

Standard 1

People with diabetes should receive high quality structured self-management education that is tailored to their individual and cultural needs. They and their families/whānau should be informed of, and provided with, support services and resources that are appropriate and locally available.

Key practice points

- Structured diabetes education is a critical component of diabetes care.
- There is no strong evidence for any particular approach to structured diabetes education over another. Therefore, it is important to consider the outcomes that are desirable for the population being treated and to consider whether the trial data support the delivery of those outcomes for that population. Content and delivery is then tailored to local need.
- Adequate resources should be funded and in place to provide structured diabetes education.
- Integral to any self-management programme, particularly group programmes, is that they are culturally appropriate. People with diabetes should have access to self-management support which is relevant to the ethnicity they identify with.

Read this standard in conjunction with the equality and diversity section in the Introduction to the Toolkit.

What the quality statement means for each audience

Service providers ensure that staff are enabled to offer structured education, either on an individual basis or via a programme, that fulfils nationally agreed criteria and is ongoing and accessible to all people with diabetes and/or their carers/family/whānau.

Health care professionals ensure they offer structured education to people with diabetes and/or their carers/family/whānau as part of their ongoing care.

Planners and funders ensure they commission and fund care that is inclusive of structured education/programmes that fulfil nationally agreed criteria and are ongoing and accessible to people with diabetes and/or their carers/family/whānau.

People with diabetes and/or their carers/family/whānau receive structured diabetes education to suit their needs, delivered by trained staff. A health care professional should check every year whether the person would find further diabetes education useful, and diabetes education should continue to be available.

Definitions

Self-management education (SME) is defined as a systematic intervention that involves the person with diabetes' active participation in their self-monitoring (physiological processes) and/or decision-making (managing). It recognises that patient-provider collaboration and the enablement of problem-solving skills are crucial to the individual's ability for sustained self-care.

Self-management education refers to **any** educational processes that provide persons with the knowledge, skills and motivation required to inform decisions and increase the individual's capacity and confidence to apply these skills in daily life situations.

The content and skill-training components of SME must be individualised according to the type of diabetes and recommended therapy, the patient's ability, barriers, motivation for learning and change, culture, literacy level and available resources.

Self-management support refers to policies and people that may support the continuation of self-management behaviours across the lifespan but that are not specific to educational processes (Canadian Diabetes Association Clinical Practice Guidelines Expert Committee 2013).



Introduction

Diabetes presents a serious health challenge for New Zealand because it is a significant cause of ill health and premature death. It is well-recognised that self-care in diabetes can be demanding and is influenced by numerous factors (Snell 2011). Diabetes is considered to be a relatively unique long term condition due to treatment regimens being carried out largely through self-care. Indeed, Anderson et al (1995) estimate that 95% of required care is provided by the person with diabetes and/or their family. This is supported by the findings of a large public health survey on people with a long term condition that states that of the potential 8760 hours in one year, on average only three hours is spent with a health professional, leaving the person with 8756 hours to care for themselves (United Kingdom National Health Service 2007). According to Norris et al (2002), a minimum knowledge base is required for optimal self-care. In addition, several psychosocial mediators are related to diabetes self-care behaviour, such as locus of control, coping styles, health beliefs and self-efficacy.

Self-management education (SME)

The **International Diabetes Foundation (IDF) International Standards for Diabetes Education** are based on the available evidence about diabetes self-management education (DSME), diabetes self-management support (DSMS) and behaviour change. A summary of the evidence is as follows:

- DSME is effective for improving clinical outcomes and quality of life – at least in the short term.
- Diabetes education has evolved from primarily didactic presentations to more theoretically-based empowerment models.
- There is no single best educational programme or approach. However, programmes incorporating behavioural and psychological strategies have demonstrated improved outcomes. Additional studies show that age and culturally appropriate programmes improve outcomes and that group education is at least as effective as individual education.

- Ongoing support is critical in order to sustain the participant's progress resulting from DSME. People with diabetes experience a significant amount of psychological distress at the time of diagnosis and throughout their life, and these psychosocial issues affect their self-management efforts.
- Strategies such as self-directed goal-setting and problem solving are effective for supporting behaviour change.

