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The National Diabetes Services Scheme (NDSS) is an initiative of the Australian Government administered by Diabetes Australia

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Trisha Dunning
Sally Savage
Susan Dabkowski

June 2009

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This project was conducted on behalf of the Australian Diabetes Society and the Australian Diabetes Educators Association.
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Acknowledgements
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The research team gratefully acknowledges the important contribution of the younger people with type 2 diabetes who participated in the project, the health professionals who completed the questionnaire, and the Reference Group for the project. Thanks to Diabetes Australia Victoria for assistance with recruiting younger people and providing the venue for the focus group and to Gil Cremer for administrative support.

Consultation period
The report was available on the Australian Diabetes Educators Association and the Australian Diabetes Society web sites for a period of four weeks, and comments were invited. Where relevant, comments were included in the final report.
The focus needs to shift away from the 'disease' which is the current focus of many education and support services. I never want to be defined by my disease or condition.

Comment made by a focus group participant when responding to recommendations.
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Executive Summary

Introduction
The project addresses the education and information needs of younger people with type 2 diabetes aged 25-45 years.

The aims of the project were:
- To identify the education and information people aged 25 to 45 who have type 2 diabetes need to enable them to effectively self-manage their diabetes.
- To identify the mode of delivery of education and information preferred by people with type 2 diabetes aged 25 to 45.
- To develop recommendations regarding the key content areas, format, appropriate language and preferred means of distributing diabetes self-management education and information to younger people with type 2 diabetes.

The methodology included a systematic literature review, a ‘one shot’ cross-sectional survey of diabetes educators, general practitioners (GPs) and endocrinologists using self-completed, anonymous questionnaires, a focus group and telephone interviews with members of the target group and consultation with a project Reference Group established in collaboration with the Australian Diabetes Educators Association.

Literature review
Given the paucity of material specifically concerning younger people with type 2 diabetes, an overview of the general literature about diabetes information and education needs was undertaken.

The literature about the learning styles of ‘Generation X’, which includes the target group, suggests people aged 25 to 45 prefer to learn independently, like information using new technologies, prefer stimulating materials and materials that can be read or scanned quickly.

There is very little Australian data about younger people with type 2 diabetes. The information that is available indicates there is a need for information about new developments in the diabetes field, travel advice, information related to drugs and alcohol and pregnancy, in addition to the information typically available on diet, food choices and complications. They also want other people they associate with and members of the community to be more knowledgeable about diabetes, and need psychological support.

The main sources of information used or preferred by the target group were parents and family, health professionals, diabetes organisations and web sites. People with diabetes also regarded peer support as desirable. The most frequent delivery modes health professionals use to deliver diabetes programs were: education and information in individual or group sessions, printed materials, and telephone advice and education.
A range of barriers to utilising education and information were discussed in the literature including receiving inconsistent information, problems accessing services and health professionals, diabetes-related costs, literacy issues and a lack of culturally appropriate education and information.

People with diabetes want reliable information based on credible sources that is clear, understandable and relevant to their real life experiences.

**Survey of health professionals**

Ninety-two health professionals completed the questionnaire; 51% were diabetes educators and 41% were GPs. Only one endocrinologist responded.

Over half the respondents indicated current resources are not adequate and current information sources are not appropriate for the target group. Almost half of the respondents indicated the way information is provided is not appropriate for people aged 25 to 45 with type 2 diabetes.

There was strong support for web-based information for the target group. However, only 25% reported they currently provide web-based information. The majority provide printed resources and provide education and information in individual teaching sessions.

Diabetes educators, compared to GPs, perceived there is a need for education and information for the target group about a wider range of topics than ‘standard’ diabetes information and indicated a wider range of factors affected the information and education needs of the target group than the GPs.

**Qualitative data—younger people**

One focus group discussion with nine participants and four telephone interviews with people who were unable to attend the focus group were conducted with representative members of the target group. Participants represented a diverse range of demographic and social characteristics and presented an interesting range of experiences with diabetes and views about appropriate education and information.

Participants wanted consistent information that is easy to understand, that includes various topics not currently covered such as information about interactions between medications they take for different health conditions and the implications of having diabetes when they require surgery. They also wanted information to be provided to the wider community, resources developed specifically for their age group, and a focus on preventing diabetes especially in their relatives and children.

Participants stressed the importance of having centralised information and strongly supported an 1800 number as a first point of contact. They indicated there is a need to provide a range of delivery mode options, including printed material, web-based information and DVDs. However, they were concerned about information on the Internet because they often wasted time searching for information, and some participants did not use the Internet.
Participants wanted age-specific support or education groups and discussed various other ways they could be supported by their peers. They preferred service and support systems to be available in their local areas and identified a need for psychological support, particularly at diagnosis. Participants noted the lack of understanding of type 2 diabetes in the community, disliked being grouped with older people with diabetes and the focus on type 1 diabetes.

Discussion

The need to address the lack of education and information that is currently available for young people with type 2 diabetes was evident in all sections of the study. There was strong support in all aspects of the study for actively involving the target group in the development of education and information that is aimed at younger people with type 2 diabetes.

A new finding from the qualitative data in the current study was the emphasis younger people with type 2 diabetes placed on information being centralised and Australia-wide. They mentioned they needed information about topics not usually included in routine diabetes education such as interactions between medications for different coexisting conditions, managing diabetes and other coexisting health conditions and how they affect each other, the implications of having diabetes when they require surgery or investigative procedures, and IVF and diabetes.

The need for individuals to have access to different education information at various life stages and different stages of the disease was highlighted in the literature and by the younger people with type 2 diabetes who participated in the current study. Younger people who participated in the current study wanted new technologies to be used, to be able to access information at home and have it presented succinctly, which is consistent with the literature about the learning styles of ‘Generation X’.

The findings from the literature review, the survey, and the qualitative data from the focus group and interviews all support the need for education and information to be available in a variety of delivery modes for younger people with type 2 diabetes. Younger people wanted a single Australia-wide Diabetes Australia website without state ‘branding’ that directed them to State websites and local services. Younger people also suggested a section of the website could focus specifically on their age group.

Consistent with their desire for centralised information, younger people with type 2 diabetes wanted a single 1800 number that could be the first contact point for younger people with type 2 diabetes. The focus group participants were not aware that an 1800 number already exists, which suggests the way the service is promoted to young people with type 2 diabetes needs to be revised.

The need for peer support for younger people with type 2 diabetes was reported in the literature, by participants in the focus group and interviews in the current study, and to a lesser extent by the health professionals who completed the questionnaire. The younger people in the focus group and interviews indicated a need for psychological support, which was also evident in the literature.
The expressed desire to have locally based services and support was largely a new finding in the current data.

The need to educate the wider community about type 2 diabetes was identified in the literature review, in the focus group and interview data, and to a very small extent by the health professionals who completed the survey.

The literature review and the current study indicate people with diabetes want consistent, clear information from credible sources.

**Recommendations**

The researchers developed draft recommendations about the education and information needs of younger people with type 2 diabetes based on the findings from the literature review, the health professional survey and the focus group and telephone interviews with people aged 25 to 45 with type 2 diabetes.

The draft recommendations were circulated by mail or email to members of the Reference Group and the focus group and telephone interview participants for comment, and revised in response to feedback received.
Information Needs of Young Adults with Type 2 Diabetes

INTRODUCTION

Type 2 diabetes is a serious public health problem in Australia. Current prevalence data suggests that 7.4% of the population aged 25 years and older have Type 2 diabetes and there is evidence that the prevalence is rising (Australian Institute of Health and Welfare, 2002). Type 2 diabetes is characterised by insulin resistance and gradual diminution in insulin production. Dietary and lifestyle modifications and for most individuals, oral medication and eventually insulin therapy are needed to control the disease (Australian Centre for Diabetes Strategies, 2001).

In the context of chronic disease such as type 2 diabetes, patients are increasingly expected to manage their own health, thus patient education now plays an important role in enhancing self-management skills and patients' understanding of the behavioural changes required to minimise the impact of diabetes and the associated complications (Eakin, Bull, Glasgow & Mason, 2002; Williams, Baker, Parker & Nurss, 1998).

The prevalence of type 2 diabetes rises with age, and self-management education and resources have typically been targeted at people aged 50 years and older. There is, however, an increase in the prevalence of type 2 diabetes amongst younger people aged 25 to 45 years. The concerns and needs of younger people in relation to managing type 2 diabetes are likely to be different from those of older people. For example, younger people are more likely to be in the paid workforce, and having children. In addition, the birth rate has increased over recent years, and due to the younger age at which type 2 diabetes is diagnosed; many women with type 2 are having children. While management of diabetes during pregnancy is similar between type 1 and type 2, there are some significant differences, for example managing glucose lowering medicines. Likewise, the incidence of gestational diabetes is increasing and is associated with increased risk of type 2 diabetes.

There is evidence that different groups of people with diabetes have different preferences for the delivery of self-management support strategies (Sarkar et al., 2008) and have different information needs (Beeney, Bakry & Dunn, 1996). It is important to develop education materials that address specific needs and issues to improve self-management skills amongst individuals living with diabetes (Eakin, Bull, Glasgow & Mason, 2002). In Australia there is a lack of materials and programs that focus specifically on the needs of younger people with type 2 diabetes as well as a lack of information about what the needs of this group are (Diabetes Australia, 2006). A recent needs analysis of young adults with diabetes, aged up to 35 years, included data from only four in-depth interviews with people with type 2 diabetes, and only 12% of survey respondents had type 2 diabetes (Diabetes Australia, 2006). The needs analysis did however highlight some problems this group experience.
Thirty-two per cent of 49 young people with type 2 diabetes reported they do not manage their diabetes well, 72% received conflicting advice from health professionals, and 35% felt they did not know enough about diabetes (Diabetes Australia, 2006). Further investigation of the needs of younger people with type 2 diabetes is warranted. The current research was a comprehensive needs analysis that focused specifically on the education information needs of this group.

Currently, information about the specific information and resource needs of younger people with type 2 diabetes appears to be limited. It is unclear whether their information needs and preferences vary significantly from older people with type 2 diabetes. Hence the target group for the current project was people with type 2 diabetes aged between 25 and 45 years.

**Aims of the project**

The aims of the project were to:

- Identify the education information people aged 25 to 45 who have type 2 diabetes need to enable them to effectively self-manage their diabetes.
- Identify the preferred delivery mode of type 2 diabetes education information for people aged 25 to 45.
- Develop recommendations regarding the key content areas, format, appropriate language and preferred means of distributing diabetes self-management education information to younger people who have type 2 diabetes.

**Methods**

A mixed methods study design was used and included:

- A systematic literature review.
- A 'one shot' cross sectional survey, using self-completed anonymous questionnaires, of diabetes educators, general practitioners (GPs) and endocrinologists.
- A focus group and telephone interviews with people with type 2 diabetes aged 25-45 years.
- Consultation with a project Reference Group established in collaboration with the Australian Diabetes Educators Association (ADEA).

Ethics approval to undertake the research was obtained from the Barwon Health Research and Ethics Advisory Committee. The ethics process at Barwon Health consists of a technical (methodological) review as well as an ethics review.

The target group referred to throughout the report is people aged 25 to 45 who have type 2 diabetes.
LITERATURE REVIEW

Search strategy
A literature search was conducted using the MEDLINE, CINAHL, AIM (Australian Medical Index), APAIS-Health databases from the 1980s to the present and the latest version of The Cochrane Database of Systematic Reviews. The search terms used were diabetes, type 2, education and information, combined with young adults, younger, and young people. Articles were excluded from the systematic literature review if they only related to type 1 diabetes, adolescents, older people or topics other than information/education. The reference lists of articles were examined and relevant articles obtained. In addition, the contents of specific diabetes journals were searched. Australian and international web sites were searched for relevant published and unpublished material (see Appendix A).

No articles or reports specifically relating to the education and information needs of young people with type 2 diabetes were identified. One Australian report, the Young Adults with Diabetes Needs Analysis (Diabetes Australia, 2006), provided survey data from 414 people aged 16 to 35 with diabetes, 49 of whom had type 2 diabetes. These data were obtained from an on-line survey accessed by participants through the Diabetes Australia web site. The same report included qualitative data obtained in ten small group discussions and six individual interviews with young people with diabetes, but only four interviews were conducted with young people with type 2 diabetes. The overall aim of the report was to “document concerns and issues faced by young adults who have diabetes, and identify areas of need in relation to information, health services and other types of support” (Diabetes Australia, 2006, p. 3). One other Australian report presents findings from regional youth forums conducted with 438 people (Diabetes Australia, 2005). Forum participants included people aged under 30 who had diabetes, carers and health professionals. Precise numbers of people with type 1 or type 2 diabetes were not provided, but the authors stated that the majority of the participants with diabetes had type 1.

Given the paucity of material specifically concerning young people with type 2 diabetes, an overview of the literature about diabetes information and education needs is presented, which draws on literature concerning people of any age group with type 2 diabetes as well as young people with type 1 or type 2 diabetes. Preference was given to Australian studies and research involving young people with type 2 diabetes.

Theoretical frameworks
Useful summaries of the principles underlying health education and relevant behaviour theories are available (Colagiuri & Goodall, 2004; Royal Australian College of General Practitioners (RACGP), 2003). These principles and theories are applicable to education generally and can be applied to young people with type 2 diabetes but are not presented in the current report. However, Colagiuri & Goodall (2004) surveyed 65 Australian diabetes service providers and found that less than one-third reported using one or more theoretical models to underpin the information and education they provide.
Some literature is available on the characteristics of the target audience, people aged 25 to 45 years, which has an impact on appropriate education information for this age group.

**Education and information for ‘Generation X’**

The majority of people currently aged 25 to 45 years fall into the ‘Generation X’ category; that is, they were born in the early 1960s to the late 1970s. It must be acknowledged that any comments made about a generation as a cohort are generalisations (Collins & Tilson, 1999). However, certain generational characteristics distinguish Generation X from the previous generation, the ‘baby boomers’. Members of Generation X grew up with fast food, remote controls, microwaves, automatic tellers and computers. Typically they expect immediate gratification, they crave stimulation and expect immediate answers and feedback (Brown, 1997). Many were latch key kids, are used to being independent and want support and feedback, but not to be controlled (Brown, 1997).

The suggestions in Table 1 (next page) for teaching members of Generation X based on their learning characteristics were sourced from the literature concerning education and Generation X, but largely relates to high school or tertiary study rather than diabetes education.

**Self-management education**

Self-management models

A frequently used definition of chronic disease self-management is that it: ‘involves (the person with the chronic disease) engaging in activities that protect and promote health, monitoring and managing the symptoms and signs of illness, managing the impact of illness on functioning, emotions and interpersonal relationships and adhering to treatment regimes’ (The Center for Advancement of Health, 1996, p. 1). The most recognised of the many self-management education approaches in Australia are the Flinders Model and the Stanford Model (Francis, Feyer & Smith, 2007). The Flinders Model is a one-on-one approach tailored to the needs of the individual while the Stanford Model is typically utilised in group settings, and uses peer educators and structured education sessions.

The Flinders Model provides a generic set of tools and structured processes that health professionals and people with chronic disease can use to assess self-management behaviours, collaboratively identify problems and set goals, and develop individualised care plans (Flinders Human Behaviour & Health Research Unit, 2008). The aims of the Flinders Model include improving the relationship between the person with chronic disease and health professional and collaboratively identifying problems. The assessment tools used include the Partners in Health Scale, the Cue and Response interview and the Problems and Goals Assessment.
Table 1: The learning styles of and appropriate teaching strategies for Generation X (From Brown, 1997; Collins & Tilson, 1999; Kerr & Gascoigne, 1996; Ryan, Romanelli, Smith & Johnson, 2003).

<table>
<thead>
<tr>
<th>Learning Style</th>
<th>Teaching Strategy</th>
</tr>
</thead>
<tbody>
<tr>
<td>They do not like to be lectured to especially by baby boomers.</td>
<td>Do not preach.</td>
</tr>
<tr>
<td>They want their ideas to be heard.</td>
<td>Ask about their learning preferences, or how they like to receive information.</td>
</tr>
<tr>
<td>They are independent problem solvers and want autonomy and flexibility.</td>
<td>Encourage independent control of their learning.</td>
</tr>
<tr>
<td>They desire personal interaction and constant feedback.</td>
<td>Provide personal interaction and regular feedback and communicate with them regarding their expectations and progress using new technologies.</td>
</tr>
<tr>
<td>They expect immediate answers.</td>
<td>Adapt instruction or resource materials so they are easily accessible at home.</td>
</tr>
<tr>
<td>They have a preference for concrete and specific information.</td>
<td>Negotiate focused objectives, emphasise guidelines.</td>
</tr>
<tr>
<td>They are technologically literate and prefer new technologies.</td>
<td>Focus on outcomes rather than techniques – emphasise situations in which the learning can be used.</td>
</tr>
<tr>
<td>They are able to engage in parallel thinking.</td>
<td>Use leading edge accessible technology – encourage learners to use new technologies, web sites, on-line materials.</td>
</tr>
<tr>
<td>They crave stimulation.</td>
<td>Present the information in a variety of ways at the same time.</td>
</tr>
<tr>
<td>They surf and scan rather than read and view.</td>
<td>Utilise resources that stimulate all the sensory organs such as charts, photos, text graphics and cartoons. Use sound, music and narration as components of interactive learning.</td>
</tr>
<tr>
<td></td>
<td>Highlight key points and scannable material or short pieces of information that outline key points or concepts.</td>
</tr>
</tbody>
</table>
The Chronic Disease Self-Management Model, commonly known as the Stanford Model, is underpinned by the assumption that patients can learn to take responsibility for the day-to-day management of their disease and that trained lay people with chronic conditions can effectively deliver the structured education program (Lorig et al., 1999). The group-based course includes weekly planning and feedback, participants and the lay leader role modelling appropriate behaviours, participants problem-solving for one another, group problem-solving and decision-making (Lorig et al., 1999).

The common aspects of these self-management models are a client-centred approach, a focus on clients being able to make informed decisions about their health, and goal-setting (RACGP, 2003). Within these models the education and information needs of individuals should ideally be addressed during the process of structured self-management education (Flinders Human Behaviour & Health Research Unit, 2008; Lorig et al., 1999).

**Diabetes self-management education**

Diabetes self-management education is defined as “the ongoing process of facilitating the knowledge, skill, and ability necessary for diabetes self-care” (Funnell et al., 2007). A more detailed definition of diabetes self-management education is provided by the Australian Diabetes Educators Association: “Diabetes self management education is about providing people with diabetes with the knowledge, skills and motivation to effectively manage their condition. Diabetes self-management education helps people to:

- Know *what* to do
- Know *how* to do it
- *Want* to do it
- Be *able* to do it!

Diabetes self-management education is about helping people with diabetes to:

- Understand diabetes and make informed lifestyle and treatment choices
- Make appropriate food choices
- Incorporate physical activity into daily life
- Use their medications effectively
- Monitor their blood glucose and understand and use the results to improve diabetes control
- Prevent and treat high and low blood glucose levels and manage diabetes when sick
- Reduce the risks of diabetes complications
Manage diabetes along with the demands of work, family and social life.”
(Australian Diabetes Educators Association, 2008).

