

Outcomes and Indicators for Diabetes Education

A National Consensus Position

Outcomes and Indicators for Diabetes Education

ndss

NDSS

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Foreword

While we still have much to learn about how best to prevent and manage diabetes, since the National Diabetes Strategy and Implementation Plan was commissioned in 1997, significant progress has been made. Many important parts of the diabetes puzzle have been filled in. Accessibility of services has been improved.

Major achievements include the AusDIAB and DiabCo\$t studies which provided the first truly comprehensive national data on the prevalence and economic costs of diabetes; the development of NHMRC endorsed diabetes guidelines; data collection systems; and, more recently a national services framework for diabetes. Most importantly, initiatives around quality of care in Aboriginal Medical Services have improved access to good diabetes care and management and general practice incentives have increased access to medical care and also to allied health professional care for people with diabetes. The emergence of a strong evidence base for the primary prevention of type 2 diabetes is enabling the development and implementation of some significant prevention programs.

What also matters greatly to people with diabetes is the quality of information and education they receive. The Outcomes and Indicators for Diabetes Education: A National Consensus is a landmark document that, for the first time, details systematically derived and nationally agreed goals, outcomes and associated indicators for diabetes patient education. It builds on the 'best practice information and education framework' published by Diabetes Australia in 2004, and provides a benchmark and policy platform for refining and evaluating the consistency, quality and effectiveness of diabetes education services.

This is another milestone for diabetes in Australia and another step in improving the quality of diabetes services.



Tony Abbott
Minister for Health and Ageing

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Prepared for
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The people with or affected by diabetes who participated in the Focus Groups

The Key Opinion Leaders who participated in the interviews

The Diabetes Service Providers who completed the survey

The Stakeholder Forum Participants

The ADEA Consultation Workshop Participants

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List of acronyms

AADE	American Association of Diabetes Educators
ADEA	Australian Diabetes Educators Association
AIHW	Australian Institute of Health and Welfare
ANDIAB	Australian National Diabetes Information Audit and Benchmarking
BEACH	Better the Evaluation And Care of Health
BGL	Blood Glucose Level
BMI	Body Mass Index
CATI	Computer Assisted Telephone Interviews
CAPI	Computer Assisted Personal Interviews
CDC	Centre for Disease Control and Prevention
DAFNE	Dose Adjustment For Normal Eating (for type 1 diabetes)
DAWN	Diabetes Attitudes Wishes and Needs
DCCT	Diabetes Control and Complications Trial
DESMOND	Diabetes Education and Self-Management for Ongoing and Newly Diagnosed (for type 2 diabetes)
DHA	[Australian] Department of Health and Aging
DKA	Diabetic Ketoacidosis
DSME	Diabetes Self-Management Education
HbA _{1c}	Glycosylated haemoglobin
HRQOL	Health Related Quality of Life
HHNC	Hyperosmolar Hyperglycaemic Nonketotic Coma
IDF	International Diabetes Federation
JDRF	Juvenile Diabetes Research Foundation
MDRTC	Michigan Diabetes Research and Training Centre
NHMRC	National Health and Medical Research Council
NICE	National Institute for Clinical Excellence
NDDWG	National Diabetes Data Working Group
NDEOS	National Diabetes Education Outcomes System
NDSS	National Diabetes Services Scheme
NHPA	National Health Priority Area
NHPC	National Health Performance Committee
NIDP	National Integrated Diabetes Program - Practice Incentive Program
PBS	Pharmaceutical Benefit Scheme
PWD	People With Diabetes
QOL	Quality Of Life
SBGM	Self Blood Glucose Monitoring
UK HDA	United Kingdom Health Development Agency
VO _{2max}	Maximal Oxygen uptake

Glossary of tools

ADDQOL	Audit of Diabetes Dependent Quality of Life
ADDQOL-Teens	Audit of Diabetes Dependent Quality of Life for Teenagers
ADS	Appraisal of Diabetes Scale
ATT39	Diabetes Integration Scale-39 items
ATT19	Diabetes Integration Scale-19 items short form
BASC	Behaviour Assessment System for Children
CHQ	Child Health Questionnaire
CHQ PF-50	Child Health Questionnaire Parent Form-50 items
CHQ CF-80	Child Health Questionnaire for adolescence 18 to 20 years old-80 items
CIDS	Confidence in Diabetes Self Care Scale (for people with type 1)
DCP	Diabetes Care Profile
DES	Diabetes Empowerment Scale
DES-SF	Diabetes Empowerment Scale-Short Form
DKN	Diabetes Knowledge Assessment scale [Australian]
DKT	Diabetes Knowledge Test [American]
DQOL	Diabetes Quality of Life
D-SMART	Diabetes Self-Management Assessment Report Tool
DSQOLS	Diabetes Specific Quality of Life Scale
EBAS	Environmental Barriers to Adherence Scale
EQ-5D	European Quality of Life-5 Dimensions
GHQ-12	General Health Questionnaire
HPAI	Habitual Physical Activity Index
K10	Kessler Psychological Distress Scale-10 items
PAID	Problem Areas in Diabetes scale
QSD-R	Questionnaire on Stress in Patients with Diabetes-Revised
SCI-R	Self-Care Inventory-Revised
SDSCA	Summary of Diabetes Self-Care Activities
SEE	Self-Efficacy for Exercise Scale
SE-Type 2	Self-Efficacy of patients with Type 2 diabetes scale
SF-36	Short Form-36 (global health related quality of life instrument)
TSRQ	Treatment Self-Regulation Questionnaire
WBQ-12	Well Being Questionnaire-12 items
WHO-5	World Health Organisation-5 Well-Being Index

Background

Opinions and perspectives about the role and purpose of diabetes education vary considerably both within and between stakeholder groups. At the time of this report, there appear to be no consensus positions reported in the international literature that have been derived comprehensively by combining evidence with systematic consultation with people with diabetes, providers and policy makers. The lack of agreement about the goals and desired outcomes of diabetes education presents difficulties in designing and evaluating patient education and health professional training programs, and results in inconsistencies in information and education provided to people with diabetes. It also presents obstacles to benchmarking and improving the quality of patient education and hampers research into the impact of diabetes education and the relative efficacy of different methods and models.

Aims and scope

The project to develop a national consensus on diabetes patient education was commissioned by Diabetes Australia under an Australian Government funded National Diabetes Services Scheme (NDSS) Strategic Funds grant with the aim of:

1. Developing a national evidence/consensus position statement on the key desired goals and outcomes of diabetes education.
2. Identifying nationally agreed indicators for assessing the effectiveness of diabetes education in achieving these goals and outcomes.

The outcomes and indicators are expected to be a) utilised by all providers who deliver education to people with diabetes and b) applied to all people with diabetes regardless of the type, duration or stage of their diabetes. However, it is recognised that, as with all aspects of patient education, the outcomes and indicators will need to be modified to suit the unique needs and circumstances of individuals and groups, particularly those whose participation in their own health care may be limited by disability, extremes of age or cultural barriers.

Methods

The project methods and processes employed to achieve the national consensus on diabetes patient education were :

- a review of relevant international literature and programs to identify the status of knowledge and activity in this area ie peer reviewed literature, websites, non-peer reviewed reports
- consultation with providers and policy makers
- focus groups with a range of people with diabetes and parents of children with diabetes
- interviews with key opinion leaders
- a survey of service providers
- a national Stakeholder Forum

Structure of the report

The report is structured into four sections which include summaries of the main consultation and investigations undertaken. Full reports of these are provided in the appendices.

Section 1 provides information on the purpose of the project and explains the principles on which the project is predicated, particularly the emphasis on the needs of people with diabetes. It provides a summary of the context and rationale for undertaking the project, and the methods used.

Section 2 describes the drafting of the initial framework of outcomes and indicators. This involved a preliminary review of the literature to a) identify the status of work already undertaken in this area and b) find standardised definitions of terminology commonly used to describe aspects, models or domains of diabetes patient education. The literature review is fully detailed in Appendix 1. Section 2 also outlines the initial consultation undertaken with diabetes educators from across Australia and lists the key education outcomes identified by means of these two processes.

Section 3 reports on the substantive investigations and consultation. These entailed key opinion leader interviews, focus groups with people with diabetes, a national service provider survey and a detailed pragmatic literature review of tools for measuring changes in the indicators. This section describes the penultimate framework of outcomes and indicators which resulted from this work.

Section 4 outlines the final consultation (Stakeholder Forum) which assisted the refinement and expansion of the outcomes and indicators from the penultimate framework into a set of nationally agreed outcomes and indicators for diabetes patient education. Section 4 also discusses implementation issues and sets out a small number of recommendations for further development and implementation of the indicators.

Results

This work resulted in a consensus, synthesised from the literature about diabetes education and from a systematic process of consultation with people with diabetes, providers, policy makers, and researchers across Australia, about the goals, outcomes and indicator areas for measuring progress towards the goals and outcomes. The overarching goals of diabetes patient education were identified as:

- Optimal adjustment to living with diabetes
- Optimal physical (health) outcomes
- Optimal (public and personal) cost effectiveness

The outcomes that could be expected to result if these goals were reached were described as optimal:

- | | |
|--|-----------------------|
| ▪ knowledge/understanding (application of knowledge) | ▪ self-management |
| ▪ self-determination | ▪ clinical outcomes* |
| ▪ psychological adjustment | ▪ cost-effectiveness* |

* Due to the difficulty of assessing the impact of education on clinical outcomes and cost effectiveness and in view of existing efforts and mechanisms for measuring the clinical and cost outcomes of diabetes, it was agreed that the project should focus on those outcomes most likely to be directly affected by diabetes education. However, diabetes education service providers who also wish to measure clinical and cost outcomes should be encouraged to do so and, ideally, clinical and cost outcomes and education outcomes should be cross-linked and reported on nationally.

Indicator areas where changes might feasibly be measured on a national or population level were identified for each of these outcomes. These centred on *processes* eg the proportion of people with diabetes receiving diabetes education; determinants of *quality* eg who delivered the education. Changes in knowledge and behaviours were also considered possible and desirable to measure at the population level. However, before this can be done there needs to be additional work around the selection of which tools or measures would be the most suited to assessing shifts in population knowledge and behaviours.

The consultation highlighted the need for indicators that reflect the unique self-care requirements of diabetes. These include self blood glucose monitoring; adherence to treatment recommendations such as medication taking; avoidance and management of acute episodes of intercurrent illness; eating and exercise behaviours. These were deemed essential for individual services/practitioners to monitor the outcomes of their services.

A subsequent literature review was conducted to determine the suitability and availability of tools for measuring both the population level and service level indicators. The review found that there are a number of validated tools which can reasonably measure changes in the identified indicator areas. However, reaching consensus about which tools should be adopted nationally in Australia was outside the scope of this project and requires further exploration and consultation.

Recommendations

A number of recommendations resulted from the project. These centred on the monitoring of diabetes education outcomes, the design and evaluation of diabetes patient education programs and the training of health care providers.

Key recommendation

Recognition of the importance of diabetes education as an integral component of good diabetes care and an important contributor to optimal health outcomes should be reflected in the adoption of selected diabetes education indicators into national and local monitoring of overall diabetes outcomes.

Recommendations for monitoring the outcomes of diabetes education

- Identify or develop an agreed, nationally standardised, core questionnaire for assessing patient knowledge of diabetes and self-care.
- Develop a consensus on which tools are best suited to measuring self-determination, self-management and psychological adjustment in the Australian context.
- Determine clinically significant scores or thresholds for each tool selected in order to better quantify the relationship of education to changes in outcomes.
- Incorporate selected population indicators into existing national and state and territory based data collection, monitoring and surveillance systems.

- Add items of service level indicators to area health service, diabetes specialist services, Diabetes Australia education services and general practice monitoring systems.
- Encourage individual service providers to use the indicators to monitor the outcomes of the education services they provide.
- Develop a diabetes education specific information system and/or incorporate selected indicators into existing clinical information systems.
- Add selected indicators to the Australian National Diabetes Information Audit and Benchmarking (ANDIAB) data set.
- Develop mechanisms for cross-comparison and feedback of clinical, cost and educational outcomes nationally, to inform an evidence base for the relationship between clinical and non-clinical outcomes.

Recommendations for health professional training

- Use the goals, outcomes and indicators from the ‘National Consensus Position’ to determine inputs for diabetes training for health professionals. The level of depth and detail will vary according to the role of health professional groups in diabetes care and education but should include training programs for:
 - diabetes educators
 - undergraduate and graduate medical, nursing and allied health training
 - vocational and continuing education programs for general practitioners, practice nurses, Aboriginal health workers, generalist nurses, teachers, personal carers, aged care assistants and health professionals involved in a peripheral role of providing diabetes education.
- Base monitoring, evaluation and quality improvement of the diabetes education component of health professional training on the goals, outcomes and indicators described in the National Consensus.

Recommendations for the design and evaluation of education programs and services for people with diabetes:

- Use the goals, outcomes and indicators from the National Consensus to determine the design and delivery (content, delivery models and approaches) of education programs for people with diabetes.
- Base monitoring, evaluation and quality improvement of the education programs for people with diabetes on the goals, outcomes and indicators described in the National Consensus.
- Use the goals, outcomes and indicators from the National Consensus as a basis for determining the staff skills mix required for diabetes education.

Section 1: Background

- **Purpose and scope**
- **Principles**
- **Definitions**
- **Context and rationale**
- **Aims and methods**

Purpose

This project was commissioned by Diabetes Australia under the National Diabetes Services Scheme Strategic Development Fund to develop a national consensus articulating agreement about:

- The purpose and overarching goals of diabetes patient education.
- The main outcomes that should be measurable as a result of diabetes patient education.
- Indicators that could be used to assess progress towards achieving these outcomes.

It is anticipated that the outcomes and indicators will form the basis for the design and evaluation of patient education programs; the diabetes component of health professional training programs; competencies for diabetes educators; a component of national and local health outcomes monitoring and surveillance; and a benchmark or anchor for research into diabetes patient education.

Scope

Notwithstanding the overriding requirement for patient education to be tailored to the unique circumstances of the individual, the outcomes and indicators developed under this project were designed to be applied to all people with diabetes regardless of the type, duration or stage of diabetes.

The goals are framed as ‘optimal’ achievement of an aspiration. This should be interpreted to mean that where physical, intellectual or other non-modifiable limitations restrict full realisation of the goals, the education of the individual or their carer/s would aim to achieve as close as possible the full realisation of the goals within the existing limitations.

The goals, outcomes and indicators are intended for use by all health care professionals who provide care to people with diabetes. However, the degree to which the goals, outcomes and indicators apply to different health professional disciplines and categories will be determined by the extent of their role in diabetes patient education.

The project was guided by the following principles:

- Identification of diabetes education outcomes and associated indicators is first and foremost about what people with diabetes need rather than what health professionals do.
- Recognition that although the outcomes and indicators describe what we aspire to achieve for all people with diabetes, these aspirations may need to be modified in the presence of individual limitations eg the very young, the very old, and people with severe mental or physical disability.
- Focus on outcomes not inputs. The National Consensus on outcomes and indicators for diabetes patient education describes outcomes eg what should a person with diabetes have (knowledge, confidence) or be able to do (skills) as a result of diabetes education. Once the outcomes are identified and agreed, specific inputs (program content, education models and modalities) can be developed or adopted.
- Universality of the outcomes and indicators ie although diabetes educators may be the primary source of comprehensive therapeutic education for people with diabetes, the outcomes and indicators apply equally to all providers of diabetes care and/or education proportionately to the service provided.
- Extensive consultation to capture the views and perceptions of a wide range of stakeholders who might use or be affected by the indicators - especially people with diabetes and the organisations that represent them.
- Predominant focus on those areas of diabetes education that are most directly influenced by education and least influenced by other aspects of care. For example those areas most influenced by education are likely to be:
 - knowledge
 - self-management
 - empowerment (and to a lesser extent psychological outcomes).
- Recognition that indicators need to be framed on two levels:
 - population level indicators ie a limited number of broad key indicators for inclusion in general diabetes data monitoring and surveillance at the national, regional, state or area health service level
 - service level indicators ie detailed indicators that can be applied at the point of individual service and that could be collected by a diabetes educator or a practice nurse.
- Recognition that there will be some overlap between the national and service level indicators.
- Need for indicators to be meaningful, feasible and practical to measure.

Definitions

The definitions listed below were adopted soon after commencement of the project and were used as working definitions throughout the project. A comprehensive range of definitions relating to various aspects and models of diabetes patient education can be found at Appendix 1: (pages A1-4 to A1-7).

- An **outcome** is defined as a result.

- An **indicator** is defined as any unit of information that can reasonably measure progress towards achievement of a result.

- **Diabetes education** is an interactive process that facilitates and supports the individual and/or their families, carers or significant social contacts to acquire and apply the knowledge; confidence; practical, problem-solving and coping skills needed to manage their life with diabetes to achieve the best possible outcomes within their own unique circumstances.

- A **tool** is defined as any given measurement instrument ie scale or questionnaire applied for the purpose of evaluating the effect of a diabetes education intervention on indicator domains (eg self-efficacy, quality of life, physical activity).

Context

The societal and personal burden of diabetes is well documented elsewhere and has been acknowledged by the Australian Government through the inclusion of diabetes as a National Health Priority Area since 1996. In July this year (2006) the Council of Australian Governments re-affirmed its commitment to reducing the burden of diabetes and is currently exploring ways of enacting this commitment.

The volume, variety and level of complexity of daily decision making and skills required in the self-care of diabetes is unique and cannot be successfully achieved without information and self-care education of the person with diabetes and/or their carer/s. Diabetes patient education is recognised globally as a vital and integral component of overall diabetes care. It is believed to be most effectively delivered face to face although other means of education eg videos and web-based education can certainly play an important role in augmenting face to face education. Comprehensive diabetes education is usually provided by diabetes educators. However, all health professional disciplines and levels involved in the care of people with diabetes have a responsibility to ensure that whatever information or education they provide to people with diabetes is timely, relevant, consistent, accurate and empowering.

Patient education is usually provided individually or in group sessions but it is generally recognised that all people with diabetes should have the opportunity for at least some of their education to be individualised to their personal circumstances, learning styles and type of treatment. Over the last decade or two the focus of diabetes education has shifted from a doctor/nurse didactic information-giving style of education to a more patient-centred approach. Therapeutic patient-centred education has been promoted since the 1970s when Jean-Phillipe Assal first introduced the approach in the treatment of diabetes including medical, psychological and educational care (Maldonato et al, 1995).

Despite the constraints imposed by resource limitations and the geographical nature of our country - large land mass with a widely scattered population - Australia has a well developed system of services capable of providing effective education to people with diabetes. These include:

- A workforce of some 1300 diabetes educators who are members of the Australian Diabetes Educators Association (ADEA) and work in diabetes centres, peripheral hospitals, community health centres, general practice settings, and private practice.
- A network of over 70 publicly funded specialist ambulatory care Diabetes Centres. These are primarily attached to metropolitan public hospitals but are increasingly found in major rural centres. These Centres commonly provide treatment as well as patient education and many provide outreach services in partnership with rural or remote hospital and primary care services and Aboriginal Medical Services.
- A small number of private specialist Diabetes Centres.
- Diabetes Australia state and territory member associations which provide education and information services.

- Community nurses and dietitians, practice nurses and Aboriginal health workers who are not necessarily qualified diabetes educators but who may have additional training in diabetes education.
- Community pharmacists who are increasingly providing preliminary diabetes patient education in the form of advice, education and ‘trouble shooting’.
- Diabetologists/endocrinologists and general practitioners who may provide limited diabetes education.

The Juvenile Diabetes Research Foundation (JDRF) does not provide discrete education services. However, it does provide information, support and mentoring to individuals and families with diabetes. Additionally, a number of diabetes support groups and web-based organisations and services that may not have education as their principal object also serve as a source of diabetes education and information.

Australian Diabetes Educators Association is the peak body for diabetes education. Celebrating its 25th anniversary at the time of this report, the ADEA provides professional support and sets standards of professional practice for its members, and undertakes a range of ongoing quality initiatives in diabetes education.

Rationale

This project is about providing a framework for the design and evaluation of diabetes education programs for people with diabetes and health professionals. It is concerned with the quality of diabetes patient education and with the identification of a robust base from which the quality and effectiveness of education can be benchmarked and improved. It is not about determining whether or not diabetes education is effective – that is not in question. Previous research cites diabetes education as responsible for reduction in amputation rates, and reduced hospital admissions, length of stay and re-admission rates and there is substantial evidence that improvement has been achieved following diabetes self-management education in the following areas:

- glycaemic control (Brown, 1990; 1999; Norris et al, 2002a; Deakin et al, 2005)
- knowledge (Brown, 1992; Deakin et al, 2005)
- self-care behaviours (Brown, 1990; Deakin et al, 2005)
- psychological outcomes (Steed et al, 2003; Deakin et al, 2005)

It has also been suggested that self-care support for chronic diseases reduces visits to general practitioners, outpatient clinics, accident and emergency units and drug expenditure (UK Dept of Health, 2006). The same report states that *“people with longer term conditions have better lives when they are supported to take care of their conditions themselves”*.

The variety and complexity of diabetes self-care is onerous and ongoing and is critically important to the avoidance of short and long term diabetes complications. It is imperative that people with diabetes have access to opportunities to acquire the necessary information and skills to self-manage their condition (Diabetes UK, 2005) and numerous guidelines and reports recommend that all people with diabetes should have access to information and self-management about their diabetes (Home et al, 1999; NICE, 2003; IDF, 2005).

Comprehensive diabetes care and education requires the input of a health care team including endocrinologists, diabetes educators, dietitians, general practitioners, podiatrists, psychologists, pharmacists and optometrists (DHA, 2006). The role of the team is to assist the person with diabetes to take control of, and responsibility, for their own diabetes self-care (Fain et al, 1999; UK Dept of Health, 2006). However, opinions vary widely within and between provider groups, and consumers about the ultimate aims of diabetes education and a number of reports have identified deficiencies and variations in the delivery of diabetes education which appear to be related to the lack of agreed outcomes. For example, Naqib (2002) identified gaps in diabetes patient education and inconsistency in information delivery. Similar findings were reported in Australia by Colagiuri & Goodall (2004) who described a range of unmet needs experienced by people with diabetes including inconsistencies in the self-care education and information they receive from providers.

Others point out that evaluation of diabetes education has been focused on the process and structure of programs and services with little input from people with diabetes with regard to their expectations and needs (Muhlhauser & Berger, 2000; Peeples et al, 2001). New models and ways of 'packaging' chronic disease self-care education such as the (former) UK Modernisation Agency's *Patient Journey* initiative are undoubtedly attempting to adopt a more consumer oriented perspective (Canterbury District Health Board, 2005). Nonetheless, as can be seen from the literature review conducted in the course of this project (Appendix 1: pages A1-8 to A1-13), there are virtually no published statements describing precisely what it is that diabetes education is trying to achieve and what people with diabetes should have, or be able to do, as a result of education about their diabetes. Even where there have been attempts to describe the desired inputs and outputs for optimal patient education, the methods employed to achieve this do not appear to have included systematic engagement of key stakeholder groups.

The lack of agreed standardised outcomes and indicators for diabetes patient education, on which educational interventions can be based and against which their effectiveness can be monitored and evaluated has been recognised in a number of national and international reports (Glasgow & Osteen, 1992; Home et al, 1999; Fain et al, 1999; Naqib, 2002; Colagiuri R et al, 2003; IDF, 2003; Colagiuri & Goodall, 2004). This deficit was highlighted locally when a workshop of Australian experts, convened to systematically identify gaps in the scientific evidence about type 2 diabetes, cited lack of agreed education benchmarks and indicators as the major barrier to generating evidence about the effectiveness of diabetes patient education - specifically, objective judgements about the relative efficacy of different educational methods and models (Colagiuri R et al, 2003).

There are also less obvious impacts. For example, the Australian Government requires ongoing evaluation of education and information resources developed under the National Diabetes Services Scheme '*against indicators that might measure and identify outcomes for people with diabetes*'. However, there are no agreed indicators to measure education related outcomes. Further, a national survey of education and information services (Colagiuri & Goodall, 2004) indicated that relatively few providers assess the outcomes of the education services they provide. The reason for this is not clear but it may well be due to the lack of agreed outcomes and indicators to support such evaluations.

Diabetes organisations and education services all over the world have documented a broad array of objectives for the programs they provide but there is still virtually no systematically derived, nationally agreed position as to what should be the key overarching goals and outcomes of diabetes education and no indicators to guide or assess its effectiveness. Fain et al (1999) point out that it is difficult to assess the unique contribution of the education to diabetes outcomes.

Consequently, the specific and unique impact of diabetes patient education on the person with diabetes has not been well researched and efforts to assess the effectiveness of diabetes education have traditionally relied on measures of metabolic control (ie HbA_{1c}, lipids, Body Mass Index (BMI)) and less often on quality of life (Berger & Muhlhauser, 1999; Peeples et al, 2001) and knowledge and attitudes towards diabetes (Fain et al, 1999).

Furthermore, the lack of education specific indicators and standardised outcome measures hinders our ability to generalise about the impact of diabetes education and its contribution to the health and economic status of individuals and populations with diabetes (Peeples et al, 2001; Colagiuri R et al, 2003). This deficit caused Glasgow (1999) to urge that we embrace the complexity of diabetes self-management education and incorporate patient-defined outcomes, and that we apply the same importance to standards of both biological and behavioural outcomes.

The results of this project provide a policy platform and framework for responding to these needs by describing a systematically derived consensus about the purpose and desired outputs of diabetes patient education that takes account of the perspectives of people with diabetes, as well as providers and policy makers alike.

Aim

The aim of this project was to develop a set of systematically derived standards and benchmarks to guide the design, delivery, monitoring and assessment of diabetes education by:

1. Developing a national evidence/consensus position statement on the key desired goals and outcomes of diabetes education.
2. Identifying nationally agreed indicators for assessing the effectiveness of diabetes education in achieving these goals and outcomes.