The full document can be found here: www.idf.org/education/resources/standards

The State of Michigan's Health Care Providers' Guide to Diabetes Self-Management Education (DSME) Programs in Michigan provides the following academic rationale:

- Norris et al (2001) reviewed 72 randomised controlled trials of diabetes self-management training (DSMT) in type 2 diabetes and concluded that there were positive effects of self-management training on knowledge, frequency and accuracy of self-monitoring of blood glucose, self-reported dietary habits and glycaemic control in studies with follow-up timeframes of six months or less.
- Another meta-analysis by Norris et al (2002) concluded that DSMT is effective in decreasing HbA1c in the short term and states '... effective diabetes education is an integral part of comprehensive diabetes care'(p 1168)
- The 10-year United Kingdom Prospective Diabetes Study (UKPDS) confirmed that intensive blood glucose control in patients with type 2 diabetes reduced the incidence of diabetic complications, especially microvascular disease.
- According to the UKPDS, for every percentage point decrease in glycosylated haemoglobin, (eg, 9% to 8%), there was a 35% reduction in the risk of microvascular complications.
- A study published in the Journal of the American Medical Association indicated that a sustained reduction in HbA1c among adult persons with diabetes was associated with a cost reduction of \$685 to \$950 less per person per year within one to two years of improvement.
- The Diabetes Prevention Program (DPP) found that lifestyle change that effects modest weight loss and increased physical activity can return the blood glucose levels of persons with 'prediabetes' (persons at risk for developing diabetes) to normal range.
- Data analysis in 2007 from the Michigan Behavioral Health Risk Factor Surveillance Survey (MiBRFSS) showed people who had taken a diabetes self-management course were twice as likely to have obtained the recommended annual dilated eye exam, foot exam and two HbA1c tests compared to people with diabetes who had not taken a self-management course.

The full document can be found here:

www.michigan.gov/documents/mdch/ProviderHandbookFINAL9-08_256129_7.pdf

Health literacy

Health literacy is an important element of structured education. A toolkit review written for the National Diabetes Service Improvement Committee describes health literacy as 'the ability to obtain, process, and understand basic health information and services to make appropriate health decisions' (Kickbusch et al 2005 cited in Ministry of Health 2010, p iii). Health literacy includes how an individual navigates and interacts with our complex health system. It also includes people's expectations about health and wellbeing, and their understanding of health messages, medicine labels and nutrition information, as well as their ability to fill out medical forms and talk with their doctor. Specifically related to diabetes, Boren (2009) states, 'health literacy is vital to enable people to manage their health. There are many activities that people are responsible for when self-managing their diabetes that can be particularly challenging when limited health literacy is an issue. These activities include taking medication, eating a healthy

diet, glucose monitoring, and reduction of risks. Persons with diabetes who have multiple complications or experience repeated hospitalizations might have some of these problems because of unrecognised low health literacy’ (p 203). The Boren (2009) article can be found here: www.jdst.org/January2009/articles/VOL-3-1-DIT1-BOREN.pdf.



Guidelines

The **Scottish Intercollegiate Guidelines Network (SIGN)** Clinical Guidelines for the Management of Diabetes (2010) state ‘structured diabetes education based on adult learning (including empowerment and experiential learning) is associated with psychological wellbeing, reduced anxiety and overall improvement in quality of life for people with type 1 and type 2 diabetes. The effect of structured education on glycaemic control in people with type 1 diabetes varies across different programmes’ (p 10). Furthermore, they state ‘Structured education based on developing problem-solving skills targeted at children and adolescents has a positive effect on a number of behavioural outcomes (including frequency of self-monitoring of blood glucose, better compliance with sick day rules, increased levels of exercise, dietary intake and improved medication adherence) and overall quality of life. There is limited evidence for a small reduction in HbA1c (approximately 3 mmol/mol)’ (p 11). www.sign.ac.uk/pdf/sign116.pdf.

The **Canadian Diabetes Association Clinical Practice Guidelines Expert Committee** (2013) state that ‘no particular delivery strategy ... appears to result in consistently superior outcomes in persons with type 2 diabetes; however, larger effect sizes have been noted with strategies that involve personal contact with health care providers, either face-to-face interactions or by telephone. A combination of didactic and interactive teaching methods, as well as group and individual sessions, appears to be most effective for persons with type 1 diabetes’ (p S29).

http://guidelines.diabetes.ca/App_Themes/CDACPG/resources/cpg_2013_full_en.pdf.

