

# Young Adults with Diabetes Needs Analysis



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# 1. Executive Summary

The following report presents the findings of the Young Adults with Diabetes Needs Analysis. This research project was commissioned by Diabetes Australia with funding under the NDSS Strategic Development Grant Program. It involved a series of group discussions and in-depth interviews with young adults aged 16-35 who have type1, type 2 or gestational diabetes, followed by a national online survey. The overall aim 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.

Outlined below are the major themes that emerged from the needs analysis, followed by relevant conclusions and implications for policy, resource development, and activities at a national and grass roots level.

## 1. There is a need for greater psychosocial support

Despite a high level of initial fear around testing their blood sugar and injecting insulin, young adults with diabetes seem to adapt very quickly to the many practical challenges associated with managing diabetes. The vast majority said they were coping reasonably well, and that having diabetes rarely stopped them from undertaking their normal daily activities. Around half of those who were diagnosed during childhood or their early teens had taken on responsibility for management and self-care by the age of 15, and almost all had done so by the time they reached 18. Around half had made an attempt to eat more appropriate foods and exercise more in order to improve their health in the last 12 months. Most are testing their blood sugar frequently, and are getting check-ups and tests.

For most young adults, the biggest challenges associated with living with diabetes were staying upbeat, positive and motivated. Data collected from the national online survey shows that:

- 46% of young adults with diabetes feel lazy sometimes and can't be bothered doing the things they know they should do to care for their diabetes
- 33% find it hard to stay positive
- 31% want to switch off and forget
- 28% feel that nothing they do makes a difference to their health
- 25% have experienced long-term depression.

## CONCLUSIONS & IMPLICATIONS

Whilst periods of denial, avoidance, anger, rebellion and sadness are all normal responses to having a life threatening health condition, if left unchecked for too long, these feelings can lead to depression, long-term neglect and irreversible health problems.

These findings serve as a reminder of how important it is that young adults are given the opportunity and encouragement to explore and understand their emotional response to having diabetes, and to get the help and support they need before they reach crisis point.

Many young adults would benefit from more regular discussions with their health care providers around things they could be doing to improve their overall health, as well as ongoing psychosocial support to help deal with the emotional issues that stem from living with a serious chronic condition.

### 2. Young adults with diabetes are not all the same

Both the quantitative and qualitative components of the research found that the specific challenges young adults face in managing their diabetes differ considerably as a function of their age, developmental stage and life circumstances.

**Mid teens (16-18 years):** Compared to older age groups, 16-18 year olds are more likely to struggle with injecting insulin. They resent being hassled about their health by parents and doctors, and long to find sometime they can talk to who truly understands what it's like to be a teenager with diabetes. Often, however, the biggest challenge at this age is dealing with the attitudes and prejudices of people who don't have diabetes. Many teenagers with diabetes feel embarrassed by their condition, and are deeply concerned about what others think of them. At high school, they face the difficult and sometimes embarrassing task of explaining their situation to new teachers who don't know them, or understand their needs. Several had stories of being berated by teachers in front of other students for eating in class, or being refused permission to leave the classroom to take their insulin.

**Early adulthood: (19-23 years):** Early adulthood appears to be a particularly challenging time for young adults with diabetes. This is a stage when many young adults are making the transition from the relative predictability and stability of the school environment, to university or work. Routines are disrupted, money is tight, and keeping control of their diabetes can seem like an insurmountable challenge. Another key issue for young adults at this stage in their lives is a lack of support for young adults as they make the transition from paediatric diabetes services to an adult system, which is seen to cater for older people who have type 2 diabetes. Challenges during this stage in their lives include staying positive and motivated, sticking to a routine, maintaining control and avoiding temptation.

**Mid twenties-early thirties:** By the mid to late twenties, the biggest challenges include time management, and learning how to 'juggle' diabetes with a hectic work and life schedule. Many careers do not follow a strict routine or allow staff the flexibility to eat when they need to, or take time off to see health professionals. The cost of health care is also a key source of resentment; even with NDSS subsidies,

medical expenses can become a significant burden. By now, many young adults are also starting to worry about their future, including complications and whether having diabetes will impact their chances of having a family.