Effectiveness of diabetes self-management education
Norris, Engelgau and Narayan (2001) undertook a systematic review of self-management education of people with type 2 diabetes based on 72 randomised controlled trials and concluded there is short-term support for its effectiveness. Positive effects on knowledge, frequency and accuracy of blood glucose self-monitoring, self-reported dietary behaviours and glycaemic control were supported. The impact on long-term clinical outcomes was not demonstrated and the results were equivocal for weight loss and activity levels (Norris et al., 2001).

The mean age of participants in the majority of trials included in the review was over 50 years. The authors noted that, while the results for the relative merits of group or individual education were inconclusive, group settings were generally more effective for lifestyle interventions (Norris et al., 2001). A later review of 10 diabetes self-management studies with an overall mean age of 60 years (and a total sample size across the studies of n = 923) reported mixed findings. Only three studies demonstrated statistically significant improvements in HbA1c, two in physical activity and three in quality of life and self-efficacy (Shaw, Hagger, Graham & Keleher, 2006).

Several authors report that it is not possible to draw reliable conclusions about the types of programs that most effectively improve self-management behaviours (Corabian & Harstall, 2001; Loveman, Frampton & Clegg, 2008; Shaw et al., 2006), although interventions that focus on multiple components rather than on particular aspects of diabetes self-care, delivered by a team of educators, with some follow-up appeared to achieve the best outcomes (Loveman et al., 2008). The reviewers indicated that it was difficult to compare the results because different study designs, sample sizes and outcome measures were used (Corabian & Harstall, 2001; Loveman et al., 2008).

US National Standards for Diabetes Self-Management Education
A US Task Force developed evidence-based National Standards for Diabetes Self-Management Education. The Task Force identified the general principles for diabetes self-management education:

1. Diabetes education effectively improves clinical outcomes and quality of life; at least in the short-term.
2. Diabetes self-management education has evolved from primarily didactic presentations to more theoretically based empowerment models.
3. There is no one ‘best’ education program or approach; however, programs that incorporate behavioural and psychosocial strategies demonstrate improved outcomes. Additional studies show that culturally and age-appropriate programs improve outcomes and that group education is effective.
4. Ongoing support is essential to sustain progress participants make during the diabetes self-management education program.
5. Behavioural goal-setting effectively supports self-management behaviours (Funnell et al., 2007).

**Young people with type 1 and type 2 diabetes**

The published literature concerning young people with diabetes largely focuses on young people with type 1 diabetes. The differences between type 1 and type 2 diabetes are sufficient to warrant separate education and information for each group. The survey data from the *Young Adults with Diabetes Needs Analysis* (Diabetes Australia, 2006) indicates there are significant differences in the responses of young people with type 1 compared with those with type 2 diabetes in relation to the challenges they face, who helps them care for their diabetes, medications and visits to health professionals.

However, the barriers to managing diabetes and the factors that helped people cope better with having diabetes were not significantly different between the two groups (Diabetes Australia, 2006). Significantly, young people themselves perceive important differences between having type 1 or type 2 diabetes and become frustrated when other people do not recognise the difference (Diabetes Australia, 2006).

**Content of information/education**

Table 2 (Appendix B) presents details of the research concerning the information/education needs and concerns of people with diabetes. Studies that asked people with diabetes about their concerns were included on the assumption that people need information about issues that concern them. Given the lack of literature relevant to the target group, the table contains studies that included participants older than 45 years. The level of evidence of the quantitative literature included in the review did not exceed Level 3 using the Joanna Briggs Institute criteria (Joanna Briggs Institute, 2008).

Qualitative literature was graded using the Critical Appraisal Skills Programme (CASP) criteria (Public Health Resource Unit, 2006), which asks ten questions that assist in rating the rigour and credibility of qualitative research. Individual studies were given a score of one for each criterion they met. A score of ten would indicate excellent quality. The two qualitative studies included in the tables in Appendices B to D were rated 6 out of 10. Both studies failed to provide important details about the methodology used such as data analysis and recruitment strategies.

There is an important methodological difference among the studies included in Table 2: some asked participants to identify areas of concern from a list (Diabetes Australia, 2006; Genev, Flack, Hoskins, Overland & Turtle, 1992); others used open questions (Beeney, Bakry & Dunn, 1996). The former cues responses and also restricts responses to those on the list. The latter approach has the advantage that participants only identify their salient concerns. The disadvantage is that participants may be reluctant to mention concerns they believe the researchers may not want to hear, or feel inhibited to mention some concerns. Woodcock and Kinmouth (2001) used both an open question and a list of concerns to identify participants’ concerns about managing their diabetes. They reported that participants more frequently cited ‘following dietary advice’ as their main concern when an open question was used but were less likely to select ‘following dietary advice’ when they were asked to select their concerns from a list of options.
As Table 2 shows, some topics are mentioned consistently, for example, concerns about making appropriate food choices or dietary restrictions and concerns about complications. Some issues are unique to younger people and these include new developments in medications and technology, travel advice, issues related to drug and alcohol use, and pregnancy. The latter topics were presented in lists to younger people (e.g. Diabetes Australia, 2006) and were not included in studies with older people with diabetes.

Other areas of need identified in the literature, particularly from qualitative studies, are not included in Table 2. These needs include wanting people in their community to be more aware of diabetes and more knowledgeable about diabetes (Chittleborough, Cheek, Grant, Phillips & Taylor, 2002; Diabetes Australia 2006). Focus group participants with diabetes, and parents of a child with diabetes suggested the immediate family need to be included in diabetes information and education programs. In addition, they indicated the extended family, teachers and classmates, friends, baby-sitters, employers and airlines require accurate information about diabetes (Colagiuri & Goodall, 2004). Similarly, both people with type 1 and type 2 diabetes need support from colleagues with sound knowledge about diabetes to enable them to remain in paid employment (Detaille, Haafkens, Hoekstra & van Dijk, 2006).

People with diabetes indicated there is a need for psychological support and counselling (Colagiuri & Goodall, 2004; Diabetes Australia, 2005). This is not surprising given the link between diabetes and depression. Almost one quarter (24%) of young people with type 2 diabetes in the Young Adults With Diabetes Needs Analysis reported having long term depression (Diabetes Australia, 2006). However, medical specialists and General Practitioners (GPs) surveyed in the Diabetes Attitudes, Wishes and Needs (DAWN) study reported referring less than 10% of their patients with diabetes to a psychologist or psychiatrist (Rutherford, Wright, Hussain, Colagiuri et al., 2004).

Differences in perceived needs – health professionals and people with diabetes

Several studies report differences between health professionals’ perceptions of areas that would concern people with diabetes and the actual concerns people with diabetes identify. Thus, health professionals should not determine the content of diabetes information without consulting people with diabetes. In a study involving 250 patients with a mean age of 58 years, those with type 2 diabetes were more likely to mention ‘fear of getting worse’ and ‘damage caused by diabetes’ one year after being diagnosed than their 47 practice nurses (Woodcock & Kinmouth, 2001). The nurses inaccurately assumed that patients with a high BMI would be concerned about being overweight, and those with a high HbA1c would mention ‘high blood glucose’ as a concern.

Likewise, in an Australian study 1159 patients with diabetes and 100 GPs identified different concerns at the time diabetes was diagnosed (Beeney et al., 1996). GPs placed more emphasis on complications while patients focused on how to cope, their uncertain future and diet restrictions. Similarly when researchers in the Netherlands asked people with diabetes what they need to enable them to continue working, health professionals and people in the workforce with type 1 or type 2 diabetes responded...
differently (Detaille et al., 2006). People with diabetes indicated they needed work colleagues and management to be informed about diabetes and to provide support, to have some control over their work pace, time of breaks, and a stable work environment. Health professionals placed more emphasis on people with diabetes receiving support from health professionals and information about diabetes (Detaille et al., 2006).

**Sources of information**

Table 3 (Appendix C) lists information from two Australian studies that describe the sources of information people with diabetes use or prefer. Almost one-third (31%) of 49 young people with type 2 diabetes rated parents or family as very useful sources of information and support, followed by health professionals and diabetes organisations (GP/family doctor 27%, endocrinologist/diabetes specialist 24%, Diabetes Australia 24%, diabetes educators 22%) (Diabetes Australia, 2006). One-fifth (20%) rated Internet web sites as very useful. People with diabetes and parents of children with diabetes also mentioned health professionals and diabetes organisations and centres as useful sources of information (Colagiuri & Goodall, 2004).

People with diabetes regarded peer support as desirable. In focus groups held with people with diabetes from a range of age groups, participants expressed a wish to “talk to someone like me”, that is, other people who have diabetes (Colagiuri & Goodall, 2004, Appendix 3b, p. iv). Young people who have diabetes and carers attending regional youth forums also stressed the value of being able to talk and share personal experiences with other young people with diabetes (Diabetes Australia, 2005).

Health professionals are an important source of information for people with diabetes. Young people with type 2 diabetes (n = 49) were asked what qualities they would like health care professionals who work with young adults with diabetes to have. The most frequent responses were:

- ‘Knows what they’re talking about’ (71%),
- ‘Provides simple, clear, practical advice’ (71%),
- ‘Doesn’t expect me to be perfect all the time’ (43%),
- ‘Understands what I’m going through’ (39%), and
- ‘Is honest and upfront’ (39%) (Diabetes Australia, 2006).

These responses suggest people with diabetes want health professionals to be knowledgeable, good communicators, and have compassion.

Indigenous people with type 1 or type 2 diabetes who participated in small focus groups or individual interviews (number not stated) indicated that an Indigenous person should provide diabetes education to Indigenous people (Diabetes Australia, 2008, draft report). Key stakeholders working with Indigenous people also noted the importance of identifying influential people in the local Indigenous community, suggested having influential mature women in Indigenous communities act as educators, and warned that some Indigenous people with diabetes do not trust white health workers (Diabetes Australia, 2008, draft report).
**Delivery modes**

The information delivery modes used or preferred by people with diabetes are listed in Table 4 (Appendix D). It is somewhat difficult to summarise the findings because some people responded to questions about how they would like to receive information by referring to the source of the information rather than the delivery (or distribution) mode. Two studies (total n = 834) indicated that people with diabetes prefer to receive information from health professionals, including diabetes educators, when asked to indicate their preferred information providers (Beeney et al., 1996; Diabetes Australia, 2006). It is not clear whether the respondents were referring to written or verbal information. In an on-line survey, 50% or more of forty-nine young people with type 2 diabetes listed Diabetes Australia, the Internet, magazines/journals/newsletters, and other people with diabetes as their preferred way of receiving information about diabetes (Diabetes Australia, 2006).

There is some information about how health professionals deliver information and/or education to people with diabetes in Australia. Table 5 presents data about the most frequent delivery modes used by 65 health professionals. The most frequently used delivery modes were individual or group sessions, printed materials and by telephone. Delivering information either individually or in group sessions is consistent with the preferences of people with diabetes. While 89% of the health professionals listed the telephone as a delivery mode they used, people with diabetes in the Australian studies included in Table 4 did not mention the telephone as a delivery mode they use or would like to use.


<table>
<thead>
<tr>
<th>Mode of delivery used by health professionals</th>
<th>% of respondents (n = 65)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Face-to-face individual sessions</td>
<td>89</td>
</tr>
<tr>
<td>Printed materials (brochures and leaflets)</td>
<td>89</td>
</tr>
<tr>
<td>Telephone</td>
<td>89</td>
</tr>
<tr>
<td>Face-to-face group sessions</td>
<td>83</td>
</tr>
<tr>
<td>Video</td>
<td>48</td>
</tr>
<tr>
<td>Internet</td>
<td>40</td>
</tr>
<tr>
<td>CD Rom</td>
<td>22</td>
</tr>
<tr>
<td>Other (seminars, email, fax, the media, electronic conferencing, social contexts, books and peer reviewed publications)</td>
<td>28</td>
</tr>
</tbody>
</table>
Indigenous Australians and CALD groups

The recent Diabetes Australia consultation report also identified the importance of materials and dissemination approaches being culturally appropriate for Indigenous Australians (Diabetes Australia, 2008, draft report). Traditional communication involves ‘having a yarn’, thus verbal or written stories are an appropriate way to provide diabetes education for Indigenous community members. Other approaches such as dance or role plays may also be appropriate. Similarly people from culturally and linguistically diverse (CALD) backgrounds require culturally appropriate resources and approaches to education (Diabetes Australia, 2008, draft report).

Needs and preferences change over time

One common theme in the literature is that the information and education needs of people with diabetes change over time as the individual moves through different life stages and different stages of the disease. The change in needs is acknowledged both by health professionals (Colagiuri & Goodall, 2004) and people with diabetes (Beeney et al., 1996; Chittleborough et al., 2002; Colagiuri & Goodall, 2004; Diabetes Australia, 2006). Significantly, people with diabetes indicate they needed follow-up education (Colagiuri & Goodall, 2004; Diabetes Australia, 2006). The literature concerning the efficacy of self-management education also supports the value of follow-up education (Funnell et al., 2007; Loveman et al., 2008). Regular education updates or continuous diabetes education is important to address the changing needs and situations of the person with type 2 diabetes.

However, there is limited evidence to suggest people’s delivery mode preferences change at different periods. Beeney et al. (1996) reported that significantly more people with type 1 diabetes preferred a one to two day course when asked one to two weeks after diagnosis compared with when they were asked their preferences at diagnosis (See Table 4). It is likely that learning styles remain the same unless there is a significant physical change such as cognitive changes, deafness or vision loss.

Barriers to utilising education and information

Barriers to managing diabetes identified by young people

The Diabetes Australia Young Adults with Diabetes Needs Analysis report provides data about some of the barriers to effective diabetes self-management that young adults with type 2 diabetes encounter (n = 49) (Diabetes Australia, 2006). See Table 6 (over the page) for details. Participants in the Diabetes Australia survey were presented with a list of issues that make it difficult for them to manage their diabetes. Having the time to manage their diabetes appropriately was a major problem for these participants, as was dealing emotionally with the fact of having diabetes. The issues younger people identified indicate key factors that need to be addressed in information developed specifically for this group, for example life skills such as strategies to use when multiple commitments make a routine difficult to establish, and time management.
Receiving inconsistent information
Two Australian studies indicate people with diabetes often become confused when they receive conflicting advice or inconsistent information from health professionals (Colagiuri & Goodall, 2004; Diabetes Australia, 2006). Importantly, 78% of 49 younger people with type 2 diabetes in the Diabetes Australia study indicated that receiving conflicting advice from health professionals occurred frequently (see Table 6) (Diabetes Australia, 2006). Similar concerns arise in overseas studies (Vermeire, Van Royen, Coenen, Wens & Denekens, 2003). Given that many people with diabetes rely on health professionals for relevant, current information, receiving conflicting advice is an important barrier to appropriate self-care behaviours and can lead to a lack of trust in health professionals.

Table 6: Barriers that younger people with type 2 diabetes reported affect their ability to manage their diabetes shown in order from most to least common (n = 49). Adapted from: Diabetes Australia. (2006). Young Adults with Diabetes Needs Analysis. Melbourne: National Diabetes Services Scheme.

<table>
<thead>
<tr>
<th>Feel this way a lot/sometimes</th>
<th>%   (n = 49)</th>
</tr>
</thead>
<tbody>
<tr>
<td>It’s hard to stick to a routine because of work/study commitments</td>
<td>92</td>
</tr>
<tr>
<td>Just want to switch off and forget that I have diabetes</td>
<td>92</td>
</tr>
<tr>
<td>Don’t have time to do all the things I know I probably should do to care for my diabetes</td>
<td>84</td>
</tr>
<tr>
<td>I’m embarrassed about having diabetes</td>
<td>78</td>
</tr>
<tr>
<td>I get scared</td>
<td>74</td>
</tr>
<tr>
<td>I get conflicting advice from health professionals</td>
<td>72</td>
</tr>
<tr>
<td>I get fed up with having diabetes and want to rebel</td>
<td>69</td>
</tr>
<tr>
<td>Sometimes I just feel lazy, and can’t be bothered any more</td>
<td>49</td>
</tr>
<tr>
<td>Nothing I do seems to make any difference, so I can’t be bothered any more</td>
<td>49</td>
</tr>
<tr>
<td>It’s all too confusing. I don’t really understand what I’m supposed to do</td>
<td>47</td>
</tr>
<tr>
<td>I’m not getting help or support from anybody</td>
<td>47</td>
</tr>
<tr>
<td>There’s no-one to talk to who understands what I’m going through</td>
<td>42</td>
</tr>
<tr>
<td>I get tempted by things that I know are not great for my health</td>
<td>38</td>
</tr>
</tbody>
</table>
Access to services and health professionals
A lack of knowledge about diabetes services, where and how to access information and what to ask for were also identified as problems for people with diabetes (Chittleborough et al., 2002; Colagiuri & Goodall, 2004).

Access to GPs and specialists was difficult or very difficult for a substantial proportion of participants in the Australian Diabetes Attitudes, Wishes and Needs study (DAWN) (Rutherford et al., 2004). Waiting lists or GP practices not accepting new patients was one of the main reasons young people with diabetes did not keep appointments with some health professionals as often as the young people would like (Diabetes Australia, 2006).

The time required to visit health professionals, and the need for after hours access to health professionals emerged in focus groups with people with diabetes and parents of children with diabetes (n = 31) (Colagiuri & Goodall, 2004). In addition, difficulty getting time away from work or study to visit a range of health professionals was a problem for young people with diabetes in the Australian needs analysis survey (Diabetes Australia, 2006). Access to specialist diabetes services is limited in regional and remote areas of Australia (Colagiuri & Goodall, 2004; Diabetes Australia, 2006) and is also a problem in the USA (Zgibor & Songer, 2001).

Cost
The cost of diabetes services and products is a problem for people with diabetes in Australia, particularly the cost of counselling services (Colagiuri & Goodall, 2004), diabetes supplies, and medication (Diabetes Australia, 2008, draft report; Diabetes Australia, 2006; Dunning & Manias, 2005). Young people with diabetes cited cost as one of the main reasons they do not keep appointments with a range of health professionals as often as the young people would like (Diabetes Australia, 2006) and indicated the cost of health care is one of the biggest challenges they face. Research conducted in the USA also identified cost as a significant barrier to people with diabetes managing their condition appropriately (e.g. Sprague, Shultz, Branen, Lambeth & Hillers, 1999; Zgibor & Songer, 2001), although there is less subsidised care in the USA than in Australia.