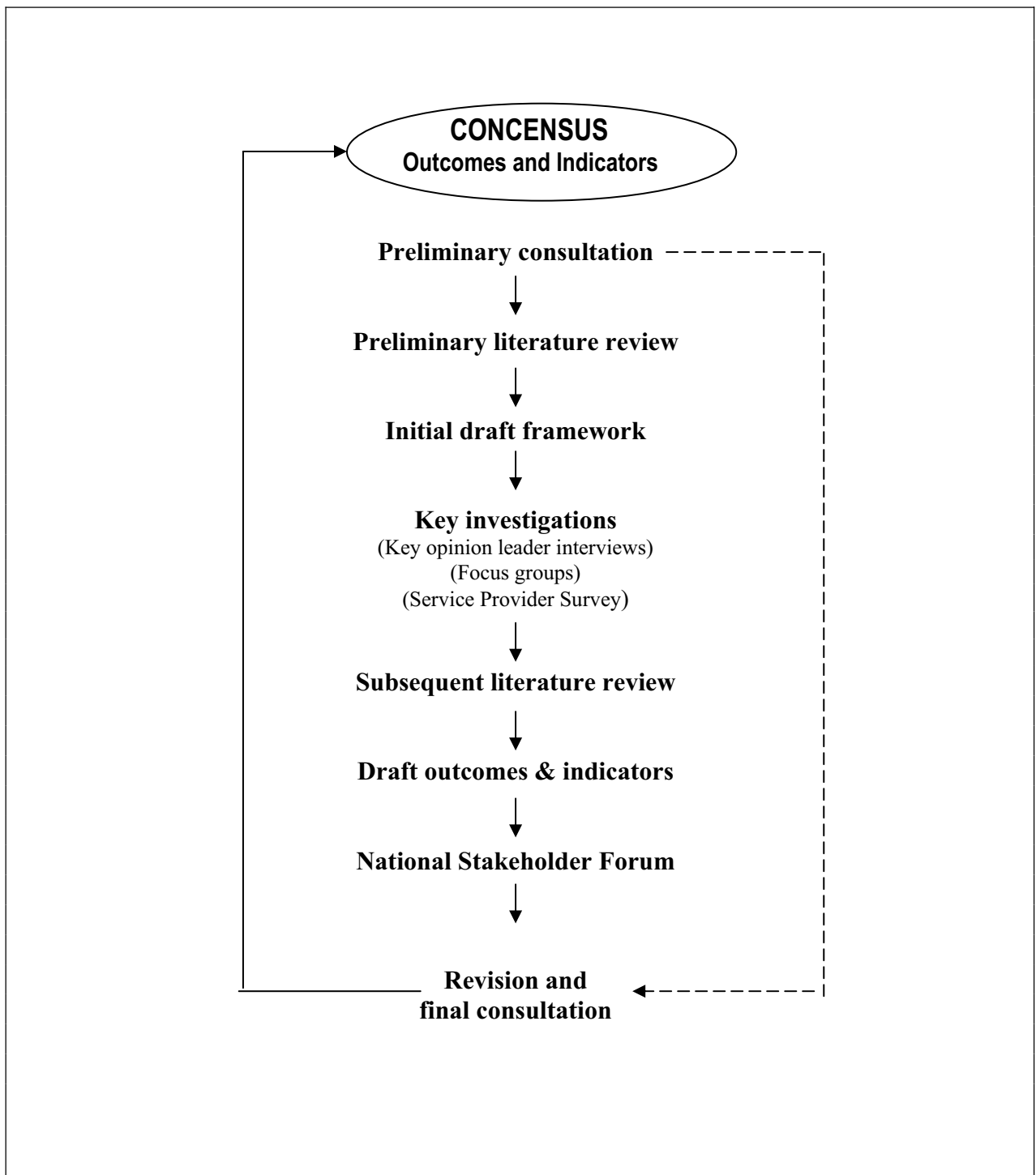
Methods and processes

The methods and processes used were:

1. Engage and inform key stakeholder groups
 - convene a representative advisory group to guide the project
 - notify Commonwealth, State and Territory Health Departments, diabetes related professionals and organisations, and other relevant groups of the commencement of the project and seek their inputs.
2. Conduct desktop research and investigations
 - search and review the international literature and government, professional society, academic and consumer websites for relevant evidence and examples
 - communicate with people undertaking peer or similar projects
 - survey relevant providers and organisations re existing outcome/indicator tools.
3. Consult with key stakeholder groups
 - interview key opinions leaders across Australia from a range of perspectives including health policy makers, health funders, planners, and providers from mainstream services and groups with special needs
 - conduct focus groups with a range of people with diabetes to identify their perspectives.
4. Analyse and synthesise the results of 2) and 3) to develop a set of draft outcomes and indicators.
5. Hold a national Stakeholder Forum to bring together key representatives of the key stakeholder groups to review findings of the research and consultation, and agree on, or amend, and endorse the outcomes and indicators.
6. Revise, amend, report and make recommendations about the agreed outcomes and indicators.

The flowchart in Figure 1 illustrates the processes undertaken.

Figure 1: Flowchart of methods and processes



Section 2: Drafting the Framework

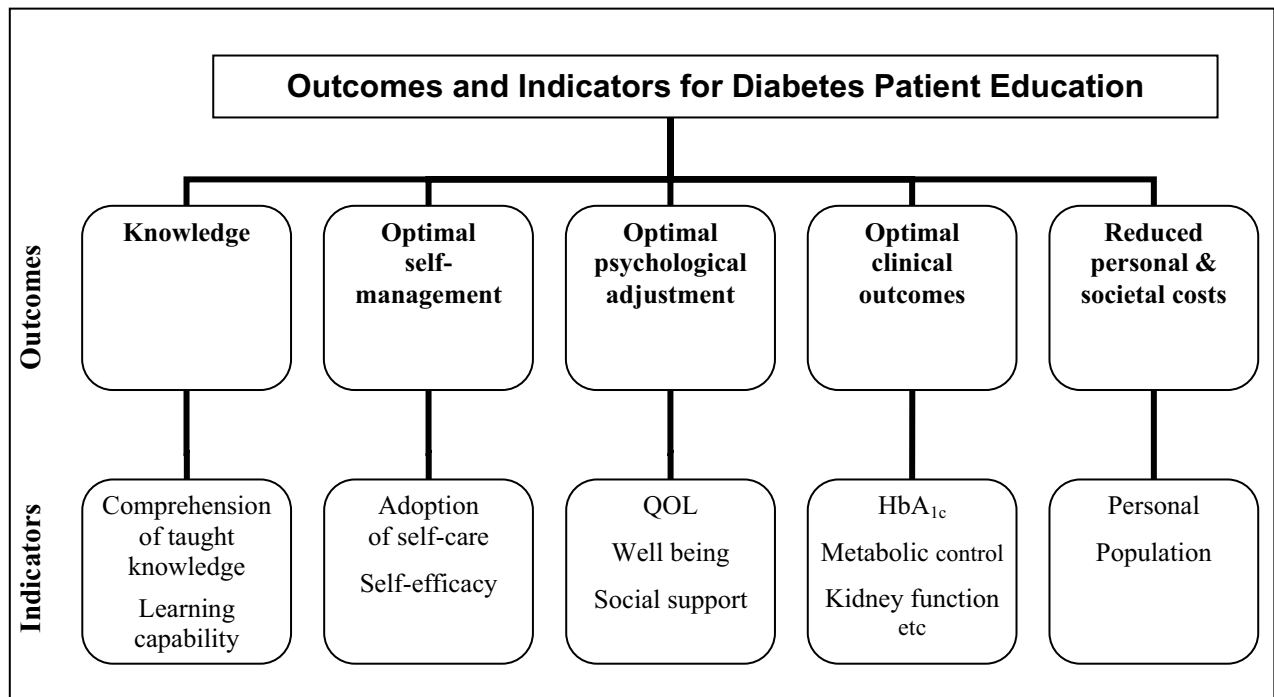
- **Drafting the initial framework**
 - **Summary of preliminary literature review**
 - **Consultation workshop with diabetes educators**
 - **Other consultation**

Drafting the initial framework

At the commencement of the project a draft framework was formulated by the project team as a tool for conceptualising and consulting about the key domains of diabetes education and areas for the development of indicators. This was subsequently presented to a workshop of diabetes educators and later to selected health authorities for their input as outlined below.

The draft framework shown in Figure 2, drew on work already completed in Australia and elsewhere as outlined in Section 1, and the collective experience and wisdom of the project Advisory Group and from opportunistic consultation with peers and colleagues. Five draft outcomes were identified as knowledge, optimal self-management, optimal psychological adjustment, optimal clinical outcomes and reduced economic cost. Examples of possible areas for corresponding draft indicators were listed as comprehension of taught knowledge, adoption of self-care recommendations, quality of life (QOL), metabolic control and personal and population costs.

Figure 2: Initial draft framework



The framework was also informed by the preliminary literature review which centred on international peer reviewed medical and education journals, and websites of relevant national and international government, professional and consumer organisations to:

- Seek information on existing consensus positions on diabetes education outcomes and indicators
- Determine the current status of work and trends in this area
- Assist in the development of a draft framework for identifying the outcomes and indicators.

Appendix 1 provides details of the preliminary literature review as well as a report on the subsequent literature review undertaken to identify potential tools for measuring the indicators following the identification of the draft indicators.

Summary of preliminary literature review

Only two examples of national efforts to establish consensus positions on diabetes education were found in the peer reviewed literature. These were from the American Association of Diabetes Educators (AADE) and a group of Canadian academics. While limited consultation formed part of the methodology for both of these initiatives, neither used a comprehensive and systematic consultation process that included all the major stakeholder groups and neither included consultation with consumers.

In 1997 the AADE established a taskforce to define outcomes specifically for diabetes education and create reliable and valid measurement tools and reporting systems (Tomky et al, 2000; Peeples et al, 2001). This led to the development of the National Diabetes Education Outcomes System which incorporates 'Standards for Outcomes Measurement of Diabetes Self-Management Education'. These standards were published as part of an AADE position statement (AADE, 2003) which identifies five main outcomes for Diabetes Self-Management Education (DSME) with behaviour change identified as the unique outcome measurement. Additionally, the position statement identifies seven diabetes self-care behaviours 'unique and measurable outcome of effective diabetes education' which should be evaluated at baseline and then at regular intervals following education. They are:

1. Being active: physical activity (exercise)
2. Eating
3. Medication taking
4. Blood glucose monitoring
5. Problem solving especially for high and low blood glucose; and sick days
6. Reducing risks of diabetes complications
7. Living with diabetes (psychosocial adaptation).

A Canadian 'consensus for the standardised evaluation of quality improvement interventions in type 2 diabetes' developed a set of indicators including health related QOL and satisfaction with diabetes care and self-care behaviours in addition to mostly clinical indicators (Majumdar et al, 2005). Some measurement tools for assessing QOL, self-care behaviours and satisfaction were listed in the document. No definition for 'quality improvement intervention' was discussed and it is unclear whether these indicators could be applied to measure diabetes education outcomes.

A number of other position statements were identified from the peer reviewed literature and websites but these did not report national consensus and were focused on methods and processes for delivering diabetes education rather than outcomes. For example, two position statements from the UK ie 'Structured Education for People with Diabetes' (Diabetes UK, 2005) and the 'National Diabetes Support Team' report on criteria for structured education programs, although outcome measures for the programs were not discussed. However, as part of the 'National Diabetes Support Team' statement, a health technology appraisal guidance published by the National Institute for Clinical Excellence (NICE, 2003) recommends relevant outcomes for educational interventions as diabetes-related knowledge, motivation and improvement in anxiety or depression. The report did not discuss implementation strategies or whether there was agreement about the proposed outcomes. Similarly, the International Diabetes Federation (IDF, 2003) 'International Consensus Standards of Practice For Diabetes Education' focuses on the structure of diabetes education programs and the only patient-centred outcome standards described are 'knowledge', 'knowledge application' and 'clinical outcomes'. Objectives but no measurable indicators are documented.

Despite the difficulty of attributing the relative contribution of education versus medical care to improved clinical outcomes, glycaemic control as measured by HbA_{1c} has been the most common outcome measure used to evaluate the effectiveness of diabetes education programs (Fain et al, 1999; Norris et al, 2002a; Norris et al, 2002b; Deakin et al, 2005). However, in recent years diabetes education outcome measures are increasingly focusing on attitudes, self-care skills, lifestyle behaviours, psychological outcomes, quality of life (Norris et al, 2001; Deakin et al, 2005) empowerment/self-efficacy and medication taking (Deakin et al, 2005).

Consultation workshop with diabetes educators

Diabetes educators are at the forefront of providing diabetes patient education in Australia. Consequently, capturing their experience and perspectives was critical to confirmation and further development of the draft outcomes and indicators. A workshop to consult with diabetes educators was held as part of the program of the ADEA Annual Scientific Meeting in Perth in September 2005. This afforded an ideal opportunity to obtain a national spread of views from different diabetes service settings and contexts. The workshop was attended by over 130 diabetes educators and a small number of others with a primary interest in diabetes education from across Australia. The 57 participants who signed the attendance sheet are listed in Appendix 2. The workshop comprised an introductory presentation about the background and rationale for the project and a structured process of consultation to obtain input on the outcomes and indicators as follows:

Outcomes

Step 1: Each participant rated what they perceived as the three most important outcomes of diabetes education by rating them in order of perceived priority. This process identified the three most important outcomes as: 1) knowledge and understanding 2) effective self-management and 3) empowerment. Other less frequently identified outcomes were: avoiding complications (short and long-term), quality of life, clinical outcomes and behaviour change. When presented with the initial draft framework (Figure 2) workshop participants unanimously agreed with the five draft outcomes ie knowledge, optimal self-management, optimal psychological adjustment, optimal clinical outcomes and reduced personal and societal costs. However, participants felt strongly that ‘empowerment’ should be included as a sixth outcome and that ‘understanding’ of the knowledge received was critical for optimal self-management and should complement knowledge as an outcome (Figure 3).

Additional comments

There was a strong general view that no outcome should stand alone but should be a continuum of steps or processes (eg improved self-management can lead to improved glycaemic control ie clinical outcomes) striving towards achieving the ultimate goal for the person with diabetes which is optimal quality of life. It was also expressed that knowledge was only a subset of outcomes as the literature clearly shows that improved knowledge alone does not necessarily lead to positive behaviour change. Vigorous discussion took place as to what degree diabetes patient education influences clinical outcomes and how this could be measured. It was concluded that multiple factors impacted on clinical outcomes with education having an indirect relationship to clinical outcomes.

Indicators

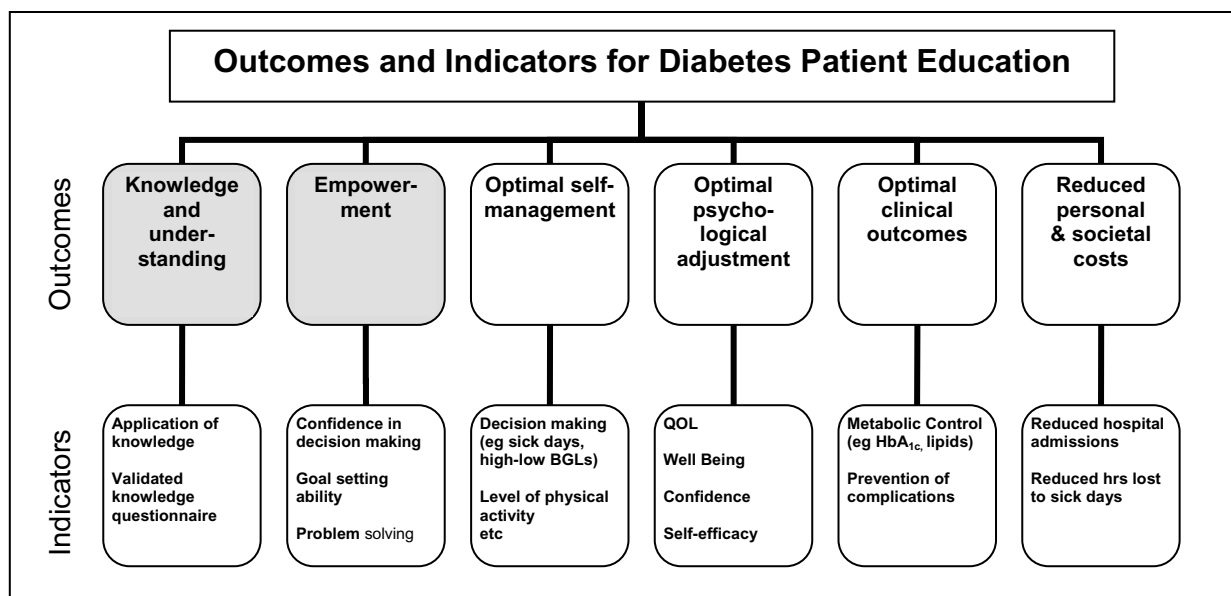
Step 2: Having agreed on the main outcomes of patient education, participants then workshopped the identification of indicators for each outcome in small groups. Table 1 presents a summary of the most commonly identified indicators for each of the six outcomes.

Table 1: ADEA workshop–indicator areas for measuring diabetes patient education outcomes

Outcomes	Knowledge	Empowerment	Optimal self-management	Optimal psychological adjustment	Optimal clinical outcomes	Reduced personal and societal cost
Indicators and indicator areas	Changes in scores on pre-post education - validated knowledge questionnaire	Confidence in decision making	Making appropriate decisions eg sick day management hypo- and hyper-glycaemia	Validated depression/ QOL scales/ measurement	Clinical eg HbA _{1c} , Blood glucose levels (BGL), Blood pressure, Lipids	Reduce number of diabetes related hospital admissions
	Checklist	Less anxious about their diabetes	Appropriate skills	Expressed well-being	Prevention of complications: - Short-term eg reduced episodes of hypoglycaemia/ diabetic ketoacidosis (DKA)	Reduced hours lost to diabetes related sick days
	Demonstrated changes in skills/ practical application of knowledge	Ability to set own goals and plans	Problem solving	Acceptance/ readiness to change	-Long-term eg cardio-vascular disease neuropathy nephropathy, retinopathy	Number of registrations with the NDSS
		Take self-responsibility	Goal setting	Confidence Self-esteem		Reduced number of episodes of hypoglycaemia
		Improved problem solving skills	Reported level of physical activity	Self-efficacy Locus of control		Appropriate attendance for education and assessment review
		Feeling of being in control	Number of hypo-glycaemic episodes	Active self-management		
		Ability to self-evaluate progress/ outcomes		Client satisfaction		
				Clinical outcomes		

The initial framework (Fig. 2 shown on p.18) was revised in accordance with comments from the ADEA workshop ie incorporating ‘empowerment’ as an additional key outcome and adding ‘understanding’ to the outcome already labelled as ‘knowledge’. These changes and revisions to the indicators made by workshop participants are listed under each of the outcomes shown in Figure 3.

Figure 3: Revised initial draft framework



Other consultation

The revised framework was taken to a meeting of Department of Health and Ageing (DHA) personnel convened by the Diabetes and Cardiovascular Health Section for the explicit purpose of consulting about the draft framework. The meeting was attended by seven DHA staff with an interest in diabetes from various departments (see Appendix 2). A separate consultation meeting was held with senior staff of the Australian Institute of Health and Welfare (AIHW) (see Appendix 2).

These meetings resulted in no specific changes to the draft framework but assisted in opening up and working through a number of important issues including; face validation of the draft outcomes and indicator areas; working definitions adopted for the project (as outlined on page 10) and some existing possibilities for collecting data on the indicators. The issue of whether the project’s primary concern should be inputs or outputs was raised. It was agreed that a focus on outputs and outcomes was, by definition, central to the project.

The difficulty of separating the effect of education on clinical outcomes from the more direct effects of medical treatment was also raised during the consultation. This has been acknowledged by many researchers (Fain et al, 1999; Brown, 1999; Glasgow, 1999; Peyrot, 1999; Snoek & Visser, 2003) and in view of the current irresolvable nature of this issue, and existing efforts and mechanisms for measuring the clinical and cost outcomes, it was agreed that the project should focus on those outcomes most likely to be directly affected by diabetes education ie:

- knowledge
- empowerment
- self-management
- psychological adjustment.

Section 3: Advancing the Framework

- **Consulting key stakeholders**
 - **Key opinion leader interviews**
 - **Focus groups with people with diabetes**
 - **Service provider survey**
- **Subsequent literature review**
- **The penultimate framework**

Consulting key stakeholders

The substantive investigations of the project centred on literature reviews and a systematic process of consultation and enquiry with key stakeholders. The consultation process aimed to confirm or amend and expand the initial draft goals, outcomes and indicators, and to categorise, refine and frame them into clear statements that synthesise the results of the preliminary literature review and initial consultations with the views of key stakeholders ie:

- Key opinion leaders
- People with diabetes
- Providers of diabetes education services

Once this phase of the project was completed a second or subsequent literature review was conducted to explore the existence of precedents and availability of tools for measuring changes in the identified indicator areas. This section summarises the results of the systematic consultation and the subsequent literature review that informed the further development of the outcomes and indicators.

Key opinion leader interviews

A purposive sample of 29 key opinion leaders (Appendix 3) was selected from among diabetes and related services and organisations with the aim of obtaining considered expert input and opinion from a range of settings and perspectives about the goal, outcomes and indicators for diabetes patient education. The interviews were conducted by the same researcher (CE) using a short structured interview guide of seven standardised questions asking opinions about the main goal, key outcomes and indicators for diabetes patient education (Appendix 3a). The majority were conducted face-to-face with a smaller proportion conducted by telephone where distance precluded a face to face interview. A thematic analysis was undertaken tabling responses, and using descriptive, qualitative frequencies of recurring themes and reporting relevant individual comments and quotes. The full results can be found at Appendix 3b and are summarised below.

Goal

The majority of key opinion leaders identified **patient empowerment** as the main goal or purpose of diabetes patient education. Expression of this included statements such as equipping, enabling, assisting, supporting and encouraging people with diabetes to effectively and confidently participate in diabetes self-management.

Key outcomes

One of the strongest key outcomes expressed was **knowledge and understanding** about diabetes. Knowledge was generally thought to be about self-care management; treatment targets; risks of complications; use of and adherence to medications and expectations of medical care. It was noted that educational information should be accurate; socially, culturally, linguistically and spiritually acceptable; address individual needs; be timely (stage of diabetes); and should enable people with diabetes to make informed choices. Similarly strong themes articulated as outcomes

of diabetes education were **quality of life and psychological adaptation**. These were variously expressed as quantity and quality of life; optimal mental health; integrating diabetes into lifestyle; psychological support; well-being; and feeling comfortable about having diabetes.

Adequate self-management skills and **patient empowerment** were also strongly identified as key outcomes. Behaviour change (physical activity, healthy eating, medication taking and adopting a healthy lifestyle); problem solving skills; engaging with the health care team; safety (ie avoiding and reducing hypoglycaemic events) were judged important as measures of self-management. Effective participation in self-management, confidence and coping with diabetes management, self-efficacy, patient reassurance, supporting patients' goals and patient confidence in decision making about diabetes self-management including 'crisis' management were included under the theme of patient empowerment. **Clinical outcomes** eg preventing/minimising risk of complications was viewed by fewer key opinion leaders as a key outcome as was accessibility to services and resources.

Interviewees noted that the identified outcomes may not be assessable as 'stand alones' but were linked together as part of a continuum of outcomes which might be achieved as the result of the education process.

Indicators

Table 2 lists key opinion leaders' most frequently identified indicators under each of the four most commonly expressed key outcomes. These were the result of a minority of interviews as many of the key opinion leaders felt they were not well equipped to list specific measures. A number of key opinion leaders pointed to available resources and literature that could aid in the development of appropriate indicators. These included validated instruments/scales for assessing behaviour change and QOL (see Appendix 3b pages A3-6 to A3-7). Pedometers were also identified as a useful indicator for physical activity. However, it should be noted that this list is not exhaustive.

Table 2: Key opinion leader interviews – indicators measuring key outcomes

Outcomes	Knowledge and understanding	Quality of life / psychological adaptation	Self-management / Behaviour change	Patient empowerment
Indicators	Validated knowledge questionnaire Improved self-care/lifestyle behaviours Practical problem solving exercises	Validated tools for assessing: - QOL - depression - anxiety - well-being - coping - confidence Referral rate to counsellors/psychologists	Medication adherence scale Standardised physical activity measure Uptake of pedometer Weight/BMI measure Standardised nutritional intake measure/food record Self-efficacy scale	Confidence Motivation for behaviour change Empowerment scale Self-efficacy

Summary

The strongest key outcomes of diabetes education articulated by key opinion leaders were knowledge and understanding, psychological adaptation/quality of life, adequate self-management skills and patient self-determination/empowerment. Clinical outcomes and accessibility to services and resources were mentioned less frequently.

Variable experience with regard to defining suitable indicators resulted in a minority of key opinion leaders identifying feasible indicators (Table 2); however some interviewees gave detailed information on specific tools for measuring behavioural and psychological outcomes.

Focus groups with people with diabetes

The purpose of the focus groups was to incorporate the views and opinions of people with diabetes and parents of children with diabetes. Six focus groups of 37 adults were conducted in two cities and two rural towns across three states and included 16 males and 21 females, 11 people with type 1 diabetes, 18 people with type 2 diabetes, 7 parents of children with diabetes and one person with pre-diabetes. The groups were categorised as follows:

- Parents of children with diabetes
- Young adult group (18 to 35 yrs)
- Adults with diabetes (> 35 to 64 years)
- Older Adults (> 64 and over)
- Two rural groups including all of the above categories

A set of seven semi-structured questions including prompts were used by the facilitator to elicit participants' views (Appendix 4). Participant's responses were analysed and reported descriptively by themes and supported by individual quotes. A full report of the results is available at Appendix 4a and is summarised below.

Goal

Each group had a slightly different focus on what they believed to be the main goal/purpose of diabetes patient education which reflected the characteristics of the group (eg age, stage of disease, parents or people with diabetes). The strongest theme expressed by young people was to stay as healthy and well as possible, to keep up to date with latest technologies and to be treated as adults. Parents of children with diabetes were more concerned about practical self-management skills (eg insulin injections, self blood glucose monitoring levels (SBGM)) and empowerment of themselves and their child to achieve best possible diabetes management. In adults, knowledge and information, self-management skills, psychological support, gaining coping and 'survival' skills and achieving best possible health and quality of life were thought to be the main goals of diabetes education.

Key outcomes

The four strongest themes with regard to the key outcomes of diabetes education are presented below, in descending order of importance.

Self-management skills – participants expressed the view that the advice they receive should include a simple tailored management plan, help motivate people to change behaviour and give them confidence in diabetes self-care.

Psychological support and quality of life – participants voiced a strong need for (professional) psychological support especially at diagnosis to enable adjustment and integration of diabetes self-care into their lifestyle.

Knowledge and understanding – parents of children with diabetes felt that knowledge was the cornerstone for diabetes self-management. Young adults emphasised that information about diabetes and self-management was invaluable for them to achieve independence and confidence in self-care and to maintain control of their diabetes. Adults noted that education needed to be simple, specific, precise and practical ie translatable into individual lifestyle, age adjusted, timely, tailored to individual needs, ongoing and include the whole family.

Clinical outcomes and access to resources and support networks received equal weight. Participants felt that knowing that their blood glucose levels and HbA_{1c} were under control was reassuring and agreed that knowing where, when and how to access help was vital for ongoing self-management. This was particularly highlighted by parents of children with diabetes. Peer support groups were seen as an important link for updating knowledge, exchanging experience and offering coping skills for daily living.

