advisory group and local mentors.

### 3.3 Trial population

This trial commenced six months later than the RCT and patients were not included from the RCT described in chapter 2. The trial recruited 398 type 2 diabetics on Eyre Peninsula between June 1997 and March 1998, mainly based in Whyalla and Port Lincoln. A quarter of these (n = 101) were Aboriginal and are outcomes are examined separately in chapter 4. Patient demographics are described in appendix 3; the control group was slightly older and with a greater proportion on pension payments. Their consent included use of a behavioural tool (goal setting), to map clinical priorities and measure outcomes, and the ability to track a number of system outcomes for 2 years. The control group was age adjusted type 2 diabetics from a similar but separate rural area in South Australia, recruited through the local division of General Practice. The decision to use geographical controls ultimately compromised the conclusions that could be drawn from this trial; at the time it was felt that contamination between intervention and control groups would be inevitable in such small communities. Patients were identified from GP databases and assigned to nurse practitioners (called service coordinators) who were trained in goal setting by a Coordinated Care Training Unit (CCTU) established at Flinders University to assist the HealthPlus trial.
3.4 Trial design

Goal setting is described in chapter 2 and was applied as a generic model across the HealthPlus trial. It was used to prioritise issues within the care plan for following 12 months. The care plan was a 3-page document that combined diabetes best practice with other medical conditions that required regular services. It was prepared by the service coordinator in consultation with the patient’s GP, and intended to be a patient held record. Patients carried their care plan (paper version) to service provider appointments and were then able to share information with other providers and the patient. Care plan reviews were scheduled 3-6 monthly.

An attempt to standardise services was made by classifying each patient’s clinical complexity as high, medium or low. Complexity was also related to service use and it was hoped that as the trial progressed, patients would move to a less complex category. Patient services allocated in the care plan approximated best care as far as possible, and GPs and service coordinators were given guidelines to help them develop individual plans. This proved both impractical and unhelpful, and was stopped after 12 months.

Health outcome measurements

Patients were followed for two years at minimum intervals of six months, depending on their problems and goals assessment. All scores were recorded on a linear analogue scale by designated service coordinators who recorded their own scores in addition to the patient’s. Goals were coded based on a framework developed by the Local Evaluation Team (LET) in 1998 for analysis of problem statements. After coding goal categories, goals were tallied according to improvement (at least 1 point unit improvement between first and final rating), no change or deterioration (of at least 1 point).

Work and Social Adjustment Scale (WSAS) scores were recorded at each visit. SF36 quality of life assessments were performed at entry, midpoint and end of trial on all patients.

Health service measurements

Services were tracked individually per patient using the following parameters for all trials:
inpatient (ISAAC) data including emergency and elective admission rates and length of stay, Medical Benefit Schedule (MBS) service use and Pharmaceutical Benefit Schedule (PBS) service use.

Some of the other trials in addition measured Allied health staff use, Community Nursing contacts, and Emergency department attendances, however this proved impractical on Eyre Peninsula.

3.5 Data quality

Intervention patient withdrawals were estimated to be 2-5% before the trial, however 32% Eyre, 38% Southern, 41% Central and 52% Western patients actually left the trial. The national withdrawal rates [1] ranged from 22 to 52%; the rate of control exits was similar (28 to 50%). The Eyre control group had a higher death rate (6.6 vs 3.1%) than the intervention group. This may have influenced admission rates. MBS results did not include some pathology services which were funded differently at the time of the trial; these include outpatient and inpatient services. PBS data did not include over the counter medications or items purchased that have exceeded the safety net costs.

Health outcome results were calculated only on patients who completed the trial. Scores were derived from baseline and endpoint results (to correct for abnormal distributions). Regression analyses were used to determine whether there were significant differences between the two groups. A repeated measures Two-Way Analysis of Variance (ANOVA) was used to test whether there was a significant difference between groups over time for each outcome variable, at baseline, midpoint and endpoint. All projects were adjusted for health care card status, but this had a minimal effect on the statistical results.

All collected data was forwarded to HealthPlus Information System (HIS). The completed trial data was analysed at the Centre for Health Care Evaluation, Flinders University, Adelaide. Some outcomes reported in this work are based on separate analyses made from the original data, and will be different from the SA HealthPlus final report where Aboriginal diabetics were aggregated with non-Aboriginal diabetics.
3.6 Results

3.6.1 Health outcomes

3.6.1.1 Problems and goals

Problems and goals results are summarised in tables 9-11; the data has been provided by A Heard, consultant statistician HealthPlus [31]. Results from some of the other trials are included for comparison. The type of problems described was similar to those described in chapter 2: medical problems, behaviour change, social distress, weight and diet issues, and diabetes education. Between 40-60% of patients made some progress toward achieving their first goal over the trial (table 10). The proportion of patients seeking just to maintain their current health was low (8.6%) in the Eyre Diabetes trial, with many seeking active goals (table 9). Patients were again frustrated at an inability to set goals against social problems through lack of services, and chose exercise programs as alternative ways of dealing with these problems. Indigenous patients set similar goals to the Eyre Diabetes trial with fewer maintenance goals; the level of achievement was similarly high at 58%. Up to 60% of patients felt their first problem improved by the end of the trial (figure 11).

Correlations between problem and goal score differences, and other health outcomes were of low strength. There were weak positive correlations between goal rating differences (baseline to endpoint) and SF36 scores changes, Spearman correlation r< 0.12. The relationship with WSAS score changes was also weak, Spearman correlation r< 0.35. Health service use was also only weakly related to goal setting. In a regression analysis with equiseps (dependent variable), improvements in goal rating but not problem rating, predicted lower health service use (r-squared <0.1).
<table>
<thead>
<tr>
<th>Category of goal for first problem as a percentage</th>
<th>Southern Aged</th>
<th>Central Cardiac</th>
<th>Western Diabetes</th>
<th>EP Chronic &amp; Complex</th>
<th>EP Diabetes</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>N=553</td>
<td>N=252</td>
<td>N=213</td>
<td>N=851</td>
<td>N=297</td>
</tr>
<tr>
<td>1. Maintenance</td>
<td>24.1</td>
<td>36.8</td>
<td>26.8</td>
<td>26.4</td>
<td>8.6</td>
</tr>
<tr>
<td>2. Exercise</td>
<td>27.3</td>
<td>27.3</td>
<td>16.9</td>
<td>24.0</td>
<td>29.8</td>
</tr>
<tr>
<td>3. Diet</td>
<td>2.4</td>
<td>0.8</td>
<td>16.0</td>
<td>9.8</td>
<td>23.2</td>
</tr>
<tr>
<td>4. Control condition</td>
<td>5.1</td>
<td>1.6</td>
<td>11.7</td>
<td>8.1</td>
<td>11.9</td>
</tr>
<tr>
<td>5. Social/emotional</td>
<td>3.8</td>
<td>5.5</td>
<td>3.8</td>
<td>3.6</td>
<td>3.0</td>
</tr>
<tr>
<td>6. Activities</td>
<td>25.3</td>
<td>20.9</td>
<td>13.1</td>
<td>17.3</td>
<td>11.0</td>
</tr>
<tr>
<td>7. Appointments</td>
<td>5.8</td>
<td>2.8</td>
<td>7.5</td>
<td>4.9</td>
<td>8.0</td>
</tr>
<tr>
<td>8. Signs/symptoms</td>
<td>6.3</td>
<td>4.3</td>
<td>6.1</td>
<td>5.8</td>
<td>4.5</td>
</tr>
<tr>
<td><strong>TOTAL</strong></td>
<td><strong>100.0</strong></td>
<td><strong>100.0</strong></td>
<td><strong>100.0</strong></td>
<td><strong>100.0</strong></td>
<td><strong>100.0</strong></td>
</tr>
<tr>
<td></td>
<td>Positive scores</td>
<td>No change</td>
<td>Negative scores</td>
<td>Mean difference between 1st &amp; final rating (Standard Deviation)</td>
<td>Median difference</td>
</tr>
<tr>
<td>-------------------------</td>
<td>-----------------</td>
<td>-----------</td>
<td>-----------------</td>
<td>-----------------------------------------------------------------</td>
<td>-------------------</td>
</tr>
<tr>
<td>Central Cardiac</td>
<td>37.6</td>
<td>48.5</td>
<td>13.9</td>
<td>0.8 (2.9)</td>
<td>0</td>
</tr>
<tr>
<td>Western Diabetes</td>
<td>38.6</td>
<td>28.1</td>
<td>33.3</td>
<td>0 (3.0)</td>
<td>0</td>
</tr>
<tr>
<td>EP Chronic/complex</td>
<td>41.9</td>
<td>31.3</td>
<td>26.8</td>
<td>0.6 (3.1)</td>
<td>0</td>
</tr>
<tr>
<td>Southern Aged</td>
<td>47.2</td>
<td>36.4</td>
<td>16.4</td>
<td>1.3 (3.2)</td>
<td>0</td>
</tr>
<tr>
<td>EP Diabetes</td>
<td>59.4</td>
<td>24.2</td>
<td>16.4</td>
<td>1.6 (3.3)</td>
<td>1</td>
</tr>
<tr>
<td>Aboriginal Diabetes</td>
<td>62.9</td>
<td>24.7</td>
<td>12.4</td>
<td>2.6 (3.6)</td>
<td>2</td>
</tr>
</tbody>
</table>

Table 10  Goal achievement for first problem as a percentage
The change in the rating of problem one was measured and demonstrated similar outcomes to the changes in goal rating. Only small numbers showed a deterioration of their first problem.

Figure 10: Change in impact of problem between first and final measurement

3.6.1.2 Work and social adjustment scale

This tool was only used in the SA HealthPlus trials so no larger comparison with the other National CCTs is possible. All but two of the projects showed statistically significant improvements over the two-year trial. Table 11 depicts the trend in total WSAS scores over time; lower scores equate to improved health status. The evaluators [31] reported that for all HealthPlus trial patients there was a positive correlation (p<0.01) with SF36 indices (MCS and PCS) at baseline midpoint and endpoint scores. Spearman coefficients ranged from r=.31 to r=.62. The implication was that improved physical and mental health might be reflected in an improved social adjustment score.
### Table 11 Mean scores for the WSAS scores in the Eyre diabetes trial (p<0.05)

<table>
<thead>
<tr>
<th></th>
<th>T1</th>
<th>T2</th>
<th>T3</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>N</td>
<td>Mean</td>
<td>SD</td>
</tr>
<tr>
<td>INTERVENTION</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>N</td>
<td>Mean</td>
<td>SD</td>
</tr>
<tr>
<td>Total</td>
<td>186</td>
<td>10.02</td>
<td>7.60</td>
</tr>
<tr>
<td>Social</td>
<td>190</td>
<td>2.66</td>
<td>2.25</td>
</tr>
<tr>
<td>Private</td>
<td>190</td>
<td>2.54</td>
<td>2.39</td>
</tr>
<tr>
<td>CONTROL</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>N</td>
<td>Mean</td>
<td>SD</td>
</tr>
<tr>
<td>Total</td>
<td>52</td>
<td>8.04</td>
<td>7.07</td>
</tr>
<tr>
<td>Social</td>
<td>59</td>
<td>1.86</td>
<td>2.18</td>
</tr>
<tr>
<td>Private</td>
<td>60</td>
<td>2.10</td>
<td>2.22</td>
</tr>
</tbody>
</table>

T1- baseline  T2- 12 months  T3- 24 months  SD- standard deviation
3.6.1.3 SF-36 Quality of life

Although there was some dispute as to whether this was the most appropriate tool given the nature of the intervention population (more complex than average) and the nature of the intervention (service delivery system), an expert committee decided in September 1999 to continue with the SF-36 [29]. The SF-36 consists of 36 questions covering eight health domains from which 2 composite scores can be generated: the physical composite score (PCS) and the mental composite score (MCS). The results were reported in the HealthPlus Evaluation and shown in tables 12 and 13.

The results showed very modest improvements, with all trials reporting modest changes in PCS of between -4 and +4 percent (mean +2) and changes in MCS between -3 and +8 percent (mean +3). The trials all showed the vast majority (67 to 89%) of patients did not change their PCS or MCS scores at all. (NER 11.6 [1])

For the Eyre diabetes trial the differences were small. A sample size of 703 in each group would have had 80% power to detect a difference in means of 3 assuming that a control group standard deviation of 19.6, and the intervention group standard deviation is 20.5, with a 5% significance level. The study was not powered to detect these small differences.

No trial however, including the Eyre diabetes trials, showed a statistically significant difference in meaningful (12 points or greater) change over the period of the trial, for intervention compared to control.
<table>
<thead>
<tr>
<th>Project/Trial</th>
<th>P Value</th>
<th>Interpretation</th>
</tr>
</thead>
<tbody>
<tr>
<td>Eyre Diabetes</td>
<td>0.035</td>
<td>Intervention better than Control</td>
</tr>
<tr>
<td>Central Cardiac</td>
<td>0.006</td>
<td>Intervention better than Control</td>
</tr>
<tr>
<td>Eyre Chronic &amp; Complex</td>
<td>0.013</td>
<td>Intervention better than Control</td>
</tr>
<tr>
<td>Southern COPD</td>
<td>0.210</td>
<td>Intervention better than Control</td>
</tr>
<tr>
<td>Southern Aged</td>
<td>0.017</td>
<td>Intervention better than Control</td>
</tr>
<tr>
<td>Southern Somatisation</td>
<td>0.711</td>
<td></td>
</tr>
<tr>
<td>Western COPD</td>
<td>0.262</td>
<td>Intervention better than Control</td>
</tr>
<tr>
<td>Western Diabetes</td>
<td>0.023</td>
<td>Intervention better than Control</td>
</tr>
</tbody>
</table>
Table 13 Results for Mental Composite Score

<table>
<thead>
<tr>
<th>Project/Trial</th>
<th>P Value</th>
<th>Direction</th>
</tr>
</thead>
<tbody>
<tr>
<td>Eyre Diabetes</td>
<td>0.322</td>
<td></td>
</tr>
<tr>
<td>Central Cardiac</td>
<td>0.086</td>
<td></td>
</tr>
<tr>
<td>Eyre Chronic &amp; Complex</td>
<td>0.028</td>
<td>Intervention better than Control</td>
</tr>
<tr>
<td>Southern COPD</td>
<td>0.661</td>
<td></td>
</tr>
<tr>
<td>Southern Aged</td>
<td>0.034</td>
<td>Intervention better than Control</td>
</tr>
<tr>
<td>Southern Somatisation</td>
<td>0.557</td>
<td></td>
</tr>
<tr>
<td>Western COPD</td>
<td>0.006</td>
<td>Intervention better than Control</td>
</tr>
<tr>
<td>Western Diabetes</td>
<td>0.310</td>
<td></td>
</tr>
</tbody>
</table>
**Service outcomes**

**3.6.2 Hospital admissions**

The NER reported that Eyre HealthPlus (E-SA) overall, when compared with controls, had statistically significant fewer hospital admissions; this was not confirmed in the Eyre diabetes trial as shown in table 15 (source Adrian Esterman consultant biostatistician Flinders University).

Actual numbers and percentage of patients requiring at least one admission are shown in table 15 with several trials included for comparison. The percentage of patients requiring at least one hospital admission in the Eyre Diabetes group fell from 44% to 34% over the trial. This compares with the control group, which rose from 40% to 48%. Poisson regression models of live admissions were undertaken in the analysis, adjusting for historical patterns and baseline differences in demographic variables. Time on trial was used as the exposure variable. There were significantly fewer elective admissions in the Eyre Diabetes group (n=172) compared with controls (n=199). The number of elective admissions was small however. The results have been adjusted to allow for baseline differences in age, sex, number of co-morbidities and health card status are shown in table 14 [7].

**Table 14 Results of Poisson Regression Analyses (adjusted) from SA HealthPlus final report**

<table>
<thead>
<tr>
<th>Project/Trial</th>
<th>All Admissions</th>
<th>Emergency Admissions</th>
<th>Elective Admissions</th>
</tr>
</thead>
<tbody>
<tr>
<td>Eyre Diabetes</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Eyre Chronic &amp; Complex</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Southern COPD</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Southern Aged</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Southern Somatisation</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Western COPD</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Western Diabetes</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
Table 15a  Percentage of intervention and control patients in each project with at least one admission to hospital, historic and live phase of trial

<table>
<thead>
<tr>
<th>Project</th>
<th>INTERVENTION</th>
<th>CONTROL</th>
<th>TOTAL</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Historic %</td>
<td>Live %</td>
<td>Historic %</td>
</tr>
<tr>
<td>Central Cardiac</td>
<td>69.7</td>
<td>57.2</td>
<td>74.6</td>
</tr>
<tr>
<td>EP Diabetes</td>
<td>44.0</td>
<td>34.2</td>
<td>40.5</td>
</tr>
<tr>
<td>EP Chronic</td>
<td>60.0</td>
<td>54.0</td>
<td>74.1</td>
</tr>
<tr>
<td>Southern Aged</td>
<td>53.6</td>
<td>52.5</td>
<td>60.0</td>
</tr>
<tr>
<td>Western Diabetes</td>
<td>50.1</td>
<td>45.7</td>
<td>49.0</td>
</tr>
<tr>
<td>TOTAL</td>
<td>56.1</td>
<td>50.3</td>
<td>60.8</td>
</tr>
</tbody>
</table>

Table 15b  Number of intervention and control patients in each project with at least one admission to hospital, historic and live phase of trial

<table>
<thead>
<tr>
<th>Project</th>
<th>INTERVENTION</th>
<th>CONTROL</th>
<th>TOTAL</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Historic</td>
<td>Live</td>
<td>Historic</td>
</tr>
<tr>
<td>Central Cardiac</td>
<td>639</td>
<td>418</td>
<td>299</td>
</tr>
<tr>
<td>EP Diabetes</td>
<td>450</td>
<td>371</td>
<td>101</td>
</tr>
<tr>
<td>EP Chronic</td>
<td>1914</td>
<td>1631</td>
<td>1038</td>
</tr>
<tr>
<td>Southern Aged</td>
<td>927</td>
<td>954</td>
<td>514</td>
</tr>
<tr>
<td>Western Diabetes</td>
<td>556</td>
<td>498</td>
<td>400</td>
</tr>
<tr>
<td>TOTAL</td>
<td>4486</td>
<td>3872</td>
<td>2352</td>
</tr>
</tbody>
</table>

3.6.3  MBS and PBS results

Aggregated costs are shown in table 17 and Medical Benefits Schedule (MBS) data are shown in tables 18a and 18b. These data included GP, specialist, radiology and pathology services. There was little change in the proportion of MBS services over time, however there was an increase in the amount spent on both groups of patients. GPs did not claim longer consultations despite stating that they spent more time with their patients; the number of level C consultations only rose by two percent in the live phase of the trial. Specialist and diagnostic services did not increase over the trial.
Pharmaceutical Benefits Scheme (PBS) use was significantly lower in the intervention group as measured by the rate of PBS use per 1000 active days. This was a trend that remained true following an adjustment for differences in historical use. This was not a consistent trend across all trials (table 16 [31]). The adjustment was reported in the HealthPlus final report as a way of overcoming the shortcomings of using geographical controls, however it was unlikely to compensate for other factors such as poorly matched controls.

Table 16  Rate of PBS use per 1000 active days, recalibrated to adjust for differences in historical use of PBS services

<table>
<thead>
<tr>
<th>PROJECT</th>
<th>Intervention Quantity/1000 active days</th>
<th>Control Quantity/1000 active days</th>
</tr>
</thead>
<tbody>
<tr>
<td>Central Cardiac</td>
<td>89.0</td>
<td>91.2</td>
</tr>
<tr>
<td><strong>EP Diabetes</strong></td>
<td><strong>61.0</strong></td>
<td><strong>75.3</strong></td>
</tr>
<tr>
<td>EP Chronic</td>
<td>92.9</td>
<td>87.2</td>
</tr>
<tr>
<td>Southern Aged</td>
<td>83.7</td>
<td>88.0</td>
</tr>
<tr>
<td>Western Diabetes</td>
<td>91.8</td>
<td>79.4</td>
</tr>
</tbody>
</table>

Further analyses demonstrated no statistical relationship between SF36 scores and health service use (MBS, PBS and hospital admissions) with any of the trials.
Table 17 Aggregated costs per patient in $ for Inpatient (inpat), MBS and PBS use

<table>
<thead>
<tr>
<th>Variable</th>
<th>Method</th>
<th>Variances</th>
<th>DF</th>
<th>t Value</th>
<th>Pr &gt; (t)</th>
</tr>
</thead>
<tbody>
<tr>
<td>inpat</td>
<td>Control</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>Mean</td>
<td>Lower CL Mean</td>
<td>Mean</td>
<td>Upper CL Mean</td>
<td>Lower CL Std Dev</td>
</tr>
<tr>
<td>inpat</td>
<td>Intervention</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>mbs</td>
<td>Control</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>Mean</td>
<td>Lower CL Mean</td>
<td>Mean</td>
<td>Upper CL Mean</td>
<td>Lower CL Std Dev</td>
</tr>
<tr>
<td>mbs</td>
<td>Intervention</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>pbs</td>
<td>Control</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>Mean</td>
<td>Lower CL Mean</td>
<td>Mean</td>
<td>Upper CL Mean</td>
<td>Lower CL Std Dev</td>
</tr>
<tr>
<td>pbs</td>
<td>Intervention</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>pbs</td>
<td>Difference</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>Mean</td>
<td>Lower CL Mean</td>
<td>Mean</td>
<td>Upper CL Mean</td>
<td>Lower CL Std Dev</td>
</tr>
</tbody>
</table>
Table 18a  Eyre Peninsula Diabetes: number and % of MBS interactions, intervention and control, historical and live phase

<table>
<thead>
<tr>
<th></th>
<th>INTERVENTION (EP)</th>
<th>CONTROL (YORKE PENINSULA)</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Historical</td>
<td>Live</td>
</tr>
<tr>
<td>GP</td>
<td>5623</td>
<td>5810</td>
</tr>
<tr>
<td>Other GPs</td>
<td>505</td>
<td>878</td>
</tr>
<tr>
<td>Specialist</td>
<td>985</td>
<td>1036</td>
</tr>
<tr>
<td>Diag procedure</td>
<td>255</td>
<td>236</td>
</tr>
<tr>
<td>Therapeutic</td>
<td>437</td>
<td>508</td>
</tr>
<tr>
<td>Diag Imaging</td>
<td>519</td>
<td>609</td>
</tr>
<tr>
<td>Pathology</td>
<td>1363</td>
<td>1676</td>
</tr>
<tr>
<td><strong>TOTAL</strong></td>
<td>9687</td>
<td>10753</td>
</tr>
</tbody>
</table>

GP items

<table>
<thead>
<tr>
<th></th>
<th>Project</th>
<th>Historical</th>
<th>Live</th>
<th>Historical</th>
<th>Live</th>
</tr>
</thead>
<tbody>
<tr>
<td>Emergency</td>
<td>4</td>
<td>39</td>
<td>0.67%</td>
<td>10</td>
<td>0.45%</td>
</tr>
<tr>
<td>A</td>
<td>174</td>
<td>180</td>
<td>3.10%</td>
<td>51</td>
<td>2.30%</td>
</tr>
<tr>
<td>B</td>
<td>5091</td>
<td>5080</td>
<td>87.44%</td>
<td>1893</td>
<td>85.50%</td>
</tr>
<tr>
<td>C</td>
<td>341</td>
<td>491</td>
<td>8.45%</td>
<td>237</td>
<td>10.70%</td>
</tr>
<tr>
<td>D</td>
<td>13</td>
<td>20</td>
<td>0.34%</td>
<td>23</td>
<td>1.04%</td>
</tr>
<tr>
<td><strong>TOTAL</strong></td>
<td>5623</td>
<td>5810</td>
<td>100.00%</td>
<td>2214</td>
<td>100.00%</td>
</tr>
</tbody>
</table>

(A Esterman 2000 personal communication)
## Table 18b  Eyre Peninsula Diabetes: cost (benefit paid) & % of MBS interactions, Intervention and control, historic and live phase

<table>
<thead>
<tr>
<th></th>
<th>INTERVENTION (EP)</th>
<th>CONTROL (YORKE PENINSULA)</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Historical</td>
<td>Live</td>
</tr>
<tr>
<td>GP</td>
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<td>Other GPs</td>
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<td>Specialist</td>
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<td>Diag procedure</td>
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<td>9245</td>
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<tr>
<td>Therapeutic</td>
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<td>46464</td>
</tr>
<tr>
<td>Diag Imaging</td>
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<td>54046</td>
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<td>25762</td>
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<td><strong>TOTAL</strong></td>
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<td><strong>333873</strong></td>
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GP items

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<tr>
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<th>Live</th>
<th>Historical</th>
<th>Live</th>
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<td>Emergency</td>
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<td>1814</td>
<td>393</td>
<td>1900</td>
</tr>
<tr>
<td>A</td>
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</tr>
<tr>
<td>C</td>
<td>12840</td>
<td>18892</td>
<td>8939</td>
<td>11821</td>
</tr>
<tr>
<td>D</td>
<td>731</td>
<td>1141</td>
<td>1277</td>
<td>1947</td>
</tr>
<tr>
<td><strong>TOTAL</strong></td>
<td><strong>122984</strong></td>
<td><strong>132766</strong></td>
<td><strong>50995</strong></td>
<td><strong>66314</strong></td>
</tr>
</tbody>
</table>

(A Esterman 2000 personal communication)
3.6.4 Overall health costs

The costs for individual services of the Eyre diabetes trial are summarised in the following table 20. Historically the control group (that was geographical) had higher PBS and MBS costs and lower inpatient costs. In the absence of adequately matched controls, the figures have been recalibrated to allow for historical differences. Costs are given in $ per active day. Unfortunately accurate outpatient costs were not collected, and emergency department billing arrangements varied depending on local service contracts. In Whyalla these were state funded, whereas elsewhere patients were privately billed.