Literacy
Low literacy restricts an individual’s ability to utilise most written education and information resources. Data from a survey to determine adult literacy levels in Australia (n = 9,032) (Australian Bureau of Statistics (ABS), 1997) estimated that between 19.2% and 19.7% of Australians had very poor literacy skills and could be classified as Level 1, and between 27.2% and 27.5% were estimated to have Level 2 literacy skills. At level 1 people have very poor literacy skills and “could be expected to experience considerable difficulties using many of the printed materials that may be encountered in daily life” (ABS, 1997, p. x). At level 2, people “could be expected to experience some difficulties in using many of the printed materials encountered in daily life. While they would be able to use some printed material, this would generally be relatively simple, short and clearly structured…” (ABS, 1997, p. x). People with limited literacy are likely to experience at least some difficulty in everyday life.
Poorer literacy levels were more common amongst older people, people for whom English is a second language, unemployed people, and those with low incomes (ABS, 1997). Thus, younger people with type 2 diabetes are more likely to experience literacy problems if they fall into the latter three groups.

Nutbeam (2000) described three types of literacy and their practical impact in everyday life, including health behaviours:

- **Basic/functional literacy** – sufficient basic skills in reading and writing to be able to function effectively in everyday situations.
- **Communicative/interactive literacy** – more advanced cognitive and literacy skills which, together with social skills can be used to actively participate in everyday activities, to extract information and derive meaning from different forms of communication, and to apply new information to changing circumstances.
- **Critical literacy** – more advanced cognitive skills which, together with social skills, can be applied to critically analyse information, and to use this information to exert greater control over life events and situations (Nutbeam, 2000, pp. 263-4).

Functional literacy is situation or context specific. Thus, reading skills that are adequate in one setting may be marginal or inadequate in a different setting (Ad Hoc Committee on Health Literacy, 1999; Baker, Parker, Williams, Pitkin, Parikh, Coates & Imara, 1996). Therefore, it is possible that a person who is functionally literate in a work situation that requires minimal reading may be unable to meet the literacy demands of the health care setting and would be classified as having inadequate health literacy. In that context a commonly accepted definition of health literacy is: “the degree to which individuals have the capacity to obtain, process, and understand basic health information and services [and use the information to make] appropriate health decisions” (Department of Health and Human Services (US), 2000, Cited in Zorn, Allen & Horowitz, 2004, p. 4).

In the context of health information, it is important that people are able to read, comprehend what they read and incorporate the health messages into their self-care regimens (Boswell, Cannon, Aung, & Eldridge, 2004), which suggests a level of literacy beyond the basic or functional level. Significantly, many people with low literacy skills hide their problems with reading and comprehending written information (Parikh, Parker, Nurss, Baker & Williams, 1996). Therefore, it is important that information is available to people with low literacy in a format that does not require a high level of health literacy.

Health literacy has been linked with poor health knowledge and poor health outcomes. Williams et al. (1998) found a strong negative relationship between functional health literacy and knowledge of hypoglycaemia symptoms in people with diabetes (n = 114). Likewise, in a US study of 408 English and Spanish-speaking patients with type 2 diabetes, Schillinger, Grumbach, Piette, Wang, Osmond and Daher (2002) found patients with inadequate health literacy were more likely to have poor glycaemic control, retinopathy and other self-reported complications of diabetes.

**Culturally appropriate education**

People from culturally and linguistically diverse backgrounds may encounter difficulty accessing information and services due to language barriers as well as when resources and services are culturally inappropriate (Hawthorne, Robles, Cannings-
John & Edwards, 2008). The authors of the Information and education for people with diabetes: A 'best practice' strategy report noted there is a lack of materials in languages other than English and that service providers need to be trained in cultural awareness and how to be sensitive to the needs of different cultural groups (Colagiuri & Goodall, 2004). Six key stakeholders in individual interviews as well as people from CALD backgrounds who participated in four focus groups in a recent Australian consultation project also identified the need for information and education materials to be culturally appropriate (Diabetes Australia, 2008, draft report). Importantly, it was noted in the report, that while material needs to be translated into indigenous languages, mere translation is not sufficient. It is also vital to acknowledge different customs and practices of individual CALD groups. Indigenous Australians experience problems using education and materials that are not culturally aligned and with materials that are not in their language if English is not their first language (Diabetes Australia, 2008, draft report).

Canadian researchers conducted telephone interviews with 267 people with diabetes and reported that those who spoke primarily Cantonese or Portuguese used fewer resources than those who primarily spoke English (Gucciardi, Smith & DeMelo, 2006). Participants born outside Canada used fewer resources than those born in Canada. The researchers argued that cultural differences need to be acknowledged and gave the example of people who use traditional Chinese medicine possibly not returning to western health professionals for fear of reproach by western practitioners for using traditional medical practices (Gucciardi et al., 2006).

There is some evidence of the effectiveness of culturally appropriate health education for people from ethnic minority groups. Short term effects on glycaemic control, diabetes knowledge and healthy lifestyles were reported in a meta-analysis of ten randomised controlled trials where the intervention comprised diabetes health education specifically tailored to the cultural needs of a target minority group (Hawthorne et al., 2008).

Quality of information

Focus group participants with different types of diabetes and parents of children with diabetes want reliable information based on research from credible sources that is clear, understandable and based on real life experience (Colagiuri & Goodall, 2004). They also wanted accurate information regarding the diagnosis and seriousness of diabetes and the possibility of a cure. However, the authors did not state whether the cure referred to type 1 or type 2 diabetes or both. The large amount of information available can be problematic. Some people with diabetes find the amount of information about diabetes ‘overwhelming’, especially at diagnosis (Colagiuri & Goodall, 2004).

Muhlhauser and Berger (2000) argued that people need unbiased information about the benefits of specific aspects of their treatment in order to participate in decisions about their diabetes treatment and self-care. They also suggested such information is not provided to people with diabetes. Some people with diabetes find the information provided too basic to meet their needs, which they referred to as ‘dumbing down’ information for consumers (Colagiuri & Goodall, 2004). Mulhauser and Berger (2000) argued that traditional patient education is often used as a means of increasing
compliance with prescribed treatment. They suggest that rather than focusing on compliance, evidence-based information should be available to enable patients to become more independent partners in their diabetes care and choose their own goals (Mulhauser & Berger, 2000). The challenge for health professionals is to provide sufficient detail to enable young people with type 2 diabetes to be informed, active participants in their treatment and management decisions, and to provide information that meets readability criteria.

Information on the Internet can be confusing and is often inaccurate. Tools are available for assessing the quality of Internet information. These tools are classified into five categories:
- codes of conduct
- quality labels
- user guides
- filters
- third party certification (Wilson, 2002).

For example, the Health on the Net Code of Conduct (HONCode), which is classified in the self-applied code of conduct or quality label group, comprises the following ethical aspects: the information contains the author’s credentials, the date of the last modification with respect to clinical documents, confidentiality of data, data reference sources, funding and advertising policy (Boyer, Selby, Scherrer & Appel, 1998). The HONCode is one of the best known tools (Wilson, 2002), however a search for and evaluation of web sites providing diabetes patient information reported that only 15 of the 53 sites identified were compliant with the HONCode (Thakurdesai, Kole & Pareek, 2004). It is likely that few people with diabetes are aware of these tools. A brief summary of how to evaluate Internet information for health professionals was published in the Australian Diabetes Educator (Dunning, 2006).

Section summary

There is a paucity of literature focusing on the education information needs of younger people with type 2 diabetes. Literature about the learning styles of people aged 25 to 45 suggests they prefer independence in their learning, new technologies, stimulating materials and materials that can be read or scanned quickly.

The limited Australian data on younger people with type 2 diabetes indicate a need for information about new developments, travel advice, information about drugs and alcohol and pregnancy, in addition to the information typically available on diet, food choices and complications.

Qualitative studies with younger people with diabetes indicated a desire for other people they associate with and members of the community to be more knowledgeable about diabetes, and a need for psychological support for people with type 2 diabetes.

The main sources of information used or preferred by the target group were parents and family, health professionals, diabetes organisations and Internet web sites. People with diabetes also regarded peer support as desirable.

The most frequent delivery modes health professionals use to deliver diabetes programs, education and information were individual or group sessions, printed materials or telephone. Younger people with diabetes indicated they would like to
receive information from health professionals, Diabetes Australia, the Internet, magazines, journals or newsletters and from other people with diabetes.

A range of barriers to utilising education information were discussed in the literature including receiving inconsistent information, problems accessing services and health professionals, cost, literacy issues and a lack of culturally appropriate education and information.

People with diabetes want reliable information based on credible sources that is clear, understandable and based on real life experiences. Some people with diabetes reported finding the amount of information available ‘overwhelming’.
SURVEY—HEALTH PROFESSIONALS

Method

Questionnaire development
A questionnaire was developed using items from previous questionnaires where possible (e.g. the questionnaire used in the Information and Education Service Provider Survey used in the Information and Education for People with Diabetes: A ‘Best Practice’ Strategy report (Colagiuri & Goodall, 2004). The first draft of the questionnaire was distributed to members of the Reference Group for comment. Additional items and response categories were added on the advice of the Reference Group. The questionnaire is presented in Appendix E.

Recruitment
Respondents were recruited for the web-based survey with the assistance of the Australian Diabetes Educators Association (ADEA) and The Australian Diabetes Society (ADS) (endocrinologists). An email inviting ADEA and ADS members to participate in the survey and a copy of the Participant Information form and the questionnaire was sent to diabetes educators and endocrinologists on the mailing lists of the respective societies current at the time of the study. People interested in participating in the research were asked to either download and complete the survey and mail the hardcopy to the ADEA or ADS or return it electronically to the ADEA or ADS. A hardcopy of the questionnaire, Participant Information sheet and reply paid envelope were mailed to members of the Geelong GP Association, with a letter inviting GPs to participate in the survey. Recruitment for the survey occurred in July and August 2008.

Analysis
The questionnaire data were entered into an SPSS database (Version 14) for analysis. Descriptive statistics of quantitative data are presented. A thematic analysis of responses to open-ended questions was undertaken. Responses containing similar words or phrases were coded and grouped together as a category. A summary of the categories identified in the thematic analysis is provided. Comparisons of the responses of diabetes educators and GPs to key items are presented in separate tables.

In the following results, total percentages may not add up to a hundred due to rounding of decimals.

Results

Demographic data
A total of 93 questionnaires were received, 92 of which are included in these results. One survey contained responses to the first four questions only and was not included in the data analysis. The response rate for the overall survey is difficult to calculate due to some uncertainty in the precise number of ADEA and ADS members receiving the email inviting them to participate due to the possibility of members being on leave or no longer using the email address. There were approximately 1400 ADEA
members and 650 ADS members on the mailing lists of these organisations at the time the questionnaire was distributed. The response rate for GPs was 15% (38 of 260).

Table 7 shows the majority of respondents were diabetes educators (51%), followed by general practitioners (GP) (41%). Respondents who described their current position as ‘other’ worked in health promotion, an emergency unit, in manager or co-ordinator roles, and as a dietitian (not a diabetes educator).

Table 7: Current health profession discipline of survey respondents (n = 92).

<table>
<thead>
<tr>
<th>Current discipline</th>
<th>Freq</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>Diabetes educator/nurse</td>
<td>43</td>
<td>47%</td>
</tr>
<tr>
<td>Diabetes educator/dietitian</td>
<td>4</td>
<td>4%</td>
</tr>
<tr>
<td>Endocrinologist</td>
<td>1</td>
<td>1%</td>
</tr>
<tr>
<td>General practitioner</td>
<td>38</td>
<td>41%</td>
</tr>
<tr>
<td>Other</td>
<td>6</td>
<td>7%</td>
</tr>
<tr>
<td>Total</td>
<td>92</td>
<td></td>
</tr>
</tbody>
</table>

The majority of respondents had worked in their current role for more than 10 years (see Table 8). Fifty-nine per cent of respondents indicated that they worked in a rural/regional area, 38% worked in a metropolitan area, and 3% worked in both rural/regional and metropolitan areas.

Table 8: Years in current role (n = 92).

<table>
<thead>
<tr>
<th>Years in current role</th>
<th>Freq</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>More than 10 years</td>
<td>57</td>
<td>62%</td>
</tr>
<tr>
<td>6 to 10 years</td>
<td>17</td>
<td>19%</td>
</tr>
<tr>
<td>2 to 5 years</td>
<td>16</td>
<td>17%</td>
</tr>
<tr>
<td>Up to 1 year</td>
<td>2</td>
<td>2%</td>
</tr>
<tr>
<td>Total</td>
<td>92</td>
<td></td>
</tr>
</tbody>
</table>

Current practice
The average number of people aged 25 to 45 with type 2 diabetes respondents educated or managed in a week is presented in Table 9. Most respondents (44%) educated or managed 1 to 2 people aged 25 to 45 with type 2 diabetes in a week.
Table 9: Average number of people aged 25 to 45 with type 2 diabetes educated or managed in a week (n = 92).

<table>
<thead>
<tr>
<th>Number of target group educated or managed in a week</th>
<th>Freq</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>None</td>
<td>13</td>
<td>14%</td>
</tr>
<tr>
<td>1 to 2</td>
<td>40</td>
<td>44%</td>
</tr>
<tr>
<td>3 to 5</td>
<td>21</td>
<td>23%</td>
</tr>
<tr>
<td>6 to 10</td>
<td>13</td>
<td>14%</td>
</tr>
<tr>
<td>More than 10</td>
<td>4</td>
<td>4%</td>
</tr>
<tr>
<td>No response</td>
<td>1</td>
<td>1%</td>
</tr>
<tr>
<td>Total</td>
<td>92</td>
<td></td>
</tr>
</tbody>
</table>

Respondents were asked what education/information resources they currently provide to people aged 25 to 45 with type 2 diabetes that specifically target this group. Their responses were categorised and are presented in Table 10. Responses indicate that many respondents mentioned resources that do not specifically target this younger age group. Resources categorised as age-specific included ‘Can I have a healthy baby’, information on drugs and alcohol, information for shift workers, and about age-specific support groups.

Table 10. Education/information resources currently provided to people aged 25 to 45 with type 2 diabetes. Responses are presented in the order in which they were cited (n = 92).

<table>
<thead>
<tr>
<th>Resources mentioned</th>
<th>Freq</th>
</tr>
</thead>
<tbody>
<tr>
<td>General resources</td>
<td>48</td>
</tr>
<tr>
<td>Nothing specific for target group</td>
<td>24</td>
</tr>
<tr>
<td>Referral to diabetes educator/dietitian</td>
<td>20</td>
</tr>
<tr>
<td>Age-specific resource mentioned</td>
<td>11</td>
</tr>
<tr>
<td>Not applicable</td>
<td>4</td>
</tr>
<tr>
<td>Can’t say as they are not a homogenous group</td>
<td>1</td>
</tr>
</tbody>
</table>
Adequacy of current education/information resources

When asked whether current education/information resources for the target age group were adequate, over half the respondents (59%) indicated they were not adequate, 27% indicated they were adequate, 12% responded ‘yes and no’ or ‘it depends’, and two respondents (2%) did not respond.

An open question asked respondents to explain why they believe the education information resources for this age group were adequate or inadequate. A thematic analysis of responses was conducted. The main themes are presented in Table 11.

Table 11: Responses to an open question asking why education/information resources for 25–45 year olds are adequate or inadequate. Responses are presented in the order of the frequency with which they were cited (n = 92).

| Adequate                                    | Freq | Inadequate                                                      | Freq |
|---------------------------------------------|------|----------------------------------------------------------------|
| General resources are applicable to this age group | 6    | Information is too generalised, younger people’s needs are different | 17   |
| Already enough available                    | 5    | Need to be other than written materials – need web-based, more interesting | 11   |
| Tailor information to specific needs        | 3    | Some topics younger people need are not covered                 | 9    |
| From competent, reliable sources e.g. Diabetes Australia, diabetes educator | 3    | Current resources developed for older people                    | 8    |
| Resources are easy to understand            | 2    | Lack of access to after hours services                          | 8    |
| Other reasons why they are adequate         | 4*   | There is little available                                        | 5    |
|                                            |      | Limited access to individual education                           | 2    |
|                                            |      | Difficult to individualise care                                  | 1    |
|                                            |      | Do not know enough about what is available                       | 4    |
|                                            |      | Other reasons why they are inadequate                            | 7*   |

* Other reasons given for why resources are adequate included have developed own resources and endeavoured to make them generic to most ages, there is too much information to be given and not enough time to deliver the information,
and it is up to themselves to correct obesity. Other reasons given by individual respondents as to why resources are inadequate included group education focuses on older age group, initial education is good but follow-up sessions would be helpful and there are long waiting times if relying on public service.

**Appropriateness of current sources of information**

Respondents were asked whether the current sources of information were appropriate for this age group: 53% indicated they are not appropriate, 36% indicated they are appropriate, 7% 'yes and no' or 'it depends', and four respondents (4%) did not respond. An open question asked respondents to give reasons for their answer. A thematic analysis of responses was conducted. The main themes are presented in Table 12. Twenty-seven respondents did not provide an answer to the open question.

Table 12. Responses to an open question asking why current sources of information are appropriate or not appropriate for 25–45 year olds. Responses are presented in the order of the frequency with which they were cited (n = 65).

<table>
<thead>
<tr>
<th>Appropriate</th>
<th>Freq</th>
<th>Not appropriate</th>
<th>Freq</th>
</tr>
</thead>
<tbody>
<tr>
<td>Information is not specific to any age group, generic information is okay</td>
<td>9</td>
<td>Nothing is available specifically for this age group</td>
<td>10</td>
</tr>
<tr>
<td>Information is easy to understand</td>
<td>2</td>
<td>Sources target older age group</td>
<td>9</td>
</tr>
<tr>
<td>Choices are wide</td>
<td>1</td>
<td>Need to deal with specific topics</td>
<td>8</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Inaccessible due to work/family commitments</td>
<td>6</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Does not catch their attention/need different presentation</td>
<td>5</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Does not cater for different experiences, needs or expectations</td>
<td>3</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Is not applicable to people from a non-English speaking background</td>
<td>2</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Do not know</td>
<td>3</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Other reasons why they are inappropriate</td>
<td>7*</td>
</tr>
</tbody>
</table>

* Other responses given why sources are inadequate were: they are okay but not great, does not cater for those with poor literacy, it is difficult to find information relevant to individual needs, and there are long delays to see a diabetes educator.
Appropriateness of the way information is delivered

Respondents were also asked whether the way information is currently delivered is appropriate for the target age group: 46% indicated it is not appropriate, 36% indicated it is appropriate, 10% responded ‘yes and no’ or ‘it depends’, and eight respondents (9%) did not respond. An open question asked respondents to give reasons for their answer. A thematic analysis of responses was conducted. The main themes are presented in Table 13. Twenty-seven respondents did not provide a reason.

Table 13: Responses to an open question asking why the way information is delivered is appropriate for 25–45 year olds. Responses are presented in the order of the frequency with which they were cited (n = 65).