Indicators

Focus Group participants identified a number of relevant and practical indicators for measuring their identified outcomes. Table 3 lists these indicators according to each outcome, ranging from level of confidence, well-being, problem solving, knowledge, attendance at medical clinic and educational support and use of SBGM strips to more clinical indicators such as BGLs, HbA_{1c} and weight. People with diabetes recommended and agreed that completing a questionnaire for measuring achievements towards the outcomes was practical and acceptable.

Table 3: Focus group participants – indicators for key outcomes

Outcomes	Practical self-management skills	Psychological support/ Quality of life	Knowledge and understanding	Clinical outcomes	Access to resources & support networks
Indicators	Questionnaire re: - self-management skills - behaviour change Level of confidence Appropriate attendance rate at clinic Changes in diet and attitudes to food Patient held chart/diary Sale of SBGM strips through NDSS Weight HbA _{1c}	Questionnaire for assessing: - well-being - coping skills Mental well-being General well-being	Test/exam/questionnaire re: - knowledge - understanding Problem solving Annual knowledge test	HbA _{1c} BGLs SBGM record Doctor's response	Number of people attending post education support groups

Summary

There was strong agreement on key outcomes among people with diabetes and key opinion leaders. However, people with diabetes placed more emphasis on clinical outcomes and access to resources than key opinion leaders. People with diabetes gave considered answers in relation to feasible indicators. This demonstrates the important impact the consultations with people with diabetes had in advancing and validating the outcomes and indicators.

Service provider survey

A purpose designed paper-based questionnaire was used as the survey instrument (Appendix 5). A total of 87 surveys were sent to all Diabetes Centres registered with the National Association of Diabetes Centres and all Diabetes Australia state and territory associations. A response rate of 42.5 % (n=37) was achieved. The aim of the survey was to consult frontline diabetes education service providers about their:

- opinions with regard to goals, outcomes and indicators of diabetes patient education
- current activities in the area of program and service evaluation

The results of the survey are detailed in Appendix 5a and summarised below.

Main goal

As illustrated in Table 4, the dominant theme from the responses to the question “*what do you see as the main goal or purpose of diabetes patient education?*” was self-management followed by knowledge and understanding, empowerment and quality of life. Other frequently occurring themes (each of which represented 11%) were behaviour change, problem solving/decision making, and prevention of complications.

Table 4: Main goals of diabetes education identified by service providers

Goal or purpose of diabetes patient education	Percentage of responses (n=36)
Diabetes self-management	63.8
Knowledge (16.7%) and understanding (8.3%)	25.0
Empowerment	22.2
Quality of life	16.7

Key outcomes

The most frequent themes with regard to the “*three or four most important key outcomes of diabetes patient education*” were self-management, quality of life/emotional wellbeing/psychological adjustment, knowledge and understanding and prevention of complications (Table 5). Outcomes less frequently identified were behaviour/lifestyle change (37.1%), improved metabolic/glycaemic control and other targets (25.7%), self-determination/empowerment (17.1%), confidence (14.2%) and safety (5.7%), respectively.

Table 5: Key outcomes of diabetes education identified by service providers

Outcomes of diabetes patient education	Percentage of responses (n=36)
Diabetes self-management	52.7
QOL/emotional wellbeing/psychological adjustment	52.7
Knowledge and understanding	44.4
Prevention of complications	44.4

Indicators

Service providers were asked to suggest indicators that could feasibly measure progress towards achieving their identified outcomes. HbA_{1c} and other clinical indicators were most frequently listed with 54.8% of 36 responses (Table 6). Measuring quality of life with a validated tool (32.2%), behaviour change assessment tools (22.5%), knowledge tests (16.1%) and complication screening/incidence (16.1%) were amongst other commonly listed indicators.

Table 6: Indicator areas identified by service providers

Indicators for measuring key outcomes	Percentage of responses (n=31)
HbA _{1c} and other clinical indicators	54.8
Measuring QOL with a validated tool	32.2
Behaviour change assessment tools	22.5
Knowledge tests	16.1
Complication screening/incidence	16.1
Patient satisfaction survey	12.9
Pre-post education questionnaire	12.9
Diabetes related hospital admissions	9.6
Medication management	6.5
Client goal setting and review	6.5

When asked “Do you routinely monitor the outcomes of your service?”, 77.7% of respondents answered in the affirmative. Of the 28 affirmatives, 18 service providers indicated that they use clinical outcomes and indicators, 16 use indicators of well-being or quality of life, 10 use behavioural outcomes and indicators and four use indicators of psychological adjustment (Table 7).

Table 7: Service provider - assessment criteria for monitoring outcomes of services

Indicators	Percentage of responses (n=28)
Clinical outcomes and indicators	64.3
Indicators of well-being or quality of life	57.2
Behavioural outcomes and indicators	35.7
Indicators of psychological adjustment	14.3
Other	21.4

Fifteen respondents indicated that they use validated tools to measure their indicators, but only 13 gave specific details on the tools. Of these, eight used clinical tools such as the National Health and Medical Research Council (NHMRC) guidelines for type 2 diabetes. The other five responses related to psychological assessment tools ie anxiety and depression scale, well-being scale (WHO-5), Diabetes Attitude Score by University of Michigan Diabetes and Training Centre (MDRTC), Australian QOL scale for children (CHQ) and parent form (CHQ PF-50) and adolescence form (CHQ CF-80).

Summary

Service providers’ most frequently expressed themes with regard to the key outcomes were self-management, quality of life/emotional wellbeing/psychological adjustment, knowledge and understanding and prevention of complications. In contrast, the most frequently listed indicators for measuring the outcomes were HbA_{1c} and other clinical indicators. Although identified as a key outcome by over half of the respondents, only ten indicated that they measure well-being and quality of life and only five service providers use a validated tool for that purpose.

Service provider’s opinions were congruent with key opinion leaders and focus group participants. Differences were seen in the order of importance with service providers rating prevention of complications and focus group members rating clinical outcomes among their four key outcomes while key opinion leaders placed more emphasis on empowering patients.

Subsequent literature review

Assessing the outcomes and indicators

The subsequent literature review aimed to explore two areas. The first was whether the identified outcomes (knowledge and understanding, self-determination, psychological adjustment and self-management) had been measured as specific outcomes of diabetes patient education. The second was, if these outcomes had been reported as resulting from diabetes patient education and what (if any) tools had been applied to measure them. To guide the literature review two research questions were developed:

1. Are there any reports/publications in the international literature that have determined 'knowledge and understanding', 'self-determination', 'self-management' and 'psychological adjustment' as outcomes of diabetes patient education?
2. If yes, what indicators and measurement tools have been used to assess these outcomes?

This section of the report summarises the structured pragmatic review of the relevant literature which addressed these two questions. The list of tools identified is comprehensive but not exhaustive. It concentrated on those tools which are potentially applicable to the outcomes identified through this project in the Australian context. A brief description of each identified tool is provided. A detailed report of the results of this literature review, including availability of tools, can be found in Appendix 1 pages A1-14 to A1-26.

Summary of the literature review

Knowledge

Despite many studies from the diabetes education literature expressing concerns that knowledge acquisition does not translate into behaviour change (Glasgow & Osteen, 1992; Maldonato et al, 1995; Glasgow, 1999; Koopman & van der Bijl, 2001; Krichbaum et al, 2003; Snoek & Visser, 2003; Knight et al, 2006), a myriad of studies acknowledge the need to assess knowledge as an important measure of effectiveness of educational interventions (Maldonato et al, 1995; Tomky et al, 2000; Koopman & van der Bijl, 2001; Mulcahy et al, 2003; Mensing et al, 2003; Heisler et al, 2005). Diabetes education has been consistently reported to improve knowledge and understanding of diabetes (Brown, 1990; 1992; Hitchcock Noel et al, 1998; van den Arend et al, 2000; Davies et al, 2001; Hampson et al, 2001; Rickheim et al, 2002; Norris et al, 2002b; Trento et al, 2004; Deakin et al, 2005). Further, the more knowledge patients have, the more likely they are to implement positive lifestyle and self-care behaviours (van den Arend et al, 2000; Persell et al, 2004; Horsten et al, 2005); have better metabolic outcomes (Hitchcock Noel et al, 1998; Horsten et al, 2005); and have a higher level of treatment satisfaction (Horsten et al, 2005).

Tools for measuring diabetes knowledge and understanding

- Diabetes Knowledge Test (DKT) - American
- Diabetes Knowledge Assessment (DKN) scale - Australian

Self-determination

During the course of the consultation process it became apparent that there were some concerns about the term ‘empowerment’. Consequently it was replaced with ‘self-determination’ as a term that encompasses identified indicator areas such as empowerment, self-efficacy, confidence, coping and participation in goal setting and decision making.

Self-determination theory describes the concept of autonomous versus controlled motivation and perceived competence versus incompetence. Self-determination theory was tested by Williams et al (2004) in the context of diabetes self-management education. The authors concluded that “*autonomous motivation and perceived competence for diabetes self-management are important predictors of long-term glycaemic control and exert their effect through diabetes self-management behaviours*”. This supports similar conclusions made by other authors.

There is evidence in support of the integrity of each of the five domains of self determination identified in the consultation conducted under this project. For example **self-empowerment** (Deakin et al, 2005); enhancement of a patients’ perceived **self-efficacy** (Anderson et al, 2000) **coping** (Grey, 2000), **self-confidence** and problem solving skills (Krichbaum et al, 2003; Trento et al, 2004) have been measured following education interventions and have been postulated as important outcomes of diabetes self-care and education.

Tools for measuring self-determination

- Treatment Self-Regulation Questionnaire (TSRQ)

Tools for measuring empowerment, self-efficacy, confidence and coping

- Diabetes Empowerment Scale (DES) and DES-Short Form (DES-SF)
- The Confidence in Diabetes Self-Care (CIDS) - for people with type 1 diabetes
- Self-Efficacy of patients with Type 2 diabetes scale (SE-Type 2)
- Problem Areas In Diabetes (PAID) scale - to assess coping

Psychological adjustment

Depression is more common in people with diabetes compared to the general population and affects 10-20% of people with diabetes (Anderson et al, 2001). Many studies have demonstrated significant reductions in psychological health status in people with diabetes compared to the general population (Luscombe, 2000; Phillips, 2006) and have shown that quality of life worsened significantly in the presence of complications (Colagiuri S et al, 2003). However, a systematic review of psychosocial outcomes following diabetes education showed that quality of life improved following self-management interventions (Steed et al, 2003). Further, quality of life, using both generic and diabetes specific instruments, has been recommended and widely used in assessing the effect of diabetes education interventions (Dunn et al, 1986; Steed et al, 2003; Phillips, 2006).

Tools for measuring psychological adjustment

- Problem Areas in Diabetes (PAID) scale
- Appraisal of Diabetes Scale (ADS)
- Diabetes Integration Scale (ATT39) and short form ATT19
- Diabetes Quality of Life (DQOL)
- Chinese and Spanish versions of the DQOL
- Audit of Diabetes Dependent Quality of Life (ADDQOL)
- Audit of Diabetes Dependent Quality of Life for Teenagers (ADDQOL-Teens)
- Diabetes Specific Quality of Life Scale (DSQOLS)

- Questionnaire on Stress in Patients with Diabetes-Revised (QSD-R)
- Diabetes Care Profile (DCP)
- Short Form-36 - global health related quality of life instrument (SF-36)
- European Quality of Life- 5 dimension questionnaire (EQ-5D)
- World Health Organisation - Five Well-Being Index (WHO-5)
- Well Being Questionnaire-12 items (WBQ-12)
- Kessler Psychological Distress Scale – 10 items (K10)
- Child Health Questionnaire (CHQ)
- Child Health Questionnaire Parent Form-50 items (CHQ PF-50)
- Child Health Questionnaire for adolescence 18 to 20 years old-80 items (CHQ CF-80)

Self-management

Domains of self-management behaviours have been assessed following education interventions and include exercise, food intake (van den Arend et al, 2000; Norris et al, 2002a; Deakin et al, 2005), self-reported dietary habits (Norris et al, 2001), self-monitoring of blood glucose level (Hampson et al, 2001; Deakin et al, 2005), self testing urine (Norris et al, 2001; Deakin et al, 2005), insulin self-management (Hampson et al, 2001), smoking (Norris et al, 2002a) and foot inspection (van den Arend et al, 2000).

Tools for assessing self-management

- Diabetes Self-Management Assessment Report Tool (D-SMART)
- Summary of Diabetes Self-Care Activities (SDSCA)
- Environmental Barriers to Adherence Scale (EBAS)
- Self-Care Inventory-Revised (SCI-R)
- Habitual Physical Activity Index (HPAI)
- Self-Efficacy for Exercise Scale (SEE)
- Pedometers (step counters)

The literature review established that knowledge and understanding, self-determination, psychological adjustment and self-management have been used as outcome measures of diabetes education interventions. Table 8 shows a selection of tools, which were identified through consultation with stakeholders and the literature review, and which are potentially suitable for measuring changes in the identified outcome and indicator areas. As already noted, this literature review did not consider tools for measuring clinical or cost outcomes as these were excluded as a focus of attention earlier in the project on the basis that they are already being addressed through other mechanisms and programs.

Diabetes specific QOL has been a commonly assessed domain in research about diabetes care and education. Less frequently, knowledge, readiness to change, empowerment, self-efficacy, coping and confidence, well-being, mental health, and self-care activities (diet, physical activity, medication taking, blood glucose testing, insulin-injecting) have been identified as measures of effectiveness following diabetes interventions.

Numerous validated QOL measurement tools exist, both generic and diabetes specific. Fewer tools are available to assess knowledge, self-determination and self-management. As many of the described tools have been developed and tested overseas, the applicability to the Australian context would need to be established. It is outside the scope of this review to recommend the most appropriate tools for measuring knowledge, self-determination, psychological adjustment and self-management in the Australian context and this requires further investigation.

Table 8: Selection of tools for measuring the identified outcomes

OUTCOMES	Knowledge and understanding	Self-determination	Psychological adjustment	Self-management	Clinical outcomes	Cost
INDICATORS Level of scores for:	Diabetes knowledge Application of knowledge	Self-efficacy Empowerment Coping skills Level of confidence with diabetes self-management Participation in goal setting and decisions	Well-being Quality of life Mental health state	Problem solving skills Practical skills (ie SBGM, Insulin injections) Medication taking Physical activity Appropriate eating	<i>Biochemical:</i> HbA _{1c} Lipids Kidney function <i>Complications:</i> Frequency and severity of short-term complications Presence/absence of long-term complications <i>Physical:</i> Blood Pressure	<i>Individual:</i> Out of pocket expenses for PWD*/carers (SBGM, medication) Loss of income for PWD/carers <i>Societal:</i> Cost of products, medication, services (NDSS, PBS**) Financial burden of complications Loss of productivity
TOOLS	Diabetes knowledge assessment scales: DKN DKT	Self-determination scales: TSRQ Empowerment, self-efficacy, confidence and coping scales: CIDS DES / DES-SF PAID SE-Type 2 scale	Well-being scales: WHO-5 WBQ-12 PAID Quality of life scales: ADDQoL ADDQoL-Teen DCP DQOL DQOL Chinese DQOL Spanish DSQOLS EQ-5D QSD-R SF-36 Mental health state scales: ADS ATT39/ATT19 CHQ CHQ PF50/80 K10	Self-management scales: D-SMART EBAS SCI-R SDSCA Physical activity scales: HPAI Pedometer (step counter) SEE		*PWD People with diabetes ** PBS Pharmaceutical Benefit Scheme

The penultimate framework

Pulling it together

Figure 4 illustrates the penultimate framework which was synthesised from the combined consultations and investigations undertaken in the course of the project and which was taken forward to the Stakeholder Forum in March 2006 for further refinement (see Section 4). Three overarching goals of diabetes education were identified:

- Optimal adjustment to living with diabetes
- Optimal physical health
- Optimal cost effectiveness

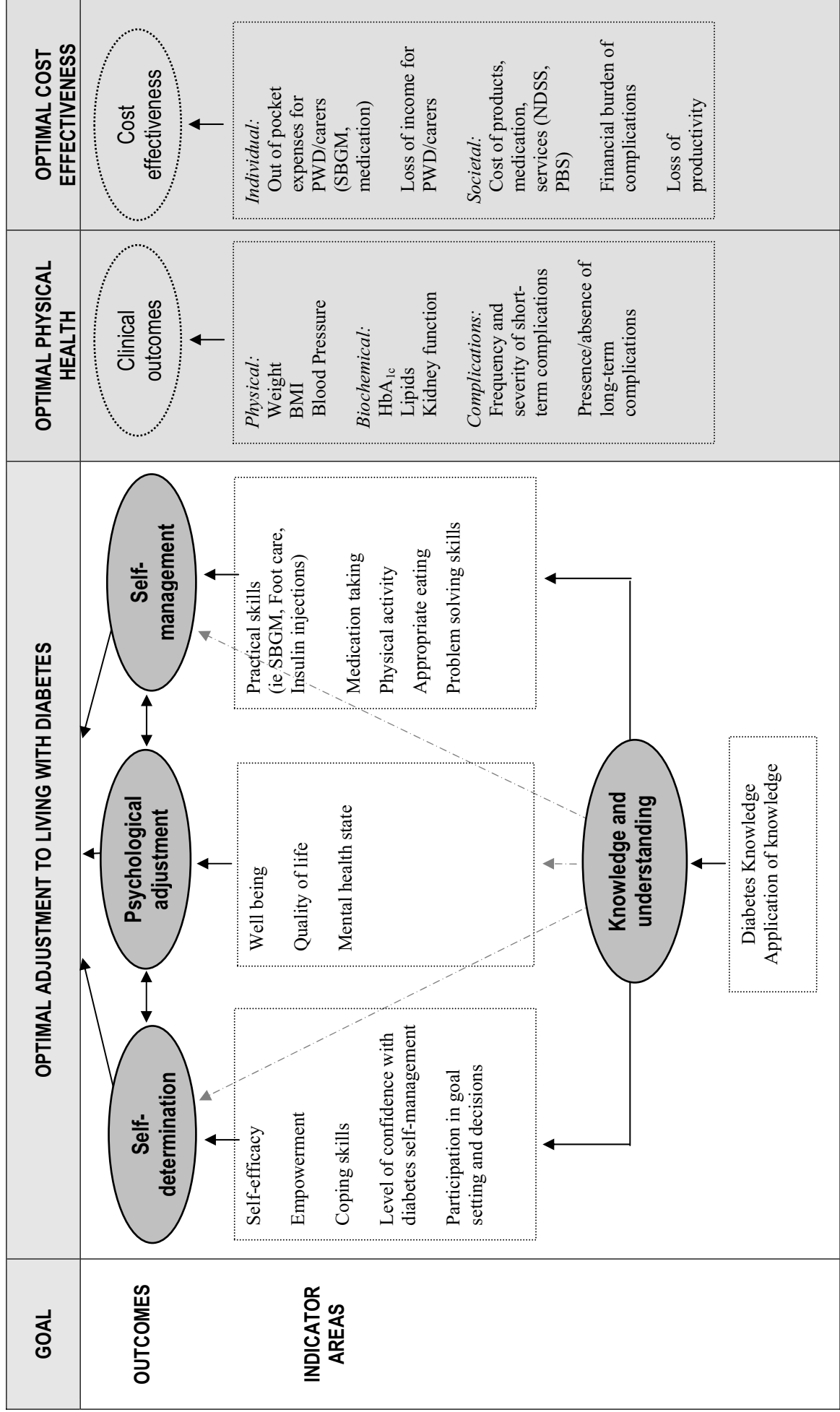
Physical health and **cost** were listed by stakeholders as important goals of patient education. Consequently, the penultimate framework shows surrogate clinical indicators such as glycaemic control and endpoint outcomes such as the presence or absence of long term diabetes complications. Optimal cost effectiveness ie best value was also identified as a key goal which could be measured by indicators of direct and indirect costs. These are shown in the framework in acknowledgment of their importance to diabetes outcomes generally and acknowledgement that patient education is an integral, even essential, component of the overall diabetes management that determines achievement of these goals. However, both from the literature reviews and consultation it is clear that it is not possible to identify and measure the effect of diabetes education on clinical and cost outcomes independently of medical treatment. As a result, the project and framework concentrated on those goals and outcomes in which, changes as a result of patient education, are most directly identifiable. Nonetheless it was agreed that education service providers should also be encouraged to collect data on clinical and cost indicators and that education, clinical and cost outcomes should be the subject of regular cross-comparison at the national level.

Four key outcomes were associated with **optimal adjustment to living with diabetes** which then became the focus of furthering the framework. They were:

- Knowledge and understanding
- Self-management
- Self-determination
- Psychological adjustment

Although it is widely believed that without motivation knowledge alone is insufficient to effect change, it is also clear that behaviour is unlikely to change unless there is a knowledge and understanding of a) the need to change and b) what to change. Both the literature and consultation supported **knowledge and understanding** as central to adjusting, self-managing and coping with diabetes. Empowerment was suggested as a key outcome by many of the stakeholders consulted to express notions of autonomy, confidence/coping, self-direction, self-efficacy, and active participation in decision making about diabetes treatment and overall management. However, empowerment is variously defined and variously regarded. Instead **self-determination**, defined as *“the ability or right to make your own decisions without interference from others”* was adopted as an outcome descriptor to encapsulate the concepts or constructs that were loosely identified as ‘empowerment’. **Psychological adjustment** was chosen as the term that best described constructs such as mental health state, quality of life and well-being, while **self-management** was defined as encompassing practical and problem solving skills and lifestyle behaviours.

Figure 4: Penultimate framework of outcomes and indicators for diabetes education



Section 4: Reaching Consensus

- **Stakeholder Forum**
- **Consensus position**
- **Existing data collection mechanisms**
- **Summary and recommendations**

Stakeholder Forum

An important component of the consultation process to reach national consensus on the goals, key outcomes and indicators for diabetes education was a national Stakeholder Forum held at Parliament House in Canberra on March 1, 2006.

The aim of the Forum was to bring together representatives of key stakeholder groups (Appendix 6) from among consumers and consumer organisations, diabetes educators, general practice, health departments and monitoring agencies to:

- Inform them about the purpose and status of the outcomes and indicators project
- Review findings of the research and consultation undertaken and agree on, or amend and endorse the resultant draft outcomes and indicators
- Consider a process for finalising the indicators and making recommendations about their application.

The Forum was attended by 35 representatives from ADEA, JDRE, AIHW, Diabetes Australia (DA), the Dietitians Association, Aboriginal diabetes services, state/territory health departments, people with diabetes, diabetes educators, general practice organisations, and academia. The Forum was officially launched by Senator Guy Barnett.

Appendix 6a shows the Forum agenda. Participants were provided with an overview of the project aims, methods and processes and the results of the consultation and investigations and presented with the penultimate framework of goals, outcomes and indicators shown in Figure 4. They were then asked to review the framework in detail and advise on the goals, outcomes and indicators. Following the Forum a summary of the main discussion points and outcomes was circulated to participants for confirmation.

Key issues raised

In the course of working towards consensus a number of important issues were raised and debated. These included:

- *Technical issues*

These revolved around issues relating to the purpose, definitions and application of indicators in relation to diabetes education and ways of framing questions around the identified indicators areas.

- *Outcomes versus inputs*

The concept of outcomes versus inputs was debated thoroughly prior to agreement that the relative relationship of these two concepts was rightly to focus on and describe the desired outcomes of diabetes education so that inputs in the form of program content, delivery modalities, and provider knowledge and skills could be designed around achieving the desired outcomes.

- *Universality*

There was considerable discussion around the application of the outcomes and indicators to ALL people with diabetes on the basis that some people experienced limitations that precluded them from achieving the goals and outcomes. This was specifically raised in relation to people with severe physical or mental disabilities that might limit their capacity for self-care or self-

determination but could also apply to the very young, the very old and people who experience barriers as a result of culture or social disadvantage. While the limitations imposed by such circumstances were well acknowledged, the prevailing principle was agreed as the need to strive for achievement of the identified goals and outcomes in all people with diabetes whilst acknowledging that:

- a) inputs need to be adapted to the unique needs and circumstances of the individual, and
- b) *optimal* means the best possible result in the circumstances and what we are trying to achieve is optimal education outcomes for all people with diabetes.

▪ *The unique nature and complexity of diabetes*

Concerns were raised that the outcomes identified in the penultimate framework did not adequately reflect the unique nature of diabetes and the complexity of its requirements for self-care. For example knowledge, self-management, self-determination and psychological adjustment could equally be applied to other chronic conditions. In view of this, the propensity for diabetes education to be subsumed into general chronic disease self-care education programs and fail to equip people with diabetes with the specific knowledge, skills and abilities for successful self-care was considered.

It was agreed that to be feasible the indicator set needed to be relatively small. This raised the dilemma of how to reconcile the definition of broad outcomes and a small set of core indicators with the uniqueness and importance of the multiplicity of the micro-aspects of diabetes management that contribute to overall health and well-being. Sick day management, adherence to medication taking, self blood glucose monitoring, carrying diabetes identification, carrying glucose to treat hypoglycaemia, balancing medications, carbohydrate intake and physical activity were among the areas identified which were thought to a) account for much of the personal daily burden of diabetes and b) be strongly influenced by diabetes education. As a result the indicator areas listed for self-care reflect many of these issues.

▪ *Defining education*

Surprisingly, diabetes education has not been well defined either in Australia or internationally. Although it was acknowledged that the Australian 'Best Practice Framework for Information and Education for People with Diabetes' (Colagiuri & Goodall, 2004) had 'gone along way towards defining it', there was a strong feeling among Forum participants that the outcomes and indicators project should provide a more explicit definition of diabetes education.

While this was outside the scope of the project and was not part of the project consultation, for the purpose of the project the investigators developed the following definition:

Diabetes education is an interactive process that facilitates and supports the individual and/or their families, carers or significant social contacts to acquire and apply the knowledge; confidence; and practical, problem-solving and coping skills needed to manage their life with diabetes to achieve the best possible outcomes within their own unique circumstances.