Overall costs of care also needed to include costs of coordination. Nationally total trial expenditure was $11582 per patient, with care coordination costs of $1097 per patient and recruitment costs of $118 per patient. The costs for the Eyre diabetes trial were $1078 for coordination and $43 for recruitment. The National cost of coordinating care per day ranged from $0.68 to $3.60; in the Eyre diabetes trial it was $2.05. In effect this meant that the cost of providing care in the Eyre diabetes trial was $10.08 per day compared with $9.54 per day for the control group.
Table 19 Costs ($) for individual services in the Eyre diabetes trial

<table>
<thead>
<tr>
<th>Category</th>
<th>Active Days</th>
<th>Qty</th>
<th>Expended</th>
<th>Cost per Active Day</th>
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<th>Qty</th>
<th>Expended</th>
<th>Cost per Active Day</th>
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<td></td>
<td></td>
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<td></td>
<td></td>
</tr>
<tr>
<td>CONTROL</td>
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<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Eyre - Diabetes</td>
<td>65873</td>
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<td>130165</td>
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<td>9301.00</td>
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<td>MBS</td>
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<td>4962.00</td>
<td>127084</td>
<td>1.93</td>
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<td>DVA</td>
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<td>0.02</td>
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<td>42</td>
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<tr>
<td>Hospital Non-IP</td>
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<td>0</td>
<td>0.00</td>
<td>207143</td>
<td>2119.00</td>
<td>72297</td>
<td>0.35</td>
</tr>
<tr>
<td>Other</td>
<td>65873</td>
<td>628202</td>
<td>9.54</td>
<td></td>
<td></td>
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</tr>
</tbody>
</table>

(A Esterman 2000 personal communication)
3.7 Discussion
3.7.1 Clinical outcomes

The clinical processes primarily focused on patient behavioural change towards improved self-management, evidence-based care planning and ongoing coordination of care by a Care Coordinator (general practitioner) and Service Coordinator (nurses). The model of care aimed to reduce the complications of illness by prospective preventative care planning and to improve or delay the progress of disability and handicap by assisting patients to achieve their goals. These two elements, would together result in ‘improved health and well being’. Surprisingly in the CCTs this was only measured by the SF36 nationally, although individual trials used other tools in some cases.

Overall the HealthPlus Eyre Diabetes trial clinical outcomes (SF36, WSAS and goal achievement) were similar to the individual goal setting trial described in chapter 2. WSAS scores and goal achievement improved, but SF36 didn’t. The modest and inconsistent outcomes highlighted several problems within the CCTs. These included different trial designs, dynamic change in the study population over time, as well as their application to changing organisations, and need to be assessed from different perspectives, in this case clinical and financial. The scientific application of a single intervention that did not change over the trial did not occur.

The factors that predicted better coordination were less clear, although one of the most important outcomes of the trials. Benefits of care planning were more likely in the following circumstances [31]:

- complex needs with few supports
- unstable support systems or health
- low confidence or ability to negotiate health needs
- strong desire to avoid residential care and remain at home
- patient was able to use the process to improve their own goals
The central theme in all these cases was a good relationship with their service coordinator and/or GP. Duration of illness was not assessed, however it is likely that patients at the early stages of their disease and in the latter stages would benefit from coordinated care.

Narrative summaries (subjective assessment of key risks) by GPs were also analysed in one national trial; these descriptions identified restricted patient mobility, a deteriorating health condition, or both as predictors of low composite SF36 scores. These groups presumably benefit from more intensive care, although there was no clear relation between these groups and health cost use (PBS and MBS) over the trial. Lastly self-rating was never used as an indicator of potential benefit, despite its obvious importance.

**The SF36 measure of health status**

The summary scores for PCS and MCS are presented in section 11.1 of the Nation Evaluation Report. The Eyre trial showed a 4% improvement in PCS compared with control, as did the Western (SA HealthPlus) trials, however the remainder showed either a worsening or no change. The MCS results were only slightly better with the greatest improvement in Western HealthPlus trial of 7%. Nationally Care21 (SA), Teamcare (Qld) and HealthPlus (Eyre, Southern and Central) also had small improvements of about 4%. All the trials had large groups showing no change with their model of care; the range was 70 and 85% of patients in all trials. Clearly the impact of the model was not great as measured by the SF36.

HealthPlus disputed the NER conclusion that no trial showed a significant change of 12 points or more, between intervention and control groups. The nature of the trial population meant that chronically ill or older patients might have scores toward the lower end of standard distribution. This may have been true for some of the trials, however 12 points equated to one standard deviation, which should have been achievable.

The merits of using the SF36 tool [196] were debated prior to the trial and it was felt at the time that the generic tool was the most suitable. The Commonwealth expert panel did express concerns about applying it to older populations, and its relative importance to the trial intervention of service delivery models [29]. The SA HealthPlus perspective was that
using disease specific quality of life measures possibly ignored the non-disease aspects of chronic care. The open-ended approach of goal setting consistently defined issues relating to family, partners health and money as more important than the disease itself. These were not addressed in diabetes quality of life measures, which focused more on specific diabetes issues such as medication, hypoglycaemia and insulin. This latter point was particularly relevant as only 20% of diabetics were on insulin in the Eyre trial.

The SF36 was ultimately chosen because it was a validated and reliable tool that had been tested on Australian populations of all ages [197]. It was also able to compare health status of patients with similar or different conditions.

The NER highlighted a number of other concerns in their technical report. These related to variation in the timing of administration of follow up questionnaires which were intended to be at 0, 12 and 24 months. The method of administration in the trials was face to face in 10% of intervention and control patients (table 11.44), however most service coordinators in our Eyre trial reported significant antipathy to phone completion of SF36 forms. The effect of any major life event in the previous 4 weeks was sought as an independent, additional question to the SF36. Between 28% and 41% of patients had a major life event in the prior 4 weeks to completing the SF36, however this was evenly distributed across all the trials and not felt to alter the overall outcomes. In theory such a life event could considerably reduce the benefits achieved by coordinated care.

The two SA trials were the only diabetes trials nationally, and both used the goal setting generic model. The clinical outcomes in these trials were principally measured as health and well being; some comparison was possible between the two trials however the city population contained a large non English-speaking group.

The composite SF36 scores for PCS improved 4% (intervention vs. control) in both trials and for MCS improved 7% in the Western trial and 1% in the Eyre trial. In both groups over 90% had improved or unchanged scores. The WSAS score improvement was 24% in the Eyre trial but negligible in the Western trial. Goal achievement was 60% for the Eyre trial and 40% for the Western trial. Unfortunately no other clinical data was collected such as
blood pressure, HbA1c or weight so few other comparisons are possible. The trend from these two trials is of modest benefit and little deterioration. The goal setting process was a successful tool that didn't alter outcomes greatly in any measured way in these trials.

SF36 scores have been shown in other analyses to be lower in diabetic populations over all domains even when adjusted for age. The effect is greater than for other chronic conditions such as asthma and hearing loss, and is greater for those with micro-vascular complications [198].

Quality of life was assessed during the UKPDS [174] however only complications were shown to affect QOL adversely. Hypoglycaemia and treatment policies (in particular insulin) were not associated with worse QOL outcomes, although the study compared two groups of diabetics. The authors QOL measure examined mood, cognitive mistakes and physical function (mobility, self-care, usual activities, pain and anxiety) over 6 years. They commented on the potential lack of sensitivity of the questionnaire to detect changes in QOL, however their measures and the SF36 both target symptoms that patients commonly complain about. Most importantly, they didn't identify any improvements in QOL within their study.

The national evaluation chose the SF36 for evaluation of changes in client health and wellbeing, essentially as a measure of health status. The outcomes of the trials however were likely to be better coordination rather than improved health status. The benefits for clients from care coordination were most likely to occur through access to services that assisted their functioning within existing health status. Measures of patient satisfaction with service organisation would therefore have been a more suitable tool. Unfortunately no such measure was available in a generic form.

3.7.2 Goal setting

Quantitative results

Goal setting was unique to the HealthPlus trials. The goal setting process offered a patient-centred method for determining needs, which improved communication and decision making. These were embedded in the care plan. The behavioural outcomes were intended to reduce problem severity, and therefore improve quality of life. It therefore also offered an
alternative assessment tool for patient health and well being. The content of problems was similar across all trials, as were the goals. Achievement of the patient's first goal, and probably their most important problem, was possible in at least 40% of all trials. Problem rating also improved in most trials.

Despite this, the trial results did not confirm improved health status. There were weak positive correlations between goal rating differences (baseline to endpoint) and SF36 scores, Spearman correlation \( r < 0.12 \). The relationship with WSAS scores was also weak, Spearman correlation \( r < 0.35 \). It appeared that goal setting improvements were related to factors other than health status and disability rating. These may have been non-health improvements within the support structures and relationships. Alternatively the goal setting changes may have been related to improving self-efficacy however no tool to measure such dynamic change was used.

Lastly health service use showed only a weak relationship to goal setting. Changes in goal and problem ratings were not related to MBS in regression analyses. Goal setting therefore was not predictive of service use. Whether individual improvements using a problems and goals approach, ultimately translate into clinically measurable improvements was not tested.

**Qualitative data**

Some changed behaviour occurred using a patient directed model during this trial. The success patients had in addressing problems associated with a whole range of chronic conditions, where self managed behaviour was central in their management, was important. The types of problem people identified were similar in all trials and related to maintenance behaviour, exercise, activity, diet, control of their condition, social and emotional issues, organisation of care and symptom control. The first three accounted for more than 70% of all problems in all trials, with symptom (5%) control and disease (7%) control rating low in patients' priorities. This may reflect areas of perceived influence by patients. Patients may indeed feel helpless to improve medical factors, and the outcome inevitable, however they
are likely to have learned that in their current medical climate. The ability of patients to alter their symptoms and disease process have become the focus of several large scale intervention CDSM programs [71, 87, 88]. The assumption was that using self-management strategies to change chronic illness behaviour change would impact both on quality of life and health care resource consumption.

In the HealthPlus trials, the local evaluators used patient focus groups, telephone interviews, service coordinator interviews and GP interviews to explore satisfaction further [199]. Nearly 85% of patients found the process of problem and goals useful, 80% felt very involved in service planning and 65% found the care plan very useful. Almost 90% of patients felt satisfied with what HealthPlus had done for them, and 75% felt that their health care was better organised. They concluded that the intervention group was significantly more satisfied with the organisation of their health care than the control group.

The concept of patient enablement or empowerment was also evaluated in a 1999 HealthPlus survey [31]. Enablement was defined as a patient’s capacity to cope and related to illness understanding, confidence, healthy behaviours and ability to help oneself [200]. Although only a small sample (n=129), intervention patients felt that their ability to cope with life, their illness, to understand their illness, their overall confidence about their health and their ability to help themselves was improved. Better enablement scores were associated with effective service coordinators, and to a lesser extent with goal setting, care plans and GP interest. No larger work was undertaken beyond this survey.

The original intention in developing the goal setting tool was to provide a scale that GPs could easily use to identify and overcome barriers to clinical care. No specific analyses were made by the evaluators of this by HealthPlus; we used focus patient groups and GP feedback to the Eyre mentor group to explore this at the completion of the trial. Patient perceptions of goal setting were positive, with patients citing more time spent discussing issues and exploring medical issues in greater detail as important factors. Sixty percent said they would continue to use the process if it remained available. Only fifteen percent found the process unhelpful.
In contrast only 34% of the Eyre GPs said they would use the goal setting approach in future clinical work. The time required to complete the scale was generally too long to allow routine use, however it remained a very useful tool for service coordinators who were able to spend longer with patients. The GPs also found that patient goals were unrealistic on some occasions, but generally deferred goal setting to the service coordinators as the trial progressed and the amount of paper work increased.

**WSAS measure of disability**

This scale measured five areas of social adjustment, and was chosen because it had a problem focus rather than a disease focus. It was administered appended to the SF36 to controls, and performed by service coordinators with intervention patients, at six monthly intervals. It was applicable to physical and psychological problems, and was easy to use. It was not a validated tool, and lacked information about its sensitivity to change or use in different populations. It was used to measure a patient's perception of handicap and the impact it made on their daily lives.

The Eyre WSAS scores improved over the trial and were statistically significant (p<0.05) compared with controls (table 11). There was a weak correlation with SF36 scores. There was also a weak association with equiseps, however in view of the different modes of administration, this was not considered significant. Overall WSAS did not predict health status changes or equiseps use.

### 3.7.3 System outcomes

Although a large and heterogeneous trial, there were many positive outcomes for the HealthPlus Diabetes trials. These can be grouped under clinical care, infrastructure reform, patient gain and economic.

#### 3.7.3.1 Clinical care

**General Practitioner involvement**

Ultimately the trial offered patients an opportunity to participate more in their care and clinical decision making. The challenge was for GPs to participate in this and to be part of a more holistic approach to care. In doing so they became more involved in advocating for
services that they and their patients felt necessary to provide high quality chronic care. These did not always exist, and resulted in pressure on service providers to meet them. The role of the regional health authorities in supporting some of these changes was critical in allowing the trial to proceed. General Practitioner involvement in the trial was greatest in the Eyre Peninsula where 34 out of 42 possible GPs were enrolled. The Eyre Peninsula Division of General Practice greatly influenced the GP enrolment in HealthPlus; the reasons were political (to bring attention to the scarcity of GPs in rural and remote areas), the promise of IT through HealthPlus involvement and the possibility of having doctors' workload assisted by the coordinated care processes.

A survey of all GPs in the Eyre trial in May 1998 revealed that the main reasons GPs gave for enrolling their patients in HealthPlus was to find out what HealthPlus was like. Improving patient care, and believing in the principle of coordinated care were the next most common reasons for enrolling. GPs were introduced to the Healthplus program and the Problems and Goals approach at group and individual GP education sessions, and by direct approach from service coordinators.

The reasons for patients enrolling were not analysed in any of the trials, however the Eyre diabetes patients remained in the trial longer than any other group (21% of patients exited). Patients were largely influenced by their GP and the belief that GPs would act in their best interests.

The distribution of patients among GPs varied between regions. In the Eyre region most GPs (about 80%) had 11 or more patients (two Eyre Peninsula GPs had more than 90 patients each and others 30-40 patients). In contrast, a high proportion of GPs in the Southern/Central (86%) and Western regions (90%) enrolled up to ten patients. The large number of GPs with ten or less patients meant that they gained experience in using care planning and goal setting at a slow rate. This was compounded by delays in some trial arrangements with local health authorities and service providers. Generally the city GPs were reluctant to risk many patients on an untried process with uncertain outcomes.
GP perceptions of the Eyre trial usefulness increased from 60% of GPs who found the approach very or fairly useful to 80% who found it very or somewhat useful in 1999. Soon after the first round of care planning, 70% of the GPs surveyed identified that the approach had uncovered problems they were unaware of and 50% stated they would use it on other patients.

The ability to assist patients toward goal achievement as generated in the care plans was central to long-term success of the care coordination process. The credibility of both the GP and service coordinator rested on providing services as directed by the patient. Consequently attitudes to care planning varied. GPs in the city were the most positive, and on Eyre Peninsula the least. On the Eyre Peninsula where medical and allied health services were limited, uncovering additional needs in patients was likely to be problematic. For rural service coordinators however, revelations about social or psychiatric problems that could not be easily addressed generated much concern. Each step in the goal setting process was built on previous successes, and failure to solve critical issues for the patient, handicapped solving related medical problems.

Local trial arrangements were critical in decided trial successes. Financial arrangements in the case of Eyre meant that (public) service provider managers were unwilling to employ additional services from the private sector unless they had long term commitments to fund them. The philosophical debate ultimately meant that funds ($120,000) were returned at the end of the trial unspent, the lessons lost on changing managers and staff, and patients were left frustrated.

Who benefited most from goal setting and care planning?
Identifying eligible patients was left for each trial nationally to resolve, with HealthPlus choosing medical need, and others choosing historical hospital use or expenditure [1]. Each GP was required to carry out a structured medical assessment of each patient at entry covering all areas of the patient’s health. It was designed to identify the patient’s level of disease severity, and any relevant co-morbidities. Implicit in this assessment was cost of caring for each patient and therefore likely savings if the coordination process were to fulfill the primary trial hypothesis.
The decision to enrol was ultimately the GPs. They identified patients who generally had a low ability to self manage, low social support, severe or moderate disease severity, age greater than 70 years, unstable medical condition, significant psycho-social needs or recent hospitalisation. Service coordinators also identified a number of other factors that suggested patients might benefit from coordinated care. These included the patient’s stage of disease, home environment, access to information sources, attitude, lifestyle, depression and willingness to change.

In the Eyre diabetes trial, GPs shared their views on who was suitable to enrol with the service coordinators in workshops, forums and informal meetings. The final separation into low, medium and high care need was dependent on individual subjective assessments. This was eventually discontinued because of the variation in grading patient complexity. The important distinction between those who would benefit from intensive coordination and those who were good managers already, was not made early in the trial, although they were likely to be categorised as needing low amounts of intervention despite their medical complexity.

Some GPs felt that many patients who could benefit from coordination had not been enrolled in the HealthPlus trial. They listed the attributes of such patients in a survey [199], although most of the patient attributes GPs identified are inaccessible on GP or hospital databases. These attributes relied on GPs’ knowledge of their patients, the severity of their condition, their social circumstances and their capacity to manage their chronic condition. The only attributes, which could easily be extracted from a database, were age (70+ years) and recent hospital admission. The latter was ranked very low by GPs as an attribute suggesting the need for coordinated care. Selecting patients for coordinated care would require the input of GPs, if these suggested patient attributes were to be the basis of further coordinated care initiatives.

**Clinical pathways**

A key element of the care process was the development of evidence based care planning. To simplify this process, the Clinical Development Group, the Care Mentors and the GP
Advisory group developed a Care Plan Generator for each project. These varied according to the perceived level of need (high, medium or low) as well as the patients’ co-morbidities and other issues raised through the Problems and Goals assessment. The Care Plan Generator was a document that stipulated the essential and optional services for each patient according to the project they were enrolled in and their disease severity as determined by the medical assessment.

When surveyed in May 1998, more than half of all HealthPlus GPs (58%) and all Eyre GPs recalled using the Care Plan Generator. A review was undertaken and some changes (format, service recommendations, guidelines) on the Care Plan Generator were made that reflected the experience gained from using the first one. By February 1999, three quarters of GPs had conducted care plan reviews. Only 20% of the Eyre GPs found the Care Plan Generator very useful and 30% did not find it useful at all.

The content of care plans evolved in a dynamic process over the trial. Critics of the care plan document felt that its size made it unwieldy, an accurate reflection given that the plans were intended to be electronic. Initial discussions envisaged patients carrying floppy disks or smart cards containing their plans. Some Eyre GPs felt that patient non-compliance (in not carrying their care plan document) frustrated their efforts at effective treatment. The care plan document was also felt to be too detailed to be useful in routine patient care, although in its revised form it represented a summary page with goals.

The national evaluation highlighted process problems around care plan [1] development, rather than the care plans themselves. They included delays in review, variations in who did the review (trial model dependent) and ironically inadequate detail in some cases. GPs who had enrolled in the trial tended to be supportive of the concepts underlying care planning and frustrated by the process.

By February 1999, fewer than 40% of Eyre GPs surveyed found the care plan document very useful. Only 35% reviewed parts of the care plan at each consultation – they were more interested (50%) in the medication list, than in the patients’ care plan. Patients by
contrast enjoyed the additional time and detail that went into their care, and local specialists commented favourably on having an up to date summary hand held record.

For many GPs on Eyre the failure to deliver system IT change and to provide local services that had been promised at the beginning of the trial, was crucial in their perception of the trials success. The idea of computerised general practice linked to hospital and other service providers, guided by best practice was lost in a paper trail. Attempts to match planned and actual service delivery were not possible due to delayed IT development in the Healthplus Information System. Some GPs were concerned that the trial preceded US style health reform; this was compounded by political change in the leadership that chose to no longer support the trial. As with goal setting, ultimately it was the peripheral issues rather than the central issues that determined the outcome.

**Service coordinator involvement**

An important outcome of the trial was the evolution of service coordinators who established working relationships with GPs, other service providers and patients. The original trial description did not define who could or could not be a Service coordinator, although wide experience within the health system was assumed. Most nurses had previous experience in developing nursing care plans.
Table 20 Service coordinator characteristics (from Service Coordinator Survey September 1998)

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<td>5</td>
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<tr>
<td>Registered Nurse (hospital)</td>
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</tr>
<tr>
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<td>3</td>
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</tr>
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<td>1</td>
<td>1</td>
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<tr>
<td>Other (office near hospital, Domiciliary Care service)</td>
<td>3</td>
<td>1</td>
<td>4</td>
<td>8</td>
<td></td>
</tr>
<tr>
<td>GP Practice</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>8</td>
</tr>
</tbody>
</table>

In May 1998, a LET survey found that 45% of GPs considered that the service coordination role was useful for the following reasons:

- supporting patients’ involvement in the trial,
- organising and scheduling services for patients,
- doing administrative tasks and filling out forms,
- patients’ appreciation of the Service Coordinator role

Their greatest ability was to perform the problems and goals process correctly, integrate this into a plan that was understandable to the patient, then to navigate the patient through the system. Their understanding of patient centred care, patient empowerment and their organisational ability generally was equal to the GPs who had less time to achieve the same. Their ability or desire to act as service providers was debated at several forums,
however their role largely remained coordination. Most GPs wanted their service coordinators to act as monitors, organisers and liaise with patients while they remained in charge medically. Service coordinator perceptions of GPs were positive in the SA trial but this was not the case in other trials where they were treated in more subordinate roles.

Communication between the GP and the Service Coordinator was critical if the care plan was to be successfully implemented. There was considerable variation reported in the quality of communications between GPs and Service Coordinators. Where problems did occur, they were either related to contact issues, or the service coordinator being unable to respond (due to workload) in a timely manner. The Eyre service coordinators developed a support network that ensured individual experiences were shared. No similar network evolved to support GPs in the trial who tended to work alone.

In the February 99 survey [199], respondents divided into three equal groups in the extent to which they considered they worked as a team with their service coordinator. Thirty three percent worked completely or to a large extent as a team, thirty three percent to some extent, and thirty four percent not at all or slightly. Those who worked as a team with service coordinators were more likely to be satisfied with other aspects of the trial.

3.7.3.2 Systems and infrastructure reform

The primary hypothesis stated that:

*coordinated care of people with multiple service needs, where care is accessed through individual care plans and funds are pooled from existing Commonwealth, State and joint programs, will result in improved individual client health and wellbeing within existing resources.*

As an ideological challenge, this motivated many GPs and service providers to participate in the trial. The opportunity to change funding arrangements was unprecedented but required significant leadership.

On Eyre Peninsula GPs sought some political gain through the trial to ease their own workload, improve service provision and draw additional funding into their local hospitals.
This was successful on all counts and allowed the region to pass easily into subsequent MBS funded areas of Enhanced Primary Care. The understanding of funding processes gave them advantage in seeking other funding packages of over 5 million dollars in the 12 months following the CCT. This was in addition to the $2 million spent during the HealthPlus trial on Eyre Peninsula coordination costs.

The system reform that occurred during the HealthPlus trial was essential to the subsequent funding that Eyre received. Strong linkages were formed between regional health authorities and the EPDGP, resulting in parallel rather than conflicting funding programs, and clear service planning allowed concentration of funds.

Management processes within individual service provider organisations, mainly allied health, were confronted with dilemmas in care provision. The enrolment process had identified many gaps in care and projected demand, which could not be met by current staff levels.

In larger centres this was met by running sessions with groups of patients, however most allied health staff identified ongoing needs for one to one treatment of up to 50% of clients. In smaller centres nurses were usually trained by allied health professionals to provide minimum levels of care, with more complex cases being referred on to professional providers. The intention was for GPs or practice nurses to provide initial information, local hospital specialist nurses to provide further information and management, and allied health staff to provide care as outreach services. This was a tiered effect that was highly effective in filling service gaps, and given the ratio of diabetes providers was 1 to 30,000 population [23], the only practical one. The ability of public providers to contract for private services, although sensible theoretically, was ultimately impossible for political reasons. This has changed with plans to fund private allied health providers through the MBS system.

The reform process for service providers at practice level was less straightforward. The overwhelming amount of seemingly unnecessary paperwork for allied health staff became a burden, and was compounded subsequently by the complicated requirements for care planning EPC MBS item numbers. Confirmation that patients had indeed attended
management sessions was required, and forms were developed to return to GPs about their content. This in turn required attention to allied health care process, individual roles in overall management, and standardisation of treatment protocols. Many public employees found themselves having to review their performance in the light of consumer demand, a source of considerable conflict.

The changes required within General Practices were equally demanding to those made by other service providers. The Division of General Practice had recruited the GPs actively through forums that added the likely IT developments to its attraction. In 1997 less than 10% of GPs had computers, and although all received computers within 12 months, most required training in their use. (The metropolitan GPs received no computers.) Although training forums were arranged, the potential gain from such technology was minimal. The envisaged daily feedback to GPs on trial costs and service use did not eventuate and only a small number of GPs received the CDs entitled Healthmart from HealthPlus. (These CDs gave up to date feedback on service use and ongoing cost.) GPs did however use their computers to establish disease registers, recall systems and review processes. The EPDGP also developed its own electronic care planning format that worked within existing (Medical Director) prescribing software. This subsequently was taken over by a pharmaceutical firm as the costs in national development became prohibitive.

The Regional Health Authority’s own IT programs were also embryonic at the trial start, however the opportunity to develop both systems together seemed sensible. Unfortunately the IT developers who were contracted by HealthPlus failed to meet any deadlines and were replaced twice before the State Government’s own IT managers took over. The lost time was crucial in terms of lost confidence.

3.7.3.3 Patient outcomes

The CCTs were based on consumer political pressure [24], and not surprisingly, patients were the most positive participants in the trials. Consumer representation on many trial advisory groups began from the earliest days of the HealthPlus trials. In general they were either consumer advocates or trial participants; in the Eyre trial they were mainly trial
participants (opposite to city trials). They were influential in the development of clinical review systems including Care Plan Generators and patient held records. Of all participants they were the most enthusiastic about IT developments such as smart card systems, internet based records, hospital links with general practice, and virtual health systems.

The networks, meetings and forums, newsletters and links with central (city) authorities gave the consumer groups much insight into otherwise mystical workings of the health system. On Eyre Peninsula their experience was as much a participatory role as a consultative one. Active participation in the trial determined this, although the HealthPlus management structure (of decision making by a core central working party) was in opposition to traditional social interactions that occurred between all local staff. Because patients and providers were unable to hide from each other in the smaller communities, much of their effort had to be transparent.