## CONCLUSIONS & IMPLICATIONS

The needs and preferences of young adults aged 15 to 35 are clearly quite different at different stages and events in their lives. This suggests that a *life-stage model* could be a useful framework for segmenting and understanding the information needs of young adults with diabetes, as well as producing and disseminating printed and electronic information materials.

Life stage	Information and support needs	Barriers to better management	Preferred communication channels
Early teens	<ul style="list-style-type: none"> <li>▪ Taking on the responsibility for self-care</li> <li>▪ Normalisation of their experiences</li> </ul>	<ul style="list-style-type: none"> <li>▪ Understanding of diabetes may be poor, if diagnosed as a child</li> </ul>	<ul style="list-style-type: none"> <li>▪ Parents</li> <li>▪ Healthcare professionals</li> <li>▪ Peers</li> </ul>
Late teens	<ul style="list-style-type: none"> <li>▪ Maintaining control of diabetes</li> <li>▪ Finding a good team of health professionals</li> <li>▪ Drugs and alcohol</li> <li>▪ Leaving school/starting work or university</li> <li>▪ Moving out of home</li> <li>▪ Relationships</li> </ul>	<ul style="list-style-type: none"> <li>▪ Changes and disruptions in routine</li> <li>▪ Staying motivated</li> <li>▪ Feelings of helplessness &amp; depression</li> </ul>	<ul style="list-style-type: none"> <li>▪ The internet</li> <li>▪ Other young adults with diabetes</li> <li>▪ Health professionals who 'understand'</li> </ul>
Mid-late twenties	<ul style="list-style-type: none"> <li>▪ Managing diabetes in the workplace</li> <li>▪ Navigating the health system &amp; NDSS</li> <li>▪ Dealing with complications</li> <li>▪ Starting a family</li> <li>▪ New developments in technology</li> </ul>	<ul style="list-style-type: none"> <li>▪ Cost of health care</li> <li>▪ Time management</li> </ul>	<ul style="list-style-type: none"> <li>▪ The internet</li> <li>▪ Health professionals</li> <li>▪ Journals/newsletters</li> <li>▪ Health professionals who are up to date and knowledgeable</li> </ul>

### **3. Strong support networks are vital**

While most young adults see themselves as responsible for taking care of their own health, they also recognise the value of having a strong support network around them to provide on-going guidance, coaching and encouragement.

The attitude and coping style of parents was felt to have a significant influence on how young adults respond to having diabetes, particularly if they were diagnosed as a child or young teenager. It was felt that parents who respond to the situation positively and confidently ultimately help their children develop and maintain a resilient outlook. By contrast, parents who are fearful and overprotective can diminish their child's confidence and ability to cope. Many young adults felt that it would be helpful if parents were coached in how they can be supportive, without taking over their children's lives.

Finding a good team of health professionals who have an extensive and up to date knowledge of diabetes and an understanding of what young adults go through can make the world of difference to a young adult with diabetes. But whilst most young adults had no major difficulties getting in to see a GP or Diabetes Educator, a high 40% reported that they had problems accessing an endocrinologist. The main barrier was the shortage of endocrinologists in their area (and subsequently long waiting lists). However, a significant proportion also had trouble getting time off work or study to attend appointments, and/or felt they couldn't afford specialist care.

The characteristics young adults seek most in their health care professionals include an extensive knowledge of diabetes and an up to date understanding of the latest developments and technology. However, it is also very important to them that health care practitioners are also willing and able to see their point of view. A common complaint amongst young adults with diabetes was that many health professionals are highly judgemental of people with diabetes, and are often ill-equipped to provide the type of emotional support and guidance that young adults yearn for and need to keep them motivated.

A further cause of frustration and grief for young adults who have diabetes is a lack of understanding around diabetes within the general community. Young adults with type 1 diabetes complained that while there is a lot of media attention on diabetes, it is often negative, and nearly always focuses on type 2 diabetes.

Interestingly, nearly half of those who had gone through the transition from paediatric to adult diabetes services felt that the treatment they received in adult settings was not as good as the care they received as a child or adolescent. A key concern was that adult diabetes services focus too much on the needs of people with type 2 diabetes.