<table>
<thead>
<tr>
<th>Appropriate</th>
<th>Freq</th>
<th>Not appropriate</th>
<th>Freq</th>
</tr>
</thead>
<tbody>
<tr>
<td>Given one-on-one, tailored for individual</td>
<td>8</td>
<td>Need more IT, web-based information</td>
<td>15</td>
</tr>
<tr>
<td>Written material available, info is always accessible</td>
<td>3</td>
<td>Need to tailor information for this age group</td>
<td>8</td>
</tr>
<tr>
<td>A range of delivery modes available</td>
<td>2</td>
<td>Need more after hours services, including groups</td>
<td>7</td>
</tr>
<tr>
<td>Other reasons why they are appropriate</td>
<td>2*</td>
<td>Groups cater for older people</td>
<td>3</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Need to give a range of delivery options</td>
<td>2</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Need more group work</td>
<td>2</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Do not know</td>
<td>5</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Other reasons why they are not appropriate</td>
<td>8*</td>
</tr>
</tbody>
</table>

* Other individual responses relating to the appropriateness of the delivery of information were: we place clients into groups that are age appropriate and until more research on the outcomes of styles, this is suitable. Individual respondents indicated delivery modes are a bit hit and miss, there are long delays to access services after diagnosis, and they do not have any handouts.

Delivery modes

Respondents were provided with a list of delivery modes and asked to indicate which methods would be the most appropriate way to deliver education/information to 25 to 45 year olds (see Table 14). Respondents could select more than one response.
Table 14: Education information delivery modes health professionals believed to be appropriate for the target group. Responses are presented in the order of the frequency with which they were cited (n = 92).

<table>
<thead>
<tr>
<th>Appropriate delivery modes</th>
<th>Freq</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>Web-based information</td>
<td>70</td>
<td>76%</td>
</tr>
<tr>
<td>Printed resources</td>
<td>58</td>
<td>63%</td>
</tr>
<tr>
<td>Individual sessions</td>
<td>53</td>
<td>58%</td>
</tr>
<tr>
<td>Group sessions</td>
<td>50</td>
<td>54%</td>
</tr>
<tr>
<td>DVD</td>
<td>46</td>
<td>50%</td>
</tr>
<tr>
<td>E-learning sessions</td>
<td>45</td>
<td>49%</td>
</tr>
<tr>
<td>Telephone</td>
<td>32</td>
<td>35%</td>
</tr>
<tr>
<td>Videos</td>
<td>19</td>
<td>21%</td>
</tr>
<tr>
<td>Other*</td>
<td>23</td>
<td>25%</td>
</tr>
</tbody>
</table>

* The majority of respondents who replied ‘Other’ (n = 13) indicated that all modes of delivery are appropriate, depending on the needs of the individual. Other suggestions were group sessions including after hours and age specific groups, home visits, low literacy printed information and workplace education.

The delivery modes respondents were able to provide are presented in Table 15. The majority of respondents mentioned printed resources and individual sessions.

Table 15: Education information delivery modes health professionals were able to provide. Responses are presented in the order of the frequency with which they were cited (n = 92).

<table>
<thead>
<tr>
<th>Delivery modes respondents provide</th>
<th>Freq</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>Printed resources</td>
<td>79</td>
<td>86%</td>
</tr>
<tr>
<td>Individual sessions</td>
<td>77</td>
<td>84%</td>
</tr>
<tr>
<td>Group sessions</td>
<td>31</td>
<td>34%</td>
</tr>
<tr>
<td>Telephone</td>
<td>25</td>
<td>27%</td>
</tr>
<tr>
<td>Web-based information</td>
<td>23</td>
<td>25%</td>
</tr>
<tr>
<td>DVD</td>
<td>10</td>
<td>11%</td>
</tr>
<tr>
<td>Other*</td>
<td>9</td>
<td>10%</td>
</tr>
</tbody>
</table>

* Other suggested delivery modes included: email contact, telehealth, video conferencing, SMS, information tailored for the individual, referrals, some individual but usually groups, and a combination of resources.
**Education information needs**

**Perceived needs**
Respondents were asked to select what they thought are the education information needs of 25 to 45 year olds with type 2 diabetes from a list of topics (see Table 16). Respondents could select more than one response.

**Table 16: Health professionals’ perceptions of the education information needs of people aged 25 to 45 with type 2 diabetes. Responses are presented in the order of the frequency with which they were cited (n = 92).**

<table>
<thead>
<tr>
<th>Education information needs</th>
<th>Freq</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>Diet</td>
<td>85</td>
<td>92%</td>
</tr>
<tr>
<td>Shopping for correct food</td>
<td>84</td>
<td>91%</td>
</tr>
<tr>
<td>Exercise</td>
<td>83</td>
<td>90%</td>
</tr>
<tr>
<td>Weight management</td>
<td>83</td>
<td>90%</td>
</tr>
<tr>
<td>Long-term effect of diabetes</td>
<td>78</td>
<td>85%</td>
</tr>
<tr>
<td>Pregnancy</td>
<td>76</td>
<td>83%</td>
</tr>
<tr>
<td>Measuring glucose</td>
<td>74</td>
<td>80%</td>
</tr>
<tr>
<td>Medication – other than insulin</td>
<td>70</td>
<td>76%</td>
</tr>
<tr>
<td>Support</td>
<td>70</td>
<td>76%</td>
</tr>
<tr>
<td>Sexuality and sexual health</td>
<td>69</td>
<td>75%</td>
</tr>
<tr>
<td>Coping</td>
<td>69</td>
<td>75%</td>
</tr>
<tr>
<td>Erectile dysfunction</td>
<td>69</td>
<td>75%</td>
</tr>
<tr>
<td>Work/career issues</td>
<td>68</td>
<td>74%</td>
</tr>
<tr>
<td>Medication – insulin</td>
<td>65</td>
<td>71%</td>
</tr>
<tr>
<td>Family issues</td>
<td>62</td>
<td>67%</td>
</tr>
<tr>
<td>Women’s health issues</td>
<td>60</td>
<td>65%</td>
</tr>
<tr>
<td>Depression</td>
<td>60</td>
<td>65%</td>
</tr>
<tr>
<td>Community services</td>
<td>56</td>
<td>61%</td>
</tr>
<tr>
<td>Discrimination</td>
<td>55</td>
<td>60%</td>
</tr>
<tr>
<td>Other*</td>
<td>17</td>
<td>19%</td>
</tr>
</tbody>
</table>

* Other topics suggested included: travel, life or health insurance, support groups, sleep apnoea, continence, men’s health, illicit drugs, long term health plan, goal setting and health coaching, peer group education, pre-pregnancy, driving, what to expect from health professionals, hypoglycaemia, recipe modification and eating out.
Factors affecting needs
Respondents were asked to indicate the factors that affect the information and education needs of younger people with type 2 diabetes from a list of factors (see Table 17). Respondents could select more than one response.

Table 17: Factors affecting the information and education needs of people aged 25 to 45 with type 2 diabetes. Responses are presented in the order of the frequency with which they were cited (n = 92).

<table>
<thead>
<tr>
<th>Factors affecting information and education needs</th>
<th>Freq</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>Phase of life</td>
<td>80</td>
<td>87%</td>
</tr>
<tr>
<td>Socio-economic status</td>
<td>72</td>
<td>78%</td>
</tr>
<tr>
<td>Education</td>
<td>71</td>
<td>77%</td>
</tr>
<tr>
<td>Denial</td>
<td>68</td>
<td>74%</td>
</tr>
<tr>
<td>Acceptance</td>
<td>66</td>
<td>72%</td>
</tr>
<tr>
<td>Age</td>
<td>65</td>
<td>71%</td>
</tr>
<tr>
<td>Literacy</td>
<td>64</td>
<td>70%</td>
</tr>
<tr>
<td>Ethnicity and culture</td>
<td>64</td>
<td>70%</td>
</tr>
<tr>
<td>Health beliefs</td>
<td>63</td>
<td>69%</td>
</tr>
<tr>
<td>Access to services</td>
<td>60</td>
<td>65%</td>
</tr>
<tr>
<td>Where they live (rural/metro)</td>
<td>57</td>
<td>62%</td>
</tr>
<tr>
<td>Specific disease stage</td>
<td>57</td>
<td>62%</td>
</tr>
<tr>
<td>Access to Internet</td>
<td>54</td>
<td>59%</td>
</tr>
<tr>
<td>Gender</td>
<td>52</td>
<td>57%</td>
</tr>
<tr>
<td>Self-efficacy</td>
<td>52</td>
<td>57%</td>
</tr>
<tr>
<td>Locus of control</td>
<td>51</td>
<td>55%</td>
</tr>
<tr>
<td>Language</td>
<td>49</td>
<td>53%</td>
</tr>
<tr>
<td>Religious beliefs</td>
<td>36</td>
<td>39%</td>
</tr>
<tr>
<td>Other*</td>
<td>15</td>
<td>16%</td>
</tr>
</tbody>
</table>

* Other factors included: work and family commitments, access to services and health professionals after hours, cognitive function, co-morbidities, mental health status, family history of diabetes, and latest media reports, which can be negative.
Other education information resources that could be provided

An open question asked respondents to indicate what other education information resources could be provided to the target group (see Table 18). Less than half the respondents (n = 44) responded to this question. Some gave more than one response.

**Table 18: Responses to an open question asking about other education resources that could be provided to this age group. Responses are presented in the order of the frequency with which they were cited (n = 44).**

<table>
<thead>
<tr>
<th>Other education information resources that could be provided to this group</th>
<th>Freq</th>
</tr>
</thead>
<tbody>
<tr>
<td>Multi-media (DVD, CD)</td>
<td>7</td>
</tr>
<tr>
<td>Personal trainers/life coaching</td>
<td>7</td>
</tr>
<tr>
<td>Information that targets this age group</td>
<td>6</td>
</tr>
<tr>
<td>None that haven’t already been mentioned</td>
<td>5</td>
</tr>
<tr>
<td>Age specific group sessions/camps</td>
<td>5</td>
</tr>
<tr>
<td>After hours appointments/group sessions</td>
<td>4</td>
</tr>
<tr>
<td>Information on specific topics (including sexual health, Indigenous, diet, cooking, community resources, smoking, drugs, CALD)</td>
<td>4</td>
</tr>
<tr>
<td>Telephone based</td>
<td>4</td>
</tr>
<tr>
<td>On-line/web-based</td>
<td>3</td>
</tr>
<tr>
<td>Diabetes educators in target age group</td>
<td>2</td>
</tr>
<tr>
<td>Other</td>
<td>6*</td>
</tr>
</tbody>
</table>

* Other education resources respondents mentioned included: access to diabetes friendly gym sessions and exercise groups for the age group, one-on-one sessions with a diabetes educator, and one respondent suggested information should be provided in an active rather than a passive mode.

Other delivery modes that would be effective

An open question asked respondents what information delivery modes would be effective for the target age group. A thematic analysis of the responses was undertaken and the major categories are presented in Table 19. Only 70 people responded to this question, but the 70 who did respond frequently mentioned more than one delivery mode.
Table 19: Responses to an open question about what information delivery modes could be effective for people aged 25 to 45. Responses are presented in the order of the frequency with which they were cited (n = 70).

<table>
<thead>
<tr>
<th>What information delivery modes might be effective for this age group</th>
<th>Freq</th>
</tr>
</thead>
<tbody>
<tr>
<td>Web-based/Internet/web site</td>
<td>47</td>
</tr>
<tr>
<td>CD/DVD/MP3</td>
<td>21</td>
</tr>
<tr>
<td>Printed information</td>
<td>10</td>
</tr>
<tr>
<td>Phone based/SMS</td>
<td>9</td>
</tr>
<tr>
<td>Evening/after hours access to services</td>
<td>8</td>
</tr>
<tr>
<td>One-on-one sessions</td>
<td>7</td>
</tr>
<tr>
<td>Age specific groups</td>
<td>6</td>
</tr>
<tr>
<td>Email</td>
<td>4</td>
</tr>
<tr>
<td>Pod casts</td>
<td>3</td>
</tr>
<tr>
<td>Social events/weekends/camps</td>
<td>3</td>
</tr>
<tr>
<td>E-learning</td>
<td>2</td>
</tr>
<tr>
<td>Do not know</td>
<td>2</td>
</tr>
<tr>
<td>Other</td>
<td>15*</td>
</tr>
</tbody>
</table>

* Other suggestions included access to regular updates through newsletters, more services provided at decreased cost by GPs and allied health, advertising on the web, in cinemas, on TV, home visits, evening group sessions in funky venues, meeting other people with type 2 diabetes who have successfully made changes, medical “infotainment”, school visits, corporate visits, diabetes call service, one-stop shop, delivering services in retail areas, email education bulletins, and life coaches.

How to support and empower young people to manage their diabetes
The final open question asked respondents what else would help support and empower young people with type 2 diabetes to manage their diabetes. Responses were subjected to a thematic analysis. The most frequently mentioned categories are presented in Table 20. Twenty people did not respond to this question. Respondents could give more than one answer.
Table 20: Responses to an open question about what else would help support and empower 25 to 45 year olds to manage their diabetes. Responses are presented in the order of the frequency with which they were cited (n = 71).

<table>
<thead>
<tr>
<th>What would help support and empower young people to manage their diabetes</th>
<th>Freq</th>
</tr>
</thead>
<tbody>
<tr>
<td>Peer groups/support groups</td>
<td>13</td>
</tr>
<tr>
<td>Motivation and support/motivational interviewing</td>
<td>9</td>
</tr>
<tr>
<td>On-line support/Web-site like Reality Check</td>
<td>8</td>
</tr>
<tr>
<td>Increase public awareness, change attitudes</td>
<td>7</td>
</tr>
<tr>
<td>Acknowledge achievements/sense of hope</td>
<td>5</td>
</tr>
<tr>
<td>After hours support</td>
<td>4</td>
</tr>
<tr>
<td>Access to exercise support/facilities</td>
<td>4</td>
</tr>
<tr>
<td>Ask them what they want</td>
<td>3</td>
</tr>
<tr>
<td>Psychological support</td>
<td>3</td>
</tr>
<tr>
<td>Life coaching</td>
<td>2</td>
</tr>
<tr>
<td>Ongoing support</td>
<td>2</td>
</tr>
<tr>
<td>Better relationships with health professionals</td>
<td>2</td>
</tr>
<tr>
<td>Regular updates/follow-up</td>
<td>2</td>
</tr>
<tr>
<td>Social activities, with education</td>
<td>2</td>
</tr>
<tr>
<td>Family involvement</td>
<td>2</td>
</tr>
<tr>
<td>Email support</td>
<td>2</td>
</tr>
<tr>
<td>Do not know</td>
<td>2</td>
</tr>
<tr>
<td>Other</td>
<td>15*</td>
</tr>
</tbody>
</table>

* Other suggestions from individual respondents included: case worker, DESMOND, DSME style programs, diabetes educator running a ‘talk-in’ radio spot, diabetes education in the community rather than in hospital, mandatory GP upskilling to a particular level, intensive workshops on diet, exercise and lifestyle, exercise facilities with childcare, local community-based programs, information about how to accept the disease, and listening rather than a didactic approach from health professionals.

**Comparison of professional disciplines**

The responses from health professional disciplines to key questions are provided in the following section. The responses of the single endocrinologist who completed the questionnaire were combined with those in the ‘other’ category. Just over half of the respondents were diabetes educators (51%), followed by GPs (41%).
Demographic characteristics

A substantially greater proportion of the GPs had been in their current position for more than 10 years compared with the diabetes educators. Substantially more GPs worked in a rural/regional area compared with the diabetes educators (see Table 21).

Table 21: Demographic information comparing diabetes educators and GPs (n = 92).

<table>
<thead>
<tr>
<th></th>
<th>Diabetes educators</th>
<th>GPs</th>
<th>Other*</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>n = 47 Freq (%)</td>
<td>n = 38 Freq (%)</td>
<td>n = 7 Freq (%)</td>
</tr>
<tr>
<td>Years in role:</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Up to 1 year</td>
<td>1 2%</td>
<td>1 3%</td>
<td>-</td>
</tr>
<tr>
<td>2 to 5 years</td>
<td>10 21%</td>
<td>3 8%</td>
<td>3 43%</td>
</tr>
<tr>
<td>6 to 10 years</td>
<td>15 32%</td>
<td>1 3%</td>
<td>1 14%</td>
</tr>
<tr>
<td>More than 10 years</td>
<td>21 45%</td>
<td>33 87%</td>
<td>3 43%</td>
</tr>
<tr>
<td>Geographic area work in:</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Metro area</td>
<td>23 49%</td>
<td>8 21%</td>
<td>4 57%</td>
</tr>
<tr>
<td>Rural/regional area</td>
<td>22 47%</td>
<td>30 79%</td>
<td>2 29%</td>
</tr>
<tr>
<td>Both metro and rural/regional</td>
<td>2 4%</td>
<td>-</td>
<td>1 14%</td>
</tr>
</tbody>
</table>

* Respondents classified as “other” worked in health promotion, an emergency unit, in manager or coordinator roles, a dietitian (not a diabetes educator), and one endocrinologist.

Current practice

Table 22 presents information about the current practice for the various groups. The majority indicated they managed between one and five people in the target group each week, with diabetes educators more likely than GPs to manage or educate over six people in the target group in a week. The diabetes educators were more likely than the GPs to indicate that education/information resources for the target group are inadequate, that current sources of information are not appropriate, and the way information is delivered is not appropriate for the target group.

When asked which education information delivery modes are appropriate for the target group, the diabetes educators were more likely than the GPs to indicate that all options were appropriate. The majority of respondents from each group indicated web-based information was appropriate (see Table 23).
Table 22: Practice data at the time of the study (July and August, 2008) comparing diabetes educators and GPs (n = 92).

<table>
<thead>
<tr>
<th></th>
<th>Diabetes educators n = 47</th>
<th>GPs n = 38</th>
<th>Other* n = 7</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Freq (%)</td>
<td>Freq (%)</td>
<td>Freq (%)</td>
</tr>
<tr>
<td>Average number of people aged 25 – 45 with type 2 diabetes managed in a week</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>None</td>
<td>3 6%</td>
<td>8 21%</td>
<td>2 29%</td>
</tr>
<tr>
<td>1 - 2</td>
<td>20 43%</td>
<td>18 47%</td>
<td>2 29%</td>
</tr>
<tr>
<td>3 - 5</td>
<td>10 21%</td>
<td>9 24%</td>
<td>2 29%</td>
</tr>
<tr>
<td>6 - 10</td>
<td>10 21%</td>
<td>2 5%</td>
<td>1 14%</td>
</tr>
<tr>
<td>More than 10</td>
<td>4 9%</td>
<td>-</td>
<td>-</td>
</tr>
<tr>
<td>No response</td>
<td>-</td>
<td>1 3%</td>
<td>-</td>
</tr>
<tr>
<td>Are education/information resources for this age group adequate?</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Yes</td>
<td>11 23%</td>
<td>13 34%</td>
<td>1 14%</td>
</tr>
<tr>
<td>No</td>
<td>31 66%</td>
<td>17 45%</td>
<td>6 86%</td>
</tr>
<tr>
<td>Yes and No/It depends</td>
<td>5 11%</td>
<td>6 16%</td>
<td>-</td>
</tr>
<tr>
<td>No response</td>
<td>-</td>
<td>2 5%</td>
<td>-</td>
</tr>
<tr>
<td>Are current sources of information appropriate for this age group?</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Yes</td>
<td>12 26%</td>
<td>21 55%</td>
<td>6 86%</td>
</tr>
<tr>
<td>No</td>
<td>32 68%</td>
<td>11 29%</td>
<td>1 14%</td>
</tr>
<tr>
<td>Yes and No/It depends</td>
<td>1 2%</td>
<td>4 11%</td>
<td>-</td>
</tr>
<tr>
<td>No response</td>
<td>2 4%</td>
<td>2 5%</td>
<td>-</td>
</tr>
<tr>
<td>Is the way information is delivered appropriate for this age group?</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Yes</td>
<td>14 30%</td>
<td>18 47%</td>
<td>1 14%</td>
</tr>
<tr>
<td>No</td>
<td>27 57%</td>
<td>10 26%</td>
<td>5 71%</td>
</tr>
<tr>
<td>Yes and No/It depends</td>
<td>3 6%</td>
<td>5 13%</td>
<td>1 14%</td>
</tr>
<tr>
<td>No response</td>
<td>3 6%</td>
<td>5 13%</td>
<td>-</td>
</tr>
</tbody>
</table>

* Respondents classified as "other" worked in health promotion, an emergency unit, in manager or coordinator roles, a dietitian (not a diabetes educator), and one endocrinologist.