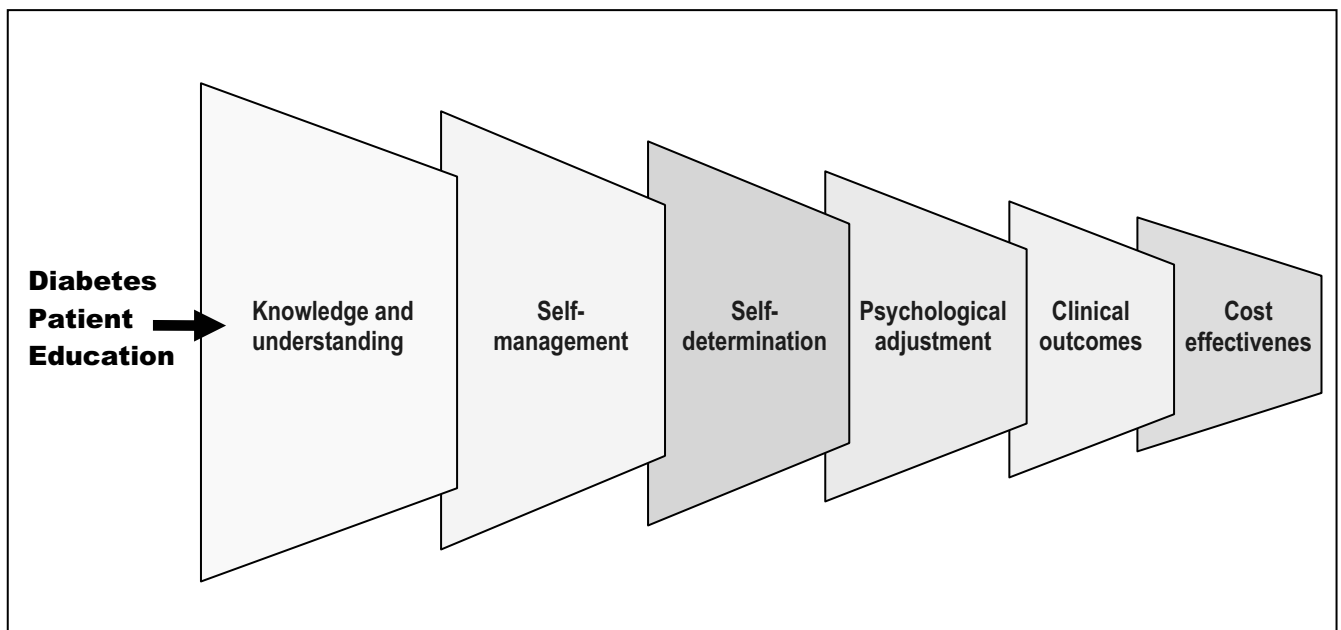
Confirming the goals and outcomes

The Stakeholder Forum confirmed the overarching goals of diabetes patient education shown in Figure 4. There was also good agreement and confirmation of the outcome areas identified by means of the previous investigations and consultation (Figure 5). Participants acknowledged that diabetes education contributes significantly to optimal physical/clinical outcomes and optimal cost effectiveness. However, due to a) the difficulties in attributing to what extent education impacts on these and b) the knowledge that indicators and data collection mechanisms for these

already exist, it was agreed by participants that the focus should be on the goal of ‘optimal adjustment to living with diabetes’.

Participants expressed concern that the outcomes shown in the penultimate framework did not adequately reflect the hierarchy of impact that patient education exerts on diabetes outcomes. It was agreed that the order in which the outcomes were shown should be re-arranged to more directly reflect the relationship and impact of education on each outcome. Following the Stakeholder Forum the framework was revised (Figure 5) to reflect the agreed key outcomes so that the outcomes were represented in a hierarchical manner with knowledge and understanding as the outcome most influenced by education, followed by self-management → self-determination → psychological adjustment → clinical outcomes → cost. It should be noted that the framework is arranged to reflect the impact of education on each outcome not the impact of the outcomes on each other.

Figure 5: Outcomes in order of direct influence by diabetes education



In addition, the unique nature of diabetes self-care requirements (eg carrying identification, sick day management) and the need for indicators to reflect them in full were acknowledged. The indicator areas agreed for use on a local service level are shown in the final framework (Figure 6) recognise and incorporate this requirement.

Consensus position

The goals, outcomes and indicators set out below represent the consensus position reached through this project on what are the main goals, key outcomes and indicator areas for diabetes patient education. These are shown in the final framework illustrated in Figure 6 and described below.

Goals

Three overarching goals were identified as the main purpose of diabetes patient education ie:

- Optimal adjustment to living with diabetes
- Optimal health (physical) outcomes
- Optimal cost effectiveness (for the individual and for society).

Outcomes

The key outcomes that can either be directly attributable to diabetes education, or in which diabetes education plays an important discernable role relate to the goal of '**optimal adjustment to living with diabetes**' and were agreed to be:

- Knowledge and understanding (includes application of knowledge)
- Self-determination (includes confidence and capacity for decision making)
- Self-management (includes skills, practices and behaviours)
- Psychological adjustment (includes well-being and quality of life).

Indicators

It should be noted that, although the framework emphasises outcomes and indicators associated with the goal of optimal adjustment to living with diabetes, diabetes education service providers are encouraged to also assess indicators of physical health and cost. It is further recommended that data on education, physical health and cost indicators for diabetes should be cross-analysed and reported on a national level at regular intervals.

The distinction between **population level** and **service level** indicators made below is arbitrary. It is potentially possible to measure changes in all the indicators listed at a population level. However, this is not feasible in the present circumstances. Consequently, six indicators were identified with a view to proposing these, either collectively or individually, for selection and inclusion into existing population surveys eg national, state based or regional surveillance mechanisms.

Population level indicators

1. The proportion of people with diabetes who received diabetes education in the previous 12 months.
2. The proportion of people with diabetes who received diabetes education in the previous 12 months from:
 - a) Diabetes Educator
 - b) Dietitian
 - c) General Practitioner
 - d) Pharmacist
 - e) Psychologist
 - f) Practice Nurse
 - g) Aboriginal Health Worker
 - h) Others please specify
3. The proportion of people with diabetes who received diabetes education in the previous 12 months who have a **‘diabetes knowledge, understanding and application of knowledge score’** of (threshold value) in a given test instrument.
4. The proportion of people with diabetes who received diabetes education in the previous 12 months who are **‘actively and confidently involved in diabetes self-care practices’** (threshold value) in a given test instrument.
5. The proportion of people with diabetes who received diabetes patient education in the previous 12 months and have a **‘self-management /behaviour change’ score’** of (threshold value) in a given test instrument.
6. The proportion of people with diabetes who have received diabetes education in the previous 12 months and have a **‘well-being/quality of life score’** of (threshold value) in a given test instrument.

Instruments that could measure indicators 3-6 are discussed in Appendix 1 (pp A1-14 to A1-26).

Service level indicators

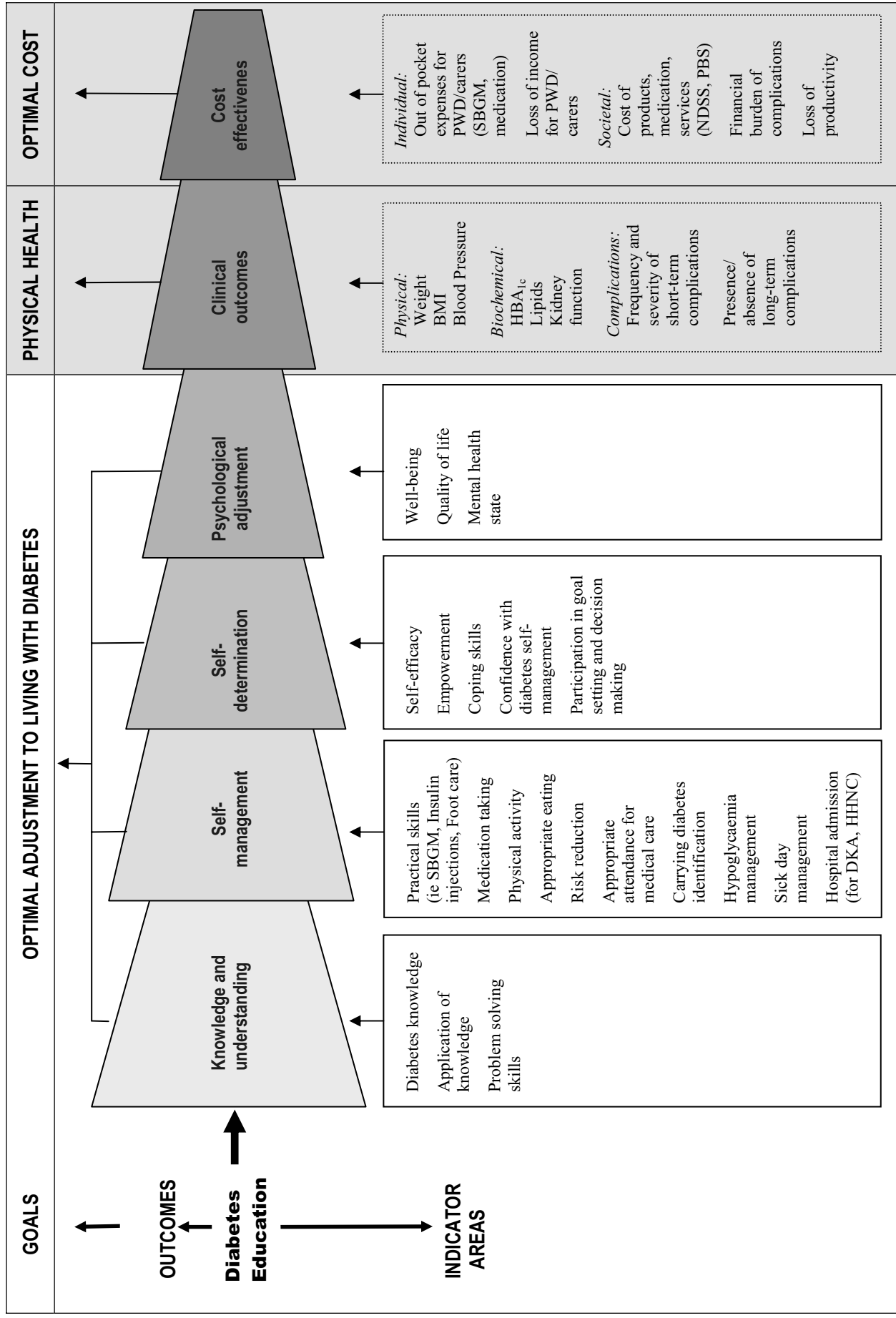
Population level indicators should and could also be used at the service level. Additionally, indicators for assessing outcomes of diabetes education at the level of individual services or practitioners were identified in the six outcome areas.

1. Knowledge and understanding as measured by scores (threshold value) on a given test instrument for:
 - knowledge and understanding
 - application of knowledge
 - problem solving skills.
2. Self-determination as measured by scores (threshold value) on a given test instrument for:
 - self-efficacy
 - empowerment
 - coping skills
 - confidence with diabetes self-management
 - participation in goal setting and decision making.

3. Self-management/self-care practices/behaviour change as measured by scores (threshold value) on a given test instrument for:
 - practical skills (ie. SBGM, insulin injections, foot care)
 - medication taking
 - physical activity
 - appropriate eating
 - risk reduction (smoking, alcohol intake)
 - appropriate attendance rate for medical care
 - carrying diabetes identification
 - hypoglycaemia management
 - sick day management
 - hospital admissions (for DKA, Hyperosmolar hyperglycaemic nonketotic coma (HHNC)).

4. Psychological adjustment as measured by scores (threshold value) on a given test instrument
 - well-being
 - quality of life
 - mental health state.

Figure 6: Final framework of goals, outcomes and indicator areas for diabetes education



Existing data collection mechanisms

At various points throughout the project consultation it was suggested that the feasibility of collecting data on indicators for diabetes education would be considerably enhanced by incorporating selected indicators into existing diabetes data collection mechanisms. The following is a summary of a recent report (AIHW: Dixon T & Webbie K, 2006) on existing national systems for monitoring diabetes in Australia.

In 1999 the Department of Health and Ageing funded the AIHW to establish 'The National System for Monitoring Diabetes' to produce efficient and reliable data. This encompasses:

- the National Centre for Monitoring Diabetes
- the National Diabetes Data Working Group (NDDWG)
- the National Diabetes Strategies Group
- information providers and experts
- outputs including reports
- guidelines, indicators sets and metadata (concerned with clinical and research use of diabetes data)

The National Centre for Monitoring Diabetes is located at the AIHW. Its role is to improve information on diabetes by coordinating national efforts to monitor diabetes, its risk factors, complications, treatment and health outcomes. It receives advice from the National Diabetes Data Working Group which in turn report to the National Diabetes Strategies Group until it was disbanded in May 2006. The NDDWG includes clinicians, policy makers, researchers, consumers and other experts in the field of diabetes.

The report describes the aims, scopes and processes for monitoring diabetes in Australia and gives a detailed list and short description of national and state based data sources and indicators relevant to diabetes. The information currently available for diabetes monitoring consists of national administrative data sources, register data sources, survey data sources and other existing and developmental data sources (AIHW: Dixon T & Webbie K, 2006).

Table 9 lists a sample of data sources identified from the AIHW report. These data collection mechanisms could be utilised for the purpose of measuring the effectiveness of diabetes education ie data collection for measuring identified indicators (eg diabetes knowledge and understanding, self-management behaviours, level of confidence with diabetes self-care, well-being and quality of life). A complete list of diabetes data sources is found in the full report (AIHW: Dixon T & Webbie K, 2006).

Additionally, the report lists state-based surveys that collect data through computer assisted telephone interviews (CATI), computer assisted personal interviews (CAPI) or by paper-based (self-complete) survey. Some of these surveys could also be tapped into for measuring and comparing state wide effects of diabetes education interventions (Table 10).

Table 9: Sample of Australian survey data sources for diabetes

Type of data source	Name of data source	Utility of data collection	Relevance/potential for monitoring the effect of diabetes education
Administrative	National Diabetes Services Scheme (NDSS)	Provides information on self-management products and services used by people with diabetes	Monitor SBGM behaviours through NDSS registration data
Register	National Diabetes Register– main sources of data from NDSS and Australasian Paediatric Endocrine Group register	Provides information on use of insulin treatment	Information (on new cases) is important for workforce planning. Potential use as a sampling frame to survey people with diabetes on aspects of diabetes education eg self-care behaviours.
National Surveys	BEACH (Better the Evaluation and Care of Health) survey in General Practice	Ongoing survey on clinical activities, problems managed and management techniques of general practitioners	Questions added to survey eg re diabetes knowledge, self-management behaviours, level of self-determination and psychological problems of people with diabetes
	National Health Survey	Conducted every three years, including self-reported diabetes status, type, treatment, risk factors, weight, blood pressure, and physical activity	Add additional questions or validated questionnaire to survey eg re diabetes knowledge, self-management behaviours, level of self-determination and psychological problems of people with diabetes
Other existing and developmental data sources	National Integrated Diabetes Program (NIDP) Practice Incentive Program	Incentives for general practitioners to improve prevention, detection and management of diabetes (eg completion of cycle of care)	Add questions to survey re diabetes knowledge, self-management behaviours, level of self-determination and psychological problems of people with diabetes

Table 10: Sample of state based survey data sources for diabetes

State	Name of data source	Utility of data collection	Relevance/potential for monitoring the effect of diabetes education
New South Wales	Continuous Health Survey Program (CAPI- since 2002)	Includes people of all ages. Data collection includes self-reported diabetes status, risk factor status (nutrition, smoking, physical activity, overweight, clinical measures), accessibility and some demographic information. Specific questions can be added as required.	Monitor access to and comprehensiveness of diabetes education. Add additional questions re diabetes knowledge, self-management behaviours, level of self-determination and psychological adjustment to living with diabetes.
Northern Territory	Health and Well-being Survey (CATI)*	Conducted in 2000. Data collected included diabetes status, risk factors, health service usage and mental health issues.	If survey is repeated add additional questions re access to and comprehensiveness of diabetes education, diabetes knowledge, self-management behaviours, level of self-determination and psychological adjustment to living with diabetes.
Queensland	General Health Survey <i>run concurrently in 2001 with</i> Diabetes Management Survey (Both CATI)	Included diabetes status, presence and knowledge of risk factors, health outcomes. Data on risk factors for complications, presence of complications, health service use, current management practices, knowledge of a) long-term outcomes and b) symptoms of hypoglycaemia.	If repeated add additional questions re access to and comprehensiveness of: diabetes education, diabetes knowledge, self-management behaviours, level of self-determination and psychological adjustment to living with diabetes.
South Australia	Health Omnibus Survey (CATI)	Annual survey on: prevalence and incidence of health problems, health knowledge and behaviours, uptake of new programs and evaluation of health interventions.	Add additional diabetes specific questions re knowledge, self-management behaviours, access and evaluation of diabetes education programs.

State	Name of data source	Utility of data collection	Relevance/potential for monitoring the effect of diabetes education
South Australia	Social, environmental and Risk Context Information System (CATI)	Flexible monitoring system designed to provide health data on large population samples, used for self-reported information on specific health issues.	Conduct specific diabetes education evaluation survey (using developed indicators and outcomes).
Tasmania	Health Communities Survey (paper-based)*	Conducted in 1998. Included diabetes related risk factors, status and quality life.	If repeated add additional questions re access to and comprehensiveness of diabetes education, diabetes knowledge, self-management behaviours, level of self-determination and psychological adjustment to living with diabetes.
Victoria	Victorian Population Health Survey (CATI)*	Annual series of surveys (since 2001); Data on diabetes: risk factors, status, screening, complications, use of and satisfaction with health services.	Add additional questions re use and evaluation of diabetes education services, risk factor and self-management behaviours, diabetes knowledge, QOL and level of self-determination.
Western Australia	Health and well-being Surveillance System (CATI)	Interviews 550 people of all ages each month. Data related to diabetes include self-reported risk factors, health status, and health service use.	Add additional questions re: use and evaluation of diabetes education services, risk factor behaviours, diabetes knowledge, QOL and level of self-determination.

* Only survey listed for this state

Existing and routinely measured indicator sets relevant to diabetes, from the National Health Priority Area (NHPA) and the National Health Performance Committee (NHPC) were developed in 2003 and are collated and reported on by the AIHW. The NHPA indicators cover diabetes incidence, prevalence, risk factors, complications, hospital separations for diabetes complications, mortality, self-assessed health status, screening and management. Indicators collected by the NHPC are based on mortality rates, determinants of health including 'fruit and vegetable intake', physical activity', overweight and obesity' and health system performance. Additionally, the NDDWG is currently finalising the development of an indicator set based on answering six questions with regard to prevention, case detection, improving quality of care according to guidelines, equitability of access and reducing serious health effects of diabetes. A draft of the indicator sets are listed in the report's appendix. Additional indicators, measuring the effect of diabetes education interventions, could be added to these NHPA and NHPC data sets.

A New South Wales Survey conducted in 2002 and 2003 of persons aged 16 years and over was reported by the New South Wales Chief Health Officer (Population Health Division, 2004). It tables the action taken by surveyed people to manage their diabetes or high blood pressure ie insulin injections, oral medication or special dietary modification and presents data collected with regard to weight loss, exercise and other behaviours.

Summary and recommendations

Summary

The project was successful in achieving national consensus on the goals, key outcomes and indicator areas associated with these. This national consensus is a first for Australia and appears to be the only national consensus of its kind worldwide that has been derived through a comprehensive process that combined evidence and systematic consultation with a range of stakeholders.

The importance of the consultation cannot be over emphasised. People with diabetes are the primary stakeholders in diabetes care but are rarely consulted about their needs and perceptions and are even more rarely asked to provide input into the design of diabetes policies or programs. The contribution of people with diabetes to the diabetes education outcomes and indicators clearly illustrates the capacity of consumers to make considered judgments that contribute to policy development and the improvement of diabetes care.

A number of recommendations resulted from the project. These centred on monitoring of diabetes education outcomes, the design and evaluation of diabetes patient education programs and the training of health care providers. However, although the project identifies possible tools for measuring changes in these, identifying national consensus on which tools are the most suited to the Australian context was beyond the scope of the project. Further work needs to be done to reach agreement on nationally standardised data collection tools and the development of a core minimum knowledge questionnaire which could be applied nationally.

Recommendations

Key recommendation

Recognition of the importance of diabetes education as an integral component of good diabetes care and an important contributor to optimal health outcomes should be reflected in the adoption of selected diabetes education indicators into national and local monitoring of overall diabetes outcomes.

Recommendations for monitoring the outcomes of diabetes education

- Identify or develop an agreed, nationally standardised, core questionnaire for assessing patient knowledge of diabetes and self-care.
- Develop a consensus on which tools are best suited to measuring self-determination, self-management and psychological adjustment in the Australian context.
- Determine clinically significant scores or thresholds for each tool selected in order to better quantify the relationship of education to changes in outcomes.

- Incorporate selected population indicators into existing national and state and territory based data collection monitoring and surveillance systems.
- Add items of service level indicators to area health service, diabetes specialist services, Diabetes Australia education services and general practice monitoring systems.
- Encourage individual service providers to use the indicators to monitor the outcomes of the education services they provide.
- Develop a diabetes education specific information system and/or incorporate selected indicators into existing clinical information systems.
- Add selected indicators to the Australian National Diabetes Information Audit and Benchmarking (ANDIAB) data set.
- Develop mechanisms for cross-comparison and feedback of clinical, cost and educational outcomes nationally, to inform an evidence base for the relationship between clinical and non-clinical outcomes.

Recommendations for health professional training

- Use the goals, outcomes and indicators from the ‘National Consensus Position’ to determine inputs for diabetes training for health professionals. The level of depth and detail will vary according to the role of health professional groups in diabetes care and education but should include training programs for:
 - diabetes educators
 - undergraduate and graduate medical, nursing and allied health training
 - vocational and continuing education programs for general practitioners, practice nurses, Aboriginal health workers, generalist nurses, teachers, personal carers, aged care assistance and health professionals involved in a peripheral role of providing diabetes education.
- Base monitoring, evaluation and quality improvement of the diabetes education component of health professional training on the goals, outcomes and indicators described in the National Consensus.

Recommendations for the design and evaluation of education programs and services for people with diabetes

- Use the goals, outcomes and indicators from the National Consensus to determine the design and delivery (content, delivery models and approaches) of education programs for people with diabetes.
- Base monitoring, evaluation and quality improvement of the education programs for people with diabetes on the goals, outcomes and indicators described in the National Consensus.
- Use the goals, outcomes and indicators from the National Consensus as a basis for determining the staff skills mix required for diabetes education.

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Appendix 1: Full Literature Review

Full Literature Review

This report details the findings of a non-systematic review of the national and international literature regarding outcomes and indicators for diabetes patient education. This review was conducted in three parts:

- Part 1 *Definitions* – a review of the literature to identify accepted definitions of terms commonly used to describe various aspects and outcomes of patient education.
- Part 2 *Preliminary literature review* – to inform the development of outcomes and identification of associated indicators for diabetes patient education
- Part 3 *Subsequent literature review* – to identify potential tools for assessing the effect of diabetes patient education on identified outcomes ie: knowledge and understanding, self-determination, self-management and psychological adjustment.

Aim

The literature review aimed to identify the status of the national and international literature with regard to:

1. National evidence/consensus position statements on goals and outcomes of diabetes patient education
2. Nationally agreed indicators for assessing the effectiveness of diabetes patient education in achieving these goals and outcomes.

Scope

Definitions

Consistent with the scope of the project, searches were conducted to clarify the meaning of specific terms commonly associated with patient and/or of direct relevance to the project.

Preliminary literature review

An initial literature review was undertaken between August and December 2005 to identify key articles and reports from the international peer-reviewed and web-based literature relating to outcomes and indicators for diabetes patient education. The literature review did not include the processes and models of diabetes education delivery or interventions but concentrated on what we (providers and consumers) are trying to achieve with diabetes patient education.

Subsequent literature review

After an extensive consultation process with national key stakeholders including people with diabetes and collation of the preliminary literature review and results of the project investigations six draft outcomes for diabetes patient education were identified ie:

- knowledge and understanding
- self-determination
- psychological adjustment
- self-management
- clinical outcomes
- cost effectiveness

The subsequent review of the international literature was conducted from January to April 2006 to determine if the outcomes identified by the project ie *knowledge and understanding, self-determination, psychological adjustment and self-management* had been measured as a means of assessing the effectiveness of diabetes patient education interventions and, if so, what indicators and/or tools have been applied to monitor progress towards achieving these outcomes.

Although it is acknowledged that '*clinical outcomes*' and '*cost effectiveness*' are significantly affected by diabetes patient education, these outcomes were excluded as a focus of the literature review due to a) the difficulties in attributing to what extent diabetes patient education impacts on these parameters and b) the knowledge that indicators and data collection mechanisms for these already exist.

Methods

Research questions for preliminary literature review

Three preliminary research questions were used to guide the literature review focusing on outcomes and indicators of diabetes patient education. These were:

1. Are there any international reports, publications and/or position statements on nationally agreed outcomes and associated indicators for measuring the effect of diabetes patient education?
2. If yes, how have nationally agreed outcomes for diabetes education been determined?
3. What methods, criteria and definitions (if any) have been used in the development of nationally agreed indicators for measuring the effect of diabetes patient education?

Research questions for subsequent literature review

Two subsequent research questions emerged following identification of draft outcomes and indicators. These were:

4. Are there any reports/publications in the international literature that have determined knowledge and understanding, self-determination, self-management and psychological adjustment as outcomes of diabetes patient education?
5. If yes, what indicators and measurement tools have been used to assess these outcomes?

Search methods

For both the preliminary and subsequent literature review databases of the peer-reviewed literature including Medline, PubMed, CINAHL and Cochrane were searched.

Web-based searches, using the internet engines 'google' and 'google scholar', were conducted to identify national and international position statements and reports on outcomes and indicators for diabetes patient education. Additional relevant Australian reports were obtained from the researchers' professional contacts and key opinion leaders.

Inclusion/selection criteria

The following criteria were used for the review and selection of the studies:

- published 1990 - 2005 for preliminary search, 1990 - 2006 for subsequent search
- international
- available in English
- specifically focused on diabetes patient education outcomes and indicators
- preference given to meta-analysis and systematic reviews where available
- articles were selected on relevance to the topic
- hand searching of relevant articles and reports
- relevant Australian and overseas reports/publications known to the researchers

Key words

Preliminary literature search

- diabet\$, and
- patient\$ and
- education and
- outcome\$ and
- indicator\$

Subsequent literature search

- diabet\$, and
- patient\$ and
- education, and
 - knowledge and understanding
 - self-determination / empowerment / self-efficacy
 - self-management
 - psychological adjustment and
- measure\$ and
- tool\$ and
- scale\$ and
- indicator\$

Results Part 1: Definitions

Definitions in the context of diabetes patient education were searched; otherwise generic definitions were chosen that could be applied to health and/or diabetes education.

Outcome

The Australian Department of Health and Ageing (DHA) and the Australian Institute of Health and Welfare (AIHW) define a health outcome as: *“a change in the health of an individual, a group of people or a population, which is wholly or partially attributable to an intervention or series of interventions”* (DHA and AIHW, 1999).

The American Association of Diabetes Educators (AADE) used Donebedian’s definition of outcome of diabetes patient education: *“a measurable product and the changed state or condition of an individual as a consequence of health care over time”* (Mulcahy et al, 2003).

Indicator

The term indicator is derived from the Latin root ‘indicare’ which means to direct or to point out. In quantitative terms it is a statistic that extracts the best possible information from a data source for succinct presentation and regular monitoring. In qualitative terms, it describes a process or aspect of an issue that provides a lead to underlying trends (AIHW, 2006).