## CONCLUSIONS & IMPLICATIONS

Opportunities exist at both a national and grass roots level to promote awareness and understanding of diabetes amongst the wider community, as well as to better equip young adults who have diabetes to deal with common prejudices and misunderstandings. Useful resources (some of which may already exist) could include:

- A series of 'diabetes fact sheets' targeting schools, counsellors, youth workers, employers and other relevant community stakeholders.
- Training resources for health professionals who care for young adults with diabetes, emphasising the psychosocial factors that impact on diabetes care and the importance of providing young adults with positive encouragement and support.
- Resources and support services for parents, partners and friends of young adults with diabetes that explain the facts, and provide advice on how they can offer support and encouragement.
- Practical advice for young adults on how to deal with challenging situations and stand up for their rights.

### 4. Young adults with diabetes would like to be better informed

Whilst this analysis suggests that there is a wealth of information and advice available for people who have diabetes, many young adults would like to be better informed:

- The vast majority (81%) of young adults had very little understanding of diabetes when they diagnosed
- 52% of young adults with diabetes have found that arming themselves with information about diabetes has helped them to cope better
- 66% of young adults say that they get conflicting advice they get from health professionals
- 53% say that dealing with diabetes is confusing
- 51% of young adults say they know quite a bit about diabetes, but could do with a refresher from time to time.

An issue raised by young adults with type 1 diabetes who were diagnosed as a child was that information and advice provided around the time of their diagnosis was generally targeted at their parents, not at them. By the time they reached adolescence and were ready to take on responsibility for self-care,

healthcare professionals often mistakenly assumed that they had already acquired an in-depth understanding of diabetes.

The most popular source of information is the internet (77%). However, young adults also value getting information from health professionals (70%), through magazines and newsletters (67%), and from diabetes organisations, such as Diabetes Australia (63%). Topics of high interest included: the latest developments in treating diabetes (especially important for those with type 1); discounts and services available through the NDSS; how to make appropriate food choices; travel advice; how to minimise the chances of getting complications; what to do if you're pregnant or planning a baby; and issues around drugs and alcohol.

Whilst diabetes camps and forums for young adults with diabetes did not rate highly overall as a source of support and information, qualitative feedback from those who had taken part in these events was tremendously positive. Not only were camps considered a great source of information for teenagers, the opportunity to meet people who are the same age and in the same situation helped normalise diabetes, and create a sense of acceptance and belonging. Sharing experiences and stories with other young adults with diabetes can be just as important for people in their late teens and twenties. However, opportunities to do this are few and far between. Whilst not everyone is keen on the idea of taking part in meetings and support groups, websites designed specifically for young adults were seen as a valuable and effective way of connecting young adults with diabetes to exchange ideas, information and offer mutual support.

## **CONCLUSIONS & IMPLICATIONS**

These findings highlight the need for a clear focal point for information that is relevant and recognisable to young adults with diabetes. Whether this requires the establishment of a new website, or ongoing development of existing internet resources, the goal should be to provide easy access to credible and up to date information for young adults with diabetes, a national directory of resources and information materials, online forums and discussion groups, a national calendar of events for young adults with diabetes, as well as links to and from other relevant websites.

There is also a need for ongoing services and activities to support young adults with diabetes and provide them with opportunities to meet other young adults in a similar situation as themselves. There is ongoing interest in annual camps and forums that bring young adults with diabetes together, regional seminars and discussion groups on topics of interest to young adults, shopping trips (designed to assist young adults with making appropriate food choices), as well as social activities.

There is also demand for a comprehensive 'guide' (or set of guides) to living with diabetes. This could cover:

- Open and honest discussion around the key issues commonly faced at various stages or events in a young adult's life (eg newly diagnosed, moving out of home, getting a job etc, entering a new relationship, planning a family, travelling etc).

- Tips on what young adults could be doing to improve their overall health (diet, exercise, checkups).
- Practical advice on how to deal with issues such as drugs and alcohol, depression, and hypoglycaemia.
- Latest developments in treating diabetes (and where to go for more information).
- A user's guide to the NDSS, and advice on how to make the most of benefits and services available.
- Autobiographical stories written by other young people with diabetes.
- An up to date directory of events, support groups, and useful resources and services for young adults with diabetes.

## **5. Women who are diagnosed with gestational diabetes missing out on 'the full picture'**

The findings of this study suggest that women with gestational diabetes are not strongly engaged with the NDSS or with diabetes organisations or support groups. If diagnosed late in pregnancy, they only have a few weeks to deal with having diabetes. Key sources of information included their obstetrician or midwives at their local maternity clinic. Once they give birth, the focus turns to their newborn child, and they quickly forget about having diabetes (and the fact that their risk of developing type 2 diabetes is now high).