Information Needs of Young Adults with Type 2 Diabetes
Table 23: Education information delivery modes health professionals believed were appropriate for people aged 25 to 45 with type 2 diabetes comparing diabetes educators and GPs (n = 92).

<table>
<thead>
<tr>
<th></th>
<th>Diabetes educators</th>
<th>GPs</th>
<th>Other*</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>n = 47</td>
<td>n = 38</td>
<td>n = 7</td>
</tr>
<tr>
<td></td>
<td>Freq (%)</td>
<td>Freq (%)</td>
<td>Freq (%)</td>
</tr>
<tr>
<td>Web-based information</td>
<td>38 81%</td>
<td>25 66%</td>
<td>7 100%</td>
</tr>
<tr>
<td>Printed resources</td>
<td>31 66%</td>
<td>22 58%</td>
<td>5 71%</td>
</tr>
<tr>
<td>Individual sessions</td>
<td>30 64%</td>
<td>20 53%</td>
<td>3 43%</td>
</tr>
<tr>
<td>Group sessions</td>
<td>28 60%</td>
<td>18 47%</td>
<td>4 57%</td>
</tr>
<tr>
<td>DVD</td>
<td>32 68%</td>
<td>11 29%</td>
<td>3 43%</td>
</tr>
<tr>
<td>E-learning sessions</td>
<td>31 66%</td>
<td>9 24%</td>
<td>5 71%</td>
</tr>
<tr>
<td>Telephone</td>
<td>22 47%</td>
<td>6 16%</td>
<td>4 57%</td>
</tr>
<tr>
<td>Videos</td>
<td>17 36%</td>
<td>2 5%</td>
<td>-</td>
</tr>
<tr>
<td>Other</td>
<td>16 34%</td>
<td>6 16%</td>
<td>1 14%</td>
</tr>
</tbody>
</table>

* Respondents classified as "other" worked in health promotion, an emergency unit, in manager or coordinator roles, a dietitian (not a diabetes educator), and one endocrinologist.

Respondents were asked about the delivery modes they provide. More diabetes educators than GPs indicated they were able to provide printed resources, individual education sessions, group sessions, telephone support, and DVDs. GPs were more likely than diabetes educators to provide web-based information (see Table 24).

Table 24: Education information delivery modes health professionals were able to provide comparing diabetes educators and GPs (n = 92).

<table>
<thead>
<tr>
<th></th>
<th>Diabetes educators</th>
<th>GPs</th>
<th>Other*</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>n = 47</td>
<td>n = 38</td>
<td>n = 7</td>
</tr>
<tr>
<td></td>
<td>Freq (%)</td>
<td>Freq (%)</td>
<td>Freq (%)</td>
</tr>
<tr>
<td>Printed resources</td>
<td>43 91%</td>
<td>30 79%</td>
<td>6 86%</td>
</tr>
<tr>
<td>Individual sessions</td>
<td>42 89%</td>
<td>29 76%</td>
<td>6 86%</td>
</tr>
<tr>
<td>Group sessions</td>
<td>22 47%</td>
<td>5 13%</td>
<td>4 57%</td>
</tr>
<tr>
<td>Telephone</td>
<td>21 45%</td>
<td>1 3%</td>
<td>3 43%</td>
</tr>
<tr>
<td>Web-based information</td>
<td>9 19%</td>
<td>11 29%</td>
<td>3 43%</td>
</tr>
<tr>
<td>DVD</td>
<td>9 19%</td>
<td>1 3%</td>
<td>-</td>
</tr>
<tr>
<td>Other</td>
<td>5 11%</td>
<td>3 8%</td>
<td>1 14%</td>
</tr>
</tbody>
</table>

* Respondents classified as "other" worked in health promotion, an emergency unit, in manager or coordinator roles, a dietitian (not a diabetes educator), and one endocrinologist.
Education and information needs

Table 25 presents respondents’ perceptions of the education information needs of the target group. All health professional groups indicated that education information about diet, shopping for correct food, exercise, weight management and the long-term effects of diabetes is needed. The diabetes educators were more likely than the GPs to perceive a need for education information on a range of topics not routinely provided including pregnancy, sexuality, coping, work/career issues, insulin, family issues, women’s health issues and discrimination.

Table 25: Health professionals’ perceptions of the education information needs of people aged 25 to 45 with type 2 diabetes comparing diabetes educators and GPs (n = 92).

<table>
<thead>
<tr>
<th></th>
<th>Diabetes educators n = 47 Freq (%)</th>
<th>GPs n = 38 Freq (%)</th>
<th>Other* n = 7 Freq (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Diet</td>
<td>43 91%</td>
<td>35 92%</td>
<td>7 100%</td>
</tr>
<tr>
<td>Shopping for correct food</td>
<td>44 93%</td>
<td>33 87%</td>
<td>7 100%</td>
</tr>
<tr>
<td>Exercise</td>
<td>41 87%</td>
<td>35 92%</td>
<td>7 100%</td>
</tr>
<tr>
<td>Weight management</td>
<td>41 87%</td>
<td>36 95%</td>
<td>6 86%</td>
</tr>
<tr>
<td>Long-term effect of diabetes</td>
<td>39 83%</td>
<td>33 87%</td>
<td>6 86%</td>
</tr>
<tr>
<td>Pregnancy</td>
<td>43 91%</td>
<td>26 68%</td>
<td>7 100%</td>
</tr>
<tr>
<td>Measuring glucose</td>
<td>38 81%</td>
<td>29 76%</td>
<td>7 100%</td>
</tr>
<tr>
<td>Medication – other</td>
<td>39 83%</td>
<td>25 66%</td>
<td>6 86%</td>
</tr>
<tr>
<td>Support</td>
<td>39 83%</td>
<td>24 63%</td>
<td>7 100%</td>
</tr>
<tr>
<td>Sexuality/sexual health</td>
<td>43 91%</td>
<td>19 50%</td>
<td>7 100%</td>
</tr>
<tr>
<td>Coping</td>
<td>40 85%</td>
<td>22 58%</td>
<td>7 100%</td>
</tr>
<tr>
<td>Erectile dysfunction</td>
<td>37 79%</td>
<td>26 68%</td>
<td>6 86%</td>
</tr>
<tr>
<td>Work/career issues</td>
<td>39 83%</td>
<td>23 61%</td>
<td>6 86%</td>
</tr>
<tr>
<td>Medication- insulin</td>
<td>38 81%</td>
<td>21 55%</td>
<td>6 86%</td>
</tr>
<tr>
<td>Family issues</td>
<td>40 85%</td>
<td>16 42%</td>
<td>6 86%</td>
</tr>
<tr>
<td>Women’s health issues</td>
<td>36 77%</td>
<td>18 47%</td>
<td>6 86%</td>
</tr>
<tr>
<td>Depression</td>
<td>37 79%</td>
<td>16 42%</td>
<td>7 100%</td>
</tr>
<tr>
<td>Discrimination</td>
<td>34 72%</td>
<td>14 37%</td>
<td>7 100%</td>
</tr>
<tr>
<td>Community services</td>
<td>29 62%</td>
<td>21 55%</td>
<td>6 86%</td>
</tr>
<tr>
<td>Other</td>
<td>12 26%</td>
<td>3 8%</td>
<td>2 29%</td>
</tr>
</tbody>
</table>

* Respondents classified as “other” worked in health promotion, an emergency unit, in manager or coordinator roles, a dietitian (not a diabetes educator), and one endocrinologist.
The diabetes educators felt a wider range of factors affected the information and education needs of people aged 25 to 45 with type 2 diabetes than GPs (see Table 26). Substantially more diabetes educators than GPs mentioned literacy, ethnicity and culture, where the person lives, gender, self-efficacy and religious beliefs, as factors affecting information and education needs of the target group.

Table 26: Factors affecting the information and education needs of people aged 25 to 45 with type 2 diabetes comparing diabetes educators and GPs (n = 92).

<table>
<thead>
<tr>
<th>Factor</th>
<th>Diabetes educators</th>
<th>GPs</th>
<th>Other*</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>n = 47 Freq (%)</td>
<td>n = 38 Freq (%)</td>
<td>n = 7 Freq (%)</td>
</tr>
<tr>
<td>Phase of life</td>
<td>46 98%</td>
<td>27 71%</td>
<td>7 100%</td>
</tr>
<tr>
<td>Socio-economic status</td>
<td>39 83%</td>
<td>26 68%</td>
<td>7 100%</td>
</tr>
<tr>
<td>Education</td>
<td>37 79%</td>
<td>28 74%</td>
<td>6 86%</td>
</tr>
<tr>
<td>Denial</td>
<td>35 74%</td>
<td>27 71%</td>
<td>6 86%</td>
</tr>
<tr>
<td>Acceptance</td>
<td>36 77%</td>
<td>24 63%</td>
<td>6 86%</td>
</tr>
<tr>
<td>Age</td>
<td>36 77%</td>
<td>23 61%</td>
<td>6 86%</td>
</tr>
<tr>
<td>Literacy</td>
<td>37 79%</td>
<td>22 58%</td>
<td>5 71%</td>
</tr>
<tr>
<td>Ethnicity and culture</td>
<td>38 81%</td>
<td>19 50%</td>
<td>7 100%</td>
</tr>
<tr>
<td>Health beliefs</td>
<td>36 77%</td>
<td>21 55%</td>
<td>6 86%</td>
</tr>
<tr>
<td>Access to services</td>
<td>34 72%</td>
<td>20 53%</td>
<td>6 86%</td>
</tr>
<tr>
<td>Where they live</td>
<td>37 79%</td>
<td>14 37%</td>
<td>6 86%</td>
</tr>
<tr>
<td>Specific disease stage</td>
<td>30 64%</td>
<td>21 55%</td>
<td>6 86%</td>
</tr>
<tr>
<td>Access to Internet</td>
<td>29 62%</td>
<td>19 50%</td>
<td>6 86%</td>
</tr>
<tr>
<td>Gender</td>
<td>32 68%</td>
<td>14 37%</td>
<td>6 86%</td>
</tr>
<tr>
<td>Self-efficacy</td>
<td>33 70%</td>
<td>12 32%</td>
<td>7 100%</td>
</tr>
<tr>
<td>Locus of control</td>
<td>31 66%</td>
<td>15 39%</td>
<td>5 71%</td>
</tr>
<tr>
<td>Language</td>
<td>29 62%</td>
<td>15 39%</td>
<td>5 71%</td>
</tr>
<tr>
<td>Religious beliefs</td>
<td>24 51%</td>
<td>7 18%</td>
<td>5 71%</td>
</tr>
<tr>
<td>Other</td>
<td>10 21%</td>
<td>1 3%</td>
<td>4 57%</td>
</tr>
</tbody>
</table>

* Respondents classified as “other” worked in health promotion, an emergency unit, in manager or coordinator roles, a dietitian (not a diabetes educator), and one endocrinologist.
Comparison of the responses of rural/regional and metropolitan respondents were not made due to the fact that 80% of GP respondents were from a rural/regional area.

**Section summary**

Ninety-two health professionals completed the questionnaire; 51% were diabetes educators and 41% were GPs. Unfortunately only one endocrinologist completed the questionnaire.

Few respondents indicated providing any education information resources specifically for 25 to 45 year olds with type 2 diabetes. Responses to questions concerning current practice clearly support a need for improving education information for the target group.

Over half the respondents indicated current resources are not adequate and current sources of information are not appropriate for the target group.

Almost half of respondents indicated the way information is provided is not appropriate for people aged 25 to 45 with type 2 diabetes. There was strong support for web-based information with over three-quarters of respondents reporting that web-based information is appropriate for the target group, followed by printed resources and individual or group sessions. However, only 25% reported they currently provide web-based information. The majority provide printed resources and individual sessions.

Respondents were asked about the topics that younger people with type 2 diabetes need information about. Interestingly, diabetes educators perceived a need for education information on a wider range of topics than GPs. While both groups indicated that education information about diet, shopping for correct food, exercise, weight management and the long-term effects of diabetes is needed, the diabetes educators were more likely to perceive a need for information about a range of other topics likely to be relevant to the younger age group including pregnancy, sexuality, coping, work/career issues, insulin, family issues, women’s health issues and discrimination.

Similarly, diabetes educators felt a wider range of factors affected the information and education needs of people aged 25 to 45 with type 2 diabetes than GPs. Diabetes educators were more likely than GPs to mention literacy, ethnicity and culture, where the person lives, gender, self-efficacy and religious beliefs as factors that affect the information and education needs of the target group. These findings suggest that diabetes educators might provide more appropriate support to younger people with type 2 diabetes than GPs.
QUALITATIVE DATA—YOUNGER PEOPLE WITH DIABETES

Qualitative data were collected from people aged 25 to 45 with type 2 diabetes in:
• One focus group discussion (nine participants).
• Four telephone interviews with participants who were unable to attend the focus group for a variety of reasons. These participants were very keen to put their point of view forward.

Method

Recruitment
Flyers inviting people with type 2 diabetes aged between 25 and 45 years to participate in a focus group were distributed to relevant organisations with a request that it be displayed in an appropriate place. The flyer was sent to Diabetes Australia Victoria, and to Diabetes Nurse Educators working in community health centres, GP practices, or in private practice. Diabetes Australia Victoria circulated the flyer to Melbourne suburban support groups and published an article inviting people to participate in the e-newsletter for their members. Initial response to the flyer was low. To facilitate recruitment, the staff at Diabetes Australia Victoria mailed the flyer to their members with type 2 diabetes in the target age group.

The flyer was addressed to the target group: people aged 25 to 45 with type 2 diabetes. People who were interested in taking part in the focus group were asked to contact one of the researchers, Susan Dabkowski. Ms Dabkowski gave potential participants more details about the project over the phone or by email. Those who indicated they would take part in the focus groups were mailed a Participant Statement and Consent Form. Potential participants were asked to provide their contact details so that the time and venue for the focus groups could be confirmed. Information that identified participants was stored separately from the data.

Procedure
During the recruitment phase, it was evident that it would not be possible to arrange a time for a focus group suitable for all of the young people with type 2 diabetes who were interested in participating. The majority of potential participants preferred an early evening focus group. The decision was made to conduct telephone interviews with three young women who were unable to attend an evening focus group due to difficulties with travelling to the venue or caring for young children. One young man with diabetes who intended to attend the focus group was unable to attend on the day due to personal reasons and was also interviewed by telephone.

Focus groups. Initially separate focus groups were planned with younger men and younger women with type 2 diabetes. However, on the night of the focus groups, two of five males who had agreed to participate were unable to attend due to unforeseen circumstances. Given that three participants was insufficient for a group discussion, the remaining three male participants joined the six women participants in a single focus group. All participants indicated they agreed with this arrangement.
Diabetes Australia Victoria kindly provided the venue for the focus group discussion, which took place on October 1st 2008. Participants were mailed a Participant Information Sheet and Consent Form prior to the focus group. Participants signed the Consent Form and completed a brief demographic data form before the focus group commenced. The discussion was tape recorded with participants’ consent.

**Telephone interviews.** Three telephone interviews were conducted in late September and one in early October at a time suitable to the participants and the researchers. Participants were mailed a Participant Information Sheet and Consent Form prior to the interviews. Participants mailed their signed Consent Forms to the researchers. The interviews were conducted using speakerphone and tape recorded with participants’ consent. Two researchers were involved in the telephone interviews: one asked the questions and one took detailed notes of responses. The same questions were used in the focus group and telephone interviews (see Appendix F).

Participants

Six females and three males participated in the focus group, and three females and one male were interviewed by telephone. These participants represented a range of backgrounds, occupations, abilities and experiences with diabetes. The demographic characteristics of participants are presented in table 27.

**Table 27: Demographic data of focus group and interview participants (n = 13).**

<table>
<thead>
<tr>
<th>Demographic data</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>Gender</td>
<td></td>
</tr>
<tr>
<td>Female</td>
<td>9</td>
</tr>
<tr>
<td>Male</td>
<td>4</td>
</tr>
<tr>
<td>Age</td>
<td></td>
</tr>
<tr>
<td>Mean</td>
<td>38 years (SD 5.9)</td>
</tr>
<tr>
<td>Median</td>
<td>41 years</td>
</tr>
<tr>
<td>Range</td>
<td>26-44 years</td>
</tr>
<tr>
<td>Time since diagnosis</td>
<td></td>
</tr>
<tr>
<td>Mean</td>
<td>29 months (SD 32.3)</td>
</tr>
<tr>
<td>Median</td>
<td>24 months</td>
</tr>
<tr>
<td>Range</td>
<td>6-132 months</td>
</tr>
<tr>
<td>Number of medications</td>
<td></td>
</tr>
<tr>
<td>None</td>
<td>5</td>
</tr>
<tr>
<td>1</td>
<td>4</td>
</tr>
<tr>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>3</td>
<td>1</td>
</tr>
<tr>
<td>Complications</td>
<td></td>
</tr>
<tr>
<td>None</td>
<td>10</td>
</tr>
<tr>
<td>Kidney and vascular disease</td>
<td>1</td>
</tr>
<tr>
<td>Hypertension</td>
<td>1</td>
</tr>
<tr>
<td>Weight gain</td>
<td>1</td>
</tr>
</tbody>
</table>
Analysis
The focus group was tape-recorded and transcribed verbatim. Detailed notes were compiled during the telephone interviews, tape recordings of the interviews were listened to, and selected quotes transcribed verbatim. The focus group and telephone interview data were amalgamated. Content analysis of the data was undertaken using the Ritchie and Spencer Framework method (1994). This method comprises five stages:

- Familiarisation—immersion by the researchers in the transcripts and notes from the focus groups, and listing key ideas and recurrent themes.
- Identifying a thematic framework—identifying all the issues, concepts and themes by which the data can be examined and referenced.
- Indexing—applying the index or thematic framework systematically to the data by annotating the transcripts with codes.
- Charting—rearranging the data according to the appropriate part of the thematic framework to which they relate, and forming charts.
- Mapping and interpretation—using the charts to define concepts and map the range and nature of phenomena and find associations among themes (Pope, Ziebland & Mays, 2000).