Similarly, O’Leary (2004) defined an indicator as a measurement tool used to quantify performance of processes and achievement of outcomes.

According to Boyce et al (1997) indicators in health care are units of information, which indirectly or directly reflect the performance of the healthcare system in increasing or maintaining the well-being of its target population. The role of indicators is to provide a set of objective criteria by which implementation and effect of an intervention can be monitored. In order to be useful, indicators must satisfy a number of criteria:

- a) acceptance by key stakeholders
- b) validity for the purpose to which they are put
- c) reliability, in that the result must be consistent and repeatable and
- d) interpretation of the indicators should be consistent among stakeholders

The DHA and AIHW define an indicator as *“a specific measure for assessing progress towards a goal. In terms of health outcomes, an indicator is a statistic or other unit of information which reflects, directly or indirectly, the performance of a health and welfare intervention, facility, service or system in maintaining or increasing the well-being of its target population”* (DHA and AIHW, 1999).

The UK Health Development Agency (UK HDA) states that an evaluation might have a range of indicators ranging from process, impact and outcome indicators. Process indicators offer evidence on the effectiveness of the planning and implementation of an intervention. They also provide its acceptability and accessibility. Impact indicators describe the immediate benefits of the intervention and are useful for keeping people engaged with the process. Finally, outcome indicators describe the longer term effects and whether change has been maintained or lost (UK HDA, 2001).

A 'Health Outcome Indicators' report published by a working group to the UK Department of Health defines outcomes as a change in health, health related status or risk factors affecting health or lack of change when change is expected. Indicators are defined as an aggregated statistical measure of a group of patients or a whole population. The definition also entails that *"an indicator may not necessarily provide answers to whether care has been 'good' or 'bad' but well chosen indicators should at least provide pointers to circumstances which may be worth further investigation"* (Home et al, 1999).

Knowledge

According to Wikipedia, (<http://en.wikipedia.org/wiki/Knowledge#Other>) the free online encyclopaedia, *"knowledge is information of which someone is aware. Knowledge is also used to mean the confident understanding of a subject, potentially with the ability to use it for a specific purpose"*.

Other definitions cited on the same website:

"knowledge is information evaluated and organised by the human mind so that it can be used purposefully, eg conclusions or explanations" (Rousa, 2002).

Knowledge is *"information combined with experience, context, interpretation, and reflection. It is a high-value form of information that is ready to apply to decisions and actions"* (Davenport, 1998).

Information

Information provision is a limited activity, it involves making discrete bits of information available (Hibbard & Jewett, 1997).

"Information (...) is simply the vehicle by which we attempt to provoke - or evoke - a human response. Information on its own is quite static and lifeless. It simply exists - on multimedia computer screens, in text books, magazines, movies, TV, CDs, reports, letters, emails, faxes, memos and so on - all waiting to be interpreted, all waiting to have meaning attached - by people" (Miller, 2002) available from: <http://InformationR.net/ir/8-1/paper140.html>.

Education

Education places information into understandable concepts and into a comprehensible context. It is a planned learning experience using a combination of methods such as teaching, counselling and behaviour modification techniques which influence patient's knowledge and health behaviours. Further, it involves an interactive process which assists patients to participate actively in their health care (Bauman & Browne, 1987).

Self-management

Lorig et al (2003) defined self-management as a decision to engage or not engage in a health-full behaviour or be actively involved in managing a disease stating that this decision reflects individual management styles. The authors explain that *"self-management aims at helping patients to maintain a wellness in the foreground perspective"*. This is done in three sets of tasks with the first being adhering to medical management (eg medication taking), the second task involves maintaining, changing and creating new meaningful behaviours or life roles and the third task deals with emotional struggle of living with a condition including anger, frustration and depression which are commonly experienced by someone with a chronic condition.

The UK Department of Health (UK Dept of Health) report ‘Supporting People with Long Term Conditions to Self-Care’ used the terms self-care and self-management interchangeably. They defined self-care as *“individuals taking responsibility for their own health and well-being including staying fit and healthy, both physically and mentally; taking action to prevent illness and accidents; the better use of medicines; treatment of minor ailments and better care of long term conditions”*. This report adapted the definition of ‘self-management’ from the mental health program ‘Rethink’ ie *“.....self-management is something we all do, and it is whatever we do to live our lives as fully, successfully, happily, whatever, in accord with our own values and goals. Everybody has difficulties and constraints in their lives, and part of self-management is coping with our limitations, minimise the way the condition limits our lives to make the most of our lives despite the condition”* (Martyn, 2002; UK Dept of Health, 2006).

The American Task Force for the development of the ‘national standards for diabetes self-management education’ defined diabetes self-management education (DSME) as *“an interactive, collaborative, ongoing process involving the person with diabetes and the educator(s)”*. This process includes 1) needs assessment 2) individual goal setting 3) educational and behavioural interventions directed at achieving an individuals’ goals and 4) evaluation of an individuals’ self-management goals (Mensing et al, 2003).

Norris et al (2001) define diabetes self-management training as the process of teaching individuals to manage their diabetes.

Self-determination

The following definitions were identified from the Thesaurus and the Self-Determination Theory website:

The Encarta Dictionary (English - UK): in individual terms: *“the ability or right to make your own decisions without interference from others”*.

Self-determination theory is a macro-theory of human motivation concerned with the development and functioning of personality within social contexts. The theory focuses on the degree to which human behaviours are volitional or self-determined - that is, the degree to which people endorse their actions at the highest level of reflection and engage in the actions with a full sense of choice. The definition from the ‘self-determination theory’ website reads as: *“To be self-determined is to endorse one’s actions at the highest level of reflection. When self-determined, people experience a sense of freedom to do what is interesting, personally important and vitalising”* (Deci & Ryan, year unknown); from <http://www.psych.rochester.edu/SDT/measures/index.html>

Self-efficacy

Many authors use the definition of Albert Bandura, the American psychologist who first described the ‘perceived self-efficacy’ theory in 1984. He defined self-efficacy as: *“people’s judgement of their capabilities to organise and execute courses of action required to attain designated types of performances”*(Bandura, 1994; Bijl et al, 1999). Bandura states that self-efficacy is based on four major sources of information: mastery accomplishment, vicarious experience, social and verbal persuasion and self-evaluation of one’s emotional and physical state (Bandura, 1994; Koopman & van der Bijl, 2001).

Empowerment

Page & Czuba (1999) suggested that empowerment is “*a multi-dimensional social process that helps people gain control over their own lives. It is a process that fosters power (that is, the capacity to implement) in people for use in their own lives, their communities, and in their society by acting on issues that they define as important*”. The authors claimed that in the empowerment literature, the meaning of the term empowerment was often assumed rather than explained or defined and that how empowerment is understood depends on peoples’ perspectives. Extracted from: <http://www.joe.org/joe/1999october/comm1.html>

Anderson et al (2000) defined the empowerment approach to diabetes education as “*helping patients make informed choices about their diabetes self-management*”.

Empowerment of patients in primary diabetes care can be defined as a process of enabling people to increase control over and to improve their health. This statement aims to define what efforts can be made by primary care team-members and surroundings to promote self-determination and self-care, increase independence from professional caregivers and diminish psychological and social consequences of disease (Baksi et al, 1998).

Results Part 2: Preliminary literature review

Outcomes and indicators for diabetes patient education

Research question:

1. Are there any international reports, publications and/or position statements on nationally agreed outcomes and associated indicators for measuring the effect of diabetes patient education?

Peer-reviewed literature

Initial Medline search using the key words (diabet\$ and education and outcome\$) yielded a list of 1276 articles but when the key word 'patient\$' was included the list reduced to 1049. Adding the key word indicator\$ further reduced the search result to 76 articles. However, the majority of these did not address the research question.

Aside from a report on the AADE position statement and a Canadian consensus for the standardised evaluation of quality improvement interventions in type 2 diabetes outlined below, no articles were found which reported on nationally agreed outcomes and indicators for diabetes patient education. Some articles described methods, processes, interventions and delivery of diabetes education mostly measuring HbA_{1c} as the main outcome whereas others reported on outcomes of diabetes care in general but were not patient education specific. The following is a summary of selected articles that reported on or discussed the research question.

Diabetes education has been evaluated for short term health outcomes such as hypoglycaemic episodes, blood pressure, weight and less often quality of life and long term outcomes such as complications (eg retinopathy, neuropathy), mortality and cost-effectiveness (Glasgow & Osteen, 1992). However, the most commonly employed outcome measure to evaluate the effectiveness of diabetes education programs has been glycaemic control as measured by HbA_{1c} (Fain et al, 1999; Norris et al, 2002a; Norris et al, 2002b; Deakin et al, 2005). Though, metabolic changes and glycaemic control can not solely be attributed to diabetes education as medical management and patient involvement in self-care among others contribute as well (Fain et al, 1999; Brown, 1999; Glasgow, 1999; Peyrot, 1999; Snoek & Visser, 2003). As Peeples et al (2001) point out "*although HbA_{1c} and other clinical outcomes may be impacted indirectly by education, they are also impacted by other factors such as medical management*". The authors consider that attempts to evaluate diabetes education programs have been too narrowly focussed, often leaving important outcomes unassessed. Fain et al (1999) also urge that evaluation of diabetes education needs to move away from using HbA_{1c} as key outcome variable.

This message appears to be increasingly heeded. For example, in their systematic review of self-management training in type 2 diabetes Norris et al (2001b) report across a variety of outcome measures including knowledge, attitude, self-care skills, lifestyle behaviours, psychological outcomes, quality of life, cardiovascular disease risk factors, economic measures and health service utilisation. Further, in a systematic review of group based diabetes education training Deakin et al (2005) reported on diabetes knowledge, self-management, quality of life, psychosocial adjustment, empowerment/self-efficacy and medication taking, as well as clinical outcomes.

Nonetheless, some problems with diabetes education evaluation methods remain. According to Naqib (2002) and Sarkadi et al (2005) attributes to describe effective education have not been described extensively and the complexities and impact of social, environmental and process factors are still not well understood. The AADE reported a lack of definition of outcomes specific to diabetes education and subsequently developed “Standards for Outcomes Measurement of Diabetes Self-Management Education” (AADE, 2003). These are described below in the web searched literature. Other authors suggest that while many measures have been collected, sometimes invalidated self-report instruments have been used (Glasgow & Osteen, 1992; Norris et al, 2001) and still others claim that interventions have been ill described (Lorig et al, 2003).

Web search

The web search identified a limited number of international reports and position statements which addressed some aspects of the research question. However, aside from the AADE position statement described below no national consensus positions on the outcomes specifically attributed to diabetes patient education were found. The following is a summary, categorised according to country, of reports and position papers which deal with this issue in some form.

United Kingdom

The Diabetes UK ‘Patient Education For Effective Diabetes Self-Management’ report, considered that patient education is not being properly evaluated in the UK (Naqib, 2002). Outcomes need to be assessed in the long term to reflect the impact of the intervention (ie patient education). The report urged that outcomes such as metabolic control as well as psychosocial markers and quality of life should be considered. The author suggests other measures such as biomedical, knowledge, self-care skills, behavioural, psychosocial and QOL, number of episodes of hypo-and hyperglycaemia, diabetes related work absence and hospital admissions. Various patient education strategies were discussed in this report and a brief reference was given to a number of validated measurement tools for assessing knowledge, attitude, feelings, functional status, QOL and psychosocial self-efficacy.

In July 2005, Diabetes UK released a **position statement** titled ‘Structured Education for People with Diabetes’ which states: “*self-management is the key to good diabetes care and structured ongoing patient education should be at the heart of any service*” (Diabetes UK, 2005). Diabetes UK considers that people with diabetes should be empowered to “*enhance their personal control over day-to-day management*” and experience the best possible quality of life. This can be achieved through knowledge skills, motivation and the persons’ understanding of the risks and benefits of lifestyle changes. This position statement discusses the need for structured education programs. However, outcome measures for such programs were not discussed.

In another **position statement** the National Diabetes Support Team (NDST) in the UK reports on the development of key criteria to meet the National Institute for Clinical Excellence (NICE) guidelines for structured education (UK NDST, 2006). Programs according to NDST should be a) structured with a written curriculum, b) have trained educators, c) be quality assured and d) should be audited. Currently there are two widely recognised national patient education programs in the UK that meet the above mentioned criteria:

1. Dose Adjustment For Normal Eating (DAFNE) for type 1 (DAFNE Study Group, 2002)
2. Diabetes Education and Self-Management for Ongoing and Newly Diagnosed (DESMOND) for people with type 2 diabetes (Davies et al, 2005).

The main emphasis of this position statement is on access and provision of structured high quality education programs. However, it fails to describe how patient education programs will be evaluated. The following papers are part of this position statement:

Diabetes UK – Structured Patient Education in Diabetes. Report from the Patient Education Working Group (UK Dept of Health, 2005)

According to this report diabetes patient education should improve people's knowledge, skills and confidence. The report outlines current education programs and provides advice on key areas such as health professional training and quality assurance. Suggested program outcomes are reported in an appendix and include biomedical measures, quality of life, patient experience and degree of self-management achieved after attending an education program.

NICE Health Technology Appraisal Guidance – No. 60 –Patient- education models for diabetes (NICE, 2003) (<http://www.nice.org.uk/page.aspx?o=68326>). Under the chapter 'clinical need and practice' this paper recommends outcome measures for diabetes management as:

- Targeted blood glucose levels as measured by HbA_{1c}
- Pre-post –meal blood/plasma glucose levels
- Prevention of acute episodes of hypoglycaemia and hyperglycaemia
- Reduction in other macro vascular risk factors, such as, dyslipidaemia, high blood pressure, smoking, obesity
- Short term QOL
- Long term effects on the incidence of diabetes complications, quality of life and mortality.

Other relevant outcomes for **educational interventions** are stated as diabetes-related knowledge, motivation and improvement in anxiety or depression however, they acknowledge that many of these outcomes have not been formally or consistently measured. This report recommends further research through high quality trials to assess the effectiveness of patient education models, particularly for people with type 2 diabetes.

A Health Outcome Indicators Report published by a working group to the Department of Health UK used diabetes as a model for developing population health outcomes and indicators (Home et al, 1999). The report gives detailed guidance on the development of indicator specifications and lists candidate indicators for prevalence of diabetes and its complications, life style risk factors (ie smoking, hypertension, obesity), metabolic indicators (HbA_{1c}, microalbuminuria), measures of psychological well-being, quality of life and service satisfaction. However, diabetes patient education specific indicators are not identified.

United States of America

In 2003, the AADE released a **position statement** titled: "Standards for Outcomes Measurement of Diabetes Self-Management Education (DSME)" (AADE, 2003). This position statement lists diabetes self-management education outcome standards for structure, process and outcomes. These standards specifically apply to the work Diabetes Educators do in their role of delivering DSME.

Five main outcomes for continuous quality improvement are:

1. Behaviour change which is a unique outcome measurement for diabetes self-management education.
2. Seven self-care behaviours, which were identified as a **‘unique and measurable outcome of effective diabetes education’** are:
 8. Being active: physical active (exercise)
 9. Eating
 10. Medication taking
 11. Blood glucose monitoring
 12. Problem solving especially for high and low blood glucose; and sick days
 13. Reducing risks of diabetes complications
 14. Living with diabetes (psychosocial adaptation)
3. Diabetes self-care behaviours should be evaluated at baseline and then at regular intervals after the education program.
4. The continuum of outcomes, including learning, behavioural, clinical and health status, should be assessed to demonstrate the interrelationship between DSME and behaviour change in the care of individuals with diabetes.
5. Individual patient outcomes are used to guide the intervention and improve care for that patient. Aggregate population outcomes are used to guide programmatic services and for continuous quality improvement activities for the DSME and the population it serves.

Canada

A Canadian ‘Consensus for the Standardised Evaluation of Quality Improvement Interventions in Type 2 Diabetes’ developed a set of indicators based on their clinical practice guidelines. However, the report does not define the meaning of quality improvement interventions. The authors’ goal was to develop and validate a set of quality indicators that would allow researchers and health care decision makers to a) measure the quality of diabetes care b) facilitate comparison with other organisations and interventions c) track changes over time and d) establish population level benchmarks for the agreed indicators of quality (Majumdar et al, 2005).

The recommended indicators include some ‘humanistic’ measures such as health related QOL and satisfaction with diabetes care as well as self-care behaviour (foot care, self blood glucose monitoring (SBGM), smoking cessation, medication adherence) (Majumdar et al, 2005). In addition, diabetes resource utilisation and self-care counselling for foot care, SBGM and smoking cessation were quality indicators listed amongst mostly clinical measures (eg glycaemic control, treatments, micro-and macro vascular indicators). The authors recommend the use of these indicators in concert with recently developed Canadian clinical guidelines. However, due to the lack of definition of ‘quality improvement intervention’ it is unclear whether these indicators are recommended for measuring the effectiveness of diabetes education interventions.

Australia

An initiative aimed at identifying evidence gaps in relation to the development of national evidence based guidelines for the management of type 2 diabetes cited difficulties with generating evidence about diabetes patient education. Three specific priorities were identified ie the need for a) a position/agreement on desired goals, outcomes and effective indicators for diabetes patient education, b) improved methods and validated assessment tools for the Australian condition, and c) training and infrastructure for educational/behavioural research (Colagiuri R et al, 2003).

Global

The International Diabetes Federation (IDF, 2003) has revised the 1997 version of the 'International Consensus Standards of Practice for Diabetes Education'. In this document, standards for diabetes education include structure, process and outcome standards and indicators with the objective of facilitating integrated high quality therapeutic education into diabetes care. The methods of revision were through a consensus process, literature review and focus groups with internationally represented health care providers. One of their four goals of diabetes education is "*to develop knowledge and skills that enable people with diabetes to make appropriate choices to maintain or improve health*". Standards focus on access and structure of diabetes education services on a global level and the only patient-centred outcome standards described are 'knowledge', 'knowledge application' and 'clinical outcomes'. The report lists objectives formulated for each outcome though measurable indicators are not documented.

Research questions:

- 2. How have nationally agreed outcomes for diabetes education been determined?**
- 3. What methods, criteria and definitions (if any) have been used in the development of nationally agreed indicators for measuring the effect of diabetes patient education?**

The only national consensus statements, as identified from the literature search, originate from the US and Canada. However, only the AADE has identified diabetes patient education specific outcomes and indicators.

In 1997, the AADE established a diabetes education outcomes taskforce in response to pressure by the national Medicare Service which was seeking information on national outcomes data on the effectiveness of diabetes self-management education. Further development resulted in the National Diabetes Education Outcomes System (NDEOS), a comprehensive web based, reporting service for diabetes outcomes on a patient, program and national level (Mulcahy et al, 2000; Tomky et al, 2000; Peeples et al, 2001).

Peeples et al (2001) describes that the determination of behaviour change as a unique outcome of DSME was based on expert consensus, a comprehensive literature review and a survey of AADE members during an AADE annual meeting. Though, details on recruitment and representation of taskforce members of the NDEOS could not be established from the literature other than it consisted of multidisciplinary experts in diabetes education.

For the Canadian consensus, development of the indicators was reached by using a 3-round Delphi technique involving 11 well-known Canadian investigators (academics and clinicians) with published expertise in the areas of type 2 diabetes and quality-improvement research.

Neither the US nor the Canadian paper described criteria or definitions used in the development of their indicators.

Summary

While there are excellent examples of national consensus position papers from the US and Canada, only the AADE has identified **diabetes patient education specific** outcomes and indicators with numerous published papers including the National Diabetes Education Outcomes System framework and a position statement on 'Standards for Outcomes Measurement of Diabetes Self-Management Education'. However, these standards and framework have been developed solely for the purpose of evaluating what Diabetes Educators are doing ie measure the effect of DSME on structure, process and patient outcomes. The consultation process for the development of the Conceptual Framework of the NDEOS did not include consultation of people with diabetes nor other stakeholders of diabetes care but solely consisted of a comprehensive literature review, AADE membership consultation and 'expert consensus'. The AADE position paper 'Standards for Outcome Measurement of DSME' did not specify the methods, processes and criteria applied in determining 'behaviour change' as the unique outcome of diabetes self-management education with seven diabetes specific self-care behaviours as indicators of overall program achievement.

A Canadian national consensus also appears to have been reached on specific indicators and measurement tools for evaluation of quality improvement intervention in type 2 diabetes. However, these do not appear to be diabetes education specific and did only consult a select group of experts mainly associated with university teaching centres and hence does not reflect opinions of other stakeholders involved in diabetes care (eg people with diabetes, government monitoring bodies).

Reports from the UK and Australia express a need for developing nationally agreed outcomes and indicators for diabetes patient education and UK reports put forward recommendations for suitable outcome measures. However, most published work from the UK is concentrated around the delivery of quality education programs. In their 'international consensus standards of practice for diabetes education' report the IDF has identified patient-centred outcome standards as 'knowledge', 'knowledge application' and 'clinical outcomes'. The report lists objectives formulated for each outcome though measurable indicators are not documented.

Results Part 3: Subsequent literature review

Indicators and measurement tools for diabetes patient education

After an extensive consultation process with national key stakeholders and collation of the preliminary results of project investigations, a draft framework of outcomes and indicator areas for diabetes patient education was defined. Six outcome areas were identified:

- knowledge and understanding
- self-management
- self-determination
- psychological adaptation
- clinical outcomes
- cost-effectiveness.

This subsequent literature review aimed to establish whether these outcomes, with the exclusion of clinical outcomes and cost-effectiveness as previously explained, had been measured as specific outcomes of diabetes patient education and if yes, what tools had been applied to assess these.

Research questions:

4. **Are there any reports/publications in the international literature that have determined knowledge and understanding, self-determination, self-management and psychological adjustment as outcomes of diabetes patient education?**
5. **If yes, what indicators and measurement tools have been used to assess these outcomes?**

Knowledge

This section discusses whether diabetes knowledge and understanding has been assessed as an outcome measure of diabetes education interventions and identifies available and validated tools for measuring participants' progress towards achieving adequate diabetes knowledge and understanding.

Patients' knowledge and understanding of diabetes mellitus and its treatment is a cornerstone for enabling people towards diabetes self-management and hence prevention of ill health (Williams et al, 1998; Persell et al, 2004; Knight et al, 2006). Even so, many studies from the diabetes education research have shown and expressed a concern that knowledge acquisition does not translate into behaviour change ie does not predict an individuals' capability to adapt diabetes self-management behaviours into every day living (Glasgow & Osteen, 1992; Maldonato et al, 1995; Glasgow, 1999; Koopman & van der Bijl, 2001; Krichbaum et al, 2003; Snoek & Visser, 2003; Knight et al, 2006). Despite this, knowledge has been one of the most widely collected outcome measures of diabetes patient education (Glasgow, 1999). A myriad of studies discuss the need for assessing knowledge as an important measure of effectiveness of educational intervention (Maldonato et al, 1995; Tomky et al, 2000; Koopman & van der Bijl, 2001; Mulcahy et al, 2003; Mensing et al, 2003; Heisler et al, 2005). In their technical review on 'diabetes self-management education core outcome measures' the AADE lists 'knowledge' as an immediate outcome for measuring each of their seven identified self-care behaviours and recommends that diabetes knowledge should be assessed at least annually (Koopman & van der Bijl, 2001; Mulcahy et al, 2003).

There is evidence that diabetes education improves participants knowledge and understanding of diabetes (Brown, 1990; 1992; Hitchcock Noel et al, 1998; van den Arend et al, 2000; Davies et al, 2001; Hampson et al, 2001; Rickheim et al, 2002; Norris et al, 2002b; Trento et al, 2004; Deakin et al, 2005). Further, more knowledgeable patients have shown to be more likely to implement positive lifestyle and self-care behaviours (van den Arend et al, 2000; Persell et al, 2004; Horsten et al, 2005), have better metabolic outcomes (Hitchcock Noel et al, 1998; Horsten et al, 2005) and treatment satisfaction (Horsten et al, 2005).

Measurement tools for assessing diabetes knowledge and understanding

The **Diabetes Knowledge Test (DKT)** was developed and validated in the mid 1980s by the Michigan Diabetes Research and Training Centre (MDRTC) to address the need of a valid and reliable diabetes specific knowledge instrument that could be used by diabetes educators and researchers (Hess & Davis, 1983; Fitzgerald et al, 1998). However, the review by MDRTC concluded that without information on responsiveness, it is impossible to know how useful the DKT would be as an outcome measure for educational interventions.

The DKT can be downloaded and used free of charge as long as the MDRTC is acknowledged in any instrument, from the following website:

http://measurementexperts.org/instrument/instrument_reviews.asp?detail=60

Later scales have been adapted from the DKT and validated to suit particular groups and interventions (Williams et al, 1998; van den Arend et al, 2000; Garcia et al, 2001; Persell et al, 2004; Knight et al, 2006). Rickheim et al (2002) used their own validated 14-point knowledge test to assess group vs individual education but failed to describe and reference specific details with regard to the scale.

A series of **diabetes knowledge assessment (DKN)** scales were developed and validated for the Australian environment (Dunn et al, 1984). A clinical trial was conducted to determine the effectiveness of a diabetes education program. All three scales DKNA, DKNB and DKNC, each of 15 items were given to all participants' pre and post education intervention (a 2-day diabetes education program). Overall DKN scores improved after the intervention; however DKNB was found to be a more difficult test. The authors concluded that in situations where comprehensive assessment of diabetes knowledge is time consuming, a rapid and reliable assessment is possible with a 15 item validated scale.

Updated and validated versions of the DKN scales are available in: Handbook of Psychology and Diabetes p160-165 (Bradley, 1994).

Self-management

The following paragraph describes identified systematic reviews and a study of diabetes education intervention in general practice, measuring aspects of self-management behaviour following education interventions.

Systematic reviews

Deakin et al (2005) identified six studies that measured some aspect of self-management in participants attending group education programs. Self-management behaviours assessed in the six studies included: exercise, self blood glucose monitoring levels, food intake, and carrying out urinalysis. There was evidence that self-management skills improved in participants attending

group programs in terms of SBGM, healthier diet and urinalysis testing; however there was conflicting evidence in regard to physical activity.

Norris et al (2001) showed positive effects of self-management training on frequency and accuracy of self-monitoring of blood glucose levels and self-reported dietary habits with short term follow up (ie < 6 months). In a subsequent review, Norris et al (2002), list short term outcomes reviewed for DSME interventions which include lifestyle assessment such as diet, physical activity and smoking as well as metabolic and mental health outcomes.

Hampson et al (2001) reported in their systematic review of 62 studies, a small to medium beneficial effect of educational and psychosocial intervention on self-management behaviours (eg diet, exercise, glucose testing, insulin self-management) in adolescents. Other researchers have shown an improvement, across four education programs integrated into general practice, in dietary adherence, glucose measurement, physical activity and foot inspection in people with type 2 diabetes (van den Arend et al, 2000).