In May 98, GPs identified some benefits for patients from the HealthPlus trial; these included: extra time and attention, improved motivation, patients had reassessed their lifestyle issues, they had increased awareness of available services, and felt more empowered to be independent. In February 99, the GPs identified the value of structured assessment, patient problems and goals, patient self management and motivation, contact and relationship between patients and Service Coordinators, education, monitoring and supervision of patients by the Service Coordinator; the care plan, access to services and information about services, and their overall coordination as benefits.

These benefits have been reiterated in follow-up surveys by the Department of Health and Aged Care [62]. The greater time spent with patients was appreciated by patients and their families, as were the more comprehensive assessments, better documentation, and improved access to services. Patients also reported feelings of increased control over their health management, increased understanding of their condition and enhanced relationships with their GP.
In South Australia these observations are particularly noteworthy with the recent release of the Generational Health Review [201], a government strategy document, that recommends greater involvement of consumers in all aspects of care from governance to service provision.

Patient satisfaction must be interpreted with some care as rural and older clients in particular, who are used to service shortages, may be grateful for any improved service commitment. Patient expectations also influence perceived satisfaction and unrealistic expectations at enrolment, as occurred in the Eyre trial, may have contributed to high exit rates for all trials. The low rate in the Eyre diabetes trial may have been related to the good relationship between service coordinators and patients. The failure to deliver services as promised in care plans was a common reason cited for dissatisfaction; this also adversely affected other outcomes. Overall ninety percent of trial patients were either satisfied or very satisfied with what HealthPlus had done for them. This appeared to be related to the relationship between patients and service coordinators [202].

Need did not necessarily predict satisfaction as some patients who required support rather than coordination, and received this, were highly satisfied. Quality care, in these trials, which was planned but not always achieved, was interpreted as better than ‘usual care’ by many patients. That clinical outcomes did not match this was not relevant to patient perceptions. In diabetes where symptoms are minimal for long periods of time, this was particularly true.

The least explored aspect of care coordination was its impact on carers. Despite their obvious importance, little data was collected about them and information was based on focus groups. Diabetes carers reported only modest improvements in satisfaction, unless the patient had high needs and they were unable to negotiate the medical system. Diabetics were largely encouraged to self manage their disease and treatment. The effect of carer attitudes on patient attitudes (and health consequences) is easier to conceptualise than the health consequences for carers undertaking their role.
3.7.3.4 Economic outcomes

The HealthPlus trial failed to achieve cost neutrality as hoped in the primary hypothesis. Clinically the trial was not designed in enough detail to demonstrate changes, and targeted groups that were too diverse. Economically it underestimated the cost of coordination. The anticipated gains in reduced hospital inpatient use, did not eventuate across all trials although the Eyre diabetes trial was able to demonstrate some small reductions. The demand for allied health providers compounded overall costs, and had not been anticipated to be so high. (Conversely current service use was not perceived to be so far below patient expectations.)

The cost of providing coordination through a specific care coordinator was expensive. HealthPlus costs were $0.5 million for enrolment, $1.04 million for care planning and $3.19 million for coordinating. These include infrastructure development such as IT, of $1.6 million. The total cost was $4.77 million above trial income.

Nationally total trial expenditure was $11582 per patient, with care coordination costs per year of $1097 per patient and recruitment costs of $118 per patient. There were similar costs for the Eyre diabetes trial; these were $1078 for coordination and $43 for recruitment. (Per capita expenditure on health in 1999 was $1923- table 1).

In the Eyre diabetes trial the cost of coordinating care was $2.05 per day for each patient. The cost nationally of coordinating care for each patient per day ranged from $0.68 to $3.60 (NER p422). The cost per day of providing care to diabetes patients on Eyre Peninsula was $8.03 (controls $9.54), and $10.05 including coordination costs. This was close to the overall HealthPlus daily cost of $11.04, but well below the national trial average of $13.99 per client day (NER p446). These figures do not include infrastructure expenditure that was $5.36 per client day nationally, and $6.01 per day for the HealthPlus trial overall.

In the Eyre Diabetes trial MBS costs and in particular, GP remuneration, was a source of much concern to those GPs involved in the trial. The Commonwealth had allowed GPs to use the MBS to reimburse them for time spent in direct patient care, as was usual practice. Table 17 and 18 shows that the profile for MBS use in the Eyre diabetes trials changed little.
in comparison with controls when adjusted for historical use. GP experiences of the time required to complete care plans was universally the same; 30 minutes was the minimum, with many plans taking much longer. The effort involved was not reflected in standard payments, and an alternative payment schedule was required. This was reflected in the MBS item numbers associated with the EPC package in November 1999. The shift to labelled funding was consistent with other health care funding arrangements, however this has yet to be appreciated by most GPs.

The fall in PBS expenditure during the live phase of the diabetes trial was a consistent finding across all the CCTs except two. The national evaluators felt that PBS income and expenditure results were inaccurate [1]. Greater use would be expected with better adherence to guidelines. Drug use should also increase as pancreatic function decreases over the natural history of diabetes, as patients and GPs strive for glycaemic control and symptom relief [17]. The diabetes trial showed reduced PBS use compared with controls, despite adjusting for historical differences (table 19). This was not a consistent finding across the HealthPlus trials suggesting further problems with the quality of data.

The lack of significant financial benefits resulting from coordinated care, led to relatively little analysis beyond the final national evaluation. Patient factors predicting cost were examined in the CareNet trial [203]. Factors such as client need, cognitive impairment, domestic and social function, motor function and carer availability failed to predict cost outcomes. Day used diaries to collect information about resource use and costs in the Southern HealthCare Network CCT [204]. These highlighted the role of carers and the extent of unreported costs.

Despite the findings, and prior to the final report being released, the Commonwealth announced the Enhanced Primary Care Initiatives in November 1999 [205]. These included Medicare item numbers that encouraged GPs to undertake care planning and case conferences, and recognised the contribution required by GPs. Their uptake has been good initially with 74% of GPs using one or more item number in the first two years. The complex conditions involved in claiming the fee have however been a barrier to widespread
use, and a recent report suggests relaxing them [62]. More pointedly, the report acknowledges that GPs need assistance in care planning, from either nurses or allied health workers, as their workloads do not allow prolonged sessions with organisational aspects of chronic care. The fear that chronic care provision may prejudice other areas of clinical care or equity of access, was not confirmed in the Eyre trials. Service provision where none existed before often contributed to the positive experiences of patients.

The injection of funds ($2 million) and services into the Eyre region was significant, and allowed providers to review services from a patient rather than program perspective. The networks and changed management structures were the essential prerequisites of any chronic disease management program. The lessons from the trial have enabled the regional health service to successfully tender for further allied health funding worth over $3 million. Funding for service coordinators has not been part of the Commonwealth's plans except in rural general practice, where practice nurses are funded to assist GPs provide general care.
Introduction

The Aboriginal communities on the west coast of Eyre Peninsula live in two principal locations although there is significant movement between the two and to an outlying homeland. Ceduna has a population of 3500 that includes 800 Aboriginal people. It has significant deficiencies in educational, medical and allied health services and there are numerous social and cultural problems. Port Lincoln has a population of 13000 with an Aboriginal population of 1200 with more health services provided through the Aboriginal health services.

Medical services within both areas vary but the Aboriginal health services have been understaffed and unable to retain those that they trained [23]. Aboriginal Health Workers (AHWs) in particular left exhausted and burnt out by the constant demands of their job [206]. Business structures and systems to support chronic disease management were absent. Neither the Ceduna and Koonibba Aboriginal Health Service (CKAHS) nor the Port Lincoln Aboriginal Health Service (PLAHS), had full time medical practitioners on any consistent basis.

Both services did provide appointment systems, transport to appointments, physical reminders rather than letters, and in Ceduna, assistance with purchase of medication.

The HealthPlus trial [31] described in chapter 3, included 101 diabetic Aboriginal clients on Eyre Peninsula. It was by far the biggest Aboriginal trial within the mainstream CCTs,
although the Commonwealth ran additional Aboriginal CCTs [2]. It ran from December 1997 to December 1999 and the opportunities it offered to the Aboriginal health services were significant. These included the opportunity to define the needs of the diabetic populations, to be involved in organising existing allied health services in a way that was more culturally appropriate, and to provide a more structured diabetes program through better management.

This was the first opportunity to use goal setting in Aboriginal communities to explore barriers to diabetes management. The personal, open-ended approach was attractive to Aboriginal people because it both acknowledged the problem and used a narrative form. Although improvements were expected in the non-Aboriginal trial, it was very unclear whether this trial would generate any useful outcomes. Goal setting defines patient and system barriers, however system changes need to occur to in many cases to allow successful goal achievement. The ability of this health system to respond to any new opportunities would be important to improved diabetes service provision and any revised model.

4 Trial Methods
4.1 Recruitment

Patients were recruited through the CKAHS and PLAHS by at community meetings or at health clinics. The initial reluctance of clients to be involved was only overcome following a series of meetings with community leaders who sought to be reassured about the usefulness of the trial. Those patients who did participate were perceived by the AHWs to be likely to finish the trial; this was based on previous health service use, duration of residence and relationships with the health services. Patients who entered the trial were as likely to complete the trial as those in other non-Aboriginal CCTs [1].

Reassurance about data ownership and management was required at an early stage by the Community Councils and the Aboriginal Health Service boards, and several meetings were needed to resolve this. Some resentment toward previous trials was evident in these discussions as information had been gathered, analysed and no clear benefit provided to
the community [207]. There was a strong feeling that white people were using Aboriginal communities to further their own research. Clear and tangible benefits to the community were identified as essential outcomes, principally as services, as well as employment for the AHWs.

The trial subsequently recruited 101 people with type 2 diabetes; demographics are shown in tables 21 and 22.

Table 21 Trial recruitment compared with other CCTs

<table>
<thead>
<tr>
<th>Trial</th>
<th>Patients (N)</th>
<th>Age</th>
<th>F</th>
<th>M</th>
<th>Completing Trial %</th>
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<tbody>
<tr>
<td>Eyre Aboriginal</td>
<td>101</td>
<td>50</td>
<td>62</td>
<td>39</td>
<td>67</td>
</tr>
<tr>
<td>All Other Aboriginal</td>
<td>47</td>
<td>59</td>
<td>30</td>
<td>70</td>
<td>57</td>
</tr>
<tr>
<td>Eyre Non Aboriginal</td>
<td>1189</td>
<td>62</td>
<td>49</td>
<td>51</td>
<td>70</td>
</tr>
</tbody>
</table>
### Table 22 Demographics of Eyre Aboriginal Diabetes patients

<table>
<thead>
<tr>
<th></th>
<th>INTERVENTION</th>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>N</td>
<td>%</td>
<td></td>
</tr>
<tr>
<td>Male</td>
<td>39</td>
<td>38.6</td>
<td></td>
</tr>
<tr>
<td>Female</td>
<td>62</td>
<td>61.4</td>
<td></td>
</tr>
<tr>
<td><strong>TOTAL</strong></td>
<td><strong>101</strong></td>
<td><strong>100.0</strong></td>
<td></td>
</tr>
<tr>
<td>Language spoken</td>
<td>English</td>
<td>101</td>
<td>100.0</td>
</tr>
<tr>
<td><strong>TOTAL</strong></td>
<td><strong>101</strong></td>
<td><strong>100.0</strong></td>
<td></td>
</tr>
<tr>
<td>&lt;25</td>
<td>2</td>
<td>1.9</td>
<td></td>
</tr>
<tr>
<td>25-34</td>
<td>9</td>
<td>9.0</td>
<td></td>
</tr>
<tr>
<td>35-44</td>
<td>26</td>
<td>25.7</td>
<td></td>
</tr>
<tr>
<td>45-54</td>
<td>37</td>
<td>36.6</td>
<td></td>
</tr>
<tr>
<td>55-64</td>
<td>19</td>
<td>18.8</td>
<td></td>
</tr>
<tr>
<td>65-74</td>
<td>7</td>
<td>6.9</td>
<td></td>
</tr>
<tr>
<td>75-79</td>
<td>1</td>
<td>0.9</td>
<td></td>
</tr>
<tr>
<td><strong>TOTAL</strong></td>
<td><strong>101</strong></td>
<td><strong>100.0</strong></td>
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</tr>
<tr>
<td>Marital Status</td>
<td>Never Married</td>
<td>25</td>
<td>24.7</td>
</tr>
<tr>
<td>Widowed</td>
<td>18</td>
<td>18.8</td>
<td></td>
</tr>
<tr>
<td>Divorced</td>
<td>3</td>
<td>2.9</td>
<td></td>
</tr>
<tr>
<td>Separated</td>
<td>4</td>
<td>3.9</td>
<td></td>
</tr>
<tr>
<td>Married (including de facto)</td>
<td>50</td>
<td>49.5</td>
<td></td>
</tr>
<tr>
<td><strong>TOTAL</strong></td>
<td><strong>101</strong></td>
<td><strong>100.0</strong></td>
<td></td>
</tr>
<tr>
<td>Living Arrangements</td>
<td>House, unit, apartment or flat.</td>
<td>101</td>
<td>100.0</td>
</tr>
<tr>
<td><strong>TOTAL</strong></td>
<td><strong>101</strong></td>
<td><strong>100.0</strong></td>
<td></td>
</tr>
<tr>
<td>Employment Status</td>
<td>Student</td>
<td>12</td>
<td>11.8</td>
</tr>
<tr>
<td>Full-Time Employed</td>
<td>18</td>
<td>17.8</td>
<td></td>
</tr>
<tr>
<td>Part-Time Employed</td>
<td>22</td>
<td>21.7</td>
<td></td>
</tr>
<tr>
<td>Unemployed</td>
<td>6</td>
<td>5.9</td>
<td></td>
</tr>
<tr>
<td>Home Duties</td>
<td>8</td>
<td>7.9</td>
<td></td>
</tr>
<tr>
<td>Retired</td>
<td>18</td>
<td>17.8</td>
<td></td>
</tr>
<tr>
<td>Other</td>
<td>17</td>
<td>16.8</td>
<td></td>
</tr>
<tr>
<td><strong>TOTAL</strong></td>
<td><strong>101</strong></td>
<td><strong>100.0</strong></td>
<td></td>
</tr>
<tr>
<td>Pension &amp; Benefits Status</td>
<td>No Pension or Benefits</td>
<td>44</td>
<td>43.5</td>
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<tr>
<td>Aged Pension</td>
<td>18</td>
<td>17.8</td>
<td></td>
</tr>
<tr>
<td>Disability Support Pension</td>
<td>8</td>
<td>7.9</td>
<td></td>
</tr>
<tr>
<td>Unemployment benefits</td>
<td>5</td>
<td>4.9</td>
<td></td>
</tr>
<tr>
<td>Sole Parent Pension</td>
<td>14</td>
<td>13.8</td>
<td></td>
</tr>
<tr>
<td>Widow's Pension</td>
<td>3</td>
<td>2.9</td>
<td></td>
</tr>
<tr>
<td>Carer's Pension</td>
<td>1</td>
<td>0.9</td>
<td></td>
</tr>
<tr>
<td>Sickness Allowance</td>
<td>0</td>
<td>0</td>
<td></td>
</tr>
<tr>
<td>Other</td>
<td>8</td>
<td>7.9</td>
<td></td>
</tr>
<tr>
<td><strong>TOTAL</strong></td>
<td><strong>101</strong></td>
<td><strong>100.0</strong></td>
<td></td>
</tr>
</tbody>
</table>
Forty three percent of this Aboriginal population received no pension compared with 20% in the non-Aboriginal trial, although their employment status is obscured by local Aboriginal employment schemes and differing mean age. There is normally considerable movement between both Aboriginal communities, and although Port Lincoln and Ceduna have different social and financial bases, they share common social problems. Family and cultural interactions are common so that any positive or negative experiences during the trial at either site rapidly became common knowledge. This interaction also allowed patients to move and be tracked for follow-up by sharing information between health services. No clients were recruited from the more remote and traditional lands of Yalata community that lays 100km west of Ceduna.

**Service coordinators**

In Port Lincoln a nurse who was accepted by the community, and had worked in remote Aboriginal communities, was chosen by the group to act as service coordinator. She was assisted by three AHWs. In Ceduna there was no fulltime GP within the CKAHS and an experienced nurse acted as care coordinator. Although not Aboriginal, she was well known and liked by the community; her knowledge of life in Ceduna, and commitment to its future, was essential in community acceptance of her role.

The care coordinator lacked the ability to provide detailed medical assessments, prescribe medicines and refer to allied health providers. These services were provided on a contractual basis by GPs doing sessions in the CKAHS; continuity was provided by the care coordinator. The position was assisted by 3 part time AHWs. Later in the trial fulltime GP services became available, although the care coordinator role remained the same.

In Ceduna the issue of the care coordinator’s age became a problem for some of the older women, many of whom were elders. Discussion of some issues was considered shameful, and could only proceed using an older AHW as intermediary.

The same training on goal setting that had been provided to other service coordinators in the other Eyre HealthPlus trials, was also provided for the Aboriginal service coordinators. Much advice about culturally appropriate methods of interviewing was sought from senior
AHWs. This related as much to presentation as content. The goal setting process was expected to take longer as many patients would view the forms with suspicion unless reassured by AHWs.

**Care planning**

The care coordination process was the same as for the Eyre diabetes trial (chapter 3). Port Lincoln clients met with GPs and a service coordinator to generate care plans, either in the health services or in the GPs rooms. The process of problem assessment, goal setting, care plan generation and planning of services occurred with the help of AHWs who embraced the goal setting as an opportunity to explore complex community issues.

This process would have been impossible without the AHWs who often interpreted language and responses. Considerable time was required, often with breaks, and renegotiation of issues that had been covered. Under pressure patients would respond with what they thought was the right answer, 'to keep people happy'. This was overcome by having the AHWs present to discuss issues before, during and after goal setting sessions.

The detailed social knowledge the AHWs held of each person allowed them to informally negotiate goals and lead them to take over the role after the trial.

Patients were to be followed at 3 monthly intervals, however this was not easily done even within a small community. Many other social and family issues, such as funerals or caring for children caused follow-up to be deferred. The AHWs however were very good at seeking out and finding patients who were hard to follow. This applied even to patients who found the goal setting and care planning useful and wanted to follow it correctly.

Records were kept on paper and transcribed later into electronic format. (A laptop computer was allocated to the Ceduna care coordinator as no computers were available in Ceduna.) Goal setting was recorded using linear analogue scales for goal rating and achievement. Many of the clients could not write and the SF36 and WSAS forms were completed by the AHWs. MBS, PBS and hospital admission data were drawn from HIC sources following trial consent. Aboriginal clients were generally reluctant to complete
complex forms such as the consent, and usually the coordinators did this with the patient and an AHW.

Care plans were stored at the health services; many Aboriginal declined to carry their own records, perhaps significantly.

**Data management and quality**

All data was owned by the two Aboriginal health services, and stored on site. All data were collected by the service coordinators. A database base constructed at the EPDGP recorded all of this information so that individuals could not be identified. This was very important to the local community who developed new and trusting relationships with mainstream services during the trial.

Many concerns emerged about goal setting data, especially problems that were based on sensitive family issues. Access to information was also a particularly difficult issue as the AHWs were related to many of the trial participants, yet were involved in regular care. Ultimately confidentiality issues were only resolved to the community's satisfaction as the trial evolved, and the realisation that the AHWs were behaving in a completely professional manner. This enhanced their community standing over the trial. Verbal reassurance alone was not considered enough.

Most participants were able to describe their problems with minimal help from the AHWs. There followed a process of negotiation or yarning, and ultimately progression to the process of goal setting. The AHWs had to provide more input into this process but the final wording was each patient's. The quality of the goal setting was limited to each patient's capacity to make any change, however all goals were owned by the patients and coordinators avoided leading their clients.

The failure to address core social issues meant that a very small number of patients initially completed goal setting half heartedly, or replied with answers that they felt the coordinators wanted to hear. This reflected differing expectations and/or lost confidence in the system to effect change. Conversely most patients used the trial to openly discuss their (the community's) problems for the first time.
4.2 Results

Quality of life

Response rates for the SF36 and the WSAS were low by other trial standards but high considering their perceived usefulness to the patients. Completion rates for the SF 36 were 63% in Port Lincoln and 26% in Ceduna, and for the WSAS were 51% in Port Lincoln and 33% in Ceduna. The SF36 scores showed no change in health status over the trial, reflecting its inappropriateness.

The WSAS scores showed no change over the trial, also reflecting its insensitivity in Aboriginal contexts.

Goal setting

Problems were divided into five main groups as follows:

A. medical issues including complications, glycaemic control, sexual dysfunction
B. behavioural problems such as smoking cessation, alcohol use and exercise
C. social and psychological problems especially depression and stress
D. weight change and dietary issues
E. education and self help strategies

Table 23 Problem category, frequency and % of all goals

<table>
<thead>
<tr>
<th>Problem category</th>
<th>Problem frequency (%)</th>
<th>% of all goals set against this problem</th>
</tr>
</thead>
<tbody>
<tr>
<td>A</td>
<td>40</td>
<td>4</td>
</tr>
<tr>
<td>B</td>
<td>16</td>
<td>42</td>
</tr>
<tr>
<td>C</td>
<td>19</td>
<td>9</td>
</tr>
<tr>
<td>D</td>
<td>20</td>
<td>24</td>
</tr>
<tr>
<td>E</td>
<td>5</td>
<td>21</td>
</tr>
</tbody>
</table>

The results reflect problems against which goals were actually set. Many lifestyle goals related to self care, exercise and diet that were central themes to general diabetes care. At least half of the category B goals related to exercise that related also to glycaemic control and management of complications.
Goal achievement was 62% that compares favourably with other trial groups. The goals chosen were similar to the non-Aboriginal diabetic group. These related to health maintenance, exercise, diet, weight, smoking cessation, alcohol use, attendance at appointments or referrals to health system, and specific signs and symptoms such as pain, sleep, incontinence or impotence.

Goal achievement is shown in table 26 with other trial results for comparison. Data has been provided by Adrian Heard, consultant statistician HealthPlus. Some figures from a small non-English speaking (NESB) subgroup in the Western diabetes trial have been included for comparison.
<table>
<thead>
<tr>
<th></th>
<th>No.</th>
<th>Positive Scores %</th>
<th>No Change %</th>
<th>Negative Scores %</th>
<th>Mean difference between 1st &amp; final rating (SD)</th>
<th>Median difference</th>
</tr>
</thead>
<tbody>
<tr>
<td>Western Diabetes</td>
<td>154</td>
<td>38.6</td>
<td>28.1</td>
<td>33.3</td>
<td>0 (3.0)</td>
<td>0</td>
</tr>
<tr>
<td>EP Chronic &amp; Complex</td>
<td>831</td>
<td>41.9</td>
<td>31.3</td>
<td>26.8</td>
<td>0.6 (3.1)</td>
<td>0</td>
</tr>
<tr>
<td>NESB</td>
<td>81</td>
<td>46.9</td>
<td>53.1</td>
<td>14.8</td>
<td>1.2 (2.5)</td>
<td>0</td>
</tr>
<tr>
<td>EP Diabetes</td>
<td>297</td>
<td>59.4</td>
<td>24.2</td>
<td>16.4</td>
<td>1.6 (3.3)</td>
<td>1</td>
</tr>
<tr>
<td>Aboriginal Diabetes</td>
<td>101</td>
<td>62.9</td>
<td>24.7</td>
<td>12.4</td>
<td>2.6 (3.6)</td>
<td>2</td>
</tr>
</tbody>
</table>

(source A Heard 2000)
Numerous problems relating to social issues were cited as primary problems affecting all aspects of diabetes care. Almost all of these were unmanageable within the trial context, and were generally not used in goal setting; they were not therefore included in table 25. These problems included poor housing conditions, domestic violence, stolen generation issues, alcohol abuse, poverty and unemployment, family tragedy and depression. In most cases no services existed to provide culturally appropriate responses. In not setting goals for these problems, their importance was only postponed. The burden on health workers was also taken into consideration; in Ceduna burnout had been high amongst AHWs and the stress of not being able to resolve these issues would have adversely affected them.

**MBS, PBS and hospital costs**

No control group was available for the Aboriginal diabetics, and no records of previous allied health service use were available. MBS and PBS use is shown in table 25 and derived from the NER; this is based on Health Insurance Commission (HIC) data and ignores local Aboriginal Health service arrangements that mix State and Commonwealth block funding to provide free services. These may have been provided but not reflected in HIC results.

Hospital admission data are shown in figure 11 published in the final SA HealthPlus report. They show differing admission rates historically, and a slight decrease during the trial (see discussion).

**Table 25  MBS and PBS data for selected CCTs**

<table>
<thead>
<tr>
<th>Trial</th>
<th>Patients (N)</th>
<th>Age F</th>
<th>M</th>
<th>PBS ($/day)</th>
<th>MBS ($/day)</th>
<th>Completing Trial %</th>
</tr>
</thead>
<tbody>
<tr>
<td>Eyre Diabetes Aboriginal</td>
<td>101</td>
<td>50</td>
<td>36</td>
<td>64</td>
<td>0.97</td>
<td>0.81</td>
</tr>
<tr>
<td>All Other Aboriginal</td>
<td>47</td>
<td>59</td>
<td>30</td>
<td>70</td>
<td>2.38</td>
<td>2.08</td>
</tr>
<tr>
<td>Eyre Diabetes</td>
<td>297</td>
<td>60</td>
<td>49</td>
<td>51</td>
<td>1.41</td>
<td>1.40</td>
</tr>
<tr>
<td>Eyre Non Aboriginal</td>
<td>1189</td>
<td>62</td>
<td>49</td>
<td>51</td>
<td>2.11</td>
<td>1.44</td>
</tr>
</tbody>
</table>

(source NER)
4.3 System outcomes

Significant changes occurred in the Aboriginal Health Services as a result of the care plan service requirements. HealthPlus purchased allied health services for Aboriginal clients directly, in some cases offering podiatry or eye reviews for the first time. These were provided within the Aboriginal health service, which would in turn provide transport to and from appointments, circumventing a previous source of frustration and reason for service withdrawal.

Group service provision became an accepted way of service provision; examples include cooking groups and a women's' walking group. These were managed by health professionals initially, although they ultimately became supervised by experienced AHWs. Significantly it was the health service that chose to purchase group rather than the providers, thereby asserting their ownership of the trial within the community.