The initial analysis was completed by one researcher and independently validated by a second researcher.

Results
The following overview presents the key themes identified in the content analysis. Quotes from focus group or telephone interview participants are de-identified and presented in italics to illustrate the points being made.

The importance of information at diagnosis
Individuals from the focus group and interviews described very different experiences of receiving information when they were diagnosed with type 2 diabetes; however a common theme to emerge was the importance of receiving sufficient, appropriate and consistent information at diagnosis. Participants reported both positive and negative experiences at the time of their diagnosis.

Negative experiences
Some participants said they received very little information from the doctor when they were diagnosed and needed to research the topic themselves:

But I went away at first and I was sort of left to my own devices.

and

I was also given nothing, absolutely nothing by my doctor.

One focus group participant and one interview participant indicated they were not initially told about the existence of diabetes educators:

It took me years to actually figure out or to find out that there is even such a thing as a diabetes educator. Took me years and years to find that out.
Another interview participant was unclear about the role of a diabetes educator and asked:

Would a diabetes educator tell me about tests I should have?

One focus group participant reflected on why some people experience a lack of support and receive little information when their diabetes was diagnosed because health professionals need to repeat the same information to many people:

But then also, the people who are telling you this information initially, they have told 20 people before you in the same day, and the way they tell you, it's as if it's nothing. Don't worry about it. You've got diabetes.

Participants who reported negative experiences at diagnosis expressed considerable frustration and sometimes anger. However, other participants were more satisfied with the information or support they were given at diagnosis.

Positive experiences

Other participants described more positive experiences when they were first diagnosed with type 2 diabetes:

My experience was completely different. When I was diagnosed my doctor referred me straightaway to the Baker Institute educators.

and

My GP gave me a pack of about 4 A4 size leaflet things. They recommended that I looked at web sites but basically gave me a whole stack of information to take away. And we talked about it as well.

These participants were satisfied with the information or referrals they received from their GP at the time of their diagnosis with type 2 diabetes.

Content of information

Participants in the focus group and interviews discussed the type of content they would prefer in education information. They wanted information that is easy to understand, brief, covers a range of specific topics, enables independent management, includes age-specific resources, and is also targeted at other people.

Easy to understand

Focus group and interview participants indicated a need for information that is easy to understand. Typically they wanted the 'who, what, where, why' information about type 2 diabetes, particularly when they were first diagnosed. One spoke of reading Diabetes for Dummies:

I understood it more because it was basic. It wasn't like, they didn't try and dumbfound me with science so to speak.
Other participants agreed with this view. This suggests the level of language and type of presentation likely to appeal to the target group and has important implications for diabetes information for the target group. An interview participant also articulated a need for clear information:

*I'm no Rhodes Scholar... I'd like clearer information, that's more understandable.*

Some participants in the focus group and telephone interviews found the amount of information available overwhelming:

*[the information] was so overwhelming ... that it's hard for me to remember any of it really at the end of the day.*

Participants also suggested the content of education information needed to be brief.

**Keep it brief**

Some participants argued that they need brief information because they have time constraints:

*But I work very long hours, I need it fed to me maybe in a different way. ... Something shorter for me to have a look at, because time is precious.*

In addition to the style of education information, participants expressed some preferences for the topics presented.

**Topics in addition to usual diabetes education**

Participants indicated they would like to access information about a range of topics that are not adequately covered at present. These topics included, in the order of most to least cited:

- Medications.
- Managing diabetes and other health conditions.
- Surgery and investigative procedures.
- Preventing diabetes.
- Questions to ask their doctor.
- Pregnancy and planning a pregnancy.
- IVF and diabetes.
- The impact of diabetes on menopause and vice versa.
- Where to access supplies in an emergency (e.g. a broken insulin pen at night).
- Community programs in their local area.

**Medications.** Both the focus group and interview participants wanted more information about medications, especially information about the actions and side effects of the medications they use for their diabetes:

*I'd like to know more about drugs, what they do, the side effects. ... I still don't know what Januvia does.*
Young people with type 2 diabetes also wanted information about possible interactions between the medications they take for different conditions that might be present in addition to diabetes:

*You can always look up what blood pressure medication does, because I take blood pressure medication … I take a cereal bowl full of pills every day, and I would really like to know how they all affect each other. We all know how they react on their own, but what happens when I put everything in this cereal bowl and eat it for breakfast?*

**Managing diabetes and other health conditions.** Focus group participants discussed their concerns about managing diabetes and other concomitant health conditions, the way they affect each other, and the need to have information about them as well as diabetes. Other health conditions mentioned included blood pressure, arthritis, cancer and heart disease.

**Surgery and investigative procedures.** The need to have information about managing diabetes if surgery or investigative procedures were required was discussed in the focus group. Participants expressed some concern that they did not know how diabetes would affect surgery and vice versa.

*Even in terms of surgery, if you have to have surgery, and be knocked out. How does being anaesthetised actually affect your medication and affect what you do, and affect how you’re going to recover?*

Participants also indicated that they would like information about how much information about their diabetes they should provide to health professionals such as a surgeon.

**Preventing diabetes.** The focus group participants discussed the need for information about preventing diabetes to be available to the general population and their family members:

*[a DVD] that’s aimed at educating to try for prevention if you follow me. Let’s try and defer it [diabetes], how do you do that, you educate people.*

An important theme emerging in the focus group discussion and interviews was participants’ desire to be involved in managing their diabetes.

**Information to enable independent management**

Implicit in many of the participants’ responses to questions about education information was their need to have sufficient information to enable them to be active partners in managing their diabetes. They did not want health professionals to tell them what to do. They wanted to understand what they needed to do and to be able to locate appropriate information to assist them to manage their diabetes independently.

The group also discussed the need to inform other people about diabetes and its management.
Information for other people

In addition to the idea of producing information to help prevent other people developing diabetes, participants suggested family members, partners, friends or carers of people with type 2 diabetes need to receive information concerning diabetes. In particular, participants suggested these people need information about how to manage any situation that might arise such as the person with diabetes having a 'hypo' or passing out, and information about appropriate food choices and shopping for food. One focus group participant stated:

*There's a huge gap for information for partners or for carers. Whether it be wife, husband, girlfriend, boyfriend, or carer.*

and another suggested:

*Quite often they're forgotten in any long term condition or disease. The partners are the ones that are left behind and forgotten, and no one looks after them.*

An important aspect of the content of education and information is that it needs to be relevant to a younger group.

Need for age-specific resources

Participants clearly identified that people in their age group are different from the older age group and baby boomers with type 2 diabetes and have different needs and concerns. Younger people responded negatively to images and stories of older people with diabetes commonly published in magazines for example:

*But once again, that's not aimed at young people, you know, they are all older people. You look at those stories and think 'Is that going to be me in 20 years?' 'Is that going to be me in 10 years?' I don't know. I find that a little bit difficult.*

and

*My era, you didn’t have kids until like 30s, maybe even 40s. So you’ve got a different lifestyle situation. And I agree, a lot of it does seem to be focused on, well now you’re older and the kids have left home, it has that feeling to it.*

Participants also noted that there was a lot of information targeting a younger audience that concerned type 1 diabetes. It appeared that some feel they are the neglected group in the middle.

Delivery mode

The focus group and interview participants were asked how they would like to receive education information. The key themes emerging focused on:

- A need for centralised information.
- An 1800 number.
- Printed materials.
- The Internet.
- The need to provide a range of options.
Centralised information

The need for centralised information was a strong theme in the focus group, including printed, web-based and telephone-based information. Participants suggested all the relevant printed information could be put together:

*There needs to almost be a manual that’s all encompassing, but doesn’t weigh 10,000 tons as such. It needs to tell you why this [diabetes] has come about, it needs to tell you what it actually means to be diabetic, how the insulin works, it needs to talk about medication. ...Have it all in one place. I find it’s all over the place.*

The focus group participants discussed their confusion about the many diabetes web sites in Australia. In particular, they found the Diabetes Australia, Diabetes Victoria, Diabetes NSW and other state web sites, confusing. One interview participant also reported being confused by these sites. Participants wanted consistent information that is not branded by each Diabetes Australia State branch. The focus group participants strongly indicated that a more centralised approach is needed:

*There's no reason why you can't have a web site that has all your meaningful research and medical information in an Australia-wide format, and then have all your support services or whatever orientated towards whatever the locality needs to be.*

They suggested one way of achieving a centralised approach to education information: an 1800 number.

An 1800 number

There was substantial discussion about the merits of an 1800 number in the focus group. The discussion was closely linked to the need for centralised information. Participants suggested the 1800 number could be used Australia-wide as a first contact point and the people manning the 1800 number could refer callers to appropriate web sites, health professionals and services. One suggestion was that counsellors could be accessed via the number. In addition, participants suggested information packs about specific topics could be accessed by contacting the 1800 number, for example information about specific surgical procedures and diabetes. Participants did not appear to know that a similar service already exists, which suggests that the current information delivery mode is not effective for people aged 25 to 45 with type 2 diabetes. Their comments included:

*If you could call an 1800 number, an expert information provider, not a doctor, not necessarily a counsellor, but somebody who’s there who has access to all of the information is available and can deal with you specifically.*

and

*It could be an Australia-wide referral service. There is so much data that you could sit on a databank and have an operator sit there and talk to you.*

Another way of receiving education information supported by focus group and interview participants was via print media.
Printed materials
Participants indicated there was still a need for printed materials despite their competence with and preference for electronic formats. Several participants indicated the National Diabetes Services Scheme (NDSS) pack was very useful:

*The initial thing was the NDSS pack, [that] was quite good.*

Not surprisingly, there was a substantial discussion about the Internet as a source of information for young people with type 2 diabetes.

The Internet
Participants expressed some ambivalence concerning the Internet as a source of information. It was seen as positive because it is always accessible and the information should or could be current.

*My personal opinion is you have to get it off the Internet, because it [printed material] will change. There's no point having something that's five years old.*

Other participants suggested:

*The Internet – it's good because you can look at it in your own time.*

and

*I find the Internet very easy and useful.*

However, there were negative aspects to the Internet and these included the amount of information available and the difficulty locating a specific piece of information when it was needed, which participants described as trying to find ‘a needle in a haystack’. Several participants mentioned wasting a lot of time searching for information on the Internet.

*I find web sites that are an absolute nightmare... if I want that one needle of information, I can’t find it.*

While most participants use the Internet, a small number do not:

*I don’t do the Internet – it’s foreign to me.*

Several participants commented that the Diabetes Australia Victoria web site is a useful one:

*The DAV web site has quite a lot of information on it if you can navigate it. It has good specific type information if that’s what you’re looking for.*

Others suggested it was targeted at older people and referred older relatives to the site:

*I refer my mum to it.*
There was a strong emphasis on the fact that individuals have different needs, therefore a range of information options and delivery modes should be available.

Provide a range of options
Participants acknowledged that a range of delivery modes was needed. They suggested a printed starter pack could be utilised that provided information about useful web sites and gave details about how to obtain more detailed information. Audiotapes, DVDs and emails were suggested as other optimal modes of delivering information.

Services and support
Participants were asked about their preferences and experiences of receiving services and support. The key themes were:
- The need for age-specific groups.
- Problems accessing health professional services.
- Local services and support.
- Health professionals and communication.
- Receiving support from peers.
- Psychological support.
- The lack of understanding about diabetes in the community.

Several main sources of information support emerged in the discussion.

Sources of information and support
The sources of information and support participants mentioned most frequently were health professionals, particularly doctors, diabetes educators, endocrinologists and dietitians. The Internet, particularly diabetes web sites, was a frequently cited source of information. Some participants mentioned family members who had diabetes were a source of support. Other information sources included magazines and newsletters. A few people mentioned friends or people they came into contact with at work or in various organisations as sources of information and support.

Participants mentioned the importance of education and support groups comprising people in their own age group.

Need for age-specific groups
As previously mentioned, participants said they wanted age-specific resources. Some also explicitly indicated they preferred group sessions to comprise people of their own age group. Group sessions where other participants were older were viewed as being problematic for younger people with type 2 diabetes:

The one I was in [group program], there were six other people, but they were older than me, they were like my Mum's age, which made it a bit difficult to relate to them. ...When I was in the group, I sat back and listened, I felt intrusive if I voiced my opinion, because they were so different to the older person's.

and
Once I went to a support group but they were all old — in their 60s. I found it sad.

Participants were also asked whether they experienced any problems accessing services.

Problems accessing services
The main issues focus group and interview participants identified were:
- There are not enough health professionals available.
- Long waiting times to get appointments.
- Needing to travel long distances to visit health professionals.
- Having to rely on public transport to travel to appointments.
- The lack of after hours services.

Not enough health professionals available. There was considerable agreement amongst focus group participants that there are not enough health professionals to cater for people’s education needs:

*Availability I think more than anything. There’s not enough of them. Of all of them — the educators, dietitians ... And they're saying the disease is getting worse ...*

*Resources aren’t increasing to match.*

Yeah.

Waiting times to get appointments. Participants in the focus group and interviews complained about waiting times for appointments with GPs, diabetes educators, dietitians and endocrinologists:

*There’s a long wait to see my GP, and 6 weeks wait to see the endocrinologist. When they give you a time you have to take it, it’s hard to get another day. It can be hard with young children.*

Travelling to health professionals. There was some discussion about the need to travel long distances to consult health professionals who are located some distance away from the home of the young person with diabetes due to shortages of some health professional disciplines, and the long waiting lists of others:

*You hope your doctor is really helpful and will find you somebody else in a different suburb, in a different council area, and you travel, if possible.*

Relying on public transport. Two participants who have vision impairments had to rely on public transport to access services, which was at times problematic:

*What's important is easy to get to, for example I can't drive because of vision loss, so I need to get public transport.*

After hours services. Several participants found the hours of health professional services restrictive, largely because of participants’ working hours:
You're constantly taking time off to go and see these people to get educated about your illness.

and

So there are some real practical things to do but that's pointless for me at midday on a Tuesday.

Participants mentioned needing to take time off work to attend appointments with health professionals, or making their appointments first thing in the morning or at the end of their working day in order to limit the time they were absent from work.

Participants suggested one solution to the difficulty accessing services was to provide services at a local level.

Local services and support
A strong theme that emerged in the focus group and the interviews was the importance of having services and support systems available locally. Participants stressed the importance of having information about the available community programs, particularly social support services such as support groups or social activities, supplies and programs such as supermarket tours. They suggested local councils could play a role in developing and advertising such services.

So, local area programs, support groups, that sort of stuff would be really helpful.

and

If we go down this track [social or support groups] I think these meetings need to be not necessarily central but out in the burbs so you can get to it nice and easily.

Participants also suggested that Diabetes Australia Victoria could consider providing a facility whereby people with type 2 diabetes could register their interest in participating in activities on-line and that activities could then be organised in specific localities when sufficient people from that location had registered their interest.

The advantages of having support services available locally included less time needed to travel to attend services or activities, accessibility for people who have difficulty travelling, and a reduced impact on the environment as a result of smaller distances travelled.

An issue raised by a smaller number of participants concerned the communication practices of health professionals.

Health professionals and communication
The interview participants in particular, commented about the level of communication among health professionals and the lack of follow-up care from health professionals. One interview participant complained that their doctor did not follow-up after the
interviewee’s visits to the dietitian or diabetes educator and felt there should be more communication among the various health professionals.

_The main problem for me is the follow-on once you’re diagnosed. You need to be referred to a dietitian, a diabetes health educator, and all of that needs to be followed up. And it isn’t followed up. My doctor has never asked me once if I’ve seen a diabetes educator or anything like that._

Another interview participant who has a care plan, commented positively on the fact that their doctor and diabetes educator share information about managing the patient’s diabetes:

_And they work in the same building so the diabetes educator can get results from my doctor, with my permission of course. They can discuss things together – the doctor and diabetes educator._

A similar idea emerged in the focus group when participants commented on the fact that the focus of each health professional was on their own area of expertise and none considered the whole person.

A clear theme to emerge was a desire to receive support from other young people with type 2 diabetes.

**Receiving support from peers**

There was vigorous discussion about the idea that young people with type 2 diabetes could support each other. Various ways peers could provide support were mentioned including:

- Support groups.
- Social outings.
- A regular ‘gathering’ that would include an element of education.
- Sports or walking groups.
- Email contact.
- A mentoring or buddy system.

Participants also proposed that the Diabetes Australia web site could have a special section for younger people with type 2 diabetes. There was enthusiastic discussion of many of these options. However, the support from peers dominated the discussion. An extended quote from the focus group with comments from several participants illustrates this point:

_Have a conversation with someone else who has got type 2 diabetes and knows exactly what you’re going through._

_And can give you some tips._

_Absolutely._

_You can share things._
And if you’re having a bad day, knowing that there are other people in a group that are having the same bad day, you don’t feel, not like a freak, that’s probably the wrong word, but you don’t feel alone.

You don’t feel alone or an outcast.

Support from psychologists or counsellors was also discussed as being appropriate for young people with type 2 diabetes.

**Psychological support**

Some focus group participants and one interview participant mentioned a need for psychological support or counselling. Such support was seen as particularly important during significant events such as a bereavement in the family and at the initial diagnosis with type 2 diabetes:

*There’s no recognition of any sort of counselling around being diagnosed with a chronic illness. It’s, I find that it’s something you very much need to deal with by yourself.*

For some participants, their experience of having type 2 diabetes was affected by the lack of understanding of diabetes amongst the people they associate with.

**Lack of understanding in the community**

Another theme to emerge was related to people in the community not understanding type 2 diabetes, which had an impact on people with diabetes. The concern particularly related to work colleagues. One interview participant was concerned that people looked at them strangely if they tested their blood glucose levels at a social event. Some participants were reluctant to tell their work colleagues they have type 2 diabetes because they feared their reactions.

*And there’s such a stigma because they say, it’s an old person’s disease and you don’t get the support from your colleagues. That’s why I don’t tell them.*

Another participant highlighted the need for people in the community to have some understanding of type 2 diabetes:

*I’ve told everybody at work because I’m absolutely paranoid that I’m going to have a hypo and no one’s going to know what to do.*

**Section summary**

Thirteen people aged 25 to 45 with type 2 diabetes participated in a focus group discussion or telephone interview. These participants represented a diverse range of characteristics and presented an interesting range of experiences with diabetes and views on appropriate education information.
A number of participants were not satisfied with the education information they received from their GP when first diagnosed with type 2 diabetes. Others described more positive experiences at diagnosis.

Participants wanted information that is easy to understand, and includes various topics not currently covered such as information about interactions between medications taken for different health conditions and the implications of having diabetes when they require surgery.

They wanted information provided to the wider community, and resources that are developed specifically for their age group. They also wanted a focus on preventing diabetes.