For type 1 diabetes, the **American Diabetes Association** recommend that people with type 1 diabetes and parents/caregivers should receive culturally sensitive and developmentally appropriate individualised DSME and DSMS according to national standards at diagnosis and routinely thereafter. The specific content is detailed in the table below:

Infancy (birth–18 months)
Period of trust versus mistrust
Providing warmth and comfort measures after invasive procedures is important
Feeding and sleeping or nap routines
Vigilance for hypoglycaemia
Play age (3–5 years)
Reassurance that body is intact, use of band-aids and kisses after procedures
Identification of hypoglycaemic signs and symptoms (temper tantrums and nightmares are common)
Include child in choosing injection and finger-prick sites
Positive reinforcement for cooperation
Begin process for teaching child awareness of hypoglycaemia
School age (6–12 years)
Integrate child into educational experience
Determine skill level
Identify self-care skills
Determine roles and responsibilities
Communication with peers and school staff who and when to tell about diabetes

Adolescence (12–18 years)

Begin transition care planning
Personal meaning of diabetes
Determine roles and responsibilities in care
Social situations and dating
Who or when to tell about diabetes
Driving
Sex and pre-conception counselling
Alcohol and drugs
College and career planning

Young adults

Personal meaning of diabetes
Roles and responsibilities in care
Social situations and dating
Who or when to tell about diabetes
Genetic risks, conception, and pre-conception
Travel
Choosing or pursuing a career
Workplace rights
Health or life insurance
Involving friends and significant others in diabetes care
Safety
Creating a support network
Establishing or maintaining independence

Middle-aged adults

Personal meaning of diabetes
Roles and responsibilities in care
Involving spouse or significant other in care
Sexual functioning
Developing a support network
Travel
Pursuing a career
Workplace rights
Health or life insurance
Talking with children or other family members about diabetes
Balancing other responsibilities with diabetes care
Safety
Facing complications

Older adults

Personal meaning of diabetes
Roles and responsibilities in care
Maintaining independence
Obtaining assistance with diabetes care tasks
Involving spouse or significant other in care
Travel
Talking with adult children or other family members about diabetes
Safety
Assessing for declines in ability to perform self-care/activities of daily living
Caring for diabetes along with other chronic illnesses or comorbidities
Obtaining health care when living in multiple locations
Community resources
Care of type 1 diabetes in long term or other care facilities



Implementation advice

Self-management education

As structured diabetes education is a critical component of diabetes care, it should be offered at diagnosis and on an ongoing basis (see Standard 16). When considering a structured education programme, the **Scottish Intercollegiate Guidelines Network (SIGN)** Clinical Guidelines for the Management of Diabetes (2010) state ‘the lack of head-to-head comparative trials renders it impossible to recommend one specific programme over another. Therefore, it is important to consider the outcomes that are desirable for the population being treated and to consider whether the trial data support the delivery of those outcomes for that population’ (p 10). Content and delivery is then tailored to local need. Overall recommendations include:

Content

- Programmes should be evidence-informed, and suit the needs of the individual.
- The programme should have specific aims and learning objectives.
- Content must be specific to the diagnosis (eg, pre-diabetes versus type 2 diabetes).
- It should support the learner plus his or her family/whānau/carers in developing attitudes, beliefs, knowledge and skills to self-manage diabetes.
- Standards in teaching and use of adult learning techniques are basic to providing interactive sessions that take into account the learning needs and abilities of the group.
- There must be flexibility of timing and venue to accommodate participants’ preferences.
- Utilisation of a variety of delivery modes should be implemented (eg, face-to-face or contemporary, quality assured and New Zealand-centric online consumer resources).
- The programme should have a structured curriculum that is theory-driven, evidence-based and resource-effective, has supporting materials, and is written down.