The provision of clinical services had several effects. It offered an opportunity to provide some clinical care to clients who largely had been unable to access it. It enhanced the position of the health services, and allowed them to request services in some meaningful terms. In Port Lincoln the AHWs became better supported by the PLAHS, and funds were redirected to support patient generated priorities. In reality this meant that two more AHWs were recruited toward the end of the trial, and less pressure placed upon AHWs. These
same AHWs remain in place four years later. Similar recruitment was not possible in Ceduna, and currently only one AHW from the trial remains.

The important consequence of having enough Aboriginal Health Workers was that work could be moved out into the community where others would access it. PLAHS and CKAHS to a lesser extent, were able to provide community screening days, that were practical (barbecues) and appropriate (capturing people who would otherwise not attend health services). These were run by the AHWs. Using portable laboratory equipment, AHWs were able to go into homes where more than one family lived, and provide clinic services, feedback and reviews.

The organisational changes were significant, particularly for PLAHS. Their improved understanding of funding arrangements resulted in a business approach to health care. Team structures, job descriptions, reporting and budget procedures, non-medical staff employment and training, and personal development programs resulted in a modern and professional health service. The community employed an Aboriginal person with an accounting degree to its CEO post and computerised much of its work. Both services bought a software program that incorporated a whole population approach to care. This included the ability to track service use and as well as link to medical services such as care plans.

4.4 Discussion

Diabetes occurs at a high rate in Aboriginal communities [14, 15] in Australia, but not consistently in overseas Aboriginal populations [208, 209]. The aetiology is multifactorial and includes genetic susceptibility [210], nutrition, obesity and social stress [211]. Increasing rates of obesity are associated with increasing rates of diabetes and cardiovascular risk [212] and reduced life expectancy 10-15 years [213-216].

Hyperinsulinaemia is more common in Aboriginal people; it does not predict the development of diabetes [217, 218] although Aboriginal people may undergo early pancreatic failure [219]. Western diets cause changes in insulin resistance that predispose to diabetes [220]; these changes are reversed by diet and exercise interventions. Systematic and planned care in Aboriginal communities is associated with better HbA1c
readings, blood pressure control and fewer hospital admissions [221, 222]. Many communities are however not following lifestyle changes that are required for successful self management of their diabetes [223].

**Barriers**

This trial used goal setting to define the barriers to care in the Eyre Aboriginal population, and care plans to provide systematic care that was patient orientated. Frequently cited barriers were housing, poverty, alcohol abuse, domestic violence, overcrowding and lack of transport. Simmons found that similar barriers existed in large multiethnic communities in New Zealand [158, 224]. He found that lack of community based care, lack of adequate services, and beliefs about the value of self-care were perceived as the most important barriers. In a rural Australian Aboriginal community, lack of resources and inappropriate approaches have been cited as additional barriers [222].

This latter point is repeated in Aboriginal political commentaries, pointing to historical origins of disempowerment and calling for totally community owned and controlled clinical care. The Australian government has invested heavily in the National Association of Community Controlled Health Organisations (NACCHO) to ensure that this indeed occurs, however financial investment has not necessarily provided better health outcomes [32, 225]. The multidimensional aspects of Aboriginal health incorporating family, community and personal perspectives are inseparable, and interventions must be multidimensional as well. Community ownership remains central to any intervention programs [226].

In this trial organisational change that surrounded the care planning was patient driven and community owned. Personal change was reflected in the unique relationship between the service coordinator and Aboriginal clients. Goal setting allowed exploration of many complex social issues in detail. In some cases, realistic goals were set against small problems, however often the narrative itself was enough to begin a process of problem solving.

**Narratives in goal setting**

Narratives or yarning by Aboriginal people remains an important part of daily communication that involves webs of relationships, interactions and ways of doing things. It
combines historical and cultural perspectives, and seeks to place problems in their family and community contexts. The process is a continuous one and eventually the narrative allows a sense release to occur, so that people are able to look at other possibilities in dealing with their problems.

The opportunities for change lie in achieving this point, and is consistent with health belief models and personal models of self-care [159, 227]. A patient’s appreciation of the benefits of behaviour change allows them to enter personal goal setting framework. Failure to reach a point of personal resolution on the other hand, may adversely affect the ability to move through goal setting. The inability of the trial to address central social outcomes that indirectly effected diabetes care, did not prevent goal setting improvements from occurring as patients in some cases achieved their own point of resolution through their narratives. It reinforced the importance of understanding problem context [228].

The community and personal trust that each service coordinator enjoyed prior to the trial, allowed an early exploration of issues that would not have been possible if the trial had started with new non-Aboriginal workers in the community. This sense of trust may take years to develop and requires a personal commitment to the community. The narratives were initially time consuming, generally twice the interview time required for other trials, and many personal issues were raised for the first time. For patients this was often a painful experience.

For service coordinators this was equally difficult. Great trust was placed in these dialogues and there was an expectation that help would be provided by the trial if it were available. Early in the trial it was obvious that, for social issues, this could not happen without major organisational and funding changes. The psychological issues that arose within the narratives, and subsequently the goal setting approach, were no easier. From an Aboriginal perspective, it was not acceptable to refer them on to a more qualified person. Trust could not be placed in a third party nor could the stories be retold without fear of compromise within the community.
This left service coordinators in the difficult position of being service providers without suitable training. Much time was spent exploring this theme common to all the Eyre trials, and a half-day workshop devoted to seeking a solution. For the Aboriginal trial coordinators, the relationship with patients and the opportunities provided by it, were too important to ignore. Limited counselling skills were provided to the two service coordinators, particularly in the areas of grief counselling, crisis intervention, and supportive psychotherapy. It resulted in greater confidence for service coordinators, further exploration of confidential issues (such as Stolen Generation) and progression through diabetes issues as intended by the trial.

The method of more detailed training has become an important issue in the Aboriginal services plan to improve service delivery. Although Aboriginal Health Workers were able to learn many of the skills in dealing with mental health issues, they usually only put them into practice with other Aboriginal people. This has left them with a sense that they are only good enough to practice on Aboriginal people. Current training processes will need to integrate training practices with both Aboriginal and non-Aboriginal clients to increase their skill base and confidence.

**Goal setting**

The process of goal setting in this trial was associated with greater positive achievement than any other sub-trial. Some common lessons from other CCTs were applicable to this group of Aboriginal diabetics; their application just required greater sensitivity and understanding of cultural issues. These lessons include allowing enough time with each patient, formulating goals in a patient’s own terms, deciding which problems will benefit from a goal setting approach (and which will not), assessing accurately the impact of a problem including how it makes a patient feel, setting realistic and achievable goals, and regularly reviewing them.

Diabetes patients in these two communities felt most comfortable with achievable life style goals (diet exercise), often in groups. The social interactions that accompanied these group sessions, included a discussion of the merits of ‘white fella’ medicine. Women were often the
leaders in these groups. Providers were invited to these groups and were able to learn through the AHWs, important and appropriate cultural ways of meeting goals that patients set. A dietician’s presentation was entirely changed by an understanding of the role some foods played in the community [229], as well as its availability. Walking groups often became education walks in the bush to teach family and children [230, 231] about bush tucker.

Other goals related to health maintenance, weight loss, smoking cessation, alcohol use, control of diabetes or complications, attendance at appointments or referrals within the health system. All of these goals were tangible and within a patient’s perceived areas of control. Weight loss as with non-Aboriginal trials, was difficult with many patients refusing to be weighed. Smoking cessation and men’s health groups evolved in the community as a result of goal setting discussions; this latter group by its nature looked at alcohol use, tolerance of misuse in the community, and domestic violence. A grief and loss group have ultimately evolved into a well-being group.

More specific goals relating to medical problems were set with low frequency (signs and symptoms such as pain, sleep, incontinence or impotence). It was likely that a considerable amount of fear surrounded medical interactions, and setting goals within a locus of control was more attractive. (The concept of fear is outlined further in the PAR trial described in appendix 1.) Some of these latter symptoms were also more complex than they initially appeared, and represented deeper family dysfunction rather than diabetes related issues. Successful management was ultimately dependent on prior success with other goals, and goal setting was not attempted without an exploration of specific issues such as shame.

In view of the longer time required to set goals, several approaches to speed up the goal setting process were tried by the care coordinators. These included cues for common issues (not solutions) to ensure that all areas of potential care were covered, or that an opportunity was available for family discussion of potential goals. Ultimately it was felt that any attempt to direct outcomes adversely affected those relationships, and patients would start to offer solutions that they thought were being sought. This process needs further evaluation and refinement to suit Aboriginal needs.
Collective decision making

As providers for extended family groups, women held considerable influence over which food sources were available. Men were generally far less likely to prepare food. Extended family groups meant that others with diabetes were often in the same household, and benefited from dietary information. There was a genuine desire for this to be passed on to children to avoid the community trends of increasing obesity [225].

As participants women made up 60% of the diabetes group, yet contributed to nearly every aspect of trial development, and were present at most meetings. Engaging Aboriginal men was not as easy [232]. The role of women in Aboriginal society is locked into the intricate system of kinship. Each person within the network has a specific guardianship role for another person within the system, and has an obligation to share knowledge that assists one person with the rest of the network.

Decisions by one person must however be agreed to by others hence many Aboriginal communities have community councils to decide on important matters, sometimes including health issues. It was important to understand that community and family needs are more important than personal needs [229, 233] (the opposite to European perspectives). This collective approach may be applicable to diabetes decision making and is led by elders and women within the Aboriginal communities, who are valued for sharing their experiences, understanding and success at managing diabetes. Successful management implies surviving until age 60 years without significant complications; community experiences are of people dying in their 30's and 40's from vascular complications are common and reinforced to children who attend community funerals.

The poor state of many Aboriginal social conditions is well documented [225]. Aboriginal patients consistently cited lack of money to buy food or medicines, lack of transport to get to appointments, overcrowding, domestic violence, alcohol abuse by family members, unemployment and poor self esteem, as barriers to better diabetes care. The discussions around what constituted appropriate care, and whether it should be followed, were more complex and made against this background. The reluctance to follow Western medical
models has historical origins and highlights the importance of context. Diabetes is a white man’s disease that threatens much of the community; loss of any community members reduces the ability of Aboriginal people to continue to resist external domination. Decisions about health care provision were inseparable from political as well as social determinants.

Goal setting highlighted many problems that were brought to families initially [234], then more extended family if necessary, and ultimately community elders if no answer was found. The collective experience and wisdom of groups was then tempered by political and social factors until a solution or impasse found. If successful, this was the starting point for goal setting. The achievements of the AHWs in arriving at this point cannot be underestimated.

This latter point was most apparent at HealthPlus coordinator review meetings. It regularly took twice as long to do care plans for Aboriginal people as non-Aboriginal people. In part this was language and communication problems [235], but equally a result of clients reluctance to accept responsibility for their own care. The issue of who owned the problem became a cultural one, and underlined their perception that this was a white man’s disease. Their reluctance to carry copies of care plans in any form confirmed who owned the problem. Not surprisingly considerably more follow-up was required than for non-Aboriginal patients. Paradoxically, Aboriginal clients did engage the open-ended strategy of goal assessment, rating and goal setting.

The role of the Ceduna care coordinator in this trial was remarkable. Nurse practitioners work regularly in Aboriginal communities, sometimes at significant personal risk and often under difficult circumstances. The care coordinator in this case successfully negotiated cultural barriers, gained community trust, accessed intimate social and family knowledge, side stepped difficult issues, and generated confidence building relationships with diabetic clients. Both the process and the outcomes were successful.

Was goal setting useful?

The goal setting process was not considered threatening by Aboriginal clients because people whom they trusted administered it. Their relationship with the care coordinators
reflected a professional approach to confidential issues, and an unbiased approach to potential solutions. The important link in this relationship was the work of the AHWs, who were the voices of the patients and the care coordinators.

How patients perceived this relationship determined how much trust to place in it, and ultimately whether it was successful. Separating work from home life, however, was not easy for the AHWs who were never released from their work. Domestic violence was a commonly cited example; often the perpetrator or victim was related to one of the workers or staff. The AHWs could not afford to lose contact with their communities and not be seen as advocates. Paradoxically their participation in the trial meant that AHW ties with the community became weaker, to ensure stronger professional working relationships. This didn't lessen AHW resolve as they gained much valuable clinical experience and community prestige.

Although the AHWs understood the principles around goal setting and their potential value in overcoming barriers to care, only a few of the patients appeared to understand the process. They invariably trusted the AHWs to guide them and not place them at risk. The relationships that developed were therefore a key success in the trial.

Most patients chose disease based goals that were achievable, and allowed themselves only small degrees of discomfort. Surprisingly over 50% of patients also discussed social based problems despite the inability of the trial to effectively manage those problems. This was generally in the second half of the trial when they had gained some confidence in goal setting.

The Aboriginal care coordinators were surprised at this openness, although the open ended nature of goal setting inevitably would lead back to key issues. They identified a number of other factors that predicted a greater likelihood of using goal setting successfully. These included:

- patients over 40 years
- regular support by a carer or partner
• independent and organised patients
• patients who indicated that they were ready for a change
• patients seen shortly after a life event or crisis
• higher literacy level or basic education

This latter point may have represented a better understanding of the process or a lower level of social distress. Lower literacy levels in Aboriginal people may also have reflected greater social disruption in childhood, which is carried into adulthood. All these factors were seen in the other HealthPlus trials.

**Quality of Life Outcomes**

The SF36 was a complex assessment tool that proved inappropriate to Aboriginal problems. Further changes at the end of the trial condensed this to a core twelve questions; these were made available for further Aboriginal trials, and have been more successful overseas [236].

The WSAS scores were heavily influenced by social factors; as little change was achieved in this area, little change was noted in WSAS scores. The care coordinators felt that the Aboriginal patients had the capacity to tolerate poor social circumstances better than non-Aboriginal patients in the trials. This lead to a tendency to delay score changes, blunting the sensitivity of WSAS scores. Neither tool on its own was useful in Aboriginal settings.

**Health service use**

The primary HealthPlus hypothesis was not assessable in this trial as service use was below national equivalents. Savings and service substitution models were also not possible. Hospital separations didn’t show any consistent trend, and MBS/PBS costs were low, primarily because of low usage. Even when services were provided through trial funding, lack of money and transport meant that Aboriginal people chose to use hospital outpatient services which were free. The trend for people to wait for crises, directly or indirectly, compounded this trend.
The interpretation of MBS and PBS costs must be done with considerable care. In comparing the Eyre diabetes trial with other CCTs and other trials, there are apparently more hospital admissions and less MBS and PBS costs. Some medicines were provided through the Aboriginal health services however many patients only filled scripts if they had enough money, regardless of need. The absence of regular GP services in Ceduna precludes any sensible interpretation of MBS figures, however attendances did rise with provision of transport and the establishment of a recall system. The fall in hospital admissions in Ceduna is however unlikely to reflect a real effect of planning care. Many hospital admissions in both towns related to social crises rather than medical crises. The attention to family and social stressors through goal setting may have offset some of these crises by timely AHW intervention. The duration of the trial is unlikely to have effected admissions related to diabetes complications.

The basic need for social determinants to be addressed remained at the end of the trial and coordinated care can only be effective if these are also included in health strategies.

**System changes and outcomes**

Key issues in the Aboriginal CCTs were health system reform and empowerment. Many infrastructure changes were successfully initiated during the trial but not completed until after the trial closure. Much of the information technology change was too great for staff to absorb within two years, although it built a strong platform for further change in the years that followed. Training and professional development of AHWs, to replace and enhance the capabilities of the Aboriginal Health services by service substitution, proved impractical. A recurring theme was inadequate numbers of motivated Aboriginal people staying involved long term in Aboriginal health services.

In this and other trials progress was often made possible by support provided by non-Aboriginal workers committed to the services, who were not subject to community demands. These workers dealt with many of the professional medical issues (rather than the social issues) either by patient choice or lack of clinical training on the part of AHWs. This apparent deficiency is less important than it appears, as no readily available training
pathway exists to teach workers how to engage the social component of Aboriginal health, other than by living and working in the field. Conversely multiple medical training pathways exist for AHWs to improve their clinical skills. Lastly non-Aboriginal workers were motivated by a desire not to place Aboriginal workers in a position to fail in a complex environment. This was important to the AHWs who felt able to explore their patient's problems without fear of failing them in more basic areas of care.

The provision of more community based services based on patient demands, forced a change in provision of services by both Aboriginal Health services. This was much more difficult politically as it was costly and detracted from core business. Both services in the past had chosen to provide quality services to their communities rather than part-time services. More remote services were also exposed to political divides within the communities, and risked losing AHW support if they became ineffective. The patients themselves resolved this by ultimately running the groups and directing themselves. This early evolution into CDSM groups was surprising, although apparently logical to the diabetic patients, particularly the women, who led the groups. Much of their motivation came from a perceived lack of control or ability to control services that were needed.

The Aboriginal Health services were able to provide and control clinical care outside mainstream health services. A broader range of services became available and the use of AHWs primarily as coordinators was a significant step [237]. All of this would not have been possible without the co-operation of the local Aboriginal Community Councils who endorsed the trial from its outset. The increased funding they received enhanced their own positions in the very complex world of Aboriginal politics. How AHWs could be funded is a more complex issue [238]. More broadly the improved services enhanced a community sense of self-determination, rather than any personal gains that were secondary.

Some AHWs reported increased patient confidence with diabetes self care and accessing services however sustainability outside the trial was uncertain. The key psychological changes in intra-personal and inter-personal skills that accompany successful goal setting were not as obvious in this trial. Patients understood the concepts around goal setting but
the lack of substantial progress around key social issues detracted from its adoption as a method of controlling a perceived external threat. Community approaches to these issues may be more successful, reducing the need for personal change.

The AHWs achieved a sense of personal empowerment by participating in the trial, and enhanced their standing in both the community and many patients' perception. This was a key success of the trial. The ability to actively conduct clinical care and research resulted in a long lasting sense of confidence in those AHWs and their ability to provide for the Aboriginal communities. Some have been involved in further trials, further tertiary study, and greater management roles, providing further positive role models for Aboriginal children. The implications for community members who strive to break out of poverty cycles were significant. The recent establishment of an Aboriginal Research body in South Australia will increase the opportunities for AHWs to gain higher degrees and become researchers in their own right.

This CCT failed to address many of the broader issues put to all Aboriginal CCTs [2]. These included long term health strategy planning, effective coordination between funding bodies, effective reconciliation and improved housing and infrastructure services. On the other hand significant progress was made toward integrating clinical care, population health and health promotion. The system changes were central to this and ideally should have preceded the trial.

4.5 Conclusions

The Aboriginal diabetes component of the HealthPlus trial was the largest Aboriginal trial of all the CCTs. The development of goals that were achievable using the problems and goals approach, was as successful in these Aboriginal communities as it was in the non-Aboriginal communities. The central social issues of poverty, inadequate housing, overcrowding, unemployment and access were not addressed in this trial, however Aboriginal diabetics were able to set many life style goals that they could achieve. Their solutions were in some cases provided in group settings that proved popular.
Many organisational changes occurred during the trial. These related to process and service delivery. Structurally both the Aboriginal health services developed their service to support chronic care services. The changes included purchasing new services based on identified need, and the renegotiation of existing arrangements. The detailed database of diabetics allowed the establishment of registration and recall systems.

New relationships between care coordinators and diabetics were explored, in particular in Ceduna where no continuous medical services were available. This model has much potential for future chronic disease care delivery in these communities.

Overall costs were not changed greatly, however the virtual absence of many services makes interpretation difficult. It is likely that further expansion of a coordinated care approach will require significant funding for both care coordination and service provision.
CHAPTER FOUR

Part 2: Integrating Goal Setting into diabetes management in Aboriginal Communities: the Chronic Disease Self Management model (Trial 4)

Introduction

The Coordinated Care Trials researched a model of goal setting that used nurses to explore barriers to diabetes care and generate solutions with their patients. As the model was too expensive to implement [239], alternative ways of using goal setting in Aboriginal health systems were explored. The impetus for this came from the Aboriginal community who sought autonomy from mainstream health services and improved health outcomes. The open ended narrative approach was appealing and familiar, and the Aboriginal Health Workers had shown an interest in learning goal setting during the previous CCT.

That Coordinated Care Trial had also enabled research into more effective management of chronic illness with the implicit assumption that much of the burden of chronic illness in the community could be prevented or managed to reduce the resultant demand for acute care and improve health outcomes for patients [240, 241]. This was based on funds being pooled for preventive care as a strategy for improving health outcomes for patients and reducing unplanned, preventable hospital admissions for this group [1, 2]. Models of care have now focused on self-management strategies that are less costly [242]. Different models [243] were needed for chronic disease management programs within minority
groups [244, 245] such as the Aboriginal communities. Such programs still required infrastructure funding [246].

The Enhanced Primary Care Package was an attempt to fund GPs and health providers in more direct ways to reduce and manage the incidence of chronic disease in the community [247]. The new approach produced a cautious uptake of the new items in rural South Australia [248], and a linking of GP care plans more directly to Allied Health service and primary care delivery systems. The Commonwealth Regional Health Service (CRHS) initiative also supported these processes and built more flexible community based funding models for preventive health care programs in rural areas. These programs were specifically aimed at improving coordination of service provision for patients with chronic illness in an attempt to reduce the increasing demand for health care services as patient populations age and develop more complex health care needs [77, 249-251].

The question arose as to which elements of the coordinated care process suited Aboriginal patients and further, which patients were most likely to participate in and benefit from self-management strategies. A number of chronic disease self-management (CDSM) programs were established in SA to measure the impact of self-management on patient behaviour change and resultant health outcomes. The Eyre Peninsula CDSM pilot program for Aboriginal people aimed to develop patient education, behaviour change and management strategies that were culturally appropriate for and applicable to Aboriginal communities, and to document these approaches as possible models for other communities.

A central hypothesis of this program was that a modified form of goal setting and initiation into self-management is possible for Aboriginal people and that when implemented, such approaches can lead to improved quality of life and health outcomes. This work was an extension of the CCTs with AHWs taking over much of the work including goal setting from nurse coordinators and GPs.
The central changes in this trial were:

- the transfer of all goal setting into AHW hands
- the measurement of quality of life using an SF12 developed by the AHWs
- use of a self assessment measurement to assist goal setting and planning
- measurement of limited clinical outcomes
- group treatment rather than individual treatment
- continued use of care plans for case management
- a reduced role for GPs and an increased clinical role for AHWs
- greater community focus rather than dealing with individual priorities

4.6 Timeframe

This project began formally in June 2001. A three-month start-up and planning phase preceded the one-year pilot program with the project being completed in September 2002. In the planning and project development phase extensive consultations occurred between the training providers, project officers and Aboriginal Health Service staff to ensure that tools and processes used were appropriate for Aboriginal people and Aboriginal Health Services.

4.7 Program aims

- These are summarised as follows:
  - development of local CDSM support coordination roles for Aboriginal Health Workers (AHWs) in Ceduna and Port Lincoln to work with Aboriginal people with type 2 diabetes and related co-morbidities
  - extension of previous preventive health programs in the Ceduna area and the development of the coordinated care service coordination function commenced by the coordinated care trials as a way of encouraging self-management through education programs
  - development of appropriate self assessment processes and tools to suit Aboriginal people in their goal setting, behaviour change and self-management approaches
• documentation of specific family, community and individual health gain resulting from patient participation in a formal CDSM program

• development of appropriate staff training that is culturally sensitive and flexible enough to promote the principles of self-management through goal setting, education, access to preventive services and lifestyle changes

• identifying the allied health services and programs relevant to and effective in achieving health improvements within Aboriginal communities

4.8 Project design

Initially 31 patients were recruited for the program in Ceduna and surrounding areas with service delivery support provided through the Ceduna Koonibba Aboriginal Health Service (CKAHS) and the Ceduna RHS program. A group of 29 patients was recruited through the Port Lincoln Aboriginal Health Service (PLAHS) in Port Lincoln, making a total population of 60 people involved in the pilot study. These 60 Aboriginal people (28 men and 32 women, mean age 46 years) with type 2 diabetes (mean duration 7 years) remained in the trial until its completion.

The target group specifically excluded patients who had been involved in the previous SA Health Plus coordinated care trials, as individuals within this cohort had already experienced intervention under the trial design brief.

An SF12, WSAS score, and diabetes assessment (appendix 4) were tested at beginning, middle and end of the project. The SF36 was reduced by the AHWS to twelve core questions that they felt most useful.

Goal setting was performed up to 3 times over the 12 month period. Health outcome data included blood pressure, weight and HbA1c. Unfortunately many patients refused to be weighed resulting in insufficient data. Participating staff in local health units, using existing data systems within Aboriginal Health Services, collected project data.
4.9 The program

Patients worked with the AHWs to develop a care plan that included specific self-management strategies. The CDSM process encouraged and reinforced long-term management principles, and advanced local organisational changes that could lead to improved uptake of the new MBS item numbers for Aboriginal patients. (The long-term financial viability of any such programs was an important consideration of the Aboriginal Health services in supporting this program).

The patient management program included formal goal setting and problem definition, physical examination and clinical review, medication management, the setting of specific management goals and the modification of lifestyle factors.

CDSM strategies

Locally trained staff worked with, trained and supported indigenous group leaders in CDSM processes in both sites. This approach was based on the service coordination model established in the region to develop support groups, education programs and CDSM strategies of particular relevance to Aboriginal communities. Although Aboriginal patients did not participate in organised and formal 'Lorig style' CDSM courses, one to one approaches were used by health teams to educate, support and encourage patients to consider more comprehensive self-management approaches as a consequence of the care planning and goal setting processes used.

The CDSM program also involved:

- provision of local support and encouragement with condition management programs already in place
- involvement in 'rehabilitation programs' through which patients participated in group education sessions about their condition, exercise and diet management programs and self-help groups run by local coordinators
- participation in community based, family group and social group meetings and discussion sessions run by local staff to encourage patients to self-manage.
participation of carers and other family members in regular sessions designed to encourage groups and family support for patients with chronic conditions

• participation in consumer group discussion, feedback and promotional sessions designed to expand such programs to include other patients beyond the pilot group

• participation in formal review, feedback, self-assessment and data reporting activities through which group leaders assessed patient progress over time towards self-management and determined the most effective CDMS strategies for Aboriginal people

Health Teams: Establishing the process

As well as developing self-help and support groups to function with the minimum of allied health professional support, a team of local allied health staff recruited through the CRHS program supported patients and encouraged independent management of their conditions. The Eyre Region was fortunate to have the support of the Flinders University Coordinated Care Training Unit (CCTU) during the SA HealthPlus trial. Some of the staff trained as CDMS program leaders were working in the region both in the EPDGP and the ERHS. These key trainers educated and supported local Aboriginal staff in the management of chronic illness with particular reference to the importance of education, goal setting and the development of support groups to maintain lifestyle change involving exercise programs and dietary modifications. Staff worked in collaboration with allied health professionals to provide the services necessary to motivate and sustain behaviour change and self-management by patients.