The focus group participants stressed the importance of having centralised information and strongly supported an 1800 number as a first point of call.

Focus group and interview participants indicated there is a need to provide a range of delivery mode options including printed material, web-based and DVDs. They were, however, ambivalent about information on the Internet, because they often wasted time searching for information and some participants did not use the Internet.

Focus group and interview participants expressed a desire for age-specific support or education groups and discussed various other ways they could be supported by peers.

Participants described problems they have accessing services and health professionals, for example long delays in getting an appointment and a lack of after hours services. They also suggested they preferred local service and support systems, and identified a need for psychological support, particularly at diagnosis.

Focus group and interview participants noted the lack of understanding of type 2 diabetes in the community and described how it affects them negatively at work when work colleagues do not understand what it means to have type 2 diabetes.
DISCUSSION

The need for education information specifically for the target group

There is clearly a need to address the lack of education and information currently available for young people with type 2 diabetes generally as well as those aged 25-45. Evidence of the need was supported in all sections of the current needs analysis literature review, focus group and interviews and stakeholder feedback. There is a paucity of literature about the needs and preferences of this group. Significantly, the needs and preferences of the target group will be different from the older age group for whom most education information is developed. The survey of health professionals identified a lack of resources specifically for younger people with type 2 diabetes and that a large proportion of health professionals indicate current education information resources are not adequate and sources of information are not appropriate for the target group. In the focus group and interviews, younger people with type 2 diabetes indicated a strong preference for education information to be developed specifically for them. This was evident in the topics they wanted information about, and their desire to have images and examples that represent their age group.

Differences between the perceptions of health professionals and the target group

Significantly, health professionals and younger people with type 2 diabetes’ perceptions of education and information needs differed in key areas. The literature suggested that the views of health professionals and people with diabetes themselves about the topics of interest to people with diabetes are different. This was supported by the findings from the survey and the new qualitative data in the present study. Many of the views the younger people in the focus group and telephone interviews expressed were different from the responses of the health professionals who completed the questionnaire. For example, the health professionals strongly supported a web-based approach as an appropriate delivery mode for education information for the target group, while the younger people were in fact ambivalent about the usefulness of some information available on the Internet. While the younger people want electronic technologies to be utilised to provide information, they had specific concerns about the time it takes to locate specific information on the Internet describing it as like ‘finding a needle in a haystack’, which the health professionals did not acknowledge. In addition, younger people still want written information. The younger people mentioned topics that they require information about that the health professionals who completed the questionnaire did not identify.

The target group should be involved in the development of education information

One of the key findings of the current study is the need for the active involvement of the target group in the development of education information aimed at younger people with type 2 diabetes. This is supported by the differences in the perceptions of education and information needs described above, and the strong desire of younger people to have images and examples that are relevant to their age group. Younger people should be actively involved at all stages of the development of resources and programs to ensure relevance to their age group.
Content of education information

A new finding from the qualitative data in the current study was the emphasis younger people with type 2 diabetes placed on information being centralised Australia-wide rather than having individual Diabetes Australia State branding with subtle differences. They were extremely frustrated by the multitude of resources and websites that contained very similar material which they found to be time wasting, but read in case it contained new information.

Specific new topics younger people in the focus group or interviews mentioned included interactions between medications for different conditions, managing diabetes and other health conditions and how they affect each other, the implications of having diabetes when they require surgery or investigative procedures, IVF and diabetes, and preventative education for their families.

Young people in the current study and the literature review highlighted the need for individuals to have access to different education information at various life stages and different stages of the disease. Diabetes educators showed a greater awareness of the many factors that affect the information needs of people with diabetes compared with GPs, which suggests diabetes educators are more likely to provide information that is appropriate to the life and disease stage of individuals they manage. However, there is no evidence in the current study to support that assumption.

One finding in the literature review was the need to provide information that is culturally appropriate for CALD groups and for Indigenous Australians. In the survey some health professionals, particularly diabetes educators, acknowledged this need.

Format

The learning styles of people aged 25 to 45 were identified in the literature review. Researchers emphasised using stimulating materials, presenting material in a variety of ways, using new technologies to deliver information, presenting key points or scannable material, and making it easily accessible at home as being important. To a large extent, the views expressed by the younger people in the focus group and interviews concurred with these suggestions. In particular, they wanted new technologies to be used, to be able to access information at home, and have it presented succinctly. Their need to have consistent, centralised information has already been discussed.

Participants in the focus group and interviews stressed the importance of using images and examples of people in resources that depict their age group. They were not impressed by pictures of older people or young people with type 1 diabetes.

Delivery mode

The findings from the literature, survey and qualitative data all support the need for education information to be available in a variety of delivery modes for younger people with type 2 diabetes. Health professionals who completed the survey viewed a web-based delivery mode as the most appropriate delivery method for the target
group. However, as previously mentioned, younger people themselves had clear ideas about how web-based information should be presented. In particular, younger people wanted a single Australia-wide Diabetes Australia web site, with directions to local, State web sites for local services, but not State 'branding' of information. They were frustrated to find the separate State organisations with their own web sites that provided similar information but not in a consistent way. They also suggested that a section of the Diabetes Australia web site should be dedicated to younger people with type 2 diabetes.

The strong preference younger people with type 2 diabetes expressed to have centralised, Australia-wide information was reflected in their desire to have a single 1800 number that could be the first contact point for younger people with type 2 diabetes, and could be used to refer callers to appropriate web sites, health professionals, services, and provide printed information on specific topics. Although such a number already exists, the focus group participants did not appear to be aware of the existence of an 1800 number, which suggests current information may not reach people with type 2 diabetes aged 25 to 45, and the number may need to be promoted differently.

Barriers to utilising education information
A number of barriers to younger people with type 2 diabetes utilising education and information were consistent among the literature, the survey, and the focus group and interview data. These barriers included problems waiting to get an appointment with health professionals, and the lack of after hours appointments. Problems with cost and literacy issues were mentioned in the literature but not raised specifically by younger people in the current study, although they did stress the need for clear and easy to understand information.

Services and support
The participants in the focus group and telephone interviews were enthusiastic about receiving support from other young people with type 2 diabetes and suggested various ways such support could be achieved. The desire for peer support was also expressed by young people with diabetes in Australian studies included in the literature review. Some health professionals acknowledged peer support groups as being desirable for the target group.

The younger people in the focus group and interviews indicated a need for psychological support, which was also expressed by other young people with diabetes in the literature. However, the desire younger people expressed to have locally based services and support was largely a new finding in the current data. This may become more important in view of the current financial crisis and petrol costs, given younger people with type 2 diabetes already find the cost of managing diabetes a burden.

It was notable that diabetes educators reported more topics that younger people need to have information about, and more factors that affected their education information needs than GPs. Diabetes educators were also more likely to perceive current resources as inadequate or inappropriate for the target group. The differences between diabetes educators and GPs in their perception of the needs of younger people with
type 2 diabetes may indicate that diabetes educators would provide more appropriate support to younger people with type 2 diabetes compared with GPs. Some GPs may need to be informed about the factors that affect younger people with type 2 diabetes.

**Educate others about type 2 diabetes**

The need to educate the wider community about type 2 diabetes was identified in the literature review, the focus group and interview data, and to a very small extent in the survey conducted with health professionals. Younger people with type 2 diabetes want partners, carers, family members and work colleagues in particular to be more knowledgeable about type 2 diabetes, its management, and how to prevent diabetes. Some younger people with type 2 diabetes reported stigma associated with a younger person having type 2 diabetes, and hoped the stigma would be reduced by increased public awareness about diabetes.

Some focus group and interview participants expressed concern at the lack of information and support they received from GPs when they were diagnosed with type 2 diabetes. Their experiences suggest a need for some GPs to have a greater awareness of how to manage type 2 diabetes in younger people and of appropriate referrals to make, for example to a diabetes educator.

**Quality of information**

There was evidence from the literature review that people with diabetes want information that is clear and from credible sources, which was echoed by the younger people with type 2 diabetes who participated in the focus group or telephone interviews in the current study. Similarly, it emerged from the literature review and from the new qualitative data that people often find the amount of information available ‘overwhelming’.

The problem of people with type 2 diabetes receiving inconsistent information from health professionals was identified in the literature. Likewise, the younger people with type 2 diabetes participating in the focus group or interviews in the current study expressed a strong desire to receive consistent information. The responses of health professionals who completed the questionnaire did not acknowledge inconsistent information as an area of concern for young people.

**Application of the findings**

Key recommendations arising from the needs analysis are described in the following section of the report.
RECOMMENDATIONS

Development of draft recommendations
The researchers developed draft recommendations about the education and information needs of younger people with type 2 diabetes based on the findings from the review of the literature, the survey of health professionals, and the focus group and telephone interviews with people aged 25 to 45 with type 2 diabetes. The draft recommendations are presented in Appendix G.

The draft recommendations were circulated by mail or email to members of the Reference Group and the focus group and telephone interview participants for comment. The focus group and telephone interview participants in particular provided detailed feedback on the recommendations. A brief summary of the feedback received is presented.

Comments on the draft recommendations

Agreement with the recommendations
To a large extent comments received on the draft recommendations confirmed the appropriateness of the recommendations. Importantly, the comments of younger people with type 2 diabetes validated the findings from the qualitative data analysis. Telephone interviewees for example agreed with suggestions made in the focus group, and vice versa, a form of member checking which supports the transferability of the findings to the wider population of younger people with type 2 diabetes.

Some participant’s comments strengthened the conclusions drawn from the qualitative data. Two people explicitly stated there is a need for younger people to be involved in the management of their diabetes:

The content of information provided should be geared towards encouraging ownership of the condition and motivation to stay on a path that will enable them to best self-manage their condition for the rest of their life.

and

Information is as much about choice as it is about education and the [target] group demands choice and education as a critical outcome for their lifestyle management and health strategies.

Another participant who had not mentioned a need for resources to include pictures of younger people responded positively to this suggestion:

I strongly agree that the images should be of younger people to stop people’s old thinking that diabetes is only for the elderly.

Another participant supported the recommendations regarding the format of information:
As a woman who is blind with diabetes, accessibility to information in an alternative format is an important factor. It is good to see that this has been addressed.

Similarly the recommendations about delivery modes were supported:

Full use of all electronic media and to a lesser extent, hard copy print would be a preferred delivery method that will suit the age group 25-45.

One focus group participant expanded on the need for centralised information, and their concerns about the various Diabetes Australia organisations presenting different information:

The state based organisations and their web sites and logos do not present a consistent face, so we think “why are they different – there must be a good reason”. We look at them all and get the same information differently, but it erodes confidence that the “official” organisations can’t seem to get along.

The importance of having clear, easy to understand information at diagnosis was stressed in the feedback, and also the strong desire for consistent information:

First point of contact is critical for the newly diagnosed Type-2 Diabetic. The questions you have outnumber the answers you have by a ratio of about 100:1. This is a confronting time in your life to say the least. Access to frontline information that is manageable and provides a positive message would be a first step in ‘service delivery’. It is about the consistency of the message that is provided by usually your primary healthcare provider, often your GP.

Similarly, the need to provide psychological support to younger people with type 2 diabetes was reiterated in the feedback about the recommendations:

I’d also like to see a higher priority given to the mental health and psychological support of Type 2 Diabetics. This is a forgotten aspect of many of the services established to assist Type 2 diabetics as a group.

Changes to the recommendations suggested

Focus group and interview participants made some additional suggestions for topics of information in their comments about the draft recommendations. These included a need for information on contraception and diabetes, time management, what to tell employers, and diabetes and Polycystic Ovarian Syndrome, period problems and weight gain. One participant noted the need to provide information for people from an Asian or Islander background about the impact of changing to a western diet once they come to Australia. These suggestions were included in the revised recommendations.
Importantly, a Reference Group member noted that the need to educate family members and carers was not included in the recommendations. This was added to the revised recommendations. A Reference Group member suggested that a recommendation that information be updated regularly be added.

One Reference Group member commented that it is unrealistic for resources aimed at the ‘average’ Australian to be culturally appropriate for CALD and Indigenous groups and that separate resources need to be developed for these groups. The recommendation was changed accordingly.

One interview participant with vision impairment noted the need for Internet sites to be suitable for people who use screen reading software, and this was added to the recommendations.

Other small changes to the wording and detail of the recommendations were also made.

Revised Draft Recommendations
The target group referred to throughout the recommendations is people aged 25 to 45 who have type 2 diabetes.

• Younger people with type 2 diabetes should be involved in developing education information strategies and resources for people aged 25 to 45.

Content of information
• Centralised, Australia-wide information should be available in print, on the web and telephone-based. Information about local services should be available as ‘click-on’ links from the central source of information.
• Information should be specific to young people with type 2 diabetes.
• Information should be developed in collaboration with young people with type 2 diabetes not solely by health professionals and should be evaluated.
• Information should be succinct and easy to understand. In addition to the usual topics covered such as diet and weight management, it should include information about:
  - New developments in medication and technology.
  - Travel advice.
  - Issues related to drugs and alcohol (not mentioned by participants in the current needs analysis but a recommendation in the literature review).
  - Preventing diabetes (in the general population and in their family members).
- Questions to ask their doctor.
- Information about medications particularly their actions and side effects.
- Interactions between medications taken for different conditions that might be present in addition to diabetes.
- Managing diabetes and other health conditions and how they affect each other.
- The implications of having diabetes when they require surgery or investigative procedures.
- What to tell the surgeon about their diabetes.
- Pregnancy and planning a pregnancy.
- IVF and diabetes.
- Contraception and diabetes.
- Diabetes and Polycystic Ovarian Syndrome, period problems, and weight gain.
- The impact of diabetes on menopause and vice versa.
- Where to access supplies in an emergency (e.g. broken insulin pen at night).
- Community programs in local areas.
- Time management.
- What to tell employers about diabetes.

• Information should be updated regularly to ensure the content is accurate and current.

• Provide strategies to use when multiple commitments make a self-care routine difficult to establish, advice about time management, how to deal with feeling embarrassed about diabetes, getting scared and wanting to rebel (not mentioned by participants in the current needs analysis but a recommendation in the literature review).

• Information should be appropriate for the needs of people with diabetes as the individual moves through different life stages and different stages of the disease.

• Separate resources need to be developed that contain information that is culturally appropriate for CALD groups and for Indigenous Australians. For example, information about the impact eating a western diet has on people with an Asian or Islander background should be included.
Format

- Information should be appropriate for the learning styles of people aged 25 to 45.
- Images and examples should represent people in this age group.
- Use leading edge accessible technology.
- Utilise resources that stimulate all the sensory organs such as charts, photos, text graphics and cartoons, sound, music and narration as components of interactive learning.
- Present the information in a variety of ways at the same time.
- Adapt instruction or resource materials so it is easily accessible at home.
- Highlight key points and scannable material or short pieces of information that outline key points or concepts.
- Use appropriate language and culture-specific delivery modes for CALD groups and for Indigenous Australians.

Delivery mode

- A variety of delivery modes should be utilised, including print, Internet, DVD, email and audiotapes.
- Internet sites must be suitable for people using screen reading software, for example by providing an option to take out graphics.
- Promote an 1800 number as an Australia-wide first contact point where the people manning the 1800 number refer callers to appropriate web sites, health professionals and services.
- A section of the Diabetes Australia web site should be dedicated to younger people with type 2 diabetes.

Services and support

- Provide age-specific support groups, education groups and social activities for 25 to 45 year old people with type 2 diabetes.
- Organise other group activities such as sporting events or walking groups for young people with type 2 diabetes.
• Provide services and support in the local community.
• Provide services after hours, including after hours education groups.
• Provide psychological counselling, especially at diagnosis.
• Increase communication among health professionals assisting an individual to manage their diabetes.

Educate GPs and the community
• Educate GPs concerning the education information needs of young people with type 2 diabetes at diagnosis.
• Educate GPs concerning the factors that are likely to affect the education information needs of young people with type 2 diabetes.
• Raise awareness about type 2 diabetes, particularly in younger people, amongst the community in general, in workplaces, in schools, and in airlines.
• Partners, family members and carers should be provided with information about type 2 diabetes and its management.

Quality of information
• Information should be reliable, based on research and credible resources.
• Information should be consistent.
Finally

Individual participants from the focus group or telephone interviews made the following comments in response to the recommendations that sum up important aspects of education and information for younger people with type 2 diabetes:

*I feel that if these points were put into action, people managing diabetes would find it easier to manage and feel supported within their local community and society in general.*

*The challenge about format will be content, not just how to deliver the content. Interactive media should be incorporated at every opportunity to provide an opportunity for self learning not just information dissemination. High level use of the internet and web-based applications allow for greater flexibility and a consistency in information management and delivery. It’s easy enough to build ‘bells & whistles’ with the graphic-driven technologies, the focus of the message needs to be consistent and relevant to all Australians and in line with Australian Standards.*
REFERENCES


Appendix A: Web sites searched

The following web sites were searched for relevant literature.