Delivery

- No particular delivery strategy results in superior outcomes in people with type 2 diabetes. A combination of didactic and interactive teaching methods, as well as group and individual sessions, appears to be most effective.
- The programme should be delivered by trained individuals who have an understanding of educational theory appropriate to the age and needs of the learners, and who are trained and competent to deliver the principles and content of the programme.
- A team approach including paid lay coaches or mentors, where possible, could be complementary.
- Community champions can be pivotal to the success of diabetes self-management education and support in ethnic communities, and therefore should be encouraged and funded to participate where possible.

Funding

- Appropriate funding must be allocated to provide for coordination, implementation and evaluation over the long term. Funding must also provide for initial and ongoing education for facilitators at all levels, as well as opportunities for feedback on performance and collegial support.

Evaluation

- Pre- and post-evaluation of participants' knowledge, skills and the usefulness of content should be standard.
- The programme should be quality assured, and be reviewed against criteria that ensure consistency and cultural safety.
- The outcomes from the programme should be regularly audited and reported (as per Outcome monitoring below).
- Patients and their medical homes (medical home: a model of the organisation of primary care that delivers the core functions of primary health care) should have confidential feedback on topics discussed and individual pre- and post-evaluation results.
- Follow-up by health care providers is required to optimise and support patient learning, the reaching of self-set goals and maintaining behaviour change over time.

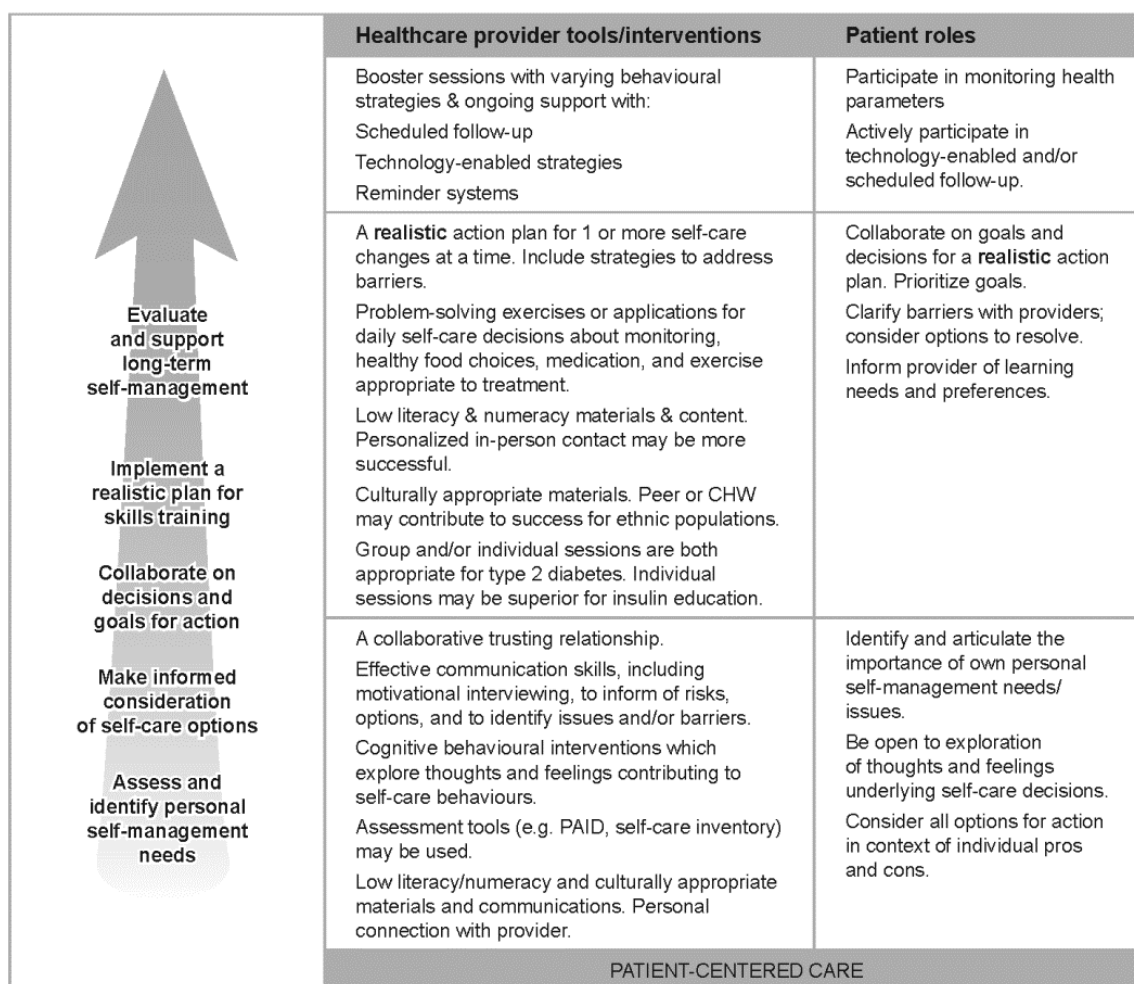
Canadian Diabetes Association Clinical Practice Guidelines Expert Committee (2013) state the following:

‘Interventions that include face-to-face delivery, a cognitive-behavioural method and the practical application of content are more likely to improve glycaemic control. The most effective behavioural interventions involve a patient-centred approach, shared decision-making, the enablement of problem-solving skills and the use of action plans directed toward patient-chosen goals. Steps to success in self-management education (SME) are summarised in Figure 1’ (p S28).

It can be accessed at:

http://guidelines.diabetes.ca/App_Themes/CDACPG/resources/cpg_2013_full_en.pdf.

Figure 1: Steps to success in self-management education



Cultural relevance for Māori

Integral to any self-management programme, particularly group programmes, is that they are culturally appropriate. People with diabetes should have access to self-management support which is relevant to the ethnicity they identify with; for example, a programme underpinned by kaupapa Māori approaches. These approaches enrich the environment for effective learning by focusing on:

- tinorangitiratanga – self-determination
- taonga tuku iho – cultural aspirations
- ako Māori – culturally preferred ways of learning
- whānau – the extended family members and their influence and support
- kaupapa – the collective philosophy of the members of the group.

Health literacy and technology

Boren (2009) undertook a review of the potential effectiveness of technology-based interventions to support health literacy. She concluded that there were a few information and communication technology opportunities that might be appropriate for intervention. These are listed here:

- communication techniques and interactive communication strategies for patients and providers
- viewpoints and experiences of the patient population to determine the optimal context, channels, and content
- computer-based algorithms that take a patient's characteristics into account, such as language, age, gender, ethnicity, reading ability, health literacy level, and specific goals or needs.
- electronic medical record to prompt the use of plain language, limit the number of concepts covered and assess patient understanding by using tell back or teach back
- interactive multimedia programs for education and counselling
- health information prescriptions that include a link or recommendation to an appropriate website and/or referral to a health librarian
- telephone or cellphone interventions for education, counselling, and reminding.



Implementation examples / innovations



Group-based diabetes self-management education

A structured, group-based diabetes self-management education (DSME) programme for people, families and whānau with type 2 diabetes (T2DM) in New Zealand: An observational study (Krebs et al 2013).

Synopsis: a six-week DSME programme tailored for the unique social and ethnic environment of New Zealand was developed using concepts from internationally developed programmes and effectiveness was assessed in an observational study with people with type 2 diabetes (aged 18–80 years) from diverse cultural backgrounds. Clinical data were collected from primary care at baseline, three, six and nine months. Krebs et al concluded that a group-based DSME programme designed specifically for the New Zealand population was effective at improving aspects of diabetes care at six months. The attenuation of these improvements after six months suggests a refresher course at that time may be beneficial.



The Manawatu, Horowhenua, Tararua Diabetes Trust offers consumer education courses for people diagnosed with diabetes and their family members. Education sessions are provided in group sessions across the MidCentral Health District and in general practices on request about:

- diabetes 'Healthy Living', including a free supermarket tour
- carbohydrate awareness courses
- diabetes 'healthy food choices and label reading'
- type 1 support persons course
- pre-diabetes education.

For more information go to: www.diabetestrust.org.nz/.



In **Waitemata District Health Board (DHB) the Dose Adjustment for Normal Eating (DAFNE)** programme for people with type 1 diabetes was implemented and assessed for clinical and cost effectiveness.