Training and support for staff and patients was provided through a partnership with the Flinders University Coordinated Care Training Unit, which was responsible for developing the staff training programs for the HealthPlus coordinated care trials in South Australia. This work culminated in the ‘Partners in Health’ program [70] and other chronic disease self-management initiatives that were modified and adapted for use in local Aboriginal communities. Local mentor and training staff located in the Eyre Peninsula Division of General Practice (EPDGP) provided the training for allied health workers on behalf of the Flinders University coordinated care training unit. My role was local mentor to both sites, to supervise and assist training, to review patients and collect data including goal setting.
4.10 Results

4.10.1 Modified SF-12 Quality of life assessment

This tool showed no significant change over the course of the trial. Clients largely needed the AHW to physically complete the forms and interpret them. Despite several revisions and the non-specific nature of this tool, it was cumbersome to use and was unable to differentiate those patients who were able to benefit most from learning self-management strategies.

4.10.2 Modified work and social adjustment scale (WSAS)

Similarly this tool showed no significant change over the course of the trial (Table 26). This questionnaire represents a revision of the original Work and Social Adjustment Scale used in the CCTs. Although simple to use, it still created confusion with Aboriginal patients due to the use of a numerical and descriptive options along with an excessive number of choices being available. Substantial support from the AHW to interpret and complete the forms was still required.
Table 26  WSAS mean (SD) at initial assessment and 12 months follow-up [252].

<table>
<thead>
<tr>
<th>WSAS Subscales</th>
<th>Initial</th>
<th>12 Mths Follow-up</th>
<th>Paired Differences</th>
<th>t[45]</th>
<th>p</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>(n = 46)</td>
<td>(n = 46)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Work (n = 16)</td>
<td>0.63</td>
<td>1.00</td>
<td>0.38 (1.09)</td>
<td>-1.38</td>
<td>0.188</td>
</tr>
<tr>
<td>Home Management</td>
<td>1.48</td>
<td>1.35</td>
<td>0.13 (0.81)</td>
<td>1.10</td>
<td>0.278</td>
</tr>
<tr>
<td>Social Leisure</td>
<td>1.35</td>
<td>1.28</td>
<td>0.07 (0.61)</td>
<td>0.72</td>
<td>0.473</td>
</tr>
<tr>
<td>Private Leisure</td>
<td>1.09</td>
<td>0.96</td>
<td>0.13 (0.86)</td>
<td>1.03</td>
<td>0.309</td>
</tr>
<tr>
<td>Family &amp; Relationships</td>
<td>1.00</td>
<td>0.91</td>
<td>0.09 (0.76)</td>
<td>0.78</td>
<td>0.439</td>
</tr>
</tbody>
</table>
4.10.3 Diabetes assessment

The Diabetes Assessment showed improvements across all domains, with the greatest change occurring in diabetes knowledge. The mean (SD) scores improved from 0.57(0.64) at entry, to 0.28(0.51) at 12 months, with a mean change of 0.29(0.62) t(45)=3.22, p<0.002. This is equivalent to a 47% improvement over the 12 month trial.

This form was viewed favourably by health workers as it was simple to administer, not time consuming and yielded useful information. It was a locally developed tool that merges the Partners in Health Scale and the Cue and Response Form [253] that were two assessment tools developed through Flinders University Coordinated Care Training Unit to test patient knowledge and self-management ability in preparation for care planning.

This form was developed to simplify the self-management status of patients with diabetes and to provide information that would assist the care planning process. General agreement suggested that the use of this form was not confrontational and promoted informal conversation between the health worker and patient about diabetes whilst at the same time providing a patient perceived self-management baseline.

Goal setting

Many of the problem areas identified were common to the previously described trials. The problems related to four main domains: A. diabetes complications, B. depression/anxiety/pain, C. social/family disharmony, D. specific diabetes management issues.

Problem ratings and goal ratings did show significant decreases from initial to final assessments. From the final data set of those patients completing goal setting, the initial problem ratings (M=6.22, SD=2.23) and the six month ratings (M=6.00, SD=2.03) were significantly higher than the one year ratings (M=5.28,SD=2.20,F(2,70)= 8.72, p<0.01).

Goals set related almost exclusively to lifestyle change; other areas included self-management strategies in conjunction with other parties such as a dietician, physiotherapist or AHW.
Initial goal ratings (M=7.26, SD=1.57) were significantly higher than the six month ratings (M=6.16, SD=1.94), both of which were significantly higher than the one year ratings (M=5.42, SD=2.18; F(2, 74) = 20.37, p<0.001).

Correlations indicated no linear relationship between problem and goal ratings.

**HbA1c** overall showed a trend slightly downward from initial readings (8.74±/-2.07) to 12 months (8.09±/-1.71; t(45)=2.86, p<0.01). For the Port Lincoln group, the mean HbA1c fell from 8.9 to 8.4; for the Ceduna group the fall was from 8.5 to 7.6. These are positive outcomes as HbA1c tends to trend slightly upwards with time [17].

**Blood pressure** measurements remained unchanged overall. The mean blood pressure was 139/84 at the start of the trial, and 136/84 at the end. (Systolic: before 139.48±/-18.72, after 136.68±/-15.13, t(24)=0.70; Diastolic before 84.64±/-8.50, after 83.76±/-11.49, t(24)=0.37).

### 4.10.4 Qualitative feedback

A workshop of providers and patients was held at the end of the trial. Patients continued to identify multiple barriers to diabetes care. These included in order of priority: housing (overcrowding, access), family problems (caring for elderly, emotional pressure), social issues (peer pressure, finance, isolation), nutrition (cost of healthy food, knowledge), medication (cost, understanding of importance), mental health (many CDSM patients suffered depression, denial, lack of counselling), relationship with health professionals (shame asking for help, medical jargon, not being taken seriously, need to please and not be a hassle). Sixty percent of patients found that goal setting assisted them in solving problems, and 100% felt more comfortable doing this with an AHW. Care plans increased comfort discussing diabetes with a GP (75%), helped emotionally (75%), and made management easier (100%).

The *Aboriginal Health Workers* confirmed that the WSAS and SF12 were not useful, that the Diabetes Assessment and Care Planning were useful, and goal setting was useful in some but not all patients. Goal setting was **not useful** in patients who: denied their diabetes,
moved frequently, lacked community trust, regularly failed to attend appointments, saw diabetes as a management rather than self-management problem and declined responsibility. The AHWs felt GPs were supportive of care planning.

4.11 Discussion

The CDSM program was designed to enhance the evolving integrated allied health service approaches to the management of chronic illness in Aboriginal communities on Eyre Peninsula. It was envisaged that the CDSM trial would lead to the development of the skills and abilities of local indigenous staff to sustain an ongoing CDSM model of care beyond this short-term program. Resources available through the MBS system (care planning and GP services) and local allied health services provided through expanding RHS clusters created the potential for sustainability of the CDSM model once the demonstration program was completed.

The CDSM process described was a valuable strategy for educating and supporting people with chronic conditions and in gaining their participation in programs designed to improve they way the manage their illness. Such work, and the subsequent health outcome research planned for rural regions will contribute to the development of more comprehensive CDSM programs for Aboriginal communities generally.

Community outcomes

Case management in combination with CDSM programs can be effective [84] and forms an important component in chronic disease management strategies [254]. Engaging families and support structures may be important [163-165], particularly in Aboriginal communities. Patient assessment of their own diabetes self-care can be associated with good HbA1c control and improved attendance at recommended diabetes services [72].

Unfortunately many of the prerequisites for providing such care are absent in minority and Aboriginal communities [32, 255], and there is disruption at each of these levels. Several Aboriginal families often live in houses together for long periods of time generating significant friction, and straining the scarce financial resources available. Alcohol, gambling,
and domestic violence contribute to a cycle of poor self-esteem and failure. Children lack role models and learn old ways of dealing with complex social and health issues.

The self-management groups that evolved from this trial therefore reflected these problems, rather than specific diabetes issues. Such groups were concerned with healthy eating for children, drug and alcohol use, accessing community services, sexual health, and risks for Aboriginal people. These were run by AHWs after initial specific professional input. A renal screening program was initiated and extended to children at the community request. The relative ease with which these were set up suggests that patient behaviour may indeed be easier to change than provider behaviour [256].

4.11.1 Provider outcomes

Aboriginal health workers

Training to manage many chronic diseases is limited for diabetes professionals [257] and almost non-existent for AHWs. The training in goal setting and preparation of care plans was well tested in the CCTs. The AHWs were provided with detailed written descriptions of the tools and received practical skill supervision during this trial [70, 180]. This support was important as they developed groups and patient relationships, extending their own experience and independence. The AHWs were in a unique position to assess the needs of individual patients and their families; they enjoyed considerable trust both because of their relatively high level of education and their contribution to the community. Goal setting represented an opportunity for these Aboriginal people to describe their health needs, and be guided to solutions by someone they could understand. Patients described many barriers.

The number of AHWs involved in this trial was small (n=3) however they expressed a number of positive experiences at the workshop analysis of the trial. All three felt confident at identifying patients who could benefit from this process, at using the diabetes assessment form, at performing goal setting, at generating care plans and integrating the goals into care plans. In addition they felt confident in advising patients about services that were available, and how to access them. All felt that a combination of group and individual
approaches to education was the most acceptable way to provide the services; a similar approach was successful in Mexican Americans [258].

Some patients were able formulate goals beyond those related to diet or exercise. Often the issues were confidential, such as childhood sex abuse, marital conflict or grief related to recent family loss. There were few services available to deal with these complex issues, and generally there was a reluctance to use non-Aboriginal services. This ultimately left the AHW to deal with the problems as best they could, in consultation with the key trainers.

One of the most difficult problems AHWs had to face was lack of time. There were other crises daily, and with multiple roles to fulfill, time was often scarce. There were delays in getting clients to the service, long delays in filling in forms which most aboriginal people couldn’t read or understand, and explanations of the meaning and interpretation of the various trial tools. The time required to complete clinical tasks was often double the expected time. There was no shortcut to this process, which generated an important rapport between parties. This mutually beneficial relationship provided depth of experience on one hand, and trust on the other.

The personal characteristics of the AHWs were not studied, however their positive approach to the program and patient-provider relationships, in combination with organisational change were likely to be important [259].

Allied health input

Specific service provision around diabetes issues was provided both individually and in groups; both have been shown to be equally effective [260]. The pressures of service shortages hastened the change from individual to group service provision, which were generally accepted by the Aboriginal patients anyway as being culturally appropriate. The involvement of allied health providers ensured that a wide range of services was offered depending on need, however actual service provision was left to each health service. Individual providers commented favourably on the contract arrangements that they developed with the health services. Not only did they receive direction on service provision and delivery model, but patients were also much more likely to attend.
The group arrangements did not exclude individual education, however this was performed by the AHWs who were trained by the allied health staff. Individual work could be combined with diabetes assessments and goal setting as needed. Less than ten percent of patients needed the direct involvement of allied health workers in one to one management.

**General Practitioners**

GP input into this trial was significantly less than the CCT. The role of GPs in this was to support the AHWs, manage medical problems and review goals. Acute problems invariably shortened precious doctor-patient contact, as care plans and goal reviews were incorporated into daily work. Our experience was that a minimum of one hour doctor-patient time was required to explore issues and devise culturally appropriate goals. In most cases, disease specific goal setting was against the background of social problems that were perceived to be more important.

**Aboriginal patients**

The aims of CDSM programs were to educate patients in ways to improve their self-efficacy. This education differed from traditional teaching by providing the ability to solve problems independently, not just receive information. In doing this, the relationship between provider and patient was changed from pupil-teacher to a more equal one [259]. Nearly all patients felt that the AHWs listened to what the patients told them, assisted them in solving issues, referred them to appropriate groups or allied health professionals, and assisted in improving their understanding of diabetes.

Further positive comments were made concerning the importance patients placed on being seen in their own home where they could relax when talking about health issues. Patient reflections on better emotional well being, improved management and ability to talk with their GP were likely to equate with better satisfaction, but need to be explored further.

Several patients and administrators commented on financial incentives for patients (such as free medication or housing subsidies) that might increase the attractiveness of CDSM programs to disadvantaged communities. Similar incentives have been successful overseas [261] compared with provider incentives that have been inconclusive [106, 107].
4.11.2 Individual trial tools

The modified SF-12 Quality of life assessment, and the modified Work and Social Adjustment Scale (WSAS) were again unhelpful in the context of CDSM planning and diabetes care. Other tools to assess the impact of interventions on the areas perceived by Aboriginal people to be the most important barriers to diabetes care must be developed [262].

Some modifications were made by the AHWs themselves to the SF12 after the trial, and are presented in appendix 7 as the SF11, however it remains to be tested further. The SF12 did provide useful clues about social functioning that was not otherwise readily evident from the other forms by identifying discrepancies between care and stated need. Only the AHWs were able to distinguish genuine responses from clients providing the answers they thought the AHW wanted. Lastly, the less transparent SF12 may actually have provided much needed clues to overall personal distress.

The Diabetes Assessment was the most helpful and the easiest form to use. It also represented one end point of improved self-efficacy. Patients felt comfortable completing this and improvements were easy to demonstrate. It is likely that the non-confrontational nature of the contents lead to a better relationship with the AHWs, increased confidence in exploring issues and pursuing treatment. The diabetes assessment is part of current CDSM and diabetes programs.

Goal setting was met with a mixed response by the health workers as it was felt that the use of this tool would reveal patient problems that they were not equipped to manage or were simply too complex to be resolved. Levels of disclosure varied between clients and consequently the quality of problems and goals varied considerably. It was clear that some patients did not find this approach useful or motivational whereas others did. The AHWs were able to identify those that did not benefit from goal setting largely on social functioning rather than any medical grounds.

Negative orientation to problems, avoidant behaviour and a negative transfer of past learning has been associated with poor glycaemic control and ineffective problem solving [144]. The AHWs were able to identify negative social functioning (that was not measurable
in the trial tools) that prevented successful goal setting. These were historical negative behaviour patterns but were almost certainly linked to social and family problems. The PAR study identified fear as a primary barrier and this is likely to be related to fear of physical symptoms, not feeling normal and loss of control [179].

In contrast many of the patients were able to learn the goal setting process. The AHWs felt that these people could deal effectively with problems associated with their illness as well as identify issues that could not be resolved. Despite initial misgivings by the AHWs, problem rating improved over time and the goal achievement improved also improved. As the AHWs developed confidence in using this tool and as the patient relationships evolved, better outcomes were recorded.

Goal setting within the CDSM program was acceptable to both patients and AHWs. It did not appear to be any more effective than goal setting alone or in combination with care plans. The main problems remain recurring, socially based and largely unresolved. The fear of complications from diabetes, associated with reduced longevity, was overtaken by more immediate daily crises. The fact that diabetes often produces no easily discernible symptoms reinforced this line of thinking.

4.11.3 Other project successes

The successes of this project in many ways mirror the successes of the Aboriginal and Torres Strait Islander Coordinated Care Trials as documented in their National Evaluation Summary [2]. Access to many services in rural areas is often difficult and in many cases on Eyre Peninsula, nonexistent. Enhanced access to appropriate services was a central theme in those trials and never adequately solved. The training and skills learnt in this program greatly enhanced the ability of AHWs and the Aboriginal Health services to provide onsite management in a culturally appropriate context.

The ability of individual Aboriginal Health Services to retain the services of AHWs will increase as they gain confidence in their own clinical skills and in turn find their work less stressful. This is a self-perpetuating cycle where successful teams generate their own
successors. This should not be confused with the already acknowledged fact that Aboriginal workforces are significantly understaffed and this was reaffirmed in this trial.

Apart from the organisational and clinical achievements that this trial brought to both participating Aboriginal health services, a number of other themes emerged. Firstly care planning and chronic disease management were perceived to be part of core business. This was a significant ideological shift away from acute care into public health strategy planning. Both health services now have information technology to support this and have dedicated resources to train AHWs to provide tangible benefits to their communities.

Secondly, the incorporation of self management skills into day to day assessments not only empowered the AHWs and their organisation, it enhanced the goal of determining health needs by Aboriginal people themselves.
CHAPTER FIVE

Discussion: Goal setting in rural diabetes populations

Introduction

Goal setting is a method for identifying barriers to care using the patient's perspective; some of these may not be immediately apparent to the treating practitioner. Systematic care can be offered to patients with diabetes and adherence to it can provide considerable benefits in terms of clinical outcomes [263]. Patients may choose not to follow this path for many reasons including fear of failure. There may be more important psycho-social issues to deal with, or it may be that the services required to provide ideal care are just not available. Identifying barriers is important so that we can address patient needs appropriately, and balance them against our own clinical requirements. Ultimately they must perform the care as part of their daily lives.

This work has concentrated on goal setting in rural settings, in three consecutive studies. The first sought the usefulness of goal setting in people with diabetes. The second tried to integrate it into general practice diabetes care on a larger scale. Lastly the model was modified in an Aboriginal setting by using Aboriginal Health Workers rather than GPs as goal setting coaches.

5 Summary of trial outcomes

5.1 Trial 1

Goal setting was performed by a GP and a diabetes educator, regardless of whether services were available to address problems that were raised. There was a small reduction in HbA1c in both groups over 2 years of 0.3%. There were also small improvements in time
spent exercising and disability rating. There was no significant improvement in BMI, blood pressure, lipids, SF36 measurements or ATT39 (adjustment to diabetes). Patients were able to learn the goal setting process easily and goal achievement was 66-85%. Many goals related to medical issues and were based on diet and exercise changes that were achievable. Goal rating improved for all categories of goal (medical, behavioural, social, diet, educational). Overall however, the randomised trial demonstrated that goal setting added no additional benefit to systematic diabetes care. The Steno 2 study [263] (a multifactorial intervention trial) that included behaviour modification, had very similar outcomes.

5.2 Trial 2
The HealthPlus Coordinated Care Trial sought to test the financial viability of case management that included goal setting. It was anticipated that patients would embrace more self-directed care, identify any barriers to high quality diabetes care, and ultimately become good self-managers. Nurses and GPs performed goal setting as part of case management and goal achievement rates were 60%. Patients were able to learn the process easily and identify barriers and generate achievable solutions. Many of the goals again related to diet and exercise. Goal setting required considerable time and was performed mainly by nurses. GPs concentrated on the medical aspects of case management. Many of the services required to address social and psychological problems as identified, were not realised during the trial. The importance of health system organisation as a barrier was highlighted in this trial. Patients and carers commented favourably on the case management approach, however in all the CCTs including the Eyre diabetes trial, the cost of case management was not sustainable. The case management model continues currently as care planning and includes goal setting performed by GPs.

5.3 Trials 3 & 4
In Aboriginal people with diabetes, narratives are an important part of health and community interactions. Nurses and AHWs performed goal setting in both trials. The process required twice as much time, but was well accepted by Aboriginal people as a form of narrative. Goal achievement was 62% however patient satisfaction was lower
because of an inability to address many social determinants of poor health. The case management model (trial 3) was not considered financially viable in the CCT evaluation. The CDSM program (trial 4) used AHWs principally to perform goal setting in a culturally acceptable model. The system changes that preceded this trial allowed the model to be incorporated into ongoing diabetes management programs. Goal setting overall was able to identify many barriers to diabetes care, and was used successfully to improve self-management around dietary and exercise based problems. HbA1c improved 0.65%, blood pressure remained close to target levels (mean 136/84), disability ratings and SF36 measures remained unchanged over 12 months during trial 4. Further progress requires social and health organisation changes to occur that will address many other identified barriers satisfactorily.

5.4 Goal setting outcomes and trial hypotheses

The first hypothesis stated that: Goal setting when used by patients with diabetes type 2 in a rural setting will result in improved clinical outcomes and improved social/ emotional outcomes. It sought to clarify whether goal setting on its own improved both clinical and quality of life outcomes in a rural setting. For people with type 2 diabetes, HbA1c improved in both the RCT (trial 1) and the Aboriginal CDSM program (trial 4). The RCT however confirmed that this was not a direct effect of goal setting and therefore not causal. Regular systematic care was more likely to be the contributing factor to the HbA1c improvement, as this was present in both control and intervention groups. The HbA1c change may have even constituted a 'Hawthorne effect' [8]. This disputed theory states that involvement in a study on its own is associated with improvements. Social and emotional improvements were lacking in all trials as measured by SF36 and WSAS scales. The first hypothesis was therefore not supported by any of the trial outcomes.

The lack of change was disappointing as many patients enjoyed this approach to complex problems. It was impractical to conduct the trials for longer however it is tempting to speculate that there may have been a delay in clinical improvements as behaviour and self-management changes occurred. In many cases this may take years. The goal setting process itself was well tested and refined throughout all of the trials to the satisfaction of those performing goal setting. It is unlikely that any changes to the process could be made.
without compromising its effectiveness as an open-ended tool. In contrast, a more selective approach to using goal setting, targeting only patients who were able to identify problems and use problem solving and goal setting, may have produced different outcomes. Lastly, goal setting may indeed be ineffective and represent a more complex form of counselling.

The second hypothesis stated that: Goal setting can be successfully performed in rural Australian General Practice as part of case management of diabetes. It sought to confirm that goal setting could be successfully performed in General Practice by being incorporated into case management of diabetes. Goal setting was successfully performed by GPs (trial 1), nurses (trials 1, 2 & 3) and AHWs (trial 4), alone and in combination. The considerable time needed to do this however saw a shift in goal setting tasks from GP to nurse or AHW. Unless GPs can find additional time, goal setting is likely to be better performed in general practice by nurses working in collaboration with GPs and patients. This new arrangement may be necessary to allow the case management model to be applied to other chronic conditions such as asthma, heart disease, arthritis and mental health. Many of the organisational aspects of chronic care such recall and review of results, blood pressure checks and foot assessment may be better delegated to these nurses.

Goal setting identified many barriers to diabetes care. Patients readily generated solutions to medical problems, but were frustrated by service delivery problems. This ultimately raises the problem of where services should be based, and was not addressed in any of the trials. A single source of care may make case management easier. It was apparent from all the trials that for diabetes case management to be successful, both the medical and service organisation arrangements must be effective. Goal setting and overcoming barriers is dependent upon patient successes, and in turn dependent upon the organisational arrangements.

The changes required to support goal setting and case management were significant and required reform in both general practice and health service delivery organisation. The costs in achieving this were not covered by savings in other areas of care (trial 2 & 3). This detracts from the successes of the case management model, and ignores the fact that a new area of health care (chronic illness management) will need some infrastructure.
funding. The current fee for service arrangements for illness care may not be best applied to chronic care, or indeed health promotion and wellness. A fixed financial model (salaried clinical nurses in general practice) would allow successful application of goal setting in case management, and fulfil government desires to contain health costs.

**Current context of thesis diabetes trials**

Although much progress has been made on the biochemical basis of diabetes, translating this into practice has not been straightforward [265, 266]. The opportunity to integrate a behavioural tool into ongoing case management is important as much of diabetes care remains self-managed. Its application in a rural diabetic community was unique. Overcoming many of the barriers to good diabetes care involves motivating patients to choose healthy lifestyle patterns and avoid less healthy ones (that are often supported by powerful media coverage [267]). Smoking, poor diet and inactivity are now the three leading causes of death in the United States [268]. Obesity and inactivity contribute at least 25% each to the increase in insulin resistance seen in most type 2 diabetics [269]. Both are improved by behaviour change (weight loss, diet and exercise) that is well understood by patients and physicians.

Behavioural outcomes are however influenced by psychosocial and economic factors [270]. Diabetes in common with many chronic diseases has impacts on patients, their carers and family. The social impact of diabetes [271] and the impact of low socio-economic status on diabetes are also known [3], yet integrating them to health policy at government planning level seems as far away as ever. Different funding streams with vastly different budgets apply to health and housing. Similarly the political and funding arrangements within health, separate diabetes from other chronic diseases, despite almost identical themes [272-274].

In South Australia a recent government review, the Generational Health Review (GHR) [201], concluded that decision making around health was neither transparent nor was the community involved. It recommended significant system changes to address this. Consumer councils [275] are now to assist policy planning and delivery, in consultation with regional health authorities that currently combine funding restrictions with clinical need.

This comes 5 years after the conclusion of the HealthPlus CCTs that sought better understanding and integration of consumer and provider demands. Although the CCTs
were based on financial models, in South Australia there was some integration at a
government level to address social determinants of health, with the joining of health and
housing portfolios under one department. It is likely that these changes would not have
occurred without the HealthPlus experience.

The national strategies that fund chronic disease intervention each have their own individual
political and funding support. The funding model around chronic disease management is
evolving as the Enhanced Primary Care package, however for GPs to continue to use it,
they will need it to be more than just a way of funding their practices. There is some
urgency now about how to make Care Plans (including goal setting) and the other items
clinically relevant, either within software programs or practice structures or both [62, 276].

5.5 Study design

These trials have sought to clarify the place of goal setting in diabetes case management,
using both randomised and observational trials. Both trial designs offered advantages and
disadvantages in outcome analysis [277-279]. Design issues are summarised in table 27.
The evaluation of health service interventions and their desired outcomes is complex [280]
because of the problems in developing, identifying, documenting and reproducing the
interventions. Single interventions in health organisations will rarely occur on their own, and
methodologies assessing dynamic change around single interventions rarer [281]. These
studies sought to improve the quality of diabetes care through a combination of clinical
best practice, behavioural change and health system reform. The evaluation is based on
quantitative data, however a small amount of qualitative data has been used.