Whilst being diagnosed with GDM can come as a great shock, reactions depend considerably on the attitudes of their health practitioners. Some felt that their health care practitioner had attempted to 'frighten them into submission'. Others said that they had gone to great lengths to provide reassurance and guidance to help them through. Either way, compliance was rarely an issue, as most women were keen to do whatever was necessary to ensure a healthy birth outcome. However, after the birth, women who were given little choice about how to manage the diabetes often felt resentful about the way they were treated, and in particular, the negative and condescending attitudes of some health practitioners towards pregnant women with diabetes.

## **CONCLUSIONS & IMPLICATIONS**

A key issue in the provision of support and information to women with gestational diabetes is ensuring that they receive appropriate follow-up after giving birth to reduce their likelihood of developing type 2 diabetes.

## **6. Access to specialist diabetes care limited in regional and remote areas**

A key issue for young adults with diabetes who are living in regional or remote parts of Australia is getting access to health professionals with expertise in diabetes. Just over half did not see an endocrinologist as often as they would like, and nearly a third experienced difficulties getting to see a counsellor or psychologist.

There were also some concerns from women with gestational diabetes who lived in regional parts of Australia that they were not permitted to give birth at their local hospital because they were considered high risk. Living away from home during the final stage of their pregnancy was extremely challenging, as this involved an extended separation from their partner and support networks.

While people in rural and remote areas are less likely to say that they want to get information from other young adults with diabetes, this is possibly because they don't know many other young adults with diabetes in their area. Forums that brought young adults with diabetes from remote parts of Australia together were often valued highly.

## **CONCLUSIONS & IMPLICATIONS**

Investigation of alternative service delivery modes for rural and remote areas is clearly warranted. Possibilities may include the development of telemedicine and online medical services for young adults who are unable to access appropriate services in their area, as well as up-skilling local health care practitioners in diagnoses, diabetes care, and appropriate referral.

## 2. Background

Diabetes is currently the sixth major cause of death in Australia and claims more than 2,700 lives every year. Type 1 diabetes strikes young people suddenly, making them insulin dependent for the rest of their lives, and at risk of developing devastating complications. Whilst most cases of diabetes in children and adolescents are type 1, there has been an increase in the number of type 2 or non-insulin dependent diabetes being diagnosed at an early age, particularly amongst Aboriginal and Torres Strait Islanders, Pacific Islanders, people of Chinese descent, and those from the Indian sub-continent.<sup>1</sup> The occurrence of type 2 diabetes in adolescents and young adults has been linked to a lack of exercise, poor diet, and obesity. Because it is typically associated with older people, diagnosis may be delayed and complications may arise before treatment is provided.

Currently, there are approximately 63,000 people aged 15-35 years who are registered as having diabetes with the National Diabetes Services Scheme (NDSS). Of these, 43% have gestational diabetes, 36% have type 1 diabetes, and 20% have type 2 diabetes.

Managing diabetes in adolescents is challenging for a number of reasons:

- erratic eating patterns and variable exercise
- greater exposure and susceptibility to viral illness
- hormonal changes associated with growth spurts
- rapid destruction of beta cells, leading to a total loss of capacity to secrete insulin.

Moreover, the psychosocial pressures on young people and their families can affect how well diabetes is managed. It is not uncommon for adolescents to go through a period of rebellion, when they ignore or reject the advice they are given by health professionals and their parents. As they move into adolescence and/or young adulthood, the urge to live for the moment may become more powerful than the threat of the long-term complications. They may refuse to take on the responsibility for managing their diabetes, start eating whatever they fancy (or whatever is offered by peers), experiment with drugs and alcohol, and even fabricate test results to get concerned parents and doctors 'off their case'.

Diabetes may also have a huge impact of young people's emotional well-being and self-confidence. Many young people with diabetes feel isolated from their peers, and experience discrimination at school or in the workplace. This in turn compromises their ability to cope.

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<sup>1</sup> Diabetes in Australia: A Snapshot (Australian Bureau of Statistics)  
[Young Adults with Diabetes Needs Analysis](#)

A major barrier to improving diabetes care for young indigenous people is the limited availability of culturally appropriate health care, particularly in remote locations. This is compounded by socio-economic problems, poor access to quality food, and housing and workforce issues.