Tools for assessing self-management

The **Diabetes Self-Management Assessment Report Tool (D-SMART)** has been developed for the American National Diabetes Education Outcomes System as a standardised, reliable and valid instrument to capture data on diabetes health status, behaviour, priority for behaviour change and barriers to behaviour change (Peeples et al, 2001). This instrument is organised around the seven behaviour change domains (as described in Part 2- preliminary literature review). Participant self-reported responses are used to guide education interventions by focusing on participants self identified priorities. To allow for adequate time for behaviour change the D-SMART is completed by individuals at initial diabetes education visit and at least two weeks following the initial visit. Changes in behaviours are then quantified as outcomes of diabetes education. The D-SMART is considered the cornerstone of the NDEOS.

Summary of Diabetes Self-Care Activities (SDSCA) has been tested and recommended by Toobert et al (2000) as a well-validated and comprehensive measure of diabetes self-care behaviours. It has been used in a variety of studies on diabetes self-management education (Toobert et al, 2000; Cooper et al, 2003; Williams et al, 2004; Aikens et al, 2005) and was a recommended tool in the Canadian consensus for the standardised evaluation of quality improvement interventions in type 2 diabetes (Majumdar et al, 2005). The SDSCA assesses aspects of diabetes self-care (diet, exercise, blood glucose testing, medication taking) by self reported behaviour seven days prior to completion of the questionnaire. Participants report on frequency and percentage of time they did a behaviour (eg “*on how many of the last 7 days did you participate in healthy eating for diabetes control?*”). The SDSCA has been revised, and includes supplemental items in an expanded version for more detailed information on the specific activities (Toobert et al, 2000).

The reliability and validity of the **Environmental Barriers to Adherence Scale (EBAS)** were determined for a sample of 214 insulin-dependent and non-insulin-dependent people with diabetes. The scale was shown to be a valid measure of barriers to adherence to diabetes regimens. The medication, testing, exercise, and diet subscales of the EBAS were correlated with four corresponding and three non-corresponding measures of self-care behaviour. Each subscale correlated well with its corresponding self-care behaviour. The results suggest that the EBAS scale is a valid and reliable measure of barriers to diabetes-regimen adherence (Irvine et al, 1990).

The **Self-Care Inventory-Revised (SCI-R)** is a self-report measure of perceived adherence to diabetes self-care recommendations among people with type 1 and 2 diabetes. Unlike other measures that evaluate the frequency of self-care behaviours the SCI-R allows for various treatment regimens across individuals, while evaluating individuals' perceptions of how well they adhere to prescribed treatment, and hence the global score makes it a concise and practical tool for outcome research (Weinger et al, 2005). Weinger et al (2005) tested its psychometric properties and concluded that the SCI-R was a valid measure of perceptions of adherence to recommended diabetes self-care behaviours of adults with type 1 and 2 diabetes.

The **Habitual Physical Activity Index (HPAI)** was tested by Gleeson-Kreig (2006). The author chose the HPAI as it assesses habitual patterns (for occupational and leisure activities) of light, moderate and higher intensity activity. Gleeson-Kreig (2006) tested the effect of keeping daily activity records on physical activity levels and self-efficacy for physical activity in adults with type 2 diabetes. Participants were randomly assigned to intervention (kept activity record) and control (no records kept) group. Individuals in the intervention group kept daily activity records for 6 weeks, mailed to the researcher every 2 weeks. Data collection was completed pre and post exercise intervention with the HPAI and the **Self-Efficacy for Exercise Scale (SEE)**. The intervention resulted in enhanced self-efficacy as assessed by SEE scores. The author reported adequate reliability and validity of both scales. Physical activity improved in both the intervention and control groups. Activity recording was judged to be acceptable and feasible.

The use of **Pedometers** (step counters) for measuring physical activity has been recommended as a practical and accurate measure of physical activity for people with type 2 diabetes (Bjorgaas et al, 2005). Pedometers have shown in previous studies to give good assessment of ambulatory activity in a 'non-diabetic' population (Bassett et al, 2000; Bjorgaas et al, 2005). Bjorgaas et al (2005) explain that although maximal oxygen uptake (VO_{2max}) is an established measure of aerobic capacity, it is not applicable for routine use. In their study, twenty-nine patients with type 2 diabetes underwent exercise testing, pedometer activity and reported their physical fitness and activity in questionnaires, before and after a 12 week exercise program. Results showed favourable effects on weight, VO_{2max} and metabolic control. Pedometer activity correlated with aerobic capacity (maximal oxygen uptake) and hence may lead to more realistic assessment of perceived everyday physical activity. Endorsement for the use of pedometers as an accurate assessment of physical activity was given by the authors of the 'First Step Program' with people with type 2 diabetes (Tudor-Locke et al, 2004).

Note: The Resource Centre for Minority Aging Research (RCMAR) website offers additional information on diabetes survey instruments and tools suitable for the elderly population with diabetes and translation into other languages.

<http://www.musc.edu/dfm/RCMAR/DiabetesTools.html>

The Michigan Diabetes Research and Training Centre allow downloading of discussed and additional survey instruments not included in this review.

<http://www.med.umich.edu/mdrtc/survey/#das>

Self-determination

A specific self-determination theory and its applicability to diabetes self-management is discussed in this section. Further, tools for assessing empowerment, self-efficacy, confidence, coping and decision making as indicator domains for measuring self-determination are mapped.

The self-determination theory has evolved over the past 30 years from psychological research done by Deci & Ryan (year unknown). Self-determination theory describes the concept of autonomous versus controlled motivation and perceived competence versus incompetence. In that, people are autonomously motivated when they experience volition and choice while behaving (eg freely choosing to follow a diet because they believe it would help their blood glucose level), contrary to people feeling controlled when they experience pressure or coercion. (eg people following a diet because they were pressured by a dietitian to do so). Further, people perceive themselves as competent when they feel able to control outcomes (eg blood glucose levels) but perceive themselves incompetent if they feel unable to control important outcomes (Williams et al, 2004). The self-determination theory was tested by Williams et al (2004) in the context of diabetes self-management education in a study examining whether patients' self-activation related to patients' perceptions of practitioners autonomous support approach to education. They concluded, and supported previous evidence, that *“autonomous motivation and perceived competence for diabetes self-management are important predictors of long-term glycaemic control and exert their effect through diabetes self-management behaviours”*.

There is evidence in support of each of the five domains of self determination. Some evidence of improved **self-empowerment** after group based training for self-management strategies was reported by Deakin et al (2005) in their Cochrane review of 14 publications describing 11 studies.

Anderson et al (2000) identified seven studies that demonstrated the effect of perceived **self-efficacy** on the adherence behaviours of various groups of people with diabetes (eg adolescence, African-American women, adults with type 1 diabetes). The authors support the enhancement of patients' perceived self-efficacy to self-manage their diabetes as an important goal of diabetes self-care and education (Anderson et al, 2000). This view was mirrored by Krichbaum et al (2003) who conclude from their systematic review that the goal for educating people with diabetes is to improve their individual self-efficacy and, consequently, their self-management ability.

Coping in diabetes was described by Grey (2000) as allowing people to use various skills, which can change with time and experiences, to manage difficulties in their lives. In her article on 'Coping and Diabetes' the author refers to a number of studies that demonstrated better self-care, metabolic outcomes and psychological well-being in both adult and children following problem-oriented coping strategies (Grey, 2000).

To avoid short and long-term complications problem solving skills and **confidence** in daily **decision making** (eg insulin adjustment for sick days, adjusting carbohydrate intake to level of exercise) are paramount in the life of a person with diabetes. Since 95% of diabetes care is provided by the person with diabetes, he/she faces daily decisions with regard to lifestyle behaviours that require self-confidence, problem solving and decision making skills (Krichbaum et al, 2003). Problem solving skills have been measured in a '5-Year Randomised Controlled Study of Learning, Problem Solving Ability, and Quality of Life Modifications in People with Type 2 Diabetes Managed by Group Care' and demonstrated statistical significant improvement in problem solving ability in year 1 in group care participants (Trento et al, 2004).

Measurement tools for assessing self-determination

The **Treatment Self-Regulation Questionnaire (TSRQ)** was used by Williams et al (2004) to assess autonomous motivation and controlled motivation for following a diabetes diet and exercise behaviour (six items), taking diabetes medication and checking blood glucose levels (eight items). They showed that the TSRQ had good internal consistency and reliability as tested in their study. In addition, they used and tested a Perceived Competence for Diabetes Scale (four items) which also showed good internal consistency.

The Diabetes Attitudes Wishes and Needs (DAWN) study has developed a ‘reflection sheet’ called “**Your plans to change your way of living**” (Zoffmann, 2004). The questionnaire is based on the ‘self-determination theory’ and assesses a persons’ needs and readiness to change (in terms of eating, exercising, medication taking, blood glucose testing, smoking, alcohol, insulin and stress). It is part of a series of developed scales made available for use in clinical practice.

Measurement tools for assessing empowerment, self-efficacy, confidence and coping

The **Diabetes Empowerment Scale (DES)**, a measure of diabetes-related psychosocial self-efficacy was assessed by Anderson et al (2000) for utility, validity and reliability. It consists of 28 items with 3 subscales: 1) managing the psychosocial aspects of diabetes, 2) assessing dissatisfaction and readiness to change and 3) setting and achieving diabetes goals. In 2003, Anderson et al revised the scale to a shorter form eight item tool (**DES-SF**) and after retesting it concluded that it was a reliable and valid measure of overall diabetes-related psychosocial self-efficacy (Anderson et al, 2003). They reported a positive effect on the DES score after a six week problem based patient education program. In another study the DES was used to assess psychosocial self-efficacy of Veterans attending a diabetes education program (Via & Salyer, 1999).

Permission to use the DES and DES-SF can be obtained free of charge from the Michigan Diabetes Research Training Centre website: www.med.umich.edu.mdrtc

The **Confidence in Diabetes Self-Care (CIDS)** scale was developed to assess diabetes specific self-efficacy in people with type 1 diabetes in a Dutch and US population. It is a 20 item self report questionnaire that covers domains of self-care (eg insulin administration, foot care, following recommendations about exercise and food). Van der Ven (2003) tested the scale and concluded that it was a valid and reliable measure of diabetes-specific self-efficacy for use in people with type 1 diabetes.

The **Self-Efficacy of patients with Type 2 diabetes (SE-Type 2 scale)** was developed and validated by Bijl et al (1999). The questionnaire measures four clusters of self-care activities (ie nutrition specific and weight; nutrition general and weight; nutrition general and medical treatment; physical exercise and blood glucose) which patients with type 2 diabetes have to complete to prevent long and short term complications. The authors concluded that the SE-Type 2 scale is a “reasonably” reliable scale. However, it does not describe whether the scale is recommended to evaluate diabetes education interventions. To confirm the findings of this study further research needs to be conducted.

The use of the **PAID** scale (discussed later under measurement tools for psychological adjustment) was recommended by Grey (2000) as a reliable instrument to assess **coping** among people with diabetes.

Psychological adjustment

This section briefly outlines the rationale for and demonstrates some evidence for assessing psychological adjustment as an outcome measure of diabetes education. Further, identified measurement tools for assessing psychological adjustment are discussed.

Depression is more common in people with diabetes compared to the general population and affects 10-20% of people with diabetes (Anderson et al, 2001). However, the diagnosis of depression is often missed by health care professionals and QOL is not often monitored systematically as an integral part of diabetes routine care (Snoek & Visser, 2003). The Centre for Disease Control and Prevention (CDC, 2004) supports monitoring of emotional well-being in patients with diabetes as a primary goal of diabetes care and recommends the use of a QOL instrument in the evaluation of interventions targeting chronic diseases or conditions.

The DAWN study was the first global study to provide comprehensive information on the psychosocial impact of living with diabetes. A report on the Australian arm of the DAWN study found that 41% of the 476 interviewed people were classified with 'poor' well-being (Rutherford et al, 2004). DAWN describes subjective well-being "*as an important dimension of overall perceived quality of life and in its own right an important outcome of diabetes care*".

Luscombe (2000) discusses significant health related quality of life (HRQOL) consequences of type 2 diabetes stating that research indicates decrements in virtually all aspects of HRQOL due to the disease or its complications. This is supported by studies using both generic QOL instruments and diabetes-specific instruments by demonstrating significant reductions in health status and multiple domains including symptoms, worries, self-care, locus of control, functional ability, social support and treatment satisfaction compared with other chronic disease populations and healthy controls.

An Australian national survey to determine personal and public financial cost of type 2 diabetes (DiabCo\$t) showed that QOL worsened significantly in the presence of complications (as measured by EQ-5D scores – described below) (Colagiuri S et al, 2003).

A North Western Adelaide Health Survey showed that people with diabetes have in general lower scores in all QOL domains (measured with the SF-36 questionnaire- described below). It gives four reasons why it is important to measure QOL in diabetes care a) to understand individual choices b) to understand the health impact of QOL c) to guide public health choices and d) to monitor diabetes health (Phillips, 2006).

Interestingly, in a five-year randomised controlled clinical trial of continuing systematic education delivered by group versus individual diabetes care, Trento et al (2004) found that QOL improved from year 2 with group care but worsened with individual care. Another publication, a systematic review of psychosocial outcomes following education, showed that QOL improved following self-management interventions (Steed et al, 2003).

Measurement tools for assessing psychological adjustment

Below is a presentation of identified diabetes specific and generic QOL scales followed by systematic reviews reporting on psychometric properties of diabetes specific health related QOL measures. Further, identified measures for well-being and mental health state are discussed.

The **Problem Areas in Diabetes (PAID)** survey was developed and tested by Polonsky et al (1995) as a tool to measure psychosocial adjustment specific to diabetes. The PAID survey is a 20-item survey with different areas of diabetes-related psychosocial distress. Each item is a six

point Likert scale. Psychosocial measures of distress include: general emotional distress, depression, diabetes self-care behaviours, diabetes coping and health beliefs. The scale has been retested and shown to have consistently high internal reliability and validity and sound test-retest reliability (Welch et al, 1997; Snoek et al, 2000; Welch et al, 2003). Studies have demonstrated the PAID scale to be unrelated to age adjusted duration of diabetes, education, ethnicity and gender (Polonsky et al, 1995; Welch et al, 1997). Numerous studies have used the PAID scale in diabetes care and education interventions. A full list of references is available from <http://www.musc.edu/dfm/RCMAR/PAID.html>

Recently the PAID scale has been adopted and recommended for use in a clinical setting as a routine or ad hoc tool by the DAWN study (Novo Nordisk, 2006).

The **Appraisal of Diabetes Scale (ADS)** was developed in 1991 to assess patients' cognitive appraisal of diabetes, ie their thoughts about having diabetes. The ADS consists of seven items, for example, "*how effective are you in coping with your diabetes?*". Scores can range from 8 to 31 and higher scores mean a more positive appraisal of diabetes. The ADS showed acceptable test-retest reliability and internal consistency (Garratt et al, 2002). Information on the availability of these scales can be found at: <http://www.musc.edu/dfm/RCMAR/ADS.html>

The **Diabetes Integration Scale (ATT39)** was developed and tested by Dunn et al (1986) in response to a lack of measure for emotional adjustment of living with diabetes following educational interventions. The authors concluded that the ATT39 provided psychologically meaningful scores and was reasonably stable for up to 6 months (Dunn et al, 1986; Rickheim et al, 2002). It was later revised and shortened to the **ATT19**. This scale consists of 19 items, such as, "*I dislike to be referred to as 'a diabetic'*" and "*I try not to let people know about my diabetes*". Scores can range from 19 to 95, and higher scores indicate that patients are accepting their diabetes, are comfortable with public awareness of their diabetes, have a sense of self-control, and feel well adjusted to their diabetes.

ATT39 and ATT19 scales are available from: Handbook of Psychology and Diabetes page 224-226 and page 230-231, respectively (Bradley, 1994).

The **Diabetes Quality of Life (DQOL)** brief questionnaire was tested for reliability and validity by Burroughs et al (2004). The authors concluded that the 15-item DQOL brief clinical inventory instrument predicts self-reported diabetes care behaviours and satisfaction as effectively as the instrument's full version. The original version of 46 items was developed for the Diabetes Control and Complications Trial (DCCT) (Jacobson et al, 1988). The revised instrument provides a method for quick screening of patients (type 1 and type 2) for readiness, and specific treatment related concerns (Burroughs et al, 2004). The instrument can be used to identify quality of life issues that may not necessarily generally arise in a patient - provider encounter, and takes about 10 minutes to administer. The 46 item scale is available as an appendix in Jacobson et al (1988). Information on the availability of the revised DQOL scale was not given.

A **Chinese version of the DQOL** measure that could be used for elderly Chinese immigrants with type 2 diabetes was developed in 1999 (Cheng et al, 1999). This was achieved by modifying the existing DQOL tool using data gained from focus groups held with the target group. The revised version was forward and back translated independently by four individuals. The modified Chinese version consists of 42 items and 3 scales, which includes satisfaction, impact of diabetes and related worries. The scale was assessed for reliability by evaluating internal consistency, item-internal consistency and test-retest reliability. The authors concluded that the results of their study indicated that this tool was a reliable and valid tool that could be used for elderly Chinese people with type 2 diabetes.

Reviriego et al (1996) tested the **Spanish version of the DQOL** questionnaire and showed a high internal consistency (reliability). They concluded that this may be a useful tool to evaluate the quality of life in Spanish speaking patients with diabetes (Reviriego et al, 1996).

The **Audit of Diabetes Dependent Quality of Life (ADDQOL)** scales purpose is to assess and measure an individual's perception of the impact of diabetes on their quality of life with the underlying principle that patients select and only rate personally applicable life domains. The ADDQOL was developed by Bradley et al in 1999 in response to the need for a diabetes specific QOL measure and consists of 18 life domains (eg freedom to work, eat, drink, social life, future, confidence, physical activity, etc). Potential domains for assessment were influenced by generic and other diabetes QOL measures, patient-centred principles and discussions with health professionals (Bradley et al, 1999). The authors concluded that this tool has demonstrated internal consistency, reliability and preliminary evidence of validity.

Later, Bradley & Speight (2002) commented that on average the ADDQOL instrument has shown almost universally negative impact of diabetes on all 18 life domains. The authors suggest that this tool may be more sensitive to change and more responsive to difference than earlier diabetes specific or generic QOL measures. The ADDQOL has been used by the DAPHNE (dose adjustment for normal eating) study group in the UK to assess the effect of their structured education program (DAFNE Study Group, 2002) and is recommended as a measure of diabetes specific HRQOL in the Canadian consensus for the standardised evaluation of quality improvement interventions in type 2 diabetes (Majumdar et al, 2005). Use of the ADDQOL instrument must be registered with Claire Bradley and a licensing fee paid to Royal Holloway, University of London.

More recently, a 25-domain **ADDQOL-Teens** has been developed which showed high internal consistency and reliability. It is a measure of perceived impact of diabetes and its treatment on the QOL of teenagers. There were two subscales: a 10-item impact-self subscale (measuring the impact of diabetes and its treatment on the individual) and a 15-item impact-other subscale (measuring impact on interactions with others and the external world). It may be used for routine clinical monitoring in a context of continuing evaluation (McMillan et al, 2004). The full scale was not provided.

The **Diabetes Specific Quality of Life Scale (DSQOLS)** was validated and assessed for its psychometric properties in a large sample of people with type 1 diabetes. This scale consists of 64 items including individual treatment goals, satisfaction and treatment success, and diabetes related distress. Six subscales were significantly correlated with a validated well-being scale. Favourable scores in different domains were associated with a flexible insulin therapy, a liberalised diet, the absence of complications and a higher social status (Bott et al, 1998). The authors found this tool to be a reliable and valid measure of quality of life related to diabetes. They state that the tool may be used to determine patients QOL managing with different treatment and diet regimens and to detect social inequities. They also suggested that this tool may be useful in assessing individual treatment goals defined by patients and to identify motivational deficits and to tailor individual treatment strategies. Subsequently, Bott et al used the tool to help evaluate the effectiveness of a diabetes treatment and teaching program (Bott et al, 2000). The DSQOLS is available as an appendix to the publication by Bott et al (1998).

The **Questionnaire on Stress in Patients with Diabetes-Revised (QSD-R)** was originally a German scale but has been translated into an English version. The version can be obtained from the authors; however the English version has not yet been validated. The QSR-R contains 45

items for which patients indicate whether the item applies to them and then rate on a 5-point scale the degree to which that particular item is a problem for them. There are eight dimensions: leisure time, work, relationship with partner, doctor-patient relationship, problems with hypoglycaemia, treatment regimen, physical complaints, and worries about long-term complications. Some of the items are not directly linked to diabetes (eg “*I suffer from irritability*”), thus the majority of items fit well within our definition of diabetes-specific HRQOL. Good reliability and validity of the German version has been demonstrated, and research indicates that each of the subscales has been found to be significantly correlated with glycaemic control (Polonsky, 2000).

The **Diabetes Care Profile (DCP)** was developed by Fitzgerald et al (1998) as an instrument to assess social and psychological factors related to diabetes and its treatment and consists of 16 profiles. The scale assesses control problems, social and personal factors, positive attitude, negative attitude, self-care ability, importance of care, self-care adherence, diet adherence, medical barriers, exercise barriers, monitoring barriers, understanding management practice, long-term care benefits, support needs, support, and support attitudes. Internal reliability was good to excellent, external validity was good. Significant differences were found between type 1 and type 2 diabetes for 6 of the 14 scales. Three scales (control problems, self-care ability, and self-care adherence) were significantly correlated with HbA_{1c} level (Fitzgerald et al, 1998).

The DCP can be obtained with permission free of charge from the University of Michigan on: <http://www.med.umich.edu/mdrtc/textonly/educmats/dcp.pdf>

The **SF-36** is a global health related quality of life instrument including both physical (physical functioning, role functioning, bodily pain, general health) and mental (vitality, social and emotional functioning, mental health) QOL component scores (Rickheim et al, 2002). The **short form-36** (SF-36) was validated in people with diabetes attending general practice and was compared with the ADDQOL (Woodcock et al, 2001). There was a higher correlation between SF-36 scores with the relevant ADDQOL scores among the respondents reporting no co-morbidity. The authors concluded that although the SF-36 scores were valid and reliable, they are strongly affected by non-diabetic co-morbidity in type 2 diabetes. The authors felt that this supported the complementary use of a diabetes-specific measure to provide information about the impact of diabetes specifically.

Phillip (2006) defines in his online presentation on QOL and diabetes the SF-36 as the gold standard for measuring QOL from a ‘smorgasbord’ of available QOL tools. He concluded from his study that the SF-36 can be used for population surveys but is not able to measure change in an individual with diabetes.

Many other studies have reported the use of the SF-36 for assessing the effect of educational interventions on QOL (Rickheim et al, 2002).

The SF-36 survey can be downloaded from the website: www.sf-36.org on <http://www.swin.edu.au/victims/resources/assessment/health/SF36.pdf>

The **European Quality of Life-5 dimensions (EQ-5D)** is a short, simple preference-based index measure. It has been applied in the measurement of HRQOL in type 2 diabetes, including the United Kingdom Prospective Diabetes Study (UKPDS Group, 1999; Clarke et al, 2002; Shaw et al, 2005) and the international DAWN study (Rutherford et al, 2004). In their Canadian consensus for the standardised evaluation of quality improvement interventions in type 2 diabetes, Majumdar et al (2005) list EQ-5D as a recommended tool for assessing HRQOL. The overall EQ-Index scores on a scale of 0 to 1.0. A difference of 0.03 on the overall EQ-Index

score is considered to be clinically important. Health problems on each of the 5 dimensions can be reported to provide profile like information, but is limited to three levels of functioning (ie none, moderate, severe) on each dimension. The Visual Analogue Scale (EQ-VAS) provides a single self-rating of health, as an additional outcome measure.

The EQ-5D can be used free of charge for non-commercial use. Additional information can be found on the website of the EuroQol Group (www.euroqol.org).

Garratt et al (2002) undertook a systematic review to identify disease-specific measures of health related quality of life for diabetes and to review the evidence for the reliability, validity and responsiveness of instruments. The review included instruments that had been patient assessed, disease-specific with HRQOL as the main focus. The review was confined to instruments evaluated in adult patients. The reviewers concluded that five of the diabetes-specific instruments had good evidence for reliability and internal and external construct validity: Audit of Diabetes Dependent Quality of Life (ADDQOL), Diabetes Health Profile (DHP-1/18), Diabetes Impact Measurement Scales, Diabetes Quality of Life Measure, Diabetes-39 (D-39), Diabetes Specific Quality of Life Scale (DSQOLS) and Questionnaire on Stress in Patients with Diabetes-Revised (QSD-R).

Another systematic review aimed to evaluate Health Related Quality of Life (HRQOL) measures used in people with type 2 diabetes (Luscombe, 2000). Their definition of HRQOL included domains of physical, role, social, and psychological functioning, general health perceptions and disease related symptoms and concerns. Diabetes-specific treatment satisfaction measures were also identified in the review. The studies selected included all reviews and studies validating questionnaires or that reported data relevant to type 2 diabetes. The authors conclude that most of the studies reviewed were cross-sectional, and that there is little research around the response of HRQOL to clinical change and treatment effects. They also comment that HRQOL is *"influenced by multiple patient and disease factors, particularly age, gender, and the presence and severity of disease complications and co-morbid conditions,"* and that these factors should be considered when designing and analysing HRQOL measures in people with diabetes.

Watkins & Connell (2004) emphasised in their review of QOL measures the importance of careful consideration of the conceptual underpinnings of the available instruments, as there is little uniformity in the definition and conceptualisation of HRQOL. However, they endorsed the use of the ADS, ADDQOL, PAID, DQOL and DSQOLS as described previously.

The **World Health Organisation-Five Well-Being Index (WHO-5)** is a self-administered five item questionnaire relating to positive mood (good spirit, relaxation), vitality (being active and waking up fresh and rested) and general interest (being interested in things). The WHO-5 has been adopted and published by the DAWN study as a series of available tools. It is recommended for use in the annual review, as a measure of emotional well-being in combination with the PAID scale or as an ad hoc measure of mood. As an additional resource, feedback on the WHO score to patients can assess the importance of well-being in the process of diabetes self-management and address psychological issues (Snoek, 2006).

The **Well Being Questionnaire-12 items (WBQ-12)** has been tested on people with diabetes for its validity and reliability. The **WBQ-12** was tested in a Dutch population and the authors concluded that the Dutch version of the WBQ-12 was a valid and reliable measure to assess the psychological well-being for people with diabetes (Pouwer et al, 1999). The authors state that the instrument could be used by clinicians and researchers.