Table 27 Comparison of design issues in thesis trials

<table>
<thead>
<tr>
<th>Issue for trial</th>
<th>RCT</th>
<th>CCT</th>
<th>Aboriginal</th>
</tr>
</thead>
<tbody>
<tr>
<td>Trial population</td>
<td>Contamination</td>
<td>Not well matched</td>
<td>No controls</td>
</tr>
<tr>
<td>Sustainable</td>
<td>No</td>
<td>Additional funding required</td>
<td>Yes with current MBS funding</td>
</tr>
<tr>
<td>Feasible</td>
<td>No</td>
<td>Yes with generic model</td>
<td>Yes with AHWs</td>
</tr>
<tr>
<td>Relevant</td>
<td>Yes</td>
<td>Yes</td>
<td>Yes</td>
</tr>
<tr>
<td>Goal setting standardised</td>
<td>Yes</td>
<td>Yes</td>
<td>Yes</td>
</tr>
<tr>
<td>Outcomes blinded?</td>
<td>No</td>
<td>No</td>
<td>No</td>
</tr>
</tbody>
</table>
From a general practice perspective the process of goal setting needed to be relevant, feasible and sustainable. None of the trial populations were ideal yet the trial outcomes were very similar across all trials. The relatively isolated population in the RCT offered the best opportunity to test goal setting yet contamination [282] was also possible in such a small community. The integration of goal setting into general practice was most likely to occur in the context of case management, and tested as such in the Eyre Diabetes CCT. In its modified form using nurses to perform the goal setting, it was feasible but not financially viable without additional funding. This included infrastructure funding. In contrast the financial model within the Aboriginal health services of fixed costs (salaried AHWs and GPs) allowed the AHWs to redirect their efforts based on service need. The Enhanced Primary Care MBS incentives were used to increase the process sustainability by being reinvested into service delivery rather than directly to GPs.

Goal setting itself as a clinical process was easily standardised and applicable as a generic process, even in Aboriginal interactions. It was not possible however to blind participants to the intervention, particularly as there was a small potential study population.

5.6 Study interventions

The levels of intervention to support goal setting were multiple and are summarised in table 28, adapted from Bradley [283]. In this rural population, providing systematic diabetes care was based on a desire to improve the quality of care provided to patients, improve their quality of life, and reduce complications that cause considerable morbidity. Systematic care required adequate systems of identification, recruitment and recall in general practice that were not available in 1997 when these trials started. This required the introduction of computers into general practices, training and the development of software to perform this. This was a large and difficult task that continues to evolve.
Behaviour change is often required to maintain and improve the many aspects of diabetes self-care. Goal setting in these trials sought to identify barriers and potential solutions. It was successfully applied in all trials, but sustainable in only the CDSM trial (trial 4) under current funding arrangements. Not all patients were good self-managers, even with assistance, and nearly all will need ongoing review. These trials successfully tested nurses and AHWs as goal setting assistants, and provided a potentially sustainable model with better funding.
Service provision became a key issue as it was identified as a barrier. There were many gaps in services, with lack of communication a recurring problem. The hospital based service providers performed need analyses, and given the overwhelming size of the problem, chose group approaches to care, with one to one care being restricted to higher risk cases. The key outcome was a formalised approach to communication and standardised care processes for all diabetics.

Coordination of care and who was best placed to do it underpinned much of this work. I have taken the position that GPs are best placed because of their broad medical expertise, their understanding of relationships and their knowledge of and access to many essential services. Nurses and AHWs were tested as assistants to the coordination process, however no other intervention was tested in these trials. The Commonwealth government continue to share this view and fund it through the MBS as the Enhanced Primary Care initiatives. That some work needs to be delegated reflects the size rather than the complexity of the chronic illness portfolio.

Unwritten in the development of systematic care delivery was the need to develop guidelines for diabetes care in South Australia. For the purpose of these trials they needed to be in an electronic format. I ultimately was involved in the development of a pathway for diabetes care in SA, although the development of a case management approach requires multiple guidelines that GPs can use. This is a challenge to computer software developers who must provide evidence based, clinical support to GPs especially if they share case management with nurses.

The system interventions required to support goal setting were the same as those required to support any chronic disease management program. These were largely dependent on strategic funding policy. The political process also defined the speed of change, which was incremental in these trials. At a local level the ability of the service delivery system to respond to change will be determined by the quality and vision of local leaders. In all these trials we were lucky to have the cooperation of the regional health services, who themselves
had to change funding allocations. By increasingly involving patients in management and planning, they created an environment receptive to change and responsive to patient needs.

All these varying levels of intervention needed to occur for goal setting to be effective. The absence of supporting processes negated any benefits derived from defining problems and setting goals. It was pointless from a patient perspective to raise issues for which there were no solutions.

For goal setting as the principal intervention the trial outcomes were similar across all four trials, for both populations. The qualitative feedback concerning the CCT is discussed in chapter 4, however it primarily covered the patient and provider experiences. This was derived from patient interviews, provider interviews and focus groups of trial progress. The experiences collectively confirmed the trial experiences.

5.6.1 Goal setting in Non-Aboriginal people with diabetes

Care planning currently requires goal setting although many GPs choose to interpret this as their own goals. This is not unreasonable in view of the study by Olivarius [154], where GP clinical goals (guidelines) were effective in diabetes management. It does not fall within the COAG and Generational Health Review (GHR) aims of improving patient involvement in decision-making and care. If the GHR changes occur in South Australia over the next 2 years, clinicians are likely to feel as frustrated with outside interference as they are with their patients’ inability to implement apparently simple behaviour change. The financial and political imperatives around system sustainability are however likely to favour system change and continuing patient input [284]. They are also likely to result in more community based care by all providers, not just GPs, and less hospital funded work.

Goal setting that is patient centred, is successful in diabetics but it is also time consuming and therefore expensive if done by GPs. Not only does it take time to perform, there is a learning phase and confidence building phase that impacts on the future success of subsequent, and usually more complicated goal setting. The RCT confirmed that goal
setting alone did not improve diabetes outcomes beyond those provided by systematic care. Whether more frequent contact beyond twice yearly would have improved this is unknown.

The goal setting process however was easy to learn, and disease orientated goals were easy to achieve. They increased patient involvement in clinical care but redirected the focus of clinical care away from medical priorities that only made up 24% of patient goals. The remaining 76% of goals did not necessarily need medical input, and were addressed by a diabetes educator or other allied health worker.

The difficult question is whether GPs are best placed to provide goal setting, or whether this is better (or at least less expensive) in the hands of others. In rural communities this is likely to be allied health workers, mainly nurses. The central role of GPs and their need to coordinate a large range of clinical and psychological issues has been acknowledged by the DHAC [1]. Patients continue to perceive them as important sources of reliable information and someone they can trust. If GPs chose not to do goal setting and sensitive information lost to other professionals, would the relationship remain the same? This already occurs with counselling and referred services, and most patients remain comfortable with this. The key theme in diabetes care is team approaches and continuity [285, 286]. The danger if this does not occur is fragmentation of services and care [287].

The SA HealthPlus trials used goal setting in several trial populations. Goal setting was effective in this diabetes population, however it was the nurses acting as service coordinators who were the principal goal setting coaches. Although the GPs also set goals, they spent most of their time in medical roles reviewing the care plan, and goals if they had time. The service coordinators had more time to follow the goal setting process through in detail, interacting formally and informally with the GPs, maintaining continuity and a team approach. This was not the case in the city trials where GPs shared different relationships with the service coordinators [1, 31]. Not surprisingly the perceptions of patients and coordinators was more positive in the rural trial.
Goal setting in the HealthPlus trial was less disease focused although it began in this way to generate patient confidence. The system changes provided by the trial enhanced the ability of goal setting to be successful, but fell short of ideal. Goal achievement was 60% and more problems that were family and psychologically based were addressed [31]. Patients remained comfortable with their dual interaction with doctor and service coordinator. The financial outcomes relating to costs within the MBS, PBS and hospital systems were positive but outweighed by the costs of coordination.

5.6.2 Goal setting in Aboriginal people with diabetes

The social and family aspects of health became much more obvious in the Aboriginal diabetes trial. It was impossible to sidestep the poor social and economic circumstances of these people in considering their health aspirations. The trial allowed some system changes to the health services environment, however it neglected the social support systems where most of the care occurred. The guiding principle throughout all the HealthPlus trials was not to explore problems unless solutions could be offered.

As a consequence the AHWs were trained, supported and guided through the learning curves of problem definition and goal setting. Their experiences were crucial in the trial outcomes, the health system outcomes and AHW involvement in the follow-up trials. The Aboriginal Health services entered a number of positive and new relationships with the Regional Health service, the local Division of General Practice and private service providers. Some of this work continued after the trial, some expanded to meet demand and some proved unworkable. The lessons were welcomed by the Aboriginal health services and increased their independence. The internal system changes became longer lasting.

Goal setting around disease problems on Eyre Peninsula was as successful in Aboriginal people with diabetes as it was in the non-Aboriginal diabetic population. The 60% achievement rate was remarkable given the gap in social circumstances between the two populations. Aboriginal people appeared more able to tolerate uncertainty and adapt to it. The yarning or exploration of problems, was a cultural way of dealing with this uncertainty, which bridged community expectations with potential solutions.
Over 50% of patients decided to use goal setting to explore their social and psychological problems. This number was far beyond expectations given that patients knew that no definite solutions were available for housing and family problems. In some cases small steps were made towards problem resolution, whilst in other cases the problem was deferred to a more tolerable state, and yet in others the problem was just better conceptualised. Both the open-ended nature of the process and the acknowledgement of each problem were important.

The care coordinators and the AHWs were both surprised by the number of patients willing to explore their social and family problems, despite their obvious initial reluctance. The training had emphasised the importance of step-wise progression through goal setting and positive reinforcement based on small successes. Insoluble problems were not part of this process. The service coordinators felt that acknowledgement of the family and social issues in itself had been a successful goal achievement; the inability to realistically solve the problems or impact on quality of life was a separate issue. The AHWs spoke more about the community desire to solve these fundamental issues and move on to the more important issues of land ownership, employment and autonomy. The goal setting process for them had become a reflection of community consciousness.

Little work has been done on collective decision-making, a process that is central to Aboriginal health, and how this affects health care outcomes. The AHWs may now be able to provide many useful insights into how this occurs, and perhaps offer solutions that will assist future planning.

The Aboriginal patients themselves remained more circumspect about goal setting. Their level of trust improved in the health services, in the services ability to understand their problems, and the services ability to define solutions. Most importantly, the AHW standing within the communities increased enormously. Their professional approach altered community perception of their role from helpers to clinicians, and provided a true primary care opportunity for future care.
Many feelings of worthlessness became apparent during problem definition stages. 'I am no good' was a common theme that reflected low personal and community levels of self-esteem. The economic and social barriers that perpetuate this mean that the community adopts a helpless position; this further impedes interventions such as goal setting. The coordinators and AHWs felt that the trial could address individual problems with self-esteem only over a prolonged period of time. Confidence in dealing with health related issues did not equate to confidence in dealing with a hostile outside world.

The relationships that subsequently evolved were based on trust that explored and moved away from feelings of worthlessness. In women this was often in groups whereas the men chose to hide their feelings of impotence. This only became apparent in working through conversion symptoms of alcohol misuse, domestic violence, depression or headache. The reduced role of men in the community made it doubly hard to overcome. In many cases the partners or carers were instrumental in resolving issues of low self-esteem.

It is worth noting that no Aboriginal patients left the trial through dissatisfaction. This is in part due to the commitment of the AHWs who sought to put the community diabetes issues in the public domain. The trial asked more questions than expected and delivered few long-term solutions. The subsequent wind down part of the trial (a separate 6 month period) to support the most vulnerable patients who had developed dependent relationships with the coordinators, was not supported. The AHWs were gradually withdrawn and patients returned to mainstream services while the trial was analysed and funding priorities determined.

The Port Lincoln community participated in the Participatory Action Research trial (appendix 1) and both communities in the CDSM trials. The non-medical priorities of diabetes care were apparent in the PAR trial, while goal setting was reintroduced in CDSM as part of core business. This required community discussion and acceptance in the context of limited budgets and community priorities.

**5.6.3 CDSM and Goal Setting**

The key question around goal setting was its applicability to general practice, and whether it could be incorporated into management by GPs alone. The trials confirmed that this was
not possible and that goal setting or problem solving fitted better into self-management strategies. The step to an increased ability to self-manage (self-efficacy), through better problem solving can be undertaken by a GP, nurse or AHW.

The term problem solving better describes the patient orientated outcome of goal setting, defining the skill required to improve self-efficacy. Care planning using coordinators proved too costly to implement despite its appeal. Patients were usually assessed on disease complexity and likely needs, however not all patients benefited from care plans. The service coordinators in reviewing the CCTs in 2000, felt that approximately 20% (<10% in Aboriginal trials) of patients were already good self-managers and virtually did their own care planning and set their own goals. They required only intermittent assistance. A further 20% were unable to benefit from any intervention as a result of internal or external problems. The other 60% were likely to benefit from case management; goal setting as part of problem solving and assessment remained central to this process.

Much of the impetus toward self-management seeks to convert this intermediate group to better, more independent self-managers. The work by Lorig and Wagner [240, 242, 288-298] has been mirrored by similar efforts in Australia, although the structural reform required to support such change has been minimal. Disease complexity alone does not
predict the ability to manage satisfactorily, although disease complexity governs the degree of service use both qualitatively and quantitatively [50]. Glasgow’s theory that beliefs about treatment effectiveness better predict self-management [159] were more in keeping with our findings, irrespective of barriers to care. Goal setting success appeared to be associated with greater confidence in treatment and adherence to treatment.

Engaging patients in goal setting and self-management may be better done by self-assessment. The CDSM trial used a number of self-assessment tools to explore this, including self-assessment of diabetes knowledge, its effects and associated problems. Efforts to integrate case management, goal setting and self-management strategies were based on these self-assessments [70, 253] developed by Battersby. By identifying deficiencies in knowledge, providers were better able to concentrate their efforts and resources. Diabetes knowledge improved 46% over the trial as a result of these strategies. The same social barriers remained during the trial as reflected in the quality of life measures, however the goal setting around problem areas was effective.

In identifying problems, patients also identified areas that they did not want to review. A number of patients returned to these areas later in the program once they had gained confidence in the system. This indirect method of choosing a course of action reinforced the importance of understanding what is said and not said in Aboriginal dialogues, and choosing courses of action that they are likely to follow successfully.

The self-assessment approach was more acceptable to Aboriginal people with diabetes and was felt to be less confronting for patients. High scores indicating knowledge deficiencies, and therefore areas of concern, became starting points for engagement and goal setting. As all the patients set goals the outcomes are probably skewed when compared to the general population, however over 50% of patients embraced self-management strategies compared with only 10% at the trial start. Low scores were revisited at subsequent meetings often resulting in new goals or problems. (Two years after the end of the CDSM trial the diabetes knowledge tool remains part of care planning and goal setting in our Aboriginal diabetes clinics.)
Patient perceptions of this approach were more positive than of the previous CCT. This is likely to reflect growing confidence and maturity within the health services, especially the Aboriginal Health Workers. It also reflects greater autonomy, better relationships and more patient centred communication. Together they emphasise the gradual nature of such change and the importance of structural change taking place with clinical reform.

5.6.4 **Goal setting in clinical practice**

Conceptually Simmons division of the barriers to care [158] also emphasizes the multidimensional nature diabetes care. Each must be dealt with satisfactorily from both patient and provider aspects. The relationships clinicians and patients share must be different to the models we learn (teacher-pupil), and the strategies are likely to be new to many practicing doctors who remain sceptical of patient based care.

The practice of team care is not familiar to many GPs, who are trained to formulate their own conclusions and diagnoses, treat and follow-up patients on their own, and use others largely for second opinions or assistance. A doctor’s age, sex, communication skills, beliefs and preferences will all effect their perceptions of team-based care. The changing roles of GPs may change this with different training programs emphasising community team approaches, more part-time GPs relying on sharing care either with each other or others, the advent of nurse practitioners and independent practitioners who may become funded by the MBS system. The government’s own incentives are also likely to favour group practices and teams based in general practice rather than hospitals.

Ninety five percent of diabetes care is patient centred and therefore many of the treatment strategies will require patient co-operation. Adherence will depend on the treatment regimen, patient provider relationships, social support and health beliefs; these include perceived severity and self-efficacy. Their satisfaction with treatment (and therefore participation) will depend on discrepancies in what they desire and believe they need, and what they get. Patient engagement requires an exploration of all these. Goal setting was one method of doing this.
Goal setting in this rural diabetes population has been able to define many of the barriers and problems to effective care, including those outside the influence of GPs and the health system. Educational issues (knowledge of diabetes/services) and internal physical issues (co-morbidities/side effects of treatment) were the most tangible problems to patients. External physical barriers (finance/access) particularly in the Aboriginal group, became understandable and potentially resolvable. The ability of GPs to influence such barriers is limited, as funding lies either with government agencies or Aboriginal community organisations. Frustration in having to ignore these identified issues leaves both patient and provider with a sense of impotence, despite their importance.

Many of the external psychological issues (psychosocial environment/inappropriate care/discrimination/ lack of support) were even less manageable through the medical system however they were regularly identified as important issues. This precipitated solutions within some systems, such as a program of regional cultural awareness for Aboriginal health service provision. Family problems on the other hand proved hard to resolve without individually solving the disturbed family dynamics.

The most difficult of all barriers were the internal psychological issues around self-efficacy, health beliefs and priorities. Although GPs receive good training in psychiatry, their psychological skills are learnt as they practice and depend on their interest and available time. Patients who repeatedly fail to live up to their own expectations and their doctors expectations, become equally adept at avoiding further embarrassment by minimising or denying their symptoms. Confidence in their own ability to control and treat diabetes is central to their long-term outcomes. Most GPs do not have the time or the training to tackle difficult or complex patients who do not wish to follow apparently logical advice because of psychological barriers.

The low number of psychologists in Australia (7567 in 2001 AIHW) means that either GPs need to learn the skills necessary to deal with chronic illness patients who have psychological barriers to their care, or that part of clinical care must be passed on to counsellors with some skill in treating them. This is a challenge to cornerstones of general practice.
This apparent increasing difficulty in dealing with problems beyond the scope of routine care, was not reflected in the approach most patients took to goal setting. Patients were able to learn the process of goal setting easily, and goal achievement was high however the process was time consuming and expensive. Although many goals were centred on achievable outcomes in the internal physical and educational fields, many goals were also set in other fields including internal psychological issues. The process of goal setting was as much an exercise in learning for the patients as it was for the service coordinators. As such they were only limited by their success and failures. The question of whether to improve the counselling and psychological skills of the service coordinators was negated during the CCT (for fear of overloading the coordinators) however it would have greatly increased the quality of treatment provided in the window of opportunity as patients explored sensitive issues.

Nurses (as service coordinators) were equally effective as GPs at defining problems, and although lacking some clinical skills, equally effective at setting goals. Patients were often more comfortable setting goals with nurses than GPs who lacked both time and interest. In the broader context of chronic illness care, practice nurses may well have a role not only in recall and review, but also service provision in aspects of psychological health. Such a combined approach would fulfill the requirements of continuity and team care.

In the Aboriginal community the Health Workers were better able to define problems and set goals by virtue of their place in the community. Their unique role enabled them to negotiate directly with patients alone; it was impossible for non-Aboriginal people to bridge the cultural, emotional, financial and political barriers without living as an Aboriginal person. Goals, problems, politics, were all explored by the AHWs and woven back into the daily struggle that is Aboriginal life.

The Aboriginal Health Workers have continued to evolve since the CCTs and currently provide much of the clinical work, problem solving, counselling, screening and treating day-to-day issues. Only the final treatment decisions are deferred to the GPs; in many cases
their acceptance is also depend on the AHWs acceptance. It is only a small step that separates the AHWs from nurse practitioners.

5.6.5 Goal setting in care plans

The decision to provide funding for care plans through the Enhanced Primary Care (EPC) MBS item numbers was made before the completion of the CCTs or their analysis. The theory behind the funding was not made public and was probably based on projected needs of an aging population. The structure of care plans was logical, comprehensive and easy to follow, unlike the conditions attached to fee payment.

The inclusion of goal setting was slightly more surprising. Few GPs used goal setting regularly or had any significant experience. Patient goals were made a requirement of the care plan and its payment in November 1999 [205, 247, 248, 299].

The original explanatory notes specified that in preparation of a care plan, there should be written plans including 'management goals with which the patient agrees'. Goal setting had not been a significant part of the CCTs outside of the HealthPlus trials. The GP experience has already been outlined but was not uniformly satisfactory. The intention of including goal setting was patient engagement in chronic disease management and planning. An analysis of care planning in September 2002 by DHAC was positive. Patients liked the time spent with their GP, the improved relationship, the comprehensive approach and the increased sense of control. Families appreciated the better documentation as did many carers [62]. GPs were also positive and, although critical of the amount of paperwork, felt they addressed a broader range of issues in care plans. They also referred to a greater range of services with better understanding of allied health service roles.

Unfortunately there was no mention of goal setting in this analysis. It is hard to draw any conclusions about the intentions of the government by including goal setting in care plans. The results of my research do not support routine use of goal setting in diabetes care by GPs because of the lack of time available. Although GPs are likely to be able to learn and apply the principles around goal setting that is patient centred, the demands of clinical care will limit the necessary time and concentration required for it to be effective. They are much
more likely to apply GP directed goals that are finite and within their influence as treatment options. GPs don’t have to negotiate many of these, and in doing so, retain their control over the relationship.

In making this conclusion, it is evident that there are significant lost opportunities. Not least is the possibility to explore issues that may remain otherwise closed to current medical encounters. Many of these are psychological barriers to care. The chance for patients to explore their own problems and improve their problem solving skills is lost, retaining system dependencies. The improvements in doctor-patient relationship that accompany this exploration, that improve confidence in treatment and outcomes, are passed up. Finally GPs miss the chance to use an open-ended tool to create new pathways in management that may not be otherwise evident in the current diabetes paradigm.

Any such open-ended exploration would only be limited by the patients’ ability to deal with problems. In 2000 a trial based on Participatory Action Research (PAR) was undertaken involving elders in the Port Lincoln community. It is described in appendix 1 and generated much interest in the Port Lincoln Aboriginal Health Service. Some of the Aboriginal elder’s comments are noteworthy:

A lot of our people died in their twenties and thirties and even their children have died young. At that time we didn’t know about diabetes, this was very new to us. A lot of our people have died from this and we didn’t know what it was. My grandmother died in a diabetic coma and I didn’t know. We need more education for our young people.

It is very hard, because I just can’t understand what the diabetes is doing to him. It affects me because I don’t know what to do and I think I must be doing something wrong, is it my cooking... I find it very hard to know what has happened to him. I don’t know what he is going through because he won’t tell me.

The PAR trial resulted in the restructuring of funding so that community needs were met, community support systems improved and education programs started with school children. It additionally provided a focus group to discuss and work through many personal
issues that arose during the trial. The open-ended nature of this small trial shared much in common with goal setting and largely bypassed the medical priorities.

**Service coordinator roles**

The outcomes of the SA HealthPlus diabetes trial defined a new role for clinical nurses that had not been explored on a similar scale before. Clinical and management tasks were organised by the service coordinators in conjunction with GPs. Goal setting was also successfully performed by these nurses, both alone and in partnership with GPs. This is different to specialist diabetes nurses working as case managers alone [300] or out of hospitals [301]. Many issues not discussed with GPs were discussed with the nurses and vice versa. The combined experience was the most informative one. The goal setting process was also a generic one that was applicable to a broad range of chronic diseases other than just diabetes. The ease with which it was learnt makes it easily transferable and adaptable to a variety of clinical situations.

These clinical nurses also adapted quickly to the changing research environment. The skills required to explore and advise sensitively, to critically analyse and review work, to work with uncertainty and the ability to adapt to it, were examples of a new and changing role. Nurses are now in a position to engage with GPs in best management practices of a range of chronic diseases. The run in phase of the CCTs was marked by much debate over who would make good coordinators, and many managers and professionals with limited health backgrounds sought the position. Ultimately the nurses in the Eyre trials proved to be experienced enough to confidently manage common medical problems, and not be distracted by them. They could then progress through to more complex physical and psychological problems that arose in the goal setting process. Similarly they were generally experienced in management issues and well placed to negotiate management barriers, including those within general practice surgeries.

The model that evolved through these trials and continues currently reflects these findings and has been confirmed elsewhere [67, 84]. In general practice, nurses now provide some services previously performed by other allied health staff (podiatry). They coordinate care
plans and follow-up, and they assist in problem and goal setting. The funding of practice nurses, who have always been part of rural general practice, now greatly facilitates this process. They play an active role in the continual review of the practical application of care plans so that the plans remain meaningful to patients and GPs alike. They are also more likely to remain patient centred with nurse involvement.

In the Aboriginal health service the model is even more advanced. Registration, recall and review is performed via electronic databases, common patient records and team treatment are the accepted structure. Goal setting is part of all care plans and is offered to all eligible patients. Aboriginal health workers perform this role completely and generally only need medical review as part of the HIC requirements. Despite working with Aboriginal people for over 15 years and being well accepted by the community, the best goal setting process is now done by the AHWs. These goals are a mixture of doctor and patient orientated goals, however they are mainly patient centred.

5.7 Limitations

Large numbers of patients were recruited for these studies and most of the patients with diabetes who lived locally were asked to be involved. It is likely that they are representative of many rural communities demographically. Over the 5 years that these trials ran, most were exposed to goal setting and shared their experiences with each other. Although only one trial was randomised, it is unlikely that further trials could have been satisfactorily randomised using goal setting as many patients continued to use goal setting after the trials. This is a problem generally for rural based research involving small numbers of patients in small communities.

The initial RCT was almost exclusively performed by two researchers, a diabetes educator and myself. Our goal setting was exhaustive and detailed. The lack of difference in HbA1c between the two groups was very disappointing, despite the overall trend of both groups. Contamination was possible as patients shared the same providers. More frequent contact than 6 monthly with patients, as occurred in the CCTs was not practically possible but may
have improved group differences. The RCT may have also been an example of the Hawthorne effect [264], with an effect being noticed as a result of increased interest in the study groups.

The Coordinated Care Trials were analysed in detail and the findings published [1, 31]. The criticisms of them were well founded in most cases. They sought to cover too many parameters and were not randomised properly. The study populations were too varied to usefully compare, lacked sufficient preparation time and support, and the trials failed to define their true aims until completion. The SA HealthPlus trial suffered significant internal interference for political reasons, which in turn affected funding during the trial [30]. Many of the system changes were stopped and structural support withdrawn. This fortunately had least effect on the Eyre trials, however some promised service outcomes could not be met and confidence was lost in the process.