Whilst there are resources and forums for parents of young children with type 1 diabetes and for older people with type 1 or type 2 diabetes, programs and materials that focus on the specific concerns of young adults are rare.

In 1999, the Juvenile Diabetes Foundation of Australia (JDRF) conducted a needs assessment of children and adolescents with Diabetes. This needs assessment identified a number of clinical and psycho-social issues that affect diabetes management of children and adolescents with type 1 diabetes, and made the following recommendations:

1. Develop national best practice evidence based guidelines on the clinical care and management of type 1 diabetes for children, adolescents and adults by a specialist multi-disciplinary team.
2. Provide access for children/adolescents with diabetes, no matter where they live, to high quality, multi-disciplinary care.
3. Provide a national 24 hour free call hotline to help families manage diabetes.
4. Increase awareness of general practitioners of the seriousness of type 1 diabetes, its psychosocial impact, and differences with type 2 diabetes.
5. Increase awareness in the general community of the seriousness of type 1 diabetes and its psychosocial impact.
6. Implement a national approach to address the problems faced by children/adolescents with diabetes in school or child care settings.
7. Develop a national directory of information/educational resources and services for those with type 1 diabetes and their families/carers.
8. Provide increased funding and support for camps and other models of care for children/adolescents with diabetes, and self-help or support groups for parents.
9. Provide automatic entitlement to the Commonwealth's Health Care Card for all children, adolescents and dependent students with type 1 diabetes, amend the Child Disability Assessment Tool to take account of the impact of chronic disease and include diabetes on the schedule of recognized disabilities.
10. Increase funding for research into all aspects of diabetes.

In response to these recommendations, the Young People With Diabetes Program (YPWDP) was launched to develop a range of services and resources to meet the needs of young people with diabetes aged 16–35.

The core aim of the research being commissioned by Diabetes Australia and the YPWDP is to build on the findings and recommendations of the JDRF survey, with a comprehensive Needs Assessment of Young People with Diabetes to identify and document current and emerging issues for the YPWDP target group, aged 16–35.

### 3. Objectives

The overall aim of this study is to undertake a comprehensive needs assessment survey of young adults with diabetes to identify and document their specific concerns and emerging issues. It will update and build on the findings and recommendations of the JDRF Needs Assessment conducted in 1999 with children and adolescents who have type 1 diabetes.

The more specific objectives of the project were:

- **Provide an in-depth understanding of the key issues facing young people with diabetes at various stages of their physical and psychosocial development. For example:**
  - What challenges do young people face when first diagnosed with diabetes?
  - What are the most difficult problems and obstacles in the ongoing management of diabetes?
  - At what age did they begin to take over responsibility for their own diabetes (if at all)?
  - Have there been times when they found it particularly difficult, or even stopped doing the things they knew they needed to do to look after themselves? What did they feel were the triggers for this? How long did the feelings last?
  - How are young people with diabetes affected by key life events, such as starting a new school, leaving home, entering the workforce, commencing a sexual relationship, having a family, travelling overseas etc?
  - What would help them cope with transition at each of these times?
  - How well do they feel they are currently managing their diabetes? What has helped them to manage? Why do they think they haven't been managing as well as they could be?
  - How often has diabetes kept them from going about their normal daily activities, such as attending school, working, having a social life, etc?
  - How often are they testing their blood glucose levels? Is this helpful in managing their diabetes? Why/why not?
  - Are they taking medicine (including insulin) as prescribed? If not, why?

- What are the similarities and differences in the experiences of young people with type 1 and type 2 diabetes?
- How long did it take between first experiencing symptoms and being diagnosed with type 2 diabetes? Did they experience any difficulties in being diagnosed?
- How does it feel to be diagnosed with type 2 diabetes at a young age?
- Did young people diagnosed with type 2 diabetes perceive they were at risk of getting diabetes? What actions if any did they take to try and prevent or delay the onset? What prevented them from taking action to improve their health and reduce the risk of diabetes?
- How can the health care system help them to take full responsibility for their diabetes management?