The **Kessler psychological Distress Scale (K10)** has been described as a simple screening tool for assessing the mental health state of a person with diabetes and can be completed during a consultation (Phillips & Aloizos, 2005). The K10 was used in 1997 by the Australian Bureau of Statistics to conduct a National household survey on mental health and well-being (Andrews & Slade, 2001) and in 2001 for the Victorian Population Health Survey (Phillips & Aloizos, 2005). Andrews & Slade (2001) noted that the K10 was suitable for assessing population morbidity and may be appropriate for use in clinical practice.

Subsequently, Furukawa (2003) reported from a performance appraisal study of the K6 (short version of K10) and K10 compared to the General Health Questionnaire (GHQ-12). The GHQ-12 was also administered for the Australian National household survey on mental health and well-being. Performance of the three screening scales in detecting mood and anxiety disorders as assessed by the K10 was marginally better than the K6, while both were significantly better than the GHQ-12.

The complete K10 scale was published in the 'Medicine Today' journal by Phillip & Aloizos (2005).

To assess the validity of the **Child Health Questionnaire (CHQ)** as a screening instrument for detecting 'at risk' mental maladjustment in children with type 1 diabetes in Australia, (Cameron et al, 2003) compared it with the Behaviour Assessment System for Children (BASC- the gold standard measure). The BASC is not suitable for general outpatient clinic use as it requires substantial resources (1-2 hours of scoring). The CHQ and the parent form of the CHQ (**CHQ PF-50**) assess physical, emotional, social, mental health and self-esteem on a 50-item scale. The authors of this study recommend the sequential use of the CHQ, as a practical, short screening tool to assess children at risk for chronic maladjustment to living with type 1 diabetes. Previously, the CHQ PF50 was tested on 5,414 parents of children aged 5-18 years in Australia and compared to US data (Waters et al, 2000). They reported good to excellent internal consistency and construct validity was supported. The authors concluded that the scale performed well in Australia at item and scale level. In addition to the CHQ PF-50 validation of the **CHQ CF-80**, an 80 item scale **for adolescence** 18 to 20 years old, demonstrated good psychometric properties (Wake et al, 2000).

Note: The Patient Reported Outcomes and Quality of Life Instruments database offers additional information on the availability of diabetes specific QOL instruments:

<http://www.proqolid.org/PathoList/Endocrino.html>

Summary

The subsequent literature review established that knowledge and understanding, self-determination, psychological adjustment and self-management have been used as outcome measures of diabetes education interventions.

Diabetes specific quality of life has been the most commonly assessed domain in diabetes care and patient education. Less frequently, knowledge, readiness to change, empowerment, self-efficacy, coping and confidence, well-being, mental health, and self-care activities (diet, physical activity, medication taking, blood glucose testing, insulin-injecting) have been identified as measures of effectiveness following diabetes interventions.

Numerous validated QOL measurement tools exist, generic and diabetes specific. Fewer tools are available to assess knowledge, self-determination and self-management. As many of the

described tools have been developed and tested overseas, the applicability to the Australian context would need to be established.

Despite the DKN (diabetes knowledge assessment scales) having been developed and tested in Australia it is outdated and hasn't been revised for over 10 years. Due to the rapid and continuous advancement in diabetes management (eg introduction of glycaemic index into dietary advice, change in exercise recommendations) and technologies (eg new blood glucose meters and insulin injection devices), the DKN scale needs to incorporate these new advances and terminologies. According to Bradley (1994) if a scale is modified we can no longer assume that the psychometric properties remain unchanged; hence the modified scale would need to be retested.

It is outside the scope of this review to recommend the most appropriate tools for measuring self-determination, psychological adjustment and self-management in the Australian context; this requires further investigation.

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Appendix 3: Key Opinion Leaders

- **Appendix 3: Key opinion leaders interviewed**
- **Appendix 3a: Key opinion leader interview guide**
- **Appendix 3b: Key opinion leader interview results**

Key Opinion Leaders Interviewed

Ms Jan Alford
 Convenor – Credentialling Committee
 Australian Diabetes Educators Association

Dr John Aloizos
 Chair - National Integrated Diabetes Program

Professor Carol Armour
 Pharmacy Care Program
 The University of Sydney

Ms Melissa Armstrong
 Dietitians Association of Australian

Professor Jennie Brand-Miller
 President (then)
 The Nutrition Society of Australia

Dr Linda Beeney
 Consultant Diabetes Psychologist

Mr Laurie Clay
 Durri Aboriginal Medical Service – NSW

A/Professor Peter Colman
 Diabetes and Endocrinology Department
 Royal Melbourne Hospital

Dr Joseph de Riva O'Phelan
 Diabetes Australia – National Office

A/Professor Trisha Dunning
 School of Nursing
 University of Melbourne

Professor Tim Davis
 Council Australian Diabetes Society
 University of Western Australia

Ms Helen Edwards
 Diabetes Educator
 Diabetes Counselling Online

Dr Spiros Fourlanos
 Endocrinologist
 Walter and Eliza Hall Research Institute – VIC

Ms Kate Gilbert
 Founder and Volunteer
 Reality Check Young Adults with Diabetes Inc.

Professor Mark Harris
 The National Divisions Diabetes Program
 University of NSW

Dr Sophie Hill
 Cochrane Consumer Collaboration

Ms Angela Hislop
 Consultant Psychologist/ Diabetes Educator – WA

Ms Gladys Hitchen
 Mental Health Dietetics & Nutrition Clinic
 Cumberland Hospital – NSW

Dr Lilian Jackson
 Manager, Education Department
 Diabetes Australia – NSW

A/Professor Ines Krass
 Faculty of Pharmacy
 University of Sydney

Professor David Lyle
 Department of Rural Health – Broken Hill
 University of Sydney

Dr Nasseem Malouf
 Dietitian - Diabetes Education Centre
 Prince of Wales Hospital – NSW

Ms Sharon Manhire
 Program Coordinator
 Diabetes Australia – ACT

Ms Kaye Neylon
 Past President
 Australian Diabetes Educators Association – WA

Dr Pat Phillips
 Diabetologist
 The Queen Elizabeth Hospital – SA

Ms Judy Reinhardt
 Convenor – Course Accreditation Committee
 Australian Diabetes Educators Association – NSW

Ms Michelle Robins
 Diabetes Educator
 Australian Diabetes Educators Association – QLD

Ms Victoria Stevenson
 Diabetes Educator
 Australian Diabetes Educators Association – VIC

Dr Paul Williams
 Department of Medicine – Endocrinology
 The University of Sydney

Key Opinion Leader Interview Guide

Thank you for agreeing to be interviewed for this project.

Background

The purpose of this project is to develop a national consensus position on outcomes and indicators for diabetes patient education. This project is funded by the National Diabetes Services Scheme Strategic Fund. The need for the project has been highlighted in a number of reports. It is being undertaken now to provide a benchmark for evaluating educational interventions and to feed into training and competencies for the diabetes (education) workforce.

The process for developing the national consensus position involves literature reviews, consultation with stakeholders and focus groups with people with diabetes. We are seeking your input as a key opinion leader and appreciate your time in sharing your views.

In the report no comments will be associated with particular individuals – rather the report will contain a summarised synthesis of the consultation. However, we would like to list your name as a contributor – is this OK with you Yes No

I will be taking written notes during the interview. A transcription of our discussion will be forwarded to you to confirm that your views are accurately reflected.

Interview guiding questions

1. What do you see as the main goal or purpose of Diabetes Patient Education?
2. What would you say are the most important 3 or 4 key outcomes of Diabetes Patient Education?
3. What is your view [with regard to key outcomes] based on?"
4. Do you think your peers/colleagues hold the same opinion [with regard to the identified key outcomes]?"
5. Do you think people with diabetes would have the same view [with regard to the identified key outcomes]?"
6. You have listed as key outcomes. Can you suggest some indicators (which could feasibly be collected) for measuring achievement towards those outcomes?
7. Are there any other comments you would like to add?

Thank you for your time and comments

Key Opinion Leader Interview Results

Aim

The aim of the interviews was to seek input from national key opinion leaders with regard to their views on what should be the goals, outcomes, and indicators for diabetes patient education.

Methods

A purposive sample of key opinion leaders was identified and included representatives of various disciplines, settings and states (Appendix 3). Selection was based on key opinion leaders' expertise in the area of diabetes and research and their characteristics of being influential, well known by their peers and well informed in the field of diabetes.

The majority of interviews were conducted face-to-face and some via telephone, by the same researcher, using a structured approach with seven standardised questions (Appendix 3a). The interviewer took written notes. A transcription of the interview was sent back to the interviewee to confirm that it was an accurate record of the interview.

A thematic analysis was undertaken by the same researcher, tabling responses and using descriptive, qualitative frequencies of themes and reporting relevant individual comments and quotes.

Results

A total of 29 interviews were completed with key opinion leaders across Australia, representing all states, except Tasmania and the Northern Territory, between August and December 2005.

The majority of key opinion leaders interviewed were representatives from diabetes specialist services including endocrinologist, diabetes educators, dietitians and psychologists specialised in diabetes. Other disciplines included primary care, academics/researchers, non-government organisations and special needs groups (remote area and Aboriginal services). Interview length ranged from 25 minutes to 40 minutes.

For the purpose of this report a 'person with diabetes' is interchangeable with 'patient'. However, 'client', 'patient' and 'person with diabetes' were all terms used by interviewees, with the majority referring to 'patient' as the person with diabetes.

Goal of diabetes patient education

“What do you see as the main goal or purpose of diabetes patient education?”

When asked about the main goal or purpose of diabetes patient education, the most frequently and homogeneously (across most disciplines) expressed view by key opinion leaders was '**patient empowerment**'. Statements such as equipping, enabling, assisting, supporting and encouraging the patient to affectively and confidently participate in diabetes self-management added to the weight to this theme. A smaller number expressed '**to provide patients with information about the condition**' as the main goal with emphasis on including the patient's family in the diabetes education process and representatives of Aboriginal groups stressed community involvement in the education process was a valuable resource.

Other less frequented goals were: 'informed decision making by patients'; 'to achieve quality of life for the person with diabetes', 'supporting the patient towards physical, emotional and social wellbeing', 'preventing/minimising diabetes complications' and 'helping patients to access available resources'.

Key outcomes of diabetes patient education

“What would you say are the most important three or four key outcomes of diabetes patient education?”

A large majority of interviewees identified **knowledge and understanding** as key outcomes of diabetes education. A number of key opinion leaders felt that knowledge should be about: self-care management; targets of treatment (ABCs); risks of complications; use of and adherence to medication; knowing oneself; and what care they should expect from their doctor. Several interviewees stated that the information should be accurate; socially, culturally, language and spiritually acceptable; addressing individual needs; timely (stage of diabetes) and should be enabling people with diabetes to make informed choices.

Quality of life and **psychological adaptation** were articulated as separate outcomes. However, when combined represented a majority of responses across all disciplines. Quantity and quality of life, optimal mental health, integrating diabetes into lifestyle, psychological support, well-being and feeling comfortable about the condition were individual responses included in the combined outcomes.

Another frequent theme represented across eight disciplines was **'adequate self-management skills'**. Concepts such as 'enabling self-management skills', 'problem solving skills', 'engaging with the health care team', 'providing safety (ie avoiding severe and reducing the frequency of less severe hypos)' and 'adequate hypoglycaemia management' were themes contributing to the frequency of adequate self-management skills.

Behaviour change including physical activity, healthy eating, medication taking and adopting a healthy lifestyle was voiced by a fewer number of key opinion leaders as key outcome. As positive behaviour change (eg physical activity and healthy eating) is an integral component of diabetes self-care, it adds weight to the theme of adequate self-management skills and hence if combined would result as the strongest theme overall.

'Patient empowerment' as a key outcome was expressed by a significant number of key opinion leaders, however dietitians, endocrinologists, representatives from non-government organisations and special needs groups did not share this view. Affective participation in self-management, confidence and coping with diabetes management, self-efficacy, patient reassurance, supporting patients' goals and patient confidence in decision making about diabetes self-management including crisis management were some comments adding weight to the theme of 'empowerment'.

Clinical outcomes including comments such as 'HbA_{1c} less than 7%', 'stable blood glucose levels', 'normal lipid profile', 'weight', and 'adherence to best practice guidelines' were identified as key outcomes by a substantial number of interviewees, preventing/minimising risk of acute and long-term complications and accessibility to services and resources by fewer interviewees. Less frequented outcomes were: 'understanding the (Australian) Health System', 'correcting cultural assumptions and myth', 'the importance of including general health checks as part of the cycle of diabetes care' and 'reducing health care and societal cost'.

There was a fairly equal spread of responses across all disciplines, especially around behavioural and psychosocial outcomes. Interestingly, medical doctors did not suggest measuring clinical parameters (HbA_{1c}, lipid levels etc) as outcomes of diabetes education.

Some concerns were raised that none of the outcomes identified could stand on their own but were linked together as a process of outcomes.

Rationale for determining outcomes

“What is your view [with regard to the identified key outcomes] based on?”

The vast majority of key opinion leaders articulated that their view was based on available literature (ie DCCT trial, UKPDS, ADEA documents and magazine and ‘evidence based guidelines for type 2 diabetes) and their professional experience. Professional experience ranged from 1-30 years with the majority having worked in the field of diabetes for over 20 years.

A small proportion of interviewees’ opinion was based on personal experience ie having diabetes themselves or living with a close relative with diabetes, conversation with peers and people with diabetes, and on their own research and projects.

Views of peers/colleagues opinion

“Do you think your peers/colleagues hold the same opinion [with regard to key outcomes]?”

Less than half of key opinion leaders thought their peers or colleagues would hold the same opinions with regard to their determined outcomes, a smaller number expressed that “*the majority would*” and some were indecisive. The following remarks augment these opinions:

“A lot of diabetes educators are still locked into clinical outcomes. They need support to be able to adopt behaviour change as an outcome”.

“I think GPs undervalue the role of goal setting and patient empowerment”.

“Some dieticians have unrealistic expectations and push people”

“A lot of educators still use an information giving approach but in low literacy areas eg Aboriginal population educators have adopted a more client-centred approach”

“People would say there are too many cross-cultural differences to be able to achieve the same outcomes”

Views on patients’ opinion

“Do you think people with diabetes would have the same view [with regard to key outcomes]?”

Around half of the interviewed key opinion leaders answered in the affirmative, a smaller number held the belief that “some would others wouldn’t”, whereas others were unsure. Some comments elucidate their answers:

“Patients would have different emphasis ie more on knowledge and management less on clinical outcomes.”

“Patients would rate QOL highest before technical skills or HbA_{1c}.”

“There are two groups - older patients like to be told, younger once ask more questions.”

“... yes we’ve done focus groups with Aboriginal people.”

“It is not something the person with diabetes would come up with but if we would explore the areas of coping, problem solving and psychosocial adjustment I think they would forward their views and opinions.”

“It is difficult for patients to decide what goals and outcomes are important until they understand their condition.”

“When patients learn and understand about risk factors they will take their condition more seriously and will change behaviour.”

“It depends on the individual person, their age and situation.”

Indicators for measuring achievement towards outcomes

“You have listed as key outcomes. Can you suggest some indicators (which could feasibly be collected) for measuring achievement towards those outcomes?”

Interviewees were asked to identify indicators that could feasibly measure achievement towards each separate outcome. This question seemed to pose some difficulty for many interviewees especially for the more qualitative outcomes of behavioural and psychological nature. A number of interviewees expressed unease about being put ‘on the spot’ but would have preferred to have time to consider their answers. This might indicate that interviewees were not familiar with or did not assess patients’ behavioural and psychological outcomes.

Comments were raised by a number of interviewees that some of these indicators could be applied to more than one outcome.

Tables 1 to 4 (page A3-7) list the most commonly identified indicators, in descending order, for the four main key outcomes. A small number of key opinion leaders pointed to available resources and literature that could aid in the development of appropriate indicators. Specific validated instruments for assessing behaviour change and quality of life were mentioned such as: ‘Diabetes Care Profile scale’, Audit of Diabetes Dependent QOL scales developed by Clare Bradley, PAID scale (coping/confidence scale), Well Being Scale (adapted from DAWN) and the SF-36 scale. The use of a pedometer was also identified as a useful indicator for measuring physical activity.

Additional comments

“Are there any other comments you would like to add?”

The majority of additional comments voiced were concerns and suggestions in regard to diabetes education delivery and access.

A number of interviewees expressed their support for this project and the need for demonstrating the effect of and hence justifying future resource allocation for diabetes education interventions. ADEA and General Practice representatives both expressed interest in implementing the outcome of this project into program evaluation and to set standards for curriculum development.

Major barriers were expressed with regard to the expense of validated tools (eg SF-36) and the lack of support and resources for using such tools.

A concern was raised about the lack of definition for ‘diabetes patient education’ which inhibits the development of standardised education interventions and national benchmarking.

Table 1: Indicators identified for measuring knowledge and understanding

- Validated scale to measure knowledge (pre-post education) reference: Diabetes knowledge assessment scale (DKN), 1984
- Improved self-care behaviours/lifestyle change
- Assess problem solving skills by case scenarios, practical problem solving exercises

Table 2: Indicators for measuring psychological adaptation and quality of life

- Tools such as QOL questionnaires/scales (depression scales, diabetes and stress questionnaire)
- Depression/anxiety scale (validated tools for diabetes eg from UK), validated instruments on patient function/coping (there are some simple repeat measure instruments)
- Well-being/confidence scale
- PAID scale (Problem Areas in Diabetes) by Polonski
- HADS scale (Hospital Anxiety and Depression)
- SF 36 scale
- ATT19 scale - emotional indicators
- Audit of Diabetes Dependent quality of life (ADDQOL)
- DMA scale (Diabetes Management Attitudes)
- Diabetes Care Profile scales (developed by Clare Bradley)
- QSD-R – Psychometric Properties of the Questionnaire on Stress in Patients with Diabetes
- Flinders scale
- Kessler Psychological distress Scale-10 (before-after intervention depression scale)
- Referral rate to counsellors/psychologists

Table 3: Indicators for measuring self-management skills

- Medication adherence scale
- Exercise habits / standardised physical activity measure / uptake of pedometer use
- Weight, BMI, waist measure
- Nutritional habits / standardised nutritional intake measures / food record sheet (to assess energy, fat and carbohydrate intake, eg fat fibre barometer)
- Self-efficacy measures/scales
- Confidence in self-management skills

Table 4: Indicators for measuring patient empowerment

- Level of confidence
- Motivation for behaviour change
- Assess level of empowerment eg proactive self-care, subjective rating scale from 0-10 before and after intervention with questions such as “*to what extent do you feel diabetes is affecting your participation in life?*”
- Self-efficacy

Summary

The most frequently expressed main goal of diabetes education expressed by key opinion leaders was 'patient empowerment' including statements such as equipping, enabling, assisting, supporting and encouraging the patient and their families to affectively and confidently participate in diabetes self-management.

Key outcomes of diabetes education most commonly expressed were 'knowledge and understanding', 'psychological adaptation/quality of life', 'adequate self-management skills' and 'patient self-determination/empowerment'.

Some concerns were raised that none of the outcomes identified could stand on their own but were linked together as a process of outcomes.

Views of key opinion leaders mirrored the opinions expressed by people with diabetes/parents of children with diabetes and service providers. However people/parents of children with diabetes placed more emphasis on learning about diabetes and its self-management and psychological support while service providers rated 'prevention of complications' as their fourth key outcome'.

There seemed to be variable expertise among key opinion leaders with regard to defining suitable indicators in particular for measuring behavioural and psychological outcomes. Indicators most frequently expressed were of clinical/biomedical nature (ie HbA_{1c}, Lipid levels, BP, BMI) followed closely by behavioural habits (ie medication adherence, eating, physical activity) and depression/anxiety and well-being. Other indicators mentioned were assessing knowledge and understanding and frequency of visits for diabetes care.

Appendix 4: Focus Groups

- **Appendix 4: Focus group discussion guide**
- **Appendix 4a: Focus group results**

Focus Group Discussion Guide

Note

The focus groups will follow a semi-structured format with the facilitator using the prompts as needed, and as appropriate to guide the discussion.

Definitions

Outcomes = results

Indicator = any unit of information that can feasibly measure progress towards achievement of a result.

Questions

- **What do you see as the main goal or purpose of Diabetes Patient Education?**

Interviewer prompts

What is the ultimate goal/priority you strive for (apart from a cure!) as a person living with diabetes. For parents of a child with diabetes, change this to: What is the ultimate goal/priority you strive for (apart from a cure!) as a parent/carer of a child with diabetes?

How could education and information about your diabetes help you achieve this? What kind of information would it be? What would be its key characteristics?

- **What would you say are the most important 3 or 4 outcomes of Diabetes Patient Education?**

Interviewer prompts

What should diabetes education help you to achieve?

What do you expect to be able to do as a result of having diabetes education?

What are your 3 to 4 main priorities for your day to day diabetes management?

(Try to cover clinical and psychological aspects).

- **What is your opinion [with regard to your identified key outcomes] based on?**
- **Do you think other people with diabetes (parents/carers of a child with diabetes) have the same opinion?**
- **Do you think Endocrinologists would have the same view?**
- **Do you think Diabetes Educators would have the same view?**
- **Do you think GPs would have the same view?**
- **You have listed as key outcomes. Can you suggest some indicators (which could feasibly be collected) for measuring achievement towards those outcomes?**
- **What would you say are the most useful aspects/elements of diabetes patient education that you have experienced to date?**
- **What would you say are the least useful aspects/elements of diabetes patient education that you have experienced to date?**
- **Finish with: is there anything else that you would like to discuss?**

Thank you very much for your time and comments.

Focus Group Results

A total of six focus groups were conducted between December 2005 and February 2006 in two cities (Sydney and Brisbane) and two rural towns (Hamilton - Victoria and Broken Hill - New South Wales) across three states.

In total 37 people, 16 males and 21 females, participated in the focus groups. The groups consisted of 11 people with type 1 diabetes, 18 people with type 2 diabetes, 7 parents of children with diabetes and one person with pre-diabetes. Specific groups and their inclusion criteria are set out below:

- Parents of children with diabetes
- Young adult group (18 to 35 yrs)
- Adults with diabetes (> 35 to 64 years)
- Older Adults (> 64 and over)
- Two rural groups including all of the above categories

All participants were over 18 years of age and from English speaking background.

Purpose

The purpose of the focus groups was to explore what people with diabetes, and parents of children with diabetes want and expect from education about their diabetes, specifically with regard to the main goal, key outcomes and associated indicators.

Method

Focus Group participants were recruited through diabetes specific consumer organisations (Diabetes Australia, Juvenile Diabetes Research Foundation), hospital based diabetes centres and a general practice and were invited because they fitted the demographics for that group.

A set of seven semi-structured questions including prompts were used by a facilitator to elicit participants' views (Appendix 4). To capture responses the facilitator was assisted by a person taking notes.

A thematic analysis was undertaken by synthesising and descriptive reporting of emerging themes, complemented by individual quotes (*in italics*). To improve the validity of reported themes, the person taking notes identified strongest themes independent from the facilitator. Any differences were discussed and reported themes reflect mutual agreement.

Results

Question

“What do you see as the main GOAL or purpose of diabetes patient education?”

Response

Every group had a slightly different focus reflecting group characteristics.

Group 1- young people

The strongest theme expressed by young people was to stay as healthy and well as possible and keep updated with latest technologies. They also unequivocally agreed it was important to them to be treated as adults.

“It is important to keep updated on the best products and latest technologies so you can maximise your diabetes self-management.”

Group 2 - parents of children with diabetes

To learn about the mechanism of how to manage diabetes including information about the condition and its treatments (eg insulin types and their actions) as well as practical self-management skills (ie insulin injections, self-monitoring of blood glucose levels (SBGM)) were the strongest expressed goals. Emphasis was placed on including siblings and teachers in the education process as they play an integral part in the child’s diabetes care. Parents also articulated that the education process should empower them and their child to enable best possible diabetes self- management.

Group 3 - adults and older adults

In the adult population knowledge and information about the condition and how to self-manage diabetes emerged as the strongest theme. Psychological support, gaining coping and ‘survival’ skills and achieving best possible health and quality of life were other frequent comments with regard to the goal of diabetes education.

“I think understanding the disease and how to minimise risks and normalise your life is the main goal of diabetes education... it is achievable.”

“When you are first diagnosed, you feel like you are lost in a storm. After seeing a diabetes educator I was more reassured.”

“Diabetes education has helped me through knowledge about diet and exercise. The outcome of this leads to the ultimate goal which is quality of life and control through self-management.”

Question

“What would you say are the most important three or four KEY OUTCOMES of diabetes patient education?”

Response

Key outcomes identified by focus group members are reported in descending order of frequency.

Self-management skills

Participants highlighted the need for advice to be packaged into a ‘simple tailored management plan’, be motivating, reassuring and confidence building in order to facilitate positive behaviour changes and diabetes self-care. One group voiced the opinion that although diabetes education could assist with behaviour change (exercise, healthy diet) it was not responsible for it; the individual needed to motivate him/herself.

Participants agreed that knowing where, when and how to access resources and support networks was vital for ongoing self-management. This need was particularly highlighted by parents of children with diabetes. Peer support groups were mentioned as a way of keeping updated and as a means for exchanging experience and coping skills for daily living.

“Learning practical skills such as using the glucometer, broad education about foot care and nutrition such as ‘food labelling’ is very useful”.

“...to motivate the patient to take ownership of their condition and self-manage it”

“Simple information and realistic advice regarding self-management that addresses the persons’ needs and enables him/her to incorporate it into their lifestyle”

Psychological support and quality of life

Participants voiced a strong need for psychological support especially at diagnosis to enable adjustment and integration of diabetes self-care into their lifestyle. This need was expressed most strongly by people with insulin treated diabetes and parents of children with diabetes however, participants struggling with behaviour change (eg unable to lose weight, difficulty with dietary adherence and exercise) also highlighted the need for access to professional counselling and psychological support services, *“which often don’t exist”*.

“Everyone with a chronic condition is more prone to depression but health professionals don’t mention this.”

“Anyone who has done first year psychology knows about the psychological developmental milestones which are stages you go through when you are diagnosed with a chronic disease or if someone dies. Identifying those steps of psychological adjustment, usually beginning with denial, anger and so forth..., I can’t remember them all but I know they exist. If I had been given access to that sort of information at a younger age, and if I had known that these feelings of denial were normal, that would have helped me a lot at that stage in life.”

“.. to be able to deal with it; to fit diabetes into my lifestyle so I can maintain my lifestyle”

“The secrecy about my diabetes caused a huge psychological burden on my relationship.”

“Diabetes is with you every day. Psychological support particularly for children and parents is necessary but is not there – they don’t teach us coping skills.”