The Aboriginal trials were extensions of the preceding ones. It is very hard to randomise Aboriginal patients who are generally suspicious of non-Aboriginal researchers, and is likely that most work in their communities will be conducted similarly. We have successfully applied for NHMRC funding to formalise research approaches in SA Aboriginal populations. There were no incentives for patients to be involved in the trials, however many patients who would have benefited from goal setting and care plans did not receive them. Participants were therefore motivated and did not represent a large number of high-risk diabetics in the community who did nothing about their diabetes.

5.8 Future work

Research in this field has largely been a continuing process. Several processes have not been reported in this work, but include development of electronic care plans, goal setting guides, state and national clinical guidelines, and goal setting in Aboriginal mental health patients. We have been and remain involved in several Aboriginal CDSM trials, locally and regionally. One Lorig based trial is also ongoing. System changes regionally to management and funding are continuing to allow further long-term use of care planning.
Several problems around goal setting remain unanswered:

- How do clinicians easily identify patients who will benefit from goal setting, and those who will not, so that valuable resources are not wasted? This key issue needs to be resolved. Medical complexity was not a predictor of engagement, nor was historical service use. Limited social support, unstable health, a low confidence or ability to negotiate health needs, and a desire to avoid residential care were identified in the CCT. It is likely that a form of self-assessment will identify those who will self-manage best, however patient groups such as the expert patient program [78, 302, 303] offer new opportunities.

- Do medical or non-medical providers perform goal setting better? Case managers who have fewer preconceptions may provide new insights into care pathways. They may be better at engaging patients. Nurse managers may also be less expensive [304].

- Do web based support systems assist goal setting and care planning? Increasingly patients access information via the internet, and support programs are being tested [305-310]. There is a potential link between self-assessment, goal setting and care plans that could allow better identification of patients who can self-manage and those who need help.

- What are the right incentives to encourage people to become more involved in self managing their chronic illness [90, 261, 311]; are they financial? It is possible to build incentives into any part of clinical care, however they could equally apply to social determinants of health such as housing, transport or food prices.

- Should penalties be included within goal setting? Goal setting theory is around positive changes and improving self-confidence, and negative goals are unlikely to be helpful. Some high achieving patients may respond to difficult problems with limited penalties, however this has not been tested [312].

- Can goal setting be harmful? Bandura’s work suggests that this is not likely [313, 314], although goal setting may have impacts on subsequent performance [315]. Our work did not support the concept that goal setting has a negative impact on clinical care or self-efficacy.
In the Aboriginal communities much work needs to be done around community decision-making as it relates to community and individual health priorities. It is very important in Aboriginal health care. (This does not have easily identifiable parallels in the non-Aboriginal community, however successful management of the AIDS epidemic required effective engagement of the homosexual community [316].) Additional research is required in:

- Story telling or yarning as part of patient care. This is an important part of daily life that allows Aboriginal people to voice their problems and negotiate solutions in the family and community contexts. Little work has been published on narratives around diabetes in Aboriginal populations, despite its obvious importance. It may represent a complex and open-ended form of goal setting.

- Group CDSM strategies as part of diabetes care and other chronic illnesses, may be applicable to non-Aboriginal populations [258] but not necessarily Aboriginal ones. This is currently being researched on Eyre Peninsula but if group work were successful, this would fit well with many other ways of socially interacting in Aboriginal communities. Such groups could be patient or expert led.

- Battersby’s work on self assessment offers new methods of measuring improved self-efficacy in Aboriginal communities [253]. This may also be applicable to non-Aboriginal populations and associated CDSM programs.
5.9 Key lessons

1. Systematic medical care may not be enough for all diabetes patients, as many barriers exist that have either behavioural, social or psychological backgrounds. Goal setting was effective at identifying barriers and generating solutions to overcome them, principally for diet and exercise based problems. Achievement rates were high in the RCT and CCTs.

2. Goal setting was effectively performed within case management of diabetes however this required additional funding to continue. The cost of coordination in diabetes case management was $8.03 per patient per day on Eyre Peninsula. Such costs were not retrieved from savings in the acute care sector during the two-year CCT.

3. Nurses were able to perform goal setting effectively with GPs as part of diabetes case management. The goal setting process was easily learnt and transferable between Aboriginal and non-Aboriginal populations. As nurses had more time to spend on goal setting during the CCT, patient perceptions were positive about their ability to undertake this role.

4. Multiple system changes were required to support providers meet goals that were set by patients. These included recall systems, clinical pathways, alternative methods of delivering services and political leadership. The changes should ideally have preceded implementation of the case management program.

5. Aboriginal populations identified many social barriers to diabetes care that were not resolvable in the current medical environment. Goal setting was still effective in an Aboriginal diabetes CDSM program, defining achievable goals around diet and exercise change. This was successfully undertaken by AHWs. Goal setting (or problem solving) was effective in improving self-efficacy as measured by improved diabetes knowledge although this requires further investigation.
APPENDIX ONE

Participatory Action Research

Summary
Participatory Action Research was used to define community-orientated barriers and priorities to diabetes care in the Port Lincoln Aboriginal community. Fifteen Aboriginal elders with diabetes met on 11 occasions, and used their life narratives to define and describe the impact of diabetes on their lives, interpret its nature and context, and formulate solutions.

There was a dominant story of fear, resulting in withdrawal from community and family. Acceptance by family members was central to successful management. Aboriginal Heath Workers became proficient facilitators in this process and achieved much valuable community and personal empowerment.

The Elders group identified human nutrition, understanding diabetes, educating young people, and support for families and community as key priorities for funding of diabetes programs.

Introduction
The outcomes of the CCTs in Aboriginal communities [2] highlighted the need to involve Aboriginal people in the planning and development of diabetes interventions at the earliest opportunity. The complex nature of problems within Aboriginal society and their relationship to health did not fit with current medical models and solutions. The apparent failure of government programs to address Aboriginal health issues [32] has lead to new opportunities to explore Aboriginal perspectives of disease and potential solutions.
In 1999 the Port Lincoln Aboriginal Health Service in conjunction with the Spencer Gulf Rural Health School, the Royal District Nursing Service (RDNS) Research Unit and the Eyre Peninsula Division of General Practice applied successfully to the National Health and Medical Research Council for funding to explore issues around diabetes in the Port Lincoln Aboriginal community. The trial used a technique called Participatory Action Research and was lead by Professor Tina Koch from the RDNS; I was involved as a chief investigator.

Diabetes prevalence in Port Lincoln in the Aboriginal community was found to be 19% following a screening program in 1999 of 500 people over 20 years age. A diabetic clinic had been running since 1994 within PLAHS however many social, family, economic and cultural barriers remained to achieving ideal care. Although most of the diabetics attending the clinic did so to receive medication and usual care, their Aboriginal perspectives of diabetes were not the same as their non-Aboriginal counterparts.

Health in Aboriginal communities is defined by the social, emotional and cultural well being of the community rather than its individuals. Community issues are more important than individual problems, and family problems take precedence over an individual’s problems. It was likely that community and family perspectives were also likely to shed light on successful individual solutions. This research project sought to explore some of these issues through a group of diabetics who were also elders within the community.

**Participatory Action Research (PAR)**

PAR can be defined as a process by which change and understanding can be pursued at the same time [317]. It is usually described as cyclic, with action and critical reflection taking place in turn. The reflection is used to review the previous action and plan the next one. It is commonly done by a group of people. Participatory action research also aims to demonstrate a culturally sensitive way to working with people and seeks to change the social and personal dynamics of the research situation.

The essence of participatory action work is the process—the way things are done—rather than the result achieved. A facilitator lets participants talk and listen, encourages a diversity
of perspectives and encourages participants to develop the process together. The key is to enable people to develop their own analysis of their issues.

**Research Method**

Following several community meetings, a group of 15 diabetics was identified who were also community elders. They undertook to be involved in the project and were assisted by two Aboriginal Health Workers. A project manager was primarily responsible for managing the role of facilitation in the project. She worked with the Aboriginal Health Workers to mentor them in the enhancement of their skills as group facilitators. As the participant sessions progressed the AHWs began co-facilitating the groups.

Facilitation of the group required managing the dynamics in the group. This included working with the principles of participatory action. These principles were discussed at the beginning of the first group with participants and were identified as the guidelines by which the group would operate. Common techniques used to facilitate sessions included:

- Using the participants own words to record and listen
- Seeking clarification and checking comments
- Responding through reflection. Not all of the group were able to describe their experiences and some gained understanding of them through group feedback
- Helping people to analyse their situation
- Enabling people to consider several courses of action
- Exploration of each suggested course of action
- Assistance in implementing an agreed plan and by helping to locate resources.

Using the skills of participatory action focused the responsibility for the project’s success on the people involved—the Elder participants.

The approach included fortnightly meetings with participants that modelled participatory action principles. Each meeting continually built on feedback from participants, involved discussion and analysis from the previous session that included exploration of suggested courses of action, joint decision-making and problem solving. The project manager and the
AHWs worked in partnership with the participants to assist them better manage diabetes as well as plan and implement identified courses of action.

The data analysis techniques previously tested by Koch were utilised in this project [318-321]. With participants’ permission, group sessions were audiotaped. An administrative assistant transcribed the notes and recording from each session the same day. The transcript was given to the project manager to initially identify and analyse the themes, issues and concerns from each session. The project manager discussed this initial summary with the AHWs the following day when the analysis was built upon and clarified. This process was included in the AHW’s Learning Guide each week and became an avenue for them to enhance their skills in the Look, Think, Act strategies of PAR. The project manager also liaised with other members of the research team regarding the unfolding discussion within the Elder’s group.

This analysis and suggested courses of action was taken back to the Elder participants the following session for further clarification, development and discussion. Each participant group meeting commenced with discussion of the summary of themes, issues and concerns from the previous week. This continuous feedback validated the emerging themes and monitored resultant action.

The dominant story is influenced by the beliefs that people have or have had about their lives. When the dominant story is viewed in the context of the entire narrative—the whole of a person’s experience—alternate stories appear that may define a person’s life other than by the dominant story. By reviewing the alternate stories, the facilitator can assist individuals to judge for themselves alternate and preferred ways of viewing their lives.

Before moving to a point where individuals can identify the alternate stories apparent in their lives, they often need to understand the dominant story that is influencing their actions. The origins of stories are historically constructed and shaped within their own communities, and how it relates to the world.

This style of approach linked well with the PAR process as they had similar guiding principles based in mutual respect and mutual sharing of knowledge and experience.
Working with the Elders soon revealed a dominant story of fear in their approach to and understanding of Type 2 Diabetes. As the group unfolded however, an alternate story of courage became apparent and it was this story that saw the Elders become pro-active in the outcomes of this project.

Outcomes
The Elders group produced a detailed account of Aboriginal families’ understandings of living with diabetes, and suggestions toward best practice diabetes management. This was called Look, Think, Act: Indigenous Stories about Living with Diabetes. Stories gathered from the Aboriginal participants generated a detailed description of their experience of living with diabetes. The Elders wanted their experiences to inform other members of their Port Lincoln community as well as other Aboriginal communities across the Eyre Peninsula. The result was a book of their stories prepared for dissemination and publication.

The Aboriginal Health Workers also benefited from the trial. They gained greater understanding of the needs of the people who were using the health service, as well as valuable experience involved in Aboriginal research. They also undertook an ongoing educational program, which was designed to use the principles of participatory action research for facilitating community groups.

Four key themes were identified by the Elders group as important components of future diabetes services. These were nutrition, understanding diabetes, education of young people, and support of family and community. Notably no medical issues were identified as a priority.

Nutritional and dietary information includes specific nutrition awareness and different ways of approaching diet, such as walking and cooking groups. This latter point includes the idea that cooking is OK for everyone. Other relevant issues were the cost of food and healthy eating that still tastes nice.

The relative good health of Aboriginal people in the past was perceived important in people’s understanding of diabetes, and how it affects communities now. An awareness
campaign of symptoms and its impact was suggested; this would help identify more diabetics. The awareness campaign should be designed to identify social and emotional impact as well as the physical impact.

The future of young Aboriginal people worried current elders greatly. Education of young school age children was seen as vital and funds needed to be set aside for this specific purpose. It was suggested that the AHWs visit schools with a person who has diabetes, and that families should be involved in the education programs.

Family support was noted to be minimal in the current system and the future funding should assist families in understanding what is happening to their loved ones, so that all the family can express their feelings, share the emotional support and acknowledge the impact of diabetes. Support networks (that include counselling services) were seen as natural methods of assisting families, with some diabetics becoming ambassadors within the community.

**Conclusion**

PAR was used as an innovative way of exploring Aboriginal perceptions of diabetes and the way it impacted on themselves and the community. It also allowed the Elders diabetes group to formulate future strategies that were based on the community’s own perceived priorities. AHWs were able to participate successfully in a research program and facilitate groups on their own, engendering feelings of empowerment for both the AHWs and the community. PAR was easy to learn and provided a good model for assessing the impact of other chronic illnesses in Aboriginal communities.
The key features of this approach are as follows:

**Problem Assessment**
- Problem assessment begins with a semi-structured pragmatic assessment of the patient’s problems as they themselves see them.
- The problem is formulated into a short sentence.
- In general this statement should be written in the patient’s own words or reflect their thoughts and should be linked to the patient’s diagnosis eg, diabetes.
- It should describe observable behaviours and the immediate impact and long-term consequences of the problem on the patient’s life.
- It is then rated on a 0-8 scale of severity by the patient and the assessor at assessment and then at planned intervals throughout the patient’s care.

**Goal Setting**
- The patient is then asked to formulate a goal, which they could work towards.
- The statement should describe a goal which when achieved or implemented would indicate that the problem had improved.
- The goal is described in measurable, observable terms.
- As for the problem, the goal should be rated on a 0-8 scale of progress towards achieving the goal rated by both the patient and the assessor at regular intervals throughout the trial.
Goal Attainment

Patients were encouraged to break their main medium term goal into smaller, incremental and achievable targets leading to small but rewarding successes. Patients are asked to attempt these targets daily or frequently. The diabetes worker is to act as coach and mentor offering encouragement, advice and support, assisting with suggestions and problem solving to achieve the tasks set by the patient. Much of the goal setting and attainment process was seen as motivational. A critical element of the process was repeated measurement of both the problem severity and progress towards achievement of the goal. Improvement in the ratings was rewarding and motivational in its own right especially as it was the patient’s own rating as well as that of the service coordinator. This process was empowering and led to improvement in self-esteem with a positive impact on other areas of the patient’s life including management of their medical condition.

A Problem Statement

Constant pain and discomfort leading to irritability and angry outbursts resulting in avoidance of friends, family and doctors.

Rating Scale

This problem interferes with my daily activities:

<table>
<thead>
<tr>
<th></th>
<th>0</th>
<th>1</th>
<th>2</th>
<th>3</th>
<th>4</th>
<th>5</th>
<th>6</th>
<th>7</th>
<th>8</th>
</tr>
</thead>
<tbody>
<tr>
<td>Does Not</td>
<td>Slight</td>
<td>Definite</td>
<td>Often</td>
<td>Severe</td>
<td></td>
<td></td>
<td></td>
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<td></td>
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</table>

Ratings

<table>
<thead>
<tr>
<th></th>
<th>Baseline</th>
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</tr>
</thead>
<tbody>
<tr>
<td>Date</td>
<td>7.5.99</td>
<td>10.6.99</td>
</tr>
<tr>
<td>Client</td>
<td>6</td>
<td>5</td>
</tr>
<tr>
<td>Assessor</td>
<td>6</td>
<td>4</td>
</tr>
</tbody>
</table>

Goal Statement

To use medication as prescribed to assist me to spend 2 hours 3 times per week socialising with my friends and family outside of home.
Rating Scale

My progress towards achieving this goal:

<table>
<thead>
<tr>
<th>Rating</th>
<th>Complete Success</th>
<th>75%</th>
<th>50%</th>
<th>25%</th>
<th>No Success</th>
</tr>
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</table>

Ratings

<table>
<thead>
<tr>
<th>Baseline</th>
<th>Date</th>
<th>Client</th>
<th>Assessor</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>7.5.99</td>
<td>7</td>
<td>6</td>
</tr>
<tr>
<td></td>
<td>10.6.99</td>
<td>5</td>
<td>5</td>
</tr>
</tbody>
</table>

Work and Social Adjustment Scale (WSAS)

This was recorded from the following form:

This problem (as per problem statement) interferes with my work/home/social leisure/private leisure/relationships on the following scale:

<table>
<thead>
<tr>
<th>Rating</th>
<th>No problem</th>
<th>Slightly</th>
<th>Marked</th>
<th>Definite</th>
<th>Extreme</th>
</tr>
</thead>
</table>

Results were recorded at each visit in tabular form.
### APPENDIX THREE

#### Demographics Eyre Diabetes Trial (Chapter 3)

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<thead>
<tr>
<th>Gender</th>
<th>Intervention</th>
<th>Control</th>
</tr>
</thead>
<tbody>
<tr>
<td>~ Female</td>
<td>141</td>
<td>57</td>
</tr>
<tr>
<td>~ Male</td>
<td>156</td>
<td>54</td>
</tr>
<tr>
<td>Total Clients</td>
<td>297</td>
<td>111</td>
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</table>

<table>
<thead>
<tr>
<th>Language Spoken</th>
<th>Intervention</th>
<th>Control</th>
</tr>
</thead>
<tbody>
<tr>
<td>~ English</td>
<td>287</td>
<td>111</td>
</tr>
<tr>
<td>~ NESB</td>
<td>10</td>
<td>0</td>
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<th>Age Group</th>
<th>Intervention</th>
<th>Control</th>
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<td>15 to 24</td>
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<td>0</td>
</tr>
<tr>
<td>25 to 34</td>
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<td>0</td>
</tr>
<tr>
<td>35 to 44</td>
<td>3</td>
<td>1</td>
</tr>
<tr>
<td>45 to 54</td>
<td>50</td>
<td>11</td>
</tr>
<tr>
<td>55 to 64</td>
<td>77</td>
<td>31</td>
</tr>
<tr>
<td>65 to 74</td>
<td>110</td>
<td>39</td>
</tr>
<tr>
<td>75 to 79</td>
<td>43</td>
<td>19</td>
</tr>
<tr>
<td>80+</td>
<td>14</td>
<td>10</td>
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<table>
<thead>
<tr>
<th>Marital Status</th>
<th>Intervention</th>
<th>Control</th>
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<tbody>
<tr>
<td>Divorce</td>
<td>15</td>
<td>6</td>
</tr>
<tr>
<td>Married (including de facto)</td>
<td>228</td>
<td>89</td>
</tr>
<tr>
<td>Never Married</td>
<td>22</td>
<td>6</td>
</tr>
<tr>
<td>Separated</td>
<td>6</td>
<td>0</td>
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<tr>
<td>Widowed</td>
<td>26</td>
<td>10</td>
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<table>
<thead>
<tr>
<th>Living Arrangements</th>
<th>Intervention</th>
<th>Control</th>
</tr>
</thead>
<tbody>
<tr>
<td>Hostel or Hostel Type Accommodation</td>
<td>3</td>
<td>1</td>
</tr>
<tr>
<td>House, unit, apartment or flat</td>
<td>287</td>
<td>110</td>
</tr>
<tr>
<td>Independent living unit as part of retirement village or similar</td>
<td>2</td>
<td>0</td>
</tr>
<tr>
<td>Missing / not stated / not recorded</td>
<td>1</td>
<td>0</td>
</tr>
<tr>
<td>Other accommodation</td>
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<td>0</td>
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<table>
<thead>
<tr>
<th>Employment Status</th>
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<th>Control</th>
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</thead>
<tbody>
<tr>
<td>Employed full-time</td>
<td>49</td>
<td>4</td>
</tr>
<tr>
<td>Employed in home duties</td>
<td>49</td>
<td>9</td>
</tr>
<tr>
<td>Employed part-time</td>
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<td>4</td>
</tr>
<tr>
<td>Missing / not stated / not recorded</td>
<td>0</td>
<td>1</td>
</tr>
<tr>
<td>Other</td>
<td>22</td>
<td>11</td>
</tr>
<tr>
<td>Retired</td>
<td>143</td>
<td>69</td>
</tr>
<tr>
<td>Student</td>
<td>3</td>
<td>1</td>
</tr>
<tr>
<td>Unemployed</td>
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<td>12</td>
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<table>
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<tr>
<th>Pensioner Status</th>
<th>Intervention</th>
<th>Control</th>
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<tbody>
<tr>
<td>Aged pension</td>
<td>134</td>
<td>47</td>
</tr>
<tr>
<td>Carer's pension</td>
<td>1</td>
<td>0</td>
</tr>
<tr>
<td>Disability support pension</td>
<td>27</td>
<td>19</td>
</tr>
<tr>
<td>Missing/ not stated / not recorded</td>
<td>1</td>
<td>0</td>
</tr>
<tr>
<td>No pension or benefits</td>
<td>95</td>
<td>22</td>
</tr>
<tr>
<td>Other</td>
<td>16</td>
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<td>Service pension</td>
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<td>12</td>
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<tr>
<td>Sickness allowance</td>
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<td>Sole parent pension</td>
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</tr>
<tr>
<td>Widow's pension</td>
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</table>

*Note: Percentages may not sum to 100 due to rounding.*
# The Diabetes Assessment Form

**Diabetes Assessment v2.**  
Date Completed ___ / ___ / ___  

**Diabetes Assessment v2.**  
Date Completed ___ / ___ / ___  

**Patient Name:** ___________________________ Date of Birth ___ / ___ / ___  

**ID Number** ___________________________

*Circle the answer next to each of the questions that most closely matches how you feel about Diabetes*

Are you taking medication for diabetes?  **YES / NO**
If not, do not answer Questions 5, 7, 8, 9, 23

## Knowledge

<table>
<thead>
<tr>
<th></th>
<th>YES</th>
<th>Not Sure</th>
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<td>1</td>
<td>0</td>
<td>1</td>
<td>2</td>
</tr>
<tr>
<td>2</td>
<td>0</td>
<td>1</td>
<td>2</td>
</tr>
<tr>
<td>3</td>
<td>0</td>
<td>1</td>
<td>2</td>
</tr>
<tr>
<td>4</td>
<td>0</td>
<td>1</td>
<td>2</td>
</tr>
<tr>
<td>5</td>
<td>0</td>
<td>1</td>
<td>2</td>
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</table>

## Treatment

<p>| | | | |</p>
<table>
<thead>
<tr>
<th></th>
<th></th>
<th></th>
<th></th>
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</thead>
<tbody>
<tr>
<td>0</td>
<td>1</td>
<td>2</td>
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</tr>
<tr>
<td>0</td>
<td>1</td>
<td>2</td>
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</tr>
<tr>
<td>0</td>
<td>1</td>
<td>2</td>
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</tbody>
</table>

## Sharing Care

<p>| | | | |</p>
<table>
<thead>
<tr>
<th></th>
<th></th>
<th></th>
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</thead>
<tbody>
<tr>
<td>0</td>
<td>1</td>
<td>2</td>
<td></td>
</tr>
<tr>
<td>0</td>
<td>1</td>
<td>2</td>
<td></td>
</tr>
<tr>
<td>Measuring</td>
<td>YES</td>
<td>Not Sure</td>
<td>NO</td>
</tr>
<tr>
<td>--------------------------------------------------------------------------</td>
<td>-----</td>
<td>----------</td>
<td>----</td>
</tr>
<tr>
<td>14 Do you know about checking your blood sugar levels regularly?</td>
<td>0</td>
<td>1</td>
<td>2</td>
</tr>
<tr>
<td>15 Do you know about keeping a record of your blood sugar levels?</td>
<td>0</td>
<td>1</td>
<td>2</td>
</tr>
<tr>
<td>16 Do you take and record your blood sugar levels regularly?</td>
<td>0</td>
<td>1</td>
<td>2</td>
</tr>
<tr>
<td>17 Do you know what to do if your blood sugar levels get too high or too low?</td>
<td>0</td>
<td>1</td>
<td>2</td>
</tr>
<tr>
<td>18 Does what you do make your blood sugar levels get better?</td>
<td>0</td>
<td>1</td>
<td>2</td>
</tr>
<tr>
<td>19 Do you always do the right thing to make your blood sugar levels better?</td>
<td>0</td>
<td>1</td>
<td>2</td>
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</table>

<table>
<thead>
<tr>
<th>Physical / Social / Emotional Impact</th>
<th>YES</th>
<th>Not Sure</th>
<th>NO</th>
</tr>
</thead>
<tbody>
<tr>
<td>20 Does having diabetes stop you from doing your daily activities? (eg, walking, work, sport)</td>
<td>0</td>
<td>1</td>
<td>2</td>
</tr>
<tr>
<td>21 Does having diabetes stop you from being part of family activities? (eg. barbecues, outings)</td>
<td>0</td>
<td>1</td>
<td>2</td>
</tr>
<tr>
<td>22 Do you feel angry, sad or distressed because you have diabetes?</td>
<td>0</td>
<td>1</td>
<td>2</td>
</tr>
<tr>
<td>23 Does taking your medication ever make you feel sick?</td>
<td>0</td>
<td>1</td>
<td>2</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Lifestyle</th>
<th>YES</th>
<th>Not Sure</th>
<th>NO</th>
</tr>
</thead>
<tbody>
<tr>
<td>24 Have you made changes in your life that have helped your diabetes?</td>
<td>0</td>
<td>1</td>
<td>2</td>
</tr>
<tr>
<td>25 Do you know what things can make your diabetes worse?</td>
<td>0</td>
<td>1</td>
<td>2</td>
</tr>
<tr>
<td>26 Do you know how important diet and exercise are as part of your diabetes care?</td>
<td>0</td>
<td>1</td>
<td>2</td>
</tr>
<tr>
<td>27 Would you like help to make your lifestyle better?</td>
<td>0</td>
<td>1</td>
<td>2</td>
</tr>
</tbody>
</table>
QUALITY OF LIFE QUESTIONS

These questions ask you what you think about your health.