■ **Identify areas of need in relation to health services and support for young people with diabetes. For example:**

- Who, if anyone, has helped these young people care for their diabetes? Who has helped them the most, and in what ways?
- What health care services have young people used in relation to their diabetes?
- Which services have been most helpful?
- How would they rate ease of access to each of these services?
- Are they seeing their relevant health care providers as often as they would like? If not, why? Would it have helped them if they could see this person more often?
- When was the last time they had relevant health care checks in relation to their diabetes (i.e. Healthy Living Check, eye check-up, a test for sign of feet problems, etc)?
- What services would young people like to see improved?

■ **Identify areas of need in relation to young people's education and information requirements. For example:**

- How much do young people feel they know about diabetes?
- What are the key gaps in understanding and knowledge of diabetes and its management?
- Have they been given sufficient information about:

- How to care for their feet?
  - Diet and exercise?
  - How to deal with hypoglycaemia?
  - How and when to test blood sugar levels?
  - How to take medicines?
  - How to prevent complications?
  - Travel advice?
  - How to cope with diabetes at school/university/in the work place?
  - Diabetes and relationships, pregnancy, etc?
- What areas of diabetes education would young people like to see improved?
  - Where do young people seek information about diabetes and diabetes management?
  - What is the current awareness and usage of diabetes information resources?
  - What do they believe are the strengths and weaknesses of current resources, including websites aimed specifically at young people, youth forums (such as the interactive Summit of Young Adults with Diabetes, camps, etc)?
  - What kind of information and support is most helpful for young people?
  - What are the most useful sources of information?
  - How helpful have doctors and health professionals been in terms of:
    - Helping them to understand how to manage diabetes?
    - Helping them to come to terms with their diagnosis?
    - Keeping them motivated?
    - Helping them to deal with complications?
    - Providing emotional support and encouragement?
    - Helping them to take medication correctly?
- **Explore reactions of the target audience and key stakeholders to possible future developments. For example:**
    - A national directory of information and education resources:
      - How useful would this be for young people?
      - What format would be of greatest use to young people?
      - How (where) should this directory be made available?
      - How could it be promoted?
      - How often would it need to be updated?

- What other information or features should be included in the directory?
- An awareness program aimed at building awareness of type 1 and type 2 Diabetes and the psychosocial impact of diabetes on families and carers.
- Support for young people with diabetes who are experiencing problems in the workplace:
  - What are the problems experienced in the workplace by young people who have diabetes?
  - What would assist young people overcome these problems?
  - Is there a need for workplace awareness and tolerance programs? What is the best way to deliver such programs?
  - What strategies have been successful in helping young people cope with problems in the workplace? How can these be communicated to other young people?
- Camps and other events for young people with diabetes:
  - What is the role and value of camps for young people with diabetes?
  - How can these be replicated in age-appropriate ways for the YPWDP target age group?
  - What other events would appeal to young people?
- **What else would help to support and empower young people in managing their diabetes?**

Ultimately, the study will provide an in-depth understanding of the key challenges faced by young people with type 1 and type 2 diabetes at various stages of their physical and psychosocial development, along with detailed recommendations on how to best meet their needs.

## 4. Methodology

The project consisted of two key stages of research:

### Phase 1: Qualitative Research

This initial component of the research consisted of a series of group discussions and one-on-one interviews to explore, first hand, the needs of young people with diabetes at various stages of their physical and psychosocial development, brainstorm solutions that may empower young people and help them to better manage their diabetes, and obtain feedback on existing and proposed services and initiatives aimed at young people with diabetes.

Ten group discussions and six one-on-one depth interviews were conducted with young adults aged 16-35. Three of the group discussions were with young women who have or have recently had gestational diabetes (some of whom have subsequently been diagnosed with type 2 diabetes). However, we were unsuccessful in recruiting young males with type 2 diabetes to any of the group sessions.

*Table 1: Sample Frame: Qualitative Research*

	<b>VIC</b>	<b>NSW</b>	<b>SA</b>	<b>NT</b>
<b>Type 1</b>	3 groups 2 interviews	2 groups	1 group	1 group
<b>Type 2</b>	2 interview	1 interview	1 interview	
<b>Gestational Diabetes</b>		1 group	2 groups	

## **Phase 2: National online survey**

Insights gleaned from the preliminary qualitative research were used to develop a comprehensive survey tool suitable for online completion by young adults with type 1, type 2 or gestational diabetes. Key areas covered by the questionnaire include:

- history and diagnosis
- current health
- management of diabetes
- interactions with health care providers
- hypoglycaemia
- information needs and preferred channels of communication
- demographics.