Knowledge and understanding

Parents of children with diabetes agreed that acquisition of knowledge was the cornerstone for diabetes self-management. This group also highlighted the importance of age adjusted, timely and ongoing education on a needs basis. Young adults emphasised that the information about diabetes and self-management had been invaluable for their independent and confident self-care and for maintaining control of their diabetes. Adult groups highlighted the need for information and advice to be timely (ie stage of the disease process whether newly diagnosed or suffering from complications) simple, specific, precise, and practical. This was summarised as education needing to be ‘translatable’ into individual lifestyle, tailored to individual needs, ongoing and including the whole family.

“I could not have coped without learning about the condition and the necessary skills.”

“Diabetes education helps you to maintain control of your diabetes.”

“It is important to get information about latest advances and technologies across to the person with diabetes as advances in this field are astounding.”

“Information should include insurance/drivers license requirements - the bread and butter stuff.”

“The initial education should be basic, simple and broad ranging but later more specific, for example concerns about feet, eyes...”

Clinical outcomes

A number of participants expressed a sense of reassurance when knowing that their blood glucose levels and HbA_{1c} were under control. However, in general clinical outcomes did not receive as a high priority as the other three identified outcomes.

Question

“What is your opinion [with regard to your identified key outcomes] based on?”

Response

All participants agreed that their opinion was based on personal experiences of living with diabetes or caring for a child with diabetes. Young adults also mentioned that they read literature such as the Diabetes Australia magazines “Conquest” and “Diatrife” and use diabetes websites such as “Reality Check” and the Internet for regular diabetes updates.

Question

“Do you think other people with diabetes (parents/carers of a child with diabetes) have the same opinion?”

Response

The majority of participants felt that most other people with diabetes would agree with the outcomes they had identified. However, a few individual comments deviated from that view:

“No, it is an individual thing, everyone deals with it differently”

“Not everyone is as motivated as me”

“A lot of people with diabetes are apathetic or in denial of their condition and its seriousness, or they don’t have enough knowledge or are lacking awareness of the importance of good diabetes self-care”.

Question

“Do you think endocrinologists would have the same view?”

Response

There were more negative than affirmative responses to this question. The following expressions and comments exemplify participant’s views:

“I think their goals differ from my ambition.”

“They don’t have the time to respond to your concerns; they don’t get the whole story.”

“They don’t have the same sense of ownership.”

“Endocrinologists tend to be more focused on the clinical aspects of the condition eg better blood glucose control” (commonly voiced view)

“Specialists don’t have a holistic approach eg they don’t want to know about my other health problems such as my arthritis which often affects my diabetes control.”

“I think the majority would agree but it depended on the Endocrinologist.” (frequently expressed view)

“Endocrinologists think more about long-term health and focusing more on clinical outcomes; they leave the education side to the educators; they vary in their approach of dealing with psychological and behavioural issues.”

Question

“Do you think diabetes educators would have the same view?”

Response

There was almost unanimous agreement amongst respondents that diabetes educators would share their opinions with one individual comment of disagreement ie *“more or less, but probably would be more inclined with clinical outcomes eg better blood glucose control.”*

Question

“Do you think general practitioners (GPs) would have the same?”

Response

All groups expressed concerns that GPs are not informed enough about diabetes, specifically lack knowledge about type 1 diabetes and unless prompted don't arrange for regular complication checkups. However, there were some positive views that despite GPs time constraints and their limited diabetes knowledge base, they would probably have the same goals ie best quality of life for their patients.

Question

“Can you suggest some indicators (which could feasibly be collected) for measuring achievement towards those outcomes?”

Response

Suggested indicators towards measuring ‘adequate self-management’:

- Level of confidence in self-management
- Attendance rate at clinic
- Changes in diet and attitudes to food
- Patient held chart/diary for monitoring regular checkups
- Sale of SBGM strips through NDSS
- Weight
- HbA_{1c}
- Survey re lifestyle, behaviour changes (pre-post)
- Number of people attending support groups after attending education session
- Statistics from service providers - number of clinic visits per year
- number of referrals

Suggested indicators towards measuring psychological adjustment/support and quality of life

- Mental well-being
- General health well-being
- Questionnaire for assessing (psychological) well-being and coping skills
- Weight

Suggested indicators towards measuring knowledge and understanding

- Test / exam / questionnaire on diabetes knowledge and understanding, including problem solving questions
- Annual knowledge test

Suggested indicators towards measuring clinical outcomes

- HbA_{1c}
- Blood Glucose Levels
- SBGM record

Question

“What would you say are the most useful aspects/elements of diabetes patient education you have experienced to date?”

Response

- Seeing a diabetes educator who provided
 - necessary self-management skills and confidence to live with diabetes
 - knowledge and skills necessary to manage diabetes
 - written information to reinforce education
- Support sources such as group education, peer support groups, attending seminars/lectures
- Ongoing support eg able to ring up (diabetes educator) for help when needed
- Regular follow up clinic visits to keep updated (eg availability of insulin pump)
- To have a continuing relationship with health professional (diabetes educator, doctor)
- Learning practical skills
- Kids camps - “my child met other children with type 1 diabetes”
- Written information, especially the book ‘diabetes for children and adolescents’ published by Westmead Children’s Hospital and magazines from Diabetes Australia
- Peer mentoring programs - *“I was asked to talk to a group of young people with diabetes to help them come to terms with their diagnosis; I think it was very successful”*.

Question

“What would you say are the least useful aspects/elements of diabetes patient education you have experienced to date?”

Response

The following are answers expressed by a number of participants with individual quotes in *“italic”*.

- Doctors/health professionals that are not understanding and don’t take the time to explain about the condition and don’t refer you to the right support people and available resources.
- Lack of awareness about available resources (one parent was not made aware [by GP] of the existence and role of the diabetes educator until two weeks after his/her child was diagnosed with type 1 diabetes)
- Conflicting and/or inconsistent information from doctors - *“doctors don’t even agree amongst each other”*
- Health professionals that ‘are not understanding’ and treat you like a child (comments from young people)
- Lack of choice of doctor and other health professionals in rural areas (especially a problem if patient has poor relationship with health professionals)
- Dietitians who enforce their views on people instead of individualising their advice – *“one size does not fit all”*.

“My visit to a GP who had no knowledge of type 1 diabetes and insulin therapy was disappointing”

“I have had bad experiences with patronising and harassing doctors and health professionals that tell you what to do. I wouldn’t go back to them”

Question

“Is there anything else you would like to discuss?”

Response

The following are answers expressed by a number of participants and categorised into concerns, suggestions and differences between rural and urban groups. Quotes are shown in *“italic”*.

Concerns

- The general public needs to be made more aware of the difference between the two types of diabetes.
- There is a need for keeping updated on research and medical breakthroughs: “we want accurate timelines on medical breakthroughs eg stem-cell research, transplant research. You can’t trust the media, it is often not accurate.”
- Transition from childhood to adulthood was expressed as a difficult time when the adolescent education needs to be tailored to the ‘adolescent’ not the parent.

Suggestions

Keeping updated

- The internet is a good way for keeping updated in diabetes management and resources.

Information

- Better disseminated information eg through GP care plans, government initiatives.
- More uniform and consistent information amongst health professionals (eg dietitians and diabetes educator give conflicting advice).

Access issues

- Access to specialist and professional psychological support is lacking (particularly in rural towns). *“We have no access to a paediatric endocrinologist or psychologist unless we travel to a city which we can’t afford. We need specialists to visit rural towns”*
- Lack of choice of doctor in rural towns.

General

- Suggestion for 24 hr call centre (covering maybe three to four chronic diseases)
- Diabetes education process should start at school.
- Diabetes education should start at the GP practice to alleviate fears after initial diagnosis.
- Peer support groups and networking can assist in adjusting and coping with diabetes self-management.

Differences between rural and urban groups

Opinions were fairly homogeneous between urban and rural people with diabetes in terms of their desired outcomes of diabetes education with the exception of access issues ie people from rural towns raised concerns about the lack of specialist and professional psychological support and the need for more choice of doctors and other health professionals.

Summary

Despite slight differences, dictated by group characteristics, knowledge and information about diabetes and how to self-manage it, psychological support, gaining coping and 'survival' skills and achieving best possible health and quality of life were clear and consistent goals of diabetes education articulated by people and parents of children with diabetes. Similarly, identified **key outcomes** were **self-management skills** including access to resources and support networks, **psychological support, quality of life, knowledge and understanding** and **clinical outcomes**. Focus group participants gave considered answers with regard to feasible indicators for measuring outcomes, some of these were: clinical measures (eg HbA_{1c}), assessing knowledge (via questionnaire), behaviour, level of confidence in self-management and QOL, patient held chart/diary, attendance rate at clinic and support groups, service provider and NDSS statistics. Willingness to complete such assessments was supported by the majority of focus group members.

Information and support from diabetes educators and peers were among the most useful aspects of diabetes education while lack of understanding and 'non-individualised' approach and conflicting information from health professionals were among the least helpful aspects expressed by participants.

Compared to views expressed by national key opinion leaders and diabetes service providers, people/parents of children with diabetes placed more emphasis on clinical outcomes and access to resources while key opinion leaders put more weight on 'patient empowerment'. Service providers identified 'prevention of complications' amongst the four main key outcomes.

Appendix 5

Service Provider Survey

- **Appendix 5: Service provider survey questionnaire**
- **Appendix 5a: Service provider survey results**

Service Provider Survey Questionnaire

Service Provider Survey

**This project is being conducted by
The Diabetes Unit – Australian Health Policy Institute
The University of Sydney**

Please return the completed questionnaire by November 28, 2005 to:

**Maria Gomez
Executive Assistant and Program Manager
The Diabetes Unit – Australian Health Policy Institute
Victor Coppleson Building D02
The University of Sydney
NSW 2006**

**Phone: (02) 9036 6562
Fax: (02) 9351 5204
Email: maria@med.usyd.edu.au**

Service Provider Survey

Guide to Completion

This survey is asking about your organizations' or services' views and activities with regard to **the goals, outcomes, and indicators for diabetes patient education**. It is not about any activities that you may engage in with regard to health professional education.

For the purpose of this project we have chosen to use the following **definitions**. Please keep them in mind when completing the questionnaire.

- An **outcome** is simply defined as a result or consequence.
- An **indicator** is defined as any unit of information that can feasibly measure progress towards the achievement of a goal, or outcome or indicators.

Please note

The project has ethics approval from the University of Sydney Human Ethics Committee (approval No.11-2005/1/8667)

The results of this survey will not be published or disclosed to other people in a way that identifies you or your organisation. Any information about your organisation that is obtained in connection with the survey will remain confidential and will only be disclosed with your written permission. If you have any questions about this please contact:

Cecile Eigenmann or Ruth Colagiuri on telephone 02 9036 6562.

Should you have any complaints or concerns about the way this survey is conducted please contact:

**The Manager, Ethics Administration
University of Sydney
Ph. (02) 9351 4811
Fax: (02) 9351 6706
Email: gail@usyd.edu.au**

Thank you for contributing to this important project.

Section 1. Information on the organisation's or service's involvement in information and education provision for people with diabetes.

1.1 What is the main diabetes information and education activity area your organisation is involved in? **(please tick one category only)**

- Information provision
- Education
- Both information provision and education
- Other - please describe _____

1.2 Please list the specific areas of diabetes care your organisation has experience with **(please tick one or more categories as applicable)**

- Prevention
- Management (clinical/educational)
- Self-management

1.3 Please list the types of groups your organisation works with. **(please tick one or more categories as applicable)**

- Children – patients (0 - 17 years)
- Young adult – patients (18- 35 years)
- Adult – patients (36 - 64 years)
- Elderly – patients (65 years and over)
- Carers
- Other - please describe _____

1.4 Where do your clients access the information and/or education services you provide? **(please tick one or more categories as applicable)**

- Hospital
- Diabetes Centre
- Diabetes Australia Office
- Community Health Centre
- General Practice
- Service Providers Premises – other than those already listed
- Community Centre
- in their own home
- other - please describe _____

Section 2. Your views on the overall goal, outcomes and indicators for diabetes patient education.

2.1 What do you see as the main goal or purpose of Diabetes Patient Education?

2.2 Please list what you believe to be the 3 or 4 most important (key) outcomes of Diabetes Patient Education?

2.3 What is your view based on?

2.4 Do you think your peers/colleagues hold the same opinion? **(please circle) Yes / No**

2.5 Do you think people with diabetes would agree? **(please circle) Yes / No**

2.6 Can you suggest some indicators (which could feasibly be collected) for measuring progress towards the outcomes you listed in 2.2 above?

Section 3. Monitoring outcomes of your patient education service

3.1 Do you routinely monitor the outcomes of the patient education services your organisation or service provide? (please circle one) **Yes / No**

3.2 If 'yes' to 3.1 what assessment criteria do you use?
(please select one or more categories as applicable)

- Behavioural outcomes and indicators
- Clinical outcomes and indicators
- Indicators of psychological adjustment
- Indicators of well-being or quality of life
- Other - please describe _____

3.3 If 'yes' to 3.1, are the tools you use validated? (please circle one) **Yes / No**

Comments: _____

3.4 If 'yes' to 3.3, please list the titles and/or references for the tools you use.

Thank you for completing this questionnaire – your assistance is much appreciated

Please return the completed questionnaire by November 28, 2005 to:

**Maria Gomez
Executive Assistant and Program Manager
The Diabetes Unit – Australian Health Policy Institute
Victor Coppelson Building D02
The University of Sydney
NSW 2006
Phone: (02) 9036 6562
Fax: (02) 9351 5204
Email: maria@med.usyd.edu.au**

Service Provider Survey Results

A survey of diabetes service providers was undertaken between November and December 2005 to ascertain views and opinions in regard to the goals, outcomes and indicators of diabetes patient education.

Purpose

The aim of the survey was to consult frontline diabetes education service providers on their service characteristics, opinions about what should be the goals, outcomes and indicators of diabetes patient education and their current activities in the area of program and service evaluation.

Methods

A paper-based questionnaire was used as the survey instrument (Appendix 5). Multiple choice questions were used with regard to demographics and open text questions were used to elicit opinions. A total of 87 surveys were sent out to the 70 Diabetes Centres registered with the National Association of Diabetes Centres and the eight Diabetes Australia State and Territory Associations. A reminder survey was sent out three weeks after initial mail out.

Data analysis was performed using SPSS for windows version 13.0. Frequency tables were used to analyse dichotomous data and emerging themes were identified to synthesise open text responses.

It should be noted that for Q1.2, Q1.3, Q1.4 and Q3.2 (Appendix 5) more than one option could be selected hence the percentages for these questions do not add up to 100.

Results

The reminder survey increased the return rate from 27 to 37 with a final response rate of 42.5 %.

Section 1. Information on the organisation or service involvement in information and education provision for people with diabetes

This section gathered demographic information on the organisations' setting, the scope of services provided and characteristics of the target groups the service works with. All questions in this section were answered by 100% of respondents.

All organisations (97%), except one who provides an education service only, indicated that they were involved in both information provision and education activities.

Specific areas of respondents' expertise in diabetes care are listed in Table 1. The majority (97.3%) of respondents indicated they have experience in diabetes management (clinical/educational), 94.6% in diabetes self-management and 62.2% in the prevention of diabetes.

Table 1: Service providers' areas of expertise in diabetes care

Area of diabetes care expertise	Percentage of responses (n=37)
Management (clinical/educational)	97.3
Self-management	94.6
Prevention	62.2

Service providers were asked to list the type of groups their organisation works with (Table 2). Both elderly (65 years and over) and adults (36-64 years) are serviced by 97% of providers, 94.6% see young adults (18-35 years) and 70.3% provide services for children (births -17 years). Eighty-nine percent also include carers in their service provision. Other groups listed (54%) were: health professionals (the most frequently listed group), families, diabetes in pregnancy, schools, Aboriginal people, health workers, divisions of general practice, communities, childcare, obstetrics and educational organisation (ie TAFE).

Table 2: Characteristics of groups serviced by providers

Characteristics of groups	Percentage of responses (n=37)
Elderly (65 years and over)	97.3
Adults (36-64 years)	97.3
Young adults (18-35 years)	94.6
Carers	89.2
Children (births -17 years)	70.3
Others	54%

The most frequent response to the multiple choice question: "Where do your clients access the information and/or education services you provide?" (Table 3) was 'hospitals' (97.0% of 37 responses), followed by diabetes centres (51.4%), general practice (32.4%), Diabetes Australia offices (29.7%), community centres (27%), clients' own homes (27%) and community health centres (16.2%). and 'service providers premises-other than already listed' (5.4%). Other facilities specified were: diabetes clinics, schools, cafes and camps, local migrant resource centre, private hospital, chemists, correction centre, hostels, lecture venues and local agencies, outreach services and 'by phone'.

Table 3. Type of facilities for clients' access to information and/or education

Type of facility	Percentage of responses (n=37)
Hospital	97.0
Diabetes Centre	51.4
General Practice	32.4
Diabetes Australia Offices	29.7
Community Centres	27.0
Clients own home	27.0
Community Health Centres	16.2
Service Providers premises-other than already listed	5.4
Other	32.4

Section 2. Your views on the overall goal, outcomes and indicators for diabetes patient education

This section consisted of four questions allowing free text responses hence frequency of occurring themes is reported.

As illustrated in Table 4, the dominant theme from the responses to the question “*what do you see as the main goal or purpose of diabetes patient education*” was **self-management** (63.8% of 36 responses). The theme ‘self-management’ was extracted from statement such ‘effective self-management to achieve optimal quality of life. Consequently, the themes ‘self-management’ and ‘quality of life’ were frequented separately. As such, knowledge and understanding (25%), empowerment (22.2%) and quality of life (16.7%) were amongst the four most frequently stated goals. Other frequent themes (each of which represented 11%) were behaviour change, problem solving/decision making, and prevention of complications.

Table 4: Main goals of diabetes education identified by service providers

Goal or purpose of diabetes patient education	Percentage of responses (n=36)
Diabetes self-management	63.8
Knowledge (16.7%) and understanding (8.3%)	25.0
Empowerment	22.2
Quality of life	16.7

Similarly to expressed goals, the most frequently emerged themes with regard to the three or four most important key outcomes of diabetes patient education were **self-management** (52.7%), **quality of life/emotional wellbeing/psychological adjustment** (52.7%), **knowledge and understanding** (44.4%) and **prevention of complications** (44.4%) (Table 5). Less frequented outcomes were: behaviour/lifestyle change (37.1%), improved metabolic/glycaemic control and other targets (25.7%), self-determination/empowerment (17.1%), confidence (14.2%) and safety (5.7%).

Table 5: Key outcomes of diabetes education identified by service providers

Outcomes of diabetes patient education	Percentage of responses (n=36)
Diabetes self-management	52.7
QOL/emotional wellbeing/psychological adjustment	52.7
Knowledge (19.4%) and understanding (25%)	44.4
Prevention of complications	44.4

Of the 33 respondents who answered the question “*what is your view based on [with regard to the identified outcomes?]*” professional experience was the most frequent response (51.0 %) followed by evidence based guidelines eg NHMRC (18.2%), the literature (12.1%), ADEA national standards/guidelines (12.1%) and patient feedback (9.1%). Other individual responses were personal experience, ADA position statement, health outcome indicators and well-being and confidence scales.

Of 37 survey respondents, 83.8% thought their peers/colleagues would hold the same opinion as themselves with regard to the desired outcomes of diabetes education and 86.5% indicated that they thought people with diabetes would also agree with their view.

Service providers were asked to suggest indicators that could feasibly measure progress towards achieving their identified outcomes. HbA_{1c} and other clinical indicators were most frequently listed with 54.8% of 31 responses to this question (Table 6). Measuring quality of life with a validated tool (32.2%), behaviour change assessment tools (22.5%), knowledge tests (16.1%) complication screening/incidence (16.1%) patient satisfaction survey and pre-post education questionnaire were amongst other commonly listed indicators. Three respondents did not provide relevant responses and a comment was made that it was difficult to collect indicators as most of the patients attending their service were referred and followed up by GPs hence patients' long term outcomes were unknown.

Table 6: Service providers identified indicator areas

Indicators	Percentage of responses (n=31)
HbA _{1c} and other clinical indicators	54.8
Measuring QOL with a validated tool	32.2
Behaviour change assessment tools	22.5
Knowledge tests	16.1
Complication screening/incidence	16.1
Patient satisfaction survey	12.9
Pre-post education questionnaire	12.9
Diabetes related hospital admissions	9.6
Medication management	6.5
Client goal setting and review	6.5

Section 3. Monitoring outcomes of patient education service

A majority of 77.7% answered in the affirmative to the question about whether their organisation routinely monitored the outcomes of its patient education services, with one answer missing.

Those who responded affirmatively (n=28) were then asked to indicate (Question 3.2-Appendix 5) the type of assessment criteria they use for monitoring outcomes of their diabetes education services (Table 7). Eighteen service providers (64.3%) indicated that they use clinical outcomes and indicators, 57.2% use indicators of well-being or quality of life, 35.7% use behavioural outcomes and indicators and 14.3 % use indicators of psychological adjustment. Other indicators listed by 21.4% were: attendance rate at consecutive group education sessions, patient acceptance and appreciation of information/seminar, service satisfaction, impact evaluation, customer feedback, and client review process regarding understanding and comfort with application of care. However, none of these "other" indicators were assessed with a validated tool as elicited by the next question "Are the tools you use validated?" Fifteen respondents indicated that they use validated tools, but only 13 gave specific details to allow a reference search. These are listed in table 8, categorised by clinical and psychological indicators.

Table 7: Assessment criteria for monitoring outcomes of diabetes education services

Indicators	Percentage of responses (n=28)
Clinical outcomes and indicators	64.3
Indicators of well-being or quality of life	57.2
Behavioural outcomes and indicators	35.7
Indicators of psychological adjustment	14.3
Other	21.4

Table 8: Validated tools used by survey respondents (n=13)

Clinical indicator assessment tools	Psychological indicator assessment tools
Australian Diabetes Society Clinical Practice Guidelines ADEA documents NHMRC evidenced based guidelines for type 2 diabetes (2 responses) National Diabetes Outcomes Working group (NDOW), ANDIAB, The rise & rise of diabetes, ANDIAB2 IDF - International Standards - Diabetes Education DAFNE program indicators	Anxiety and depression WHO-5 Well being scale (2 responses) Diabetes Attitude Score-University of Michigan Diabetes and Training Centre CHQ (QOL for kids), Aust CHQ, PF50/PF80-1998 adapted with permission Waters, Salmon, Centre of Community Child Health, Melbourne, AUS

Summary

Adequate self-management and quality of life were identified as key outcome of diabetes education. In contrast, when asked what assessment criteria service providers use to measure outcomes of their education services, clinical outcomes and indicators were cited most frequently.

Although well-being and quality of life were identified as a key outcome by over half of service providers, only ten respondents indicated that they measure these outcomes and only five use a validated tool for that purpose.

Service provider's opinions are congruent with key opinion leaders and focus group participants. Differences were seen in the order of importance with service providers rating prevention of complications and focus group members rating clinical outcomes among their four key outcomes while key opinion leaders placed more emphasis on empowering patients.

Appendix 6: Stakeholder Forum

- **Appendix 6: Stakeholder Forum participants**
- **Appendix 6a: Stakeholder Forum agenda**

Stakeholder Forum Participants

Ms Jan Alford
Australian Diabetes Educators Association – NSW

Dr Kuldeep Bhatia
Australian Institute of Health and Welfare

Ms Liz Bingham
Tasmania Health Department

Mr Will Bonney
Juvenile Diabetes Research Foundation

Mrs Lyn Brown
Dietitians Association of Australia

Ms Louise Catanzariti
Australian Institute of Health and Welfare

Mr Laurie Clay
Durri Aboriginal Medical Service – NSW

A/Prof Ruth Colagiuri
The Diabetes Unit, Australian Health Policy Institute
The University of Sydney

Ms Shirley Cornelius
Australian Diabetes Educators Association – WA

Ms Leanne Cowan
Diabetes Australia – ACT

Ms Gil Cremer
Diabetes Australia – ACT

Ms Jennifer Cross
Diabetes Australia – VIC

Ms Cecile Eigenmann
The Diabetes Unit, Australian Health Policy Institute
The University of Sydney

Ms Chris Faulks
Diabetes Australia - National Office

Dr Michael Frommer (Facilitator)
The University of Sydney

Ms Kay Gally
Diabetes Australia – SA

Ms Maria Gomez
The Diabetes Unit, Australian Health Policy Institute
The University of Sydney

Ms Virginia Hagger
International Diabetes Institute

Ms Megan Hansford
Australian Division of General Practice

Dr Lilian Jackson
Diabetes Australia – NSW

Ms Jen Kinsella
Australian Diabetes Educators Association – NSW

Ms Nicole Le-Cornu
Person with diabetes

Ms Jayne Lehmann
EdHealth

Ms Anne Muskett
Australian Diabetes Educators Association – TAS

Ms Kaye Neylon
Australian Diabetes Educators Association – WA

Mrs Jaycinta Pitson
Juvenile Diabetes Research Foundation

Ms Judy Reinhardt
Australian Diabetes Educators Association – NSW

Ms Dianne Roberts
Australian Diabetes Educators Association – ACT

Ms Michelle Robins
Australian Diabetes Educators Association – QLD

Ms Michelle Roffey
Department of Health and Ageing

Mr Chris Thorpe
Australian Diabetes Professional Organisations – ACT

Dr Lyndal Trevena
The University of Sydney

Ms Diane Williamson
Person with diabetes

Ms Dawn Wilson
Health Department – ACT

Mrs Natalie Wischer
Australian Diabetes Educators Association –VIC

Ms Erica Wright
Australian Diabetes Educators Association – ACT

Stakeholder Forum Agenda

"Towards a National Consensus on Outcomes and Indicators for Diabetes Patient Education"

9am to 4pm March 1, 2006 – Parliament House Canberra

9.00am	Registration
9.30am	Welcome Senator Guy Barnett
9.35am	Introduction and purpose of the Forum Professor Michael Frommer
9.50am	Overview and Framework A/Professor Ruth Colagiuri
10.20am	The findings: <ul style="list-style-type: none">- key opinion leader interviews- providers survey- focus groups with people with diabetes Ms Cecile Eigenmann
11.00am	Morning tea
11.30am	Getting to know the Indicators <ul style="list-style-type: none">- presentation of the draft Outcomes and Indicators- relevance to participants- questions and answers Professor Michael Frommer & Forum participants
12.00 midday	Panel and plenary discussion How can the Outcomes and Indicators help? Possible applications and mechanisms for data collection and application Mr Laurie Clay Ms Kaye Neylon Dr Kuldeep Bhatia and Forum participants
12.30 pm	Summary of the discussion so far and briefing and preparation for the afternoon's agenda Professor Michael Frommer
12.40pm	Lunch
01.20pm	Refining the indicators Forum participants
02.40pm	Afternoon tea
3.00pm	Recommendations and way forward Professor Michael Frommer and Forum participants
3.30pm	Thank you and close