(please read the choices and tick one answer)

1. How would you say your health is?
   1. Excellent [  ]
   2. Very good [  ]
   3. Good [  ]
   4. Fair [  ]
   5. Poor [  ]

2. Does your health make it hard to do things like moving a table, sweeping the floor, walking fast or playing with children?
   1. A lot [  ]
   2. A little [  ]
   3. Not at all [  ]

3. Does your health make it hard for you to walk up a steep hill?
   1. A lot [  ]
   2. A little [  ]
   3. Not at all [  ]

4. In the last 4 weeks, have you done less than you would like to in your work or usual activities because of your physical health?
   1. Yes [  ]
   2. No [  ]

5. In the last 4 weeks, have you done less than you would like in your usual work or regular activities because of feeling down, depressed, sad, worried or angry?
   1. Yes [  ]
   2. No [  ]

6. In the last 4 weeks, did you do your work or other activities less carefully than usual because of feeling down, depressed, sad, worried or angry?
   1. Yes [  ]
   2. No [  ]

7. In the last 4 weeks, how much did pain interfere with your normal work including work both outside the home and housework?
   1. Not at all [  ]
   2. A little bit [  ]
   3. Moderately [  ]
   4. Quite a bit [  ]
   5. Extremely [  ]
The next few questions are about how you have been feeling in the 4 weeks. Please give one answer that comes the closest to the way you have been feeling.

8. How much of the time in the last 4 weeks have you felt relaxed and peaceful?
   1. All of the time [ ]
   2. Most of the time [ ]
   3. A good bit of the time [ ]
   4. Some of the time [ ]
   5. None of the time [ ]

9. In the last 4 weeks, how much of the time did you have a lot of energy?
   1. All of the time [ ]
   2. Most of the time [ ]
   3. A good bit of the time [ ]
   4. Some of the time [ ]
   5. None of the time [ ]

10. How much of the time in the last 4 weeks have you felt sad or unhappy?
    1. All of the time [ ]
    2. Some of the time [ ]
    3. A good bit of the time [ ]
    4. Some of the time [ ]
    5. None of the time [ ]

11. In the last 4 weeks, how much has your physical health or feelings interfered with visiting friends or relatives?
    1. All of the time [ ]
    2. Some of the time [ ]
    3. None of the time [ ]
    4. A good bit of the time [ ]
    5. None of the time [ ]
APPENDIX SIX
The SF-11

QUALITY OF LIFE QUESTIONS

These questions ask you what you think about your health

(Please read the choices and tick one answer)

1. How would you say your health is?
   a. Good/Excellent
   b. OK / Fair
   c. Bad

2. Does your health make it hard to do things like moving a table, sweeping the floor, walking fast or playing with children?
   a. Yes
   b. Sometimes
   c. No

3. Does your health make it hard for you to walk up a steep hill or on soft sand?
   a. Yes
   b. Sometimes
   c. No

4. In the last month, did you do less than you would normally because of your physical health?
   a. Yes
   b. No

5. In the last month did you feel sad, depressed, angry or stressed etc?
   a. Yes
   b. No

6. If yes to the question 5, did it affect your normal activities?
   a. Yes
   b. No

7. In the last month, how much did pain affect your normal activities?
   a. Not at all
   b. Sometimes
   c. All the time

The next few questions are about how you have been feeling in the 4 weeks. Please give one answer that comes the closest to the way you have been feeling.

8. In the last month how much of the time have you felt relaxed?
   a. All of the time
   b. Some of the time
   c. None of the time

9. In the last month how much of the time did you have a lot of energy?
   a. All of the time
   b. Some of the time
   c. None of the time
10. In the last month how much of the time have you felt sad or unhappy?

<p>| | |</p>
<table>
<thead>
<tr>
<th></th>
<th></th>
</tr>
</thead>
</table>
a. All of the time | [ ] |
b. Some of the time | [ ] |
c. None of the time | [ ] |

11. In the last month, how much has your health or feelings stopped you from visiting friends or relatives?

<p>| | |</p>
<table>
<thead>
<tr>
<th></th>
<th></th>
</tr>
</thead>
</table>
a. All of the time | [ ] |
b. Some of the time | [ ] |
c. None of the time | [ ] |
WORK AND SOCIAL ADJUSTMENT SCALE  [REVISED EP2]

Some people's problems affect how they are able to do certain things.
On each of the lines below, use a pen to mark the following:

HOW MUCH DOES YOUR HEALTH AFFECT THE FOLLOWING AREAS OF YOUR LIFE?

1. WORK
If you are retired, not working or not looking for work then circle N/A (Not Applicable).

<table>
<thead>
<tr>
<th>Does Not</th>
<th>Sometimes</th>
<th>All the time</th>
<th>(N/A)</th>
</tr>
</thead>
</table>

2. LOOKING AFTER YOUR HOME AND FAMILY
Including cleaning, tidying, shopping, cooking, gardening etc.

<table>
<thead>
<tr>
<th>Does Not</th>
<th>Sometimes</th>
<th>All the time</th>
<th>(N/A)</th>
</tr>
</thead>
</table>

3. THINGS YOU LIKE TO DO WITH OTHER PEOPLE
Such as outings, parties, groups, clubs, sport

<table>
<thead>
<tr>
<th>Does Not</th>
<th>Sometimes</th>
<th>All the time</th>
<th>(N/A)</th>
</tr>
</thead>
</table>

4. THINGS YOU LIKE DOING ALONE
Such as reading, walking, other exercise, hobbies, gardening, interests etc.

<table>
<thead>
<tr>
<th>Does Not</th>
<th>Sometimes</th>
<th>All the time</th>
<th>(N/A)</th>
</tr>
</thead>
</table>

5. FAMILY & RELATIONSHIPS
Making and keeping close relationships with other people – your family, people you live with, other relatives, friends etc.

| Does Not | Sometimes | All the time | (N/A) |
REFERENCES


320: p. 563-566.


Ideas developed in this thesis have been published in the following academic journals or reports, and other articles are currently being reviewed for publication.

**Published**

Beyond Community based diabetes management and the COAG coordinated care trial.
AJRH 11(3): 131-7. 2003

Small-scale rural pilot programmes in chronic illness management - what next?
AJPH 9(2&3): 114-117. 2003

Chronic Disease Self Management in Aboriginal Communities - an effective and sustainable programme of care for Aboriginal people in rural communities.
AJPH 9(2&3): 168-76. 2003

The impact of SA HealthPlus: GP Perspectives Eyre Region

Health reform through coordinated care: SA HealthPlus
BMJ;330;662-665. 2005

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NOTE:
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NOTE:
This publication is included in the print copy of the thesis held in the University of Adelaide Library.

It is also available online to authorised users at:  
https://doi.org/10.1071/PY03043
The Impact of SA HealthPlus: GP Perspectives Eyre Region

David Mills and Peter Morton

The Eyre Peninsula Division of General Practice was involved in the concept of coordinated care and other primary health care initiatives before the advent of SA HealthPlus coordinated care program. In fact, the existence of active primary health care programs in the Eyre Region, together with the progressive diabetes trial conducted in this region, were the principal reasons for SA HealthPlus extending its trial program to the rural sector. The Eyre context was also seen as an ideal site in which to develop IT applications for care planning and patient record management as the distances and isolation involved in the region meant that such applications could be truly effective in the delivery of care.

Initially it was thought that participation in a coordinated care trial would assist in the development of the region and enable improved services to be provided across the Eyre Peninsula, but it was problematic that coordinated care per se could actually reduce costs in the acute sector. Most hospitals in the region are ‘minimum funded’ or subsidized hospitals which means that they are effectively funded by the State over and above their demonstrated case mix levels in order for them to be locally viable units. In this context, it was difficult to see how any so-called savings, whether real or theoretical, could actually be shifted from acute activity to fund primary care and early intervention programs as ‘savings’ as such were simply reductions in an existing deficit. Further, the inclusion of Aboriginal patients in the trial added additional risk and meant that more services would be required than were currently available. Early assessments of the availability of essential primary health services which are taken for granted in the metropolitan area showed that around half of the major and necessary services required for the management of chronic illness were actually available. In some places like Ceduna, virtually no preventive, allied health services were available.

This meant that, in the first instance at least, involvement in formal care planning and coordinated care would necessitate the provision of a significant amount of new and additional services to the region. So, not only could acute efficiencies not be realised to fund the new model, additional funding was also required to develop IT systems to make service provision more coordinated and effective and to ensure that services were available to meet the best practice requirements of the care planning system.

The difficulties of funding ongoing coordination and paying for additional services, service coordination and the cost of care planning notwithstanding, the Division embraced the model as a strategy to assist GPs to manage their work loads and to improve the quality of their lives as rural GPs. GPs were overworked and their numbers were dwindling. They are also an aging group of doctors with the average age of GPs in the region being around 45 years. Given that more GPs were not being attracted to work in rural settings, new solutions had to be found to the demand for primary health services. The SA HealthPlus model offered a possible option for GPs to explore.

Consequently, most of the GPs in the region became involved in the trial, enrolling up to 100 patients each in some circumstances and generally engaging in the process to a much higher degree than their metropolitan counterparts. This may have been due to many things, but clearly the unique position of the Eyre Peninsula Division of General Practice in the region was a significant element in this involvement, as was the fact that GPs saw that they had nothing to lose from becoming involved and everything to gain. They were to be funded to coordinate care, they had a loyal patient following in the main, and the prospect of having service coordinators involved in some of the traditional areas of GP work was not really threatening to GPs in Eyre. This provided an alternative way of managing chronic and complex patients whilst freeing GPs to see other patients who would perhaps benefit more directly from their input. Perhaps patients with chronic and ongoing conditions could be supported more effectively by the SA HealthPlus service coordination team working in collaboration with community health services than they would by GPs alone!
The trial offered GPs an option for the management of patients with chronic illness and encouraged the development of integrated provider networks through which patients could be better cared for. Being part of the trial enabled GPs to test new strategies for the provision of care and to learn about care planning and more holistic approaches to care. The care planning process gave them more time to listen to and collaborate with their patients in the management of their care and to begin developing more comprehensive patient records that would facilitate the provision of better care.

Once the trial was underway and care planning implemented, GPs began to change their minds about the coordinated care process. More doctors in the second round of GP surveys indicated that they felt the coordination process was beneficial for patients and that they were happy with the trial than did in the first round of surveys (1). In addition to the patient management processes and patient health outcomes that some GPs were acknowledging, the SA HealthPlus IT project offered the possibility of training and support for GPs to become familiar with computer applications for managing patient records.

SA HealthPlus arranged the purchase of computers for all participating GPs with the aim of developing a GP network through which more effective communication of patient records would be possible. Stage one of this project has now been completed with all doctors now having access to the Internet, training to use the Medical Director application for patient management and access to ongoing support via the Division for the implementation of other IT applications. SA HealthPlus, in collaboration with the Eyre Peninsula Division and the Eyre Regional Health Service employed a local IT manager to assist GPs develop their systems and to arrange ongoing training and support in the use of new systems.

One clear and tangible benefit of the GPs being involved in the trial has been the development, across the range of surgeries and practices, of a more comprehensive approach to the use of IT within general practice. The next proposed trial, along with the Quality Use of Medicines project (QUMEP) promise to extend the use of IT further through networking pharmacies and GP surgeries to facilitate the effective transmission of patient records and follow-up in relation to scripts and use of medication.

But of all the impacts of the SA HealthPlus trial, by far the most significant has been the development of a culture of change among the general practice community. In essence, the trial has been about building this culture of change and demonstrating new ways for GPs to work across the spectrum of health service provision. Paradoxically, the rural GPs; those most remote and endangered of the species, may actually be leading the field in changing the way medicine functions within the community.

Professor Peter Yellowlees, in his paper on the future of medical practice (2) suggested that major changes were occurring in the way medicine was being practiced. Along with greater access to information, greater patient empowerment and greater patient control of the management of well being he suggested would also develop a new way for GPs to work in collaboration with other allied health providers. He concluded that doctors would soon be working as coordinators and facilitators of health care rather than sole providers of it. Much like modern educators have become mentors and facilitators of student learning, doctors will become facilitators of integrated, preventive care.

If this scenario is realised, the GPs in the Eyre Region, as a result of their dalliance with the SA HealthPlus trial and early experiments with coordinated care, will be well placed to assume these roles. Already the EPDGP is negotiating with members to utilize the new Enhanced Primary Care package funding to extend the work begun by SA HealthPlus and ensure that the progress made through the trial is not lost. We also plan to integrate a QUM project with a new round of coordinated care trials by the middle of next year. This will enable us to build a formal coordinated care program for up to 4000 patients with chronic illness and people who are at risk of events in their lives that may impact adversely upon their health and well being. Many of these crisis events may be prevented through the implementation of new models of coordinated care. The Division may also become central
to the collection, collation and retrieval of patient records and data giving GPs much more control over and confidence in the care planning and patient management processes involved in effective primary care.

In summary, GPs have had a positive experience in the Eyre Region with coordinated care and begun developing new ways of working with patients and allied health professionals. They have led the change process in the Region, which has been associated with the Coordinated Care Trial initiative and have made a significant commitment to implementing IT systems and electronic patient records.

This background in outcome focused health care practices has prepared the GPs to implement the new Enhanced Primary Care packages from November 1 and put the Division in a key position to participate in and lead ongoing initiatives involving various permutations of coordinated care, cash pooling and outcome based health care. In short, the Division’s involvement in, and leadership of the coordinated care trial initiative in Eyre has been a successful initial step in developing a new primary health care system in which GPs will have a significant role as coordinators and facilitators of health care programs.

The challenge now is to stay ahead of the herd in this expanding field and ensure that the new systems that are developed in rural communities actually create greater financial flexibility in the region and result in improved health outcomes for patients whilst enhancing GP practice.

References


Health reform through coordinated care: SA HealthPlus
Malcolm W Battersby and the SA HealthPlus Team

How can care for chronic illness best be coordinated? An Australian study sought to move towards collaborative and patient centred planned care

Chronic illnesses contribute 60% of the global burden of disease, which by the year 2020 will increase to 80%. With ageing populations, no developed country can afford the projected increase in costs of chronic illness. To address this crisis, governments and healthcare organisations in developed countries have initiated programmes aimed at shifting the focus of health care from acute illness to chronic illness. Australian governments have initiated health reform using trials of coordinated care. We describe the largest of these trials, SA HealthPlus, its aims, outcomes, and lessons learnt.

The problem
In Australia, state and commonwealth governments share the financing of health—the states being responsible for hospitals and the commonwealth being responsible for primary care. This has provided financial and clinical barriers to the management of care for people with chronic illnesses. General practice is funded on a fee for service basis, reinforcing a reactive rather than a planned model of care. This has led to poor coordination and inadequate attention to prevention of crises and complications of chronic illness. Public hospitals face excessive demand and bed shortages. Emergency departments are under pressure, with patients waiting acceptably long periods for assessment and admission.

The questions
The SA HealthPlus trial asked several questions. Can coordination of care for people with multiple service needs, where care is accessed through individual care plans and funds pooled from existing commonwealth and state programmes, result in improved individual client health and wellbeing within existing resources? Given a research design, would the trials facilitate health reform to help general practice to move towards collaborative and patient centred planned care? Would hospitals become partners with the primary care system, and would funding reward outcomes rather than output?

The evidence
Innovative models aiming to improve outcomes in chronic care have been described as managed care, integrated care, disease management, coordinated care, and case management. Determining which models are most successful is difficult because there are no agreed definitions of each model and because of overlap of components between models. All models are multi-component, and research designs have not compared different types of interventions to find the most effective.

A review of coordinated care defined coordinated care as targeting "at risk" people with assessment of medical, functional, social, and emotional needs; provision of optimal medical treatment, self care education, and integrated services; and monitoring of progress and early signs of problems. The aim of coordinated care was to improve health outcomes and reduce costs. Programmes were divided into either disease management or case management. Case management targeted complex patients who had multiple conditions and social problems. Disease management targeted patients with a single diagnosis. Staff in both models were nurses. A common feature of successful programmes was the defining of patients’ problems and setting goals for each problem.

A meta-analysis of disease management, which incorporated case management, found that improved quality control was associated with education of providers, reminders, and feedback, and with education of patients, reminders, and incentives. A systematic review of disease management for depression found evidence of improvements in depressive symptoms and adherence to treatment but more admissions to hospital and increased costs.

Disease specific programmes have dominated the literature yet do not address the clinical reality that patients and their health providers have to deal with more than one condition. The programmes reviewed above highlight conceptual confusion in the care of chronic illness, and although several interventions were effective, the cost savings were equivocal. In some instances the patient’s doctor had no involvement, suggesting that the models would not be sustained. As a way forward, elements of successful programmes for chronic disease have been organised under the six domains of the chronic care model. The SA HealthPlus model incorporated these elements into its design and developed a generic model of care rather than a disease specific model of care.

Implementation
One million of South Australia’s 1.5 million people live in Adelaide, the remainder in rural and remote areas. The trial aimed to create a fundamental shift from a funding based model of care to a population outcomes based model of care. Compared with purely experimental trials, this programme was developed as eight projects in four regions to inform a statewide implementation of coordinated care. The trial was conducted between July 1997 and December 1999. The projects had either geographical or randomised control groups allocated to intervention or control in the ratio of 2:1.

Inclusion criteria
The four regional subtrials consisted of eight projects: diabetes (two projects), cardiac, respiratory (two...
projects), care of aged people, somatisation, and chronic and complex conditions. Eligibility to enter the trial included a hospital admission in the 12 months before enrolment and frequent use of visits to a general practitioner (more than eight a year) or emergency visits (more than four a year). Participants were aged 18 and over except for the western diabetes project and southern aged care project, where participants were over 65. During the recruitment phase, the requirement of prior admission to hospital was relaxed to achieve recruitment targets and to accommodate some general practitioners who considered that their patients with complex problems would benefit.

The model of care

The generic model of assessment and care planning incorporated disease specific evidence based guidelines that recommended services to be delivered over 12 months. The role of service coordinator was provided mainly by nurses, who conducted an assessment of patient defined life problems and goals, collated information from other providers, and initiated the care plan. They provided support and coordination for self management but did not provide disease specific services. The general practitioners as care coordinators completed a medical assessment and, with the patients, finalised the care plan, allocating services based on one of three levels of severity. Care mentors participated in case conferences and monitored care coordinators. The care mentor group modified care plan guidelines as part of continuous improvement.

Patient centred care was formalised by the problems and goals assessment, a semi-structured interview originally developed for psychiatric disorders.7 The patient's perception of their main life problem, self rated on a 0-8 scale, was incorporated into the care plan. This signified a shift away from a focus on disease.

The cost of usual care was based on the cost of service use in the control group. Admission diagnoses were defined as either fully (1.0) or partially (0.5) preventable. Each project aimed to achieve a 50% reduction in preventable admissions over two years, thereby improving outcomes within existing resources.

Outcome measures

The SF-36,6 which measures quality of life on eight domains, was administered to intervention and control patients by post at enrolment, 12 months, and the end of the trial. The rating for problems and goals by patient and service coordinator was used as an outcome measure with intervention patients. Ratings were made monthly, then every three months. Costs and data for medical services, drugs, inpatient admissions, metropolitan domiciliary services, and district nursing services were tracked. Hospital data on outpatients and emergency presentations were not available. Qualitative data included surveys, focus groups, and interviews.

Results

Project specific outcomes have been described elsewhere.15-18 Overall, 3115 intervention patients, 1488 control patients, and 287 intervention group general practitioners were recruited (table 1).

Table 1 Number of patients enrolled in SA HealthPlus projects

<table>
<thead>
<tr>
<th>Project</th>
<th>Type of controls</th>
<th>Intervention group (n=3115)</th>
<th>Control group (n=1488)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Central region cardiac</td>
<td>Randomised</td>
<td>271</td>
<td>138</td>
</tr>
<tr>
<td>Respiratory</td>
<td>Randomised</td>
<td>165</td>
<td>82</td>
</tr>
<tr>
<td>Somatisation</td>
<td>Randomised</td>
<td>90</td>
<td>35</td>
</tr>
<tr>
<td>Aged care</td>
<td>Randomised</td>
<td>632</td>
<td>310</td>
</tr>
<tr>
<td>Eyre Peninsula region</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Diabetes</td>
<td>Geographical</td>
<td>398</td>
<td>111</td>
</tr>
<tr>
<td>Chronic and complex</td>
<td>Geographical</td>
<td>965</td>
<td>412</td>
</tr>
<tr>
<td>Western region</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Respiratory</td>
<td>Geographical</td>
<td>223</td>
<td>154</td>
</tr>
<tr>
<td>Diabetes</td>
<td>Geographical</td>
<td>361</td>
<td>256</td>
</tr>
</tbody>
</table>

In total, 1900 (61%) intervention patients and 841 (57%) control patients remained in the trial until December 1999. In July 1999, when reconvening was required to extend the trial, 1059 (54%) intervention patients and 238 (16%) control patients had withdrawn. Withdrawals included 158 (5.3%) of intervention patients and 86 (5.8%) control patients who had died.

Two projects showed improvements in SF-36 mental health domains and four showed improvements in both physical and mental domains compared with controls (table 2).

Problems and goals

Goals were coded according to improvement (at least 1 point), no change, or deterioration (at least 1 point) between the first and last ratings. Between 992 (40%) and 1487 (60%) of patients made some progress towards achieving their goal. Achievement in indig-
enous patients (59; 58.4%) was similar to other patients with diabetes in the Eyre Peninsula project (195; 56.3%).

When projects were combined, 1401 (55%) patients set their first goal in exercise, diet, or activities. Overall, 586 (23%) first goals related to maintaining the patient’s current activities. Up to 1487 (60%) of patients and service coordinators rated their problem as improved. Significantly positive correlations were found between the SF-36 and difference in scores for problems and goals; however, the correlations were of low strength (Spearman correlations r ≤0.12).

Service use
Control group patients who were geographically isolated differed from matched intervention patients in use of services before the trial, so data on service use was recalibrated by adjusting for inpatient, medical, and pharmaceutical services for the two years before enrolment. The southern and central regions showed no significant change. In the Eyre Peninsula chronic and complex project, compared with the control group, fewer admissions in the intervention group were accounted for by an increase in emergency admissions. In the Western projects, an increase in admissions in the intervention group was due to an increase in elective admissions. Use of medical services or drugs did not differ significantly between intervention and control patients. Intervention patients used more domiciliary services. Savings in admissions were not sufficient to pay for service coordination and additional community services. Coordination costs were high, with all patients receiving service coordination throughout the trial. However, service coordinator roles in trial development, data collection, and provider education were not separated from trial costs.

Lessons from the trial
A generic model of coordinated care was successfully implemented for people with a wide range of chronic conditions in both rural and urban settings. Improved wellbeing was achieved, with evidence suggesting that the key components of the model were the problems and goals, approach, the care plan, and service coordinators working with general practitioners and patients. The semistructured assessment initiated self-management support, a core element of the chronic care model. The finding that the key determinant of coordination was self-management and not severity of illness led to the development of the partners in health self management assessment and care planning process to target education to the individual. This model has become the basis of clinician led self-management support in the National Sharing Health Care initiative. Patients who benefited most were not linked with services, lacked knowledge of their condition, were depressed, lacked motivation to change behaviour, and had lifestyle risk factors or poorly controlled conditions. Some patients had minimal benefit, needing coordination for a short time or being already well coordinated.

Better targeting of patients is required to achieve cost savings within a short period. Original selection criteria included at least one admission to hospital in the 12 months before enrolment. Table 3 shows costing data segmented to include only this group.

The reduction in the deficit by over $42m results not only from increased hospital savings, but from substantially reduced coordination costs.

Cost neutrality was affected by incomplete adherence to the care plan by the doctor or patient, limited availability of services, insufficient time to reduce complications, and an increase in service use from thorough assessment and patient demand.

Implementation of organised care for chronic illness in Australia requires commitment from state and commonwealth governments to pool funds and information systems that provide population data and decision support. A change in the business processes of general practice will be required. Some elements of health reform have been achieved with the creation of item numbers for general practitioners to provide health assessments, care planning, and case conferences. A large scale collaborative to introduce organised care of chronic illness into general practice is in the planning stage.

During the trial, a change of state government led to a loss of momentum for health reform. A new state government instituted the generational health review, which has recommended a need to integrate care for chronic illness, enhance primary care networks, and implement self management programmes. Governments need to balance the competing risks of offending entrenched professional interests against not addressing the crisis in care of chronic illness.

Conclusions
A generic population based model of coordinated care was feasible and resulted in improved health outcomes.

<table>
<thead>
<tr>
<th>Variable</th>
<th>Net difference between intervention and control patients (% variation)</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>All patients recalibrated</td>
</tr>
<tr>
<td></td>
<td>Hospital Inpatient</td>
</tr>
<tr>
<td></td>
<td>Medical Benefits Schedule</td>
</tr>
<tr>
<td></td>
<td>Pharmaceutical Benefits Schedule</td>
</tr>
<tr>
<td></td>
<td>Other community services</td>
</tr>
<tr>
<td>Subtotal</td>
<td></td>
</tr>
<tr>
<td>Coordinators</td>
<td></td>
</tr>
<tr>
<td>Approximate net resource savings</td>
<td>-4 942 898 (-28.6)</td>
</tr>
</tbody>
</table>

$41.00=£0.41; €0.69.

*Only patients with at least one hospital admission in 12 months before enrolment. **Includes costs of recruitment, care planning, and coordination.
Summary points

Barriers to coordinated care for chronic illness in Australia include multiple sources of funding, and general practice that focuses on acute care, with doctors working individually, not in teams.

Definitions of managed care, coordinated care, and disease management models have not been agreed.

SA HealthPlus successfully implemented a generic model of coordinated care with improved health outcomes but savings that were not sufficient to pay for all coordination costs.

Self-management capacity is a necessary component of assessment in determining allocation to coordinated care for chronic conditions.

in both rural and urban settings. Cost savings were not sufficient to pay for coordinated care. However, the contribution to costs by service coordinator non-clinical roles suggests that a longitudinal study (five to 10 years) is required to assess the effects of service substitution on costs. Service coordination was found to be a necessary additional role than is currently available in the Australian health system. Better targeting of coordination should be based on prior admission to hospital and a potential to improve self-management.

Source data was obtained from local and national evaluations of the coordinated care trials.

Contributors: Members of the SA HealthPlus Team participated in the conception and design of the study, data collection and analysis, or work-up and review. MWB is guarantor for the paper. The guarantor accepts full responsibility for the work and/or the conduct of the study, had access to the data, and controlled the decision to publish.

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