The survey could be accessed through the Diabetes Australia website between 13<sup>th</sup> July and August 31<sup>st</sup> 2006, and all young adults aged 16-35 who have diabetes were eligible to take part. A printed version of the questionnaire was also made available to young adults who do not have internet access, or had trouble completing the questionnaire online. (A copy of this has been appended).

State and Territory Member Organisations of Diabetes Australia were notified of the research activities and encouraged to promote the survey widely. Other activities that were undertaken to increase awareness and access to the survey included arranging notice in Reality Check's e-mail newsletter, and a series of mail-outs organised by Ipsos and members of the YAWD committee.

By 31<sup>st</sup> August 2006, a total of 414 young adults aged 16-35 completed the survey. Of these:

- The vast majority (86%) were diagnosed with type 1 diabetes, whilst 12% percent had type 2 diabetes and 1% currently had (or had a prior diagnosis of) gestational diabetes.
- The majority were female (78%).
- The average age was 26.9 years.
- 10% were diagnosed with diabetes before they were 10 years old; 38% were diagnosed as adolescents (between 11 and 20 years old), and 27% were diagnosed in their twenties or early thirties.

- 14% were born outside Australia (24% of young adults with type 2 diabetes).
- 3% were of ATSI heritage (significantly higher, 14%, amongst young adults with type 2 diabetes).
- 71% were living in a metropolitan city whilst 26% were from regional or remote parts of Australia.
- Around two thirds had private health insurance (almost double the national average for this age group).
- Almost all (86%) were registered with the NDSS (lower amongst young adults with type 2 or gestational diabetes).
- Around two thirds were members of Diabetes Australia.

The characteristics of the sample are presented in Table 2 below.

*Table 2: Characteristics of Sample (On-Line Survey)*

	<b>Total</b>	<b>Type 1</b>	<b>Type 2</b>	<b>Gestational Diabetes</b>
<i>Base</i>	<i>(414)</i>	<i>(358)</i>	<i>(49)</i>	<i>(7*)</i>
<b>GENDER:</b>				
Male	22%	22%	33%	0
Female	78%	78%	67%	100%
<b>CURRENT AGE:</b>				
16-18 years	9%	11%	2%	0
19-23 years	22%	22%	22%	0
24-29 years	31%	34%	20%	0
30-35 years	37%	34%	55%	100%
Average age (yrs)	26.9	26.5	28.8	32.4
<b>AGE DIAGNOSED WITH DIABETES:</b>				
<10 years	30%	34%↑	0%↓	0
11-15 years	20%	23%	2%	0
16-20 years	18%	18%	16%	0
20-25 years	16%	15%	26%↑	14%
25+ years	17%	12%	54%↑	85%

Table 2: Characteristics of Sample (On-Line Survey) ...cont'd

	Total	Type 1	Type 2	Gestational Diabetes
<i>Base</i>	<i>(414)</i>	<i>(358)</i>	<i>(49)</i>	<i>(7*)</i>
<b>NATIONALITY:</b>				
Born Australia	86%	88%	76%	86%
Born overseas	14%	12%	24%	14%
<b>OF ABORIGINAL AND TORRES STRAIT ISLANDER HERITAGE:</b>				
	3%	1%↓	14%↑	14%
<b>LOCATION:</b>				
Metro	71%	72%	63%	43%
Regional	15%	14%	22%	14%
Remote	11%	11%	10%	43%
Outside Australia	3%	3%	4%	0
<b>STATE/TERRITORY:</b>				
Victoria	30%	32%↑	17%↓	29%
NSW	30%	30%	28%	71%
QLD	12%	12%	19%	0
Other	26%	26%	36%	0
<b>HAS PRIVATE HEALTH INSURANCE</b>				
Yes	67%	69%↑	59%↓	14%
No	31%	29%	39%	86%
Don't Know	2%	2%	2%	0
<b>MEMBERSHIP OF DIABETES ORGANISATIONS</b>				
Registered with NDSS	86%	89%↑	65%↓	57%
Diabetes Australia	64%	68%↑	43%↓	0
Other diabetes organisation	23%	27%	4%	0

↑↓ indicates that the differences between these two figures are statistically significant

# Detailed Findings

## 5. Living with diabetes - an overview of the findings

In so many respects, young adults with diabetes are no different from any other young adults growing up in Australia. Like other people of their age, they want to go out, have fun, stay up late, and sleep in. They want independence, and to make their own choices. They want to travel and see the world. Like other young adults, they don't always see eye to eye with their parents. They get stressed out by exams and deadlines. They fret about how they look. They fall in and out of love. They're not sure yet if they want to settle down and have children.