Australian Diabetes Educators Association
http://www.adea.com.au

National Diabetes Services Scheme
http://www.ndss.com.au

Diabetes Australia
http://www.diabetesaustralia.com.au

Diabetes ACT

Diabetes Association of the NT Inc.
http://www.healthyliving.org.au

Diabetes Australia MyD

Diabetes Australia New South Wales
http://www.diabetessw.com.au

Diabetes Australia Queensland
http://www.daq.org.au

Diabetes South Australia
http://www.diabetessa.com.au

Diabetes Australia Tasmania
http://www.datas.org.au

Diabetes Australia Victoria
http://www.dav.org.au

Reality Check – Young Adults with Diabetes: Type 1 Diabetes Network
http://www.realitycheck.org.au

The Diabetes Research Foundation of Western Australia Inc.
http://www.diabetesresearchfoundation.asn.au

Diabetes New Zealand
http://www.diabetes.org.nz

American Diabetes Association
http://www.diabetes.org
Diabetes UK
http://www.diabetes.org.uk

Canadian Diabetes Association
http://www.diabetes.ca

European Association for the Study of Diabetes
http://www.easd.org

International Diabetes Federation
http://www.idf.org/home

National Institute of Diabetes and Digestive and Kidney Diseases
http://www2.niddk.nih.gov
Appendix B: People with diabetes’ needs identified in the literature

Table 2. Concerns/information needs identified by people with diabetes in various studies

<table>
<thead>
<tr>
<th>Author / Country</th>
<th>Purpose</th>
<th>Sample</th>
<th>Methods</th>
<th>Concerns / information needs of people with type 2 diabetes</th>
<th>Strength of evidence</th>
</tr>
</thead>
<tbody>
<tr>
<td>Colagiuri &amp; Goodall (2004) Australia</td>
<td>Consultation with people who have diabetes, or who are directly affected by it, about ‘what is needed’.</td>
<td>31 people with type 1, type 2 or gestational diabetes, and parents of children with diabetes. Aged ≥18 years Number of participants with type 2 not stated. Purposive sampling for focus groups with specific groups.</td>
<td>Focus groups</td>
<td>Lifestyle changes – diet and nutrition, sport and exercise Psychosocial – counselling, peer support, help with coping skills Understanding ‘why me’ and ‘where do I go from here’ Education on the serious of diabetes Navigating the health system Hypo-hyperglycaemia Complications Management of diabetes Pregnancy Sport Keeping up to date</td>
<td>Critical Appraisal Skills Program (CASP) score 6 (out of 10)</td>
</tr>
<tr>
<td>Author / Country</td>
<td>Purpose</td>
<td>Sample</td>
<td>Methods</td>
<td>Concerns / information needs of people with type 2 diabetes</td>
<td>Strength of evidence</td>
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<tr>
<td>Diabetes Australia (2006)</td>
<td>To understand the key issues facing young people with diabetes. To identify areas of need - education and information.</td>
<td>Survey: 414 young adults including, 49 with type 2. On-line survey (number distributed not stated): Mean age type 2 – 29 yrs Sampling population – people aged 16 to 35 with diabetes. Self-selected by completing on-line survey.</td>
<td>On-line survey</td>
<td>Which topics would you like to receive more information about: How to make appropriate food choices (69%) How to exercise appropriately (65%) How to minimise chances of getting complications (53%) Discounts and services available through NDSS (51%) New developments in medication / technology (47%) How to care for feet (41%) Complications of diabetes (41%) Travel advice (39%) Support groups / activities for young people (37%) What to do if pregnant or planning a baby (31%) Impact of diabetes on your baby (if pregnant) (31%) Issues relating to drugs and alcohol (31%) How and when to test your blood glucose (27%) What to do if you have a hypo (24%) How to take your medicines (16%)</td>
<td>Level 3b, Joanna Briggs Institute (JBI) levels of evidence</td>
</tr>
<tr>
<td>Diabetes Australia (2005)</td>
<td></td>
<td>Total of 438 people – many with diabetes, but mostly type 1, some health professionals</td>
<td>Discussions held during youth forums across Australia.</td>
<td>Areas of interest to young people who have diabetes: Practical information to help them manage their diabetes. Information on the impact of drugs and alcohol.</td>
<td>CASP score 6 (out of 10)</td>
</tr>
<tr>
<td>Author / Country</td>
<td>Purpose</td>
<td>Sample</td>
<td>Methods</td>
<td>Concerns / information needs of people with type 2 diabetes</td>
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</tr>
<tr>
<td>Beeney, Bakry &amp; Dunn (1996) Australia</td>
<td>To identify diabetes patient needs for information and emotional support at diagnosis</td>
<td>1159 patients with diabetes (presents data as type 1 and type 2) Type 1 Mean age 40 Type 2 Mean age 64 Sampling population: Diabetes</td>
<td>Questionnaire</td>
<td>Concerns: Type 1: Injections (28%) Lifestyle impact (23%) Diet restrictions (13%) Complications (12%) Not knowing enough (9%) How to cope (5%) No concerns (14%) Type 2: Diet restrictions (21%) Injections (15%) Complications (13%) Lifestyle impact (13%)</td>
<td>Level 3b, JBI</td>
</tr>
</tbody>
</table>

Information Needs of Young Adults with Type 2 Diabetes
<table>
<thead>
<tr>
<th>Author / Country</th>
<th>Purpose</th>
<th>Sample</th>
<th>Methods</th>
<th>Concerns / information needs of people with type 2 diabetes</th>
<th>Strength of evidence</th>
</tr>
</thead>
<tbody>
<tr>
<td>Australia</td>
<td>To compare diabetes educational needs as judged independently by educators and patients</td>
<td>200 patients with type 2 diabetes 5 nurse educators Mean age 55 Sampling population: Patients with type 2 diabetes referred from education and/or ambulatory stabilisation at a Sydney hospital Diabetes Centre. Consecutive patients invited to participate.</td>
<td>Brief questionnaire</td>
<td>What I want to know: Diet (62%) What is diabetes (31%) Long-term complications (31%) Oral hypoglycaemic agents (26%) Sick day management (26%) Blood glucose monitoring (21%) Exercise (18%) Urinalysis (18%) Hypoglycaemia (17%) Eyes (15%) Insulin therapy (11%) Footcare (9%) Alcohol (9%) Smoking (7%)</td>
<td>Level 3b, JBI</td>
</tr>
<tr>
<td>Author / Country</td>
<td>Purpose</td>
<td>Sample</td>
<td>Methods</td>
<td>Concerns / information needs of people with type 2 diabetes</td>
<td>Strength of evidence</td>
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</tr>
<tr>
<td>Woodcock &amp; Kinmouth (2001 UK)</td>
<td>Differences between patient and practice nurse perceptions of the patient’s concerns</td>
<td>250 patients with type 2 diabetes Aged 31-71 years Mean age 58 Sampling population: Patients newly diagnosed with type 2 diabetes in 41 general practices in Southern England, and all practice nurses in same practices. All eligible patients invited to participate.</td>
<td>Questionnaire</td>
<td>Main concern (n = 250): Following dietary advice Fear of getting worse Damage caused by diabetes Concerns most frequently circled from list (n = 209): Damage caused by diabetes (54%) Fear of getting worse (46%) Tiredness / lack of energy (40%) Overweight (37%) Following dietary advice (24%) High blood glucose levels (19%) Mood changes (14%) Illness or pain unrelated to diabetes (11%) Insurance (10%) Causes of diabetes (10%) Tablets / insulin (10%) Taking exercise (10%) Work / retirement (9%) Costs of diet or other treatment (8%) Driving (8%) Illness or pain related to diabetes (7%) Sexual problems (6%) Smoking (6%)</td>
<td>Level 3b, JBI</td>
</tr>
</tbody>
</table>
### Appendix C: Source of information identified in the literature

#### Table 3. Source of information used or preferred by people with diabetes

<table>
<thead>
<tr>
<th>Author / Country</th>
<th>Purpose</th>
<th>Sample*</th>
<th>Methods</th>
<th>Source of information</th>
<th>Strength of evidence</th>
</tr>
</thead>
<tbody>
<tr>
<td>Colagiuri &amp; Goodall (2004) Australia</td>
<td>Consultation with people who have diabetes, or who are directly affected by it, about 'what is needed'.</td>
<td>31 people with type 1, type 2 or gestational diabetes, and parents of children with diabetes. Aged ≥ 18 years</td>
<td>Focus groups</td>
<td>Diabetes specific organisations Other people with diabetes Diabetes specialist doctors Diabetes centres Community Health Centres Library Pharmacists Health promotion stalls in community settings Internet (credible sites preferred)</td>
<td>Critical Appraisal Skills Program (CASP) score 6 (out of 10)</td>
</tr>
<tr>
<td>Diabetes Australia (2006) Australia</td>
<td>To understand the key issues facing young people with diabetes. To identify areas of need - education and information.</td>
<td>Survey: 414 young adults including, 49 with type 2. On-line survey (number distributed not stated): Mean age type 2 - 29 yrs</td>
<td>On-line survey</td>
<td>Sources of information and support rated as very useful: (n = 49) Parents / family (31%) GP / family doctor (27%) Endocrinologist / diabetes specialist (24%) Diabetes Australia (24%) Diabetes educators (22%) Web sites (20%) Magazines / journals / newsletters (14%) Other people I know who have diabetes (14%)</td>
<td>Level 3b, Joanna Briggs Institute (JBI) levels of evidence</td>
</tr>
</tbody>
</table>

* Details on the sampling population and recruitment are provided in Table 2.
### Appendix D: Delivery modes identified in the literature

**Table 4. Delivery mode used or preferred by people with diabetes**

<table>
<thead>
<tr>
<th>Author Country</th>
<th>Purpose</th>
<th>Sample*</th>
<th>Methods</th>
<th>Delivery mode</th>
<th>Strength of evidence</th>
</tr>
</thead>
<tbody>
<tr>
<td>Colagiuri &amp; Goodall (2004) Australia</td>
<td>Consultation with people who have diabetes, or who are directly affected by it, about 'what is needed'.</td>
<td>31 people with type 1, type 2 or gestational diabetes, and parents of children with diabetes. Aged ≥ 18 years</td>
<td>Focus groups</td>
<td>Types of information and education accessed: Group sessions (typically run by diabetes specific organisations) Individual sessions (with diabetes specialist doctors, diabetes educators and other health professionals) Internet Diabetes specific magazines Videos, cassette tapes, books used by a small number of participants</td>
<td>Critical Appraisal Skills Program (CASP) score 6 (out of 10)</td>
</tr>
<tr>
<td>Diabetes Australia (2006) Australia</td>
<td>To understand the key issues facing young people with diabetes. To identify areas of need – education and information.</td>
<td>On-line survey: including, 49 with type 2 (number distributed not stated). Mean age type 2 – 29 yrs</td>
<td>On-line survey</td>
<td>“How would you like to receive information?” (n = 49) Through health professionals (69%) Diabetes Australia (67%) Internet (63%) Magazines / journals / newsletters (63%) From other people who have diabetes (51%) Conferences / forums for young people with diabetes (20%) Through parents (14%)</td>
<td>Level 3b, Joanna Briggs Institute (JBI) levels of evidence</td>
</tr>
</tbody>
</table>

* Details on the sampling population and recruitment are provided in Table 2.
<table>
<thead>
<tr>
<th>Author Country</th>
<th>Purpose</th>
<th>Sample</th>
<th>Methods</th>
<th>Delivery mode</th>
<th>Strength of evidence</th>
</tr>
</thead>
<tbody>
<tr>
<td>Australia</td>
<td>To identify diabetes patient needs for information and emotional support at diagnosis</td>
<td>1159 patients with diabetes Presents data as type 1 (n = 360) and type 2 (n = 785) Type 1 Mean age 40 Type 2 Mean age 64</td>
<td>Questionnaire</td>
<td>Preferred form of information at diagnosis / 1-2 weeks later: Type 1 Diabetes educator (41% / 31%) I - 2 day course (18% / 33%) Written materials (14% / 12%) A-V materials (13% / 11%) Doctor only (13% / 11%) Type 2 Diabetes educator (37% / 35%) I - 2 day course (13% / 20%) Written materials (17% / 14%) A-V materials (8% / 9%) Doctor only (23% / 19%)</td>
<td>Level 3b, JBI</td>
</tr>
<tr>
<td>US</td>
<td>To identify interest in different modes of self-management support.</td>
<td>796 English and Spanish speaking diabetes patients Mean age 58 Sampling population: Patients from 7 public hospitals receiving diabetes care as outpatient or inpatient over a 24 mth period,</td>
<td>Telephone survey</td>
<td>Telephone support (69%) Group medical visits (55%) Internet-based support (42%) None of these (18%)</td>
<td>Level 3b, JBI</td>
</tr>
<tr>
<td>Author Country</td>
<td>Purpose</td>
<td>Sample*</td>
<td>Methods</td>
<td>Delivery mode</td>
<td>Strength of evidence</td>
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<tr>
<td></td>
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<td>with at least 2 outpatient visits and aged over 18. Random sampling – stratified by site and ethnicity.</td>
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</table>

Information Needs of Young Adults with Type 2 Diabetes
Appendix E: Health Professional Questionnaire

HEALTH PROFESSIONAL QUESTIONNAIRE

What information do younger people with type 2 diabetes need to enable them to effectively manage their diabetes? A needs analysis study.

Instructions:
- Please either double-click on the box you wish to select, and select 'checked' or place a cross in the relevant box.
- For open questions either write or type in your response.
- Your responses are confidential.

Section 1: Demographics

1. Are you currently working as a:
   - Diabetes educator/Nurse
   - Diabetes educator/Dietitian
   - Diabetes educator/Podiatrist
   - Endocrinologist
   - General Practitioner
   - Other (please specify) __________________________

2. How many years have you worked in this role?
   - Up to 1 year
   - 2 to 5 years
   - 6 to 10 years
   - More than 10 years

3. Do you work in a:
   - Metropolitan area
   - Rural/regional area
   - Other (please specify) __________________________

Section 2: Current Practice

4. What is the average number of people aged 25 to 45 with type 2 diabetes that you educate/manage in a week?
   - None
   - 1 – 2
   - 3 – 5
   - 6 – 10
   - More than 10
5. What education/information resources do you currently provide to people aged 25 to 45 who have type 2 diabetes that specifically target this age group? (Please list)

__________________________________________________________________________

__________________________________________________________________________

6. Are the education/information resources for this age group adequate?

☐ Yes
☐ No
☐ Other (please specify) ____________________________________________________

7. Please explain why you believe the education/information resources for this age group are adequate or inadequate.

__________________________________________________________________________

__________________________________________________________________________

8 (a). Are the current sources of information appropriate for this age group?

☐ Yes
☐ No
Please give reasons for your answer __________________________________________

__________________________________________________________________________

8 (b). Is the way the information is delivered appropriate for this age group?

☐ Yes
☐ No
Please give reasons for your answer __________________________________________

__________________________________________________________________________

9. What would be the best way to deliver education/information to this age group?

☐ Printed resources
☐ Web based information
☐ DVD
☐ E-learning sessions
☐ Videos
☐ Telephone
☐ Group sessions
☐ Individual sessions
☐ Other (please specify) ____________________________________________________

Information Needs of Young Adults with Type 2 Diabetes
10. Please indicate which information delivery mode you currently provide?

☐ Printed resources
☐ Web based
☐ DVD
☐ Telephone
☐ Group sessions
☐ Individual sessions
☐ Other (please specify) ___________________

Section 3: Education Information Needs

11. What do you think the education/information needs of people aged 25 to 45 who have type 2 diabetes are?

☐ Diet
☐ Shopping for correct food
☐ Exercise
☐ Weight management
☐ Long-term effect of diabetes (eg: eyes, kidneys, feet, heart)
☐ Measuring glucose
☐ Medication – insulin
☐ Medication - other
☐ Sexuality and sexual health
☐ Women’s health issues
☐ Pregnancy
☐ Erectile dysfunction
☐ Coping
☐ Support
☐ Depression
☐ Discrimination
☐ Community services
☐ Work/career issues
☐ Family issues
☐ Already get enough information
☐ None
☐ Other (please specify) ___________________

12. What factors affect the information/education needs of younger people with type 2 diabetes?

☐ Age
☐ Phase in life
☐ Specific disease stage
☐ Socio-economic status
☐ Where they live (rural/metro)
☐ Education
☐ Gender
☐ Literacy
☐ Ethnicity and culture
☐ Religious beliefs
☐ Acceptance
☐ Denial
☐ Health beliefs
13. What other education resources could be provided to this group?

________________________________________________________________________
________________________________________________________________________
________________________________________________________________________

14. What information delivery modes might be effective for this age group?

________________________________________________________________________
________________________________________________________________________
________________________________________________________________________

15. What else would help support and empower young people to manage their diabetes?

________________________________________________________________________
________________________________________________________________________
________________________________________________________________________

Thank you for completing this questionnaire. Please email it as an attachment to: (Details)
OR
mail it as a hardcopy to: (Details)
Appendix F: Focus Group Questions

FOCUS GROUP QUESTIONS

1. How useful have you found the resources and education/information that you have received on diabetes self-management?

2. Where do you get the most useful information from?

3. What are the gaps in your understanding and knowledge of diabetes and its management?

4. What other things would you like to have information about?

5. How would you like to receive information about diabetes? (e.g. In what format would you prefer to receive information about diabetes self-management?)

6. What kind of support would be most helpful for you?

7. How would you prefer to receive support?

8. How do key life events affect your ability to manage diabetes, such as starting a new job, commencing a new sexual relationship, having a family, travelling overseas?

9. What would help you to cope with your diabetes at these times?

10. Do you have any problems accessing the services you need to help you manage your diabetes?

11. What sort of problems do you have?

12. Do you have any problems testing your blood glucose levels?

13. Does testing your blood glucose levels help you manage your diabetes?

14. Do you have any problems taking prescribed medicine as instructed?

Note: The facilitator will use probing questions and clarify responses where appropriate. These questions are a guide only.
Appendix G: Draft Recommendations Circulated for Feedback

Draft Recommendations

Content of information

- Centralised, Australia-wide information should be available.
- Information should be specific for young people with type 2 diabetes.
- Information should be developed in collaboration with young people with type 2 diabetes not solely by health professionals.
- Information should be succinct and easy to understand and should include information about:
  - New developments in medication and technology.
  - Travel advice.
  - Issues related to drugs and alcohol (not mentioned by participants in the current needs analysis but a recommendation in the literature review).
  - Preventing diabetes (in the general population and in their family members).
  - Questions to ask their doctor.
  - Information about medications particularly their actions and side effects.
  - Interactions between medications taken for different conditions that might be present in addition to diabetes.
  - Managing diabetes and other health conditions and how they affect each other.
  - The implications of having diabetes when they require surgery or investigative procedures.
  - What to tell the surgeon about their diabetes.
  - Pregnancy and planning a pregnancy.
  - IVF and diabetes.
  - The impact of diabetes on menopause and vice versa.
  - Where to access supplies in an emergency (e.g. broken insulin pen at night).
  - Community programs in the local area.
• Provide strategies to use when multiple commitments make a self-care routine difficult to establish, advice about time management, how to deal with feeling embarrassed about diabetes, getting scared and wanting to rebel (not mentioned by participants in the current needs analysis but a recommendation in the literature review).

• Information should be appropriate for the needs of people with diabetes as the individual moves through different life stages and different stages of the disease.

• The content of information should be culturally appropriate for CALD groups and for Indigenous Australians.

Format

• Information should be appropriate for the learning styles of people aged 25 to 45.
• Images and examples should represent people in this age group.
• Use leading edge accessible technology.
• Utilise resources that stimulate all the sensory organs such as charts, photos, text graphics and cartoons, sound, music and narration as components of interactive learning.
• Present the information in a variety of ways at the same time.
• Adapt instruction or resource materials so it is easily accessible at home.
• Highlight key points and scannable material or short pieces of information that outline key points or concepts.
• Use appropriate language for CALD groups and for Indigenous Australians.

Delivery mode

• A variety of delivery modes should be utilised, including print, Internet, DVD, email and audiotapes.
• Promote a 1800 number as an Australia-wide first contact point where the people manning the 1800 number refer callers to appropriate web sites, health professionals and services.
• A section of the Diabetes Australia web site should be dedicated to younger people with type 2 diabetes.

Services and support
• Provide age-specific support groups, education groups and social activities for 25 to 45 year old people with type 2 diabetes.
• Organise other group activities such as sporting events or walking groups for young people with type 2 diabetes.
• Provide services and support in the local community.
• Provide services after hours.
• Provide psychological counselling.
• Increase communication among health professionals assisting an individual to manage their diabetes.

Educate GPs and the community
• Educate GPs concerning the education information needs of young people with type 2 diabetes at diagnosis.
• Educate GPs concerning the factors that are likely to affect the education information needs of young people with type 2 diabetes.
• Raise awareness about type 2 diabetes, particularly in younger people, amongst the community in general, and in workplaces.

Quality of information
• Information should be reliable, based on research and credible resources.
• Information should be consistent.