Synopsis: DAFNE is recommended by NICE in the UK as best clinical management for patients with type 1 diabetes. The DAFNE team currently comprises six DAFNE educators, a part-time administrator and two physicians. DAFNE graduates are invited to a rolling program of follow-up, which is currently being piloted. Clinical contact is recorded on the patient information management system (PIMS) and the concerto, cardiovascular and diabetes information system (CVDIS). The authors report that they have delivered 18 courses (152 patients) with 100% attendance. Principal DAFNE goals to improve quality of life and reduce severe hypoglycaemia have been achieved (PAID [diabetes distress] score reduced 50%, hypos reduced by 70%). Lipids, creatinine and HbA1c all improved. Mean improvement in HbA1c at one year was 0.1% but this included patients who have improved from overly tight control. Course costs per patient include a salary for educator time allocated to a pre-course assessment, a five-day course, a follow-up rolling programme, preparation and stats collection and email support, a one-year follow-up clinic and 30% overhead. This calculates to \$466 per patient. Compared to a clinic setting, if a patient sees a nurse twice per year, a dietitian and consultant once a year, this calculates to \$236 per patient. The authors concluded that initial outlay costs for the course are feasible. When the amount of time the patient has alongside a clinician, 50 hours for the DAFNE programme (including FU,) is compared with 3.67 hours of standard care, the cost benefit is \$9/hour of clinician time for DAFNE and \$64/hour for standard care. They go on to say that increased patient autonomy, which is another key goal of the DAFNE programme, will reduce patient dependency on one-to-one clinic visits.

www.hiirc.org.nz/page/20562/how-to-incorporate-dafne-into-routine-clinical/?q=McNamara%20&highlight=mcnamara§ion=10538



Central Primary Health Organisation (PHO), MidCentral DHB and Arthritis NZ work together to offer a free Stanford 'Living a Healthy Life' Course for patients and/or their carers/families/whānau to improve their self-management skills to manage their long term conditions in daily life.

The key principles of self-management covered in the course content are:

- know and understand your condition
- monitor and manage signs and symptoms
- actively share in decision-making with health professionals
- adopt lifestyles that promote health
- manage the impact of the condition on your physical, emotional and social life
- follow your care plan, that has been developed in partnership with your health professional.

The course runs for 2–2.5 hours each week, for six weeks in a safe, non-judgmental environment. For further information go to: www.centralhealth.org.nz/?News.



In 2012, the **Ministry of Health** commissioned the New Zealand Guidelines Group to publish a review of the literature surrounding the effectiveness of behaviour change, including possible interventions. These include:

- RapidE: Chronic Care: A systematic review of the literature on health behaviour change for chronic care
- Effective health behaviour change in long-term conditions: A review of New Zealand and international evidence
- case studies of five New Zealand interventions:
 - Case study 1: The Heart Guide Aotearoa (HGA) Programme
 - Case study 2: The Diabetes Self-management Education programme
 - Case study 3: Māori Diabetes Self-management Education
 - Case Study 4: The Samoan Self-management education programme for people with long term conditions
 - Case study 5: Implementation of the Flinders program by a Primary Health Organisation
 - Health literacy Interventions: A brief summary.

These documents can be found at www.health.govt.nz/publication/effective-behaviour-change-long-term-conditions.



Assessment tools

Structure

The National Health Service (NHS)/Diabetes UK developed a resource for evaluating patient diabetes education: **Assessment of Patient Education in Diabetes in Scotland & Tool for the Assessment of Patient Education in Diabetes in Scotland** (2012). It contains guidance on quality assurance and measurement and can be accessed at: www.diabetesinscotland.org.uk/Publications/211112Diabetes%20-%20ADEPTS_TADEPTS-web-revised.pdf.

Assessment of Primary Care Resources and Supports for Chronic Disease Self-Management (PCRS): Assessment of how well general practice services are structured to provide long term condition care can be useful to identify gaps and required improvements. The following tool was developed for primary health care settings interested in improving self-management support systems and service delivery (2006 by the *Diabetes Initiative* with support from the Robert Wood Johnson Foundation® in Princeton, New Jersey. Revised December 2008. Copyright© 2006 Washington University School of Medicine in St Louis). It is to be used with primary health care multidisciplinary teams (eg, medical practitioners, nurses, dietitians, social workers, community health workers or others) that work together to manage patients' health care and assist them to focus on actions that can be taken to support self-management by patients with diabetes and/or other chronic conditions. It is suggested that teams use it periodically (eg, quarterly, semi-annually) as a way to monitor their progress and guide the integration of self-management supports into their system of health care. <http://improveselfmanagement.org/PCRS.pdf>.

Outcomes

When considering a structured education programme, the Scottish Intercollegiate Guidelines Network (SIGN) Clinical Guidelines for the Management of Diabetes (2010) state, ‘the lack of head-to-head comparative trials renders it impossible to recommend one specific programme over another. Therefore, it is important to consider the outcomes that are desirable for the population being treated and to consider whether the trial data support the delivery of those outcomes for that population’ (p 10).

The **American Association of Diabetes Educators** (AADE) published the updated Diabetes Self-Management Education and Training (DSME/T) Core Outcomes Measures Technical Review. This document is composed of six parts: 1) Background, 2) Defining Outcomes, 3) Outcomes Associated with Diabetes Self-Management Education and Training (DSME/T), 4) Assessment for Continuous Quality Improvement (CQI), 5) Self-Care Behaviour Outcomes, and 6) Summary and Conclusion. It builds upon the earlier technical review, and it is further supported by AADE practice documents and seven systematic reviews. It also complements the ‘Standards for Outcomes Measurement for Diabetes Self-Management Education and Training’ position statement that provides a framework for educators and DSME/T stakeholders to use as a guide in assessing the value and effectiveness of DSME/T. www.diabeteseducator.org/export/sites/aade/_resources/pdf/general/Outcomes_Technical_Review_Aug_2013.pdf.

Because of the complex nature of DSME, it draws upon a variety of outcome metrics, including those that measure educational, behavioural, clinical health status, utilisation cost, and satisfaction. The AADE recommend application of seven core behavioural outcomes/performance measures to evaluate the effectiveness of DSME: 1) Being active: Physical activity; 2) Healthy eating; 3) Monitoring; 4) Taking medication; 5) Problem solving; 6) Reducing risks; and 7) Healthy coping.



Resources

The **Health Mentor Online** resource for people with diabetes has been developed to help people with diabetes gain knowledge and self-management skills. Its content is quality assured by the New Zealand Society for the Study of Diabetes. It can be accessed at: www.healthmentoronline.com

Health Navigator New Zealand developed a Self-Management Support Toolkit (2012). It provides practical tools, resources, programme information and examples to help teams apply evidence and knowledge-based approaches to self-management support. Over time, it is hoped this toolkit can be localised for different regions of the country as well as updated, revised and refined to become an essential guide to self-management support for health care teams throughout New Zealand. It can be accessed at: www.healthnavigator.org.nz/self-management/resourcestoolkit/.

The **Institute for Health Care Improvement** has developed a toolkit for clinicians to assist the partnering in self-management support. It can be accessed at: www.ihc.org/resources/Pages/Tools/SelfManagementToolkitforClinicians.aspx.

The **World Health Organization**'s document 'Making health services adolescent friendly' contains useful guidance on tailoring services to meet the specific needs of adolescents. This guidebook sets out the public health rationale for making it easier for adolescents to obtain the health services that they need to protect and improve their health and wellbeing, including sexual and reproductive health services. It defines 'adolescent-friendly health services' from the perspective of quality, and provides step-by-step guidance on developing quality standards for health service provision to adolescents. Drawing upon international experience, it is also tailored to national epidemiological, social, cultural and economic realities, and provides guidance on identifying what actions need to be taken to assess whether appropriate standards have been achieved. The guidebook is intended to be a companion to the 'Quality Assessment Guidebook: A guide to assessing health services for adolescent clients,' which was published by the World Health Organization (WHO) in 2009. These two guidebooks are part of a set of tools to standardise and scale up the coverage of quality health services to adolescents, as described in another WHO publication, 'Strengthening the health sector's response to adolescent health and development'. It can be accessed at:

www.who.int/maternal_child_adolescent/documents/adolescent_friendly_services/en/



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