They are also adamant that having diabetes doesn't change their core needs, wants and desires. It makes some aspects of life more difficult, but it doesn't define who they are.

### **Whilst the majority of young adults feel that they're managing ok, they admit that it's hard to stay motivated**

Interestingly, most adapt quickly to the practical challenges associated with managing their diabetes, such as testing their blood glucose and taking insulin, if required. However, many struggle in the long-term emotionally. A key challenge faced by young adults with diabetes is staying motivated to take care of their diabetes, especially on days when it seems like no matter what they do, no matter how careful they have been, their blood sugar levels are raging out of control. Days like this are de-motivating, and leave young adults feeling deflated and quite often depressed.

- 46% of young adults with diabetes feel lazy some of the time and can't be bothered anymore
- 33% find it hard to stay positive
- 31% of young adults with diabetes often just want to switch off and forget they have diabetes
- 28% of young adults sometimes feel that nothing they do makes a difference
- 25% of young adults with diabetes experience long-term depression

***"Some days, it doesn't matter what you do, because it doesn't make any difference."***

***"The thing that annoys me most the most after 24 years is that even when I do the right things, things can go wrong. I'm not really in control, ever."***

***"There are times when you get over it, and can't be bothered. It makes you feel low when things aren't working. You just want to push it aside, but you can't. It's always there."***

Living with diabetes can be exhausting. There's no holiday. No opportunity for a break. No chance of putting things on hold, especially for young adults with type 1 diabetes. This constant pressure takes its toll, and almost all experience feelings of depression and anxiety at times.

***“Sometimes, I just haven’t got the mental energy to deal with life, let alone diabetes as well.”***

A number of young adults in this study said that they had been through a phase of denial, or angry rebellion, where they tried to forget that they had diabetes. Some went on a food binge. Some stopped eating altogether. Many have been through a stage where they drank and smoked heavily, experimented with drugs, ignored their parents and failed to show up to medical appointments. While this is an understandable and normal response to their situation, the consequences were often devastating.

***“I went through a bad time in my teenage years. I had lots of arguments with my parents. I started working as an apprentice, and started drinking spirits every Friday afternoon. Sometimes I didn’t think about my diabetes at all. I didn’t care. Then one day when I was 21, I felt a huge pain in my back. It turns out my BGL was 32 and I had a huge abscess on my kidney. It took something like that to turn my life around.”***

## **“We’re only human”**

Once they start taking over responsibility for managing their diabetes, it doesn’t take long for young adults to discover that, chances are, there will be days when they can’t or won’t follow their doctor’s instructions. It also doesn’t take long to work out that sometimes it doesn’t matter what they do, their blood glucose will rage out of control. Total compliance and perfect control is considered, by and large, unachievable.

- *49% of young adults with diabetes believe that it is important that health professionals that don’t expect them to be perfect all the time*

***“Non-compliance is just living your life.”***

***“There are days when you stuff up, let’s face it.”***

Health professionals, on the other hand, have a reputation for seeing things differently, and for treating those who are struggling with disdain and disapproval. Instead of encouraging young adults to grow from the experience, judgemental attitudes from health professionals serve as a barrier to open communication and development of a positive therapeutic relationship. It is no wonder that many young adults with diabetes seek information and advice from other people who have diabetes.

***“They expect you to be perfect, and it’s just not going to happen.”***

***“I just lie, to get them off my back.”***

***“If they tell you off, chances are you’ll continue to do whatever you’re supposed to be doing wrong, but just not tell them next time.”***

***“Doctors treat me like a retard when I say I can’t control it. They say you must be doing something wrong. I completely lost faith in the medical profession years ago.”***

## **Information is plentiful, but getting hold of the right information is hard**

This analysis suggests that there is no real shortage of information and advice available for people who have diabetes. The internet alone is a ready source of material on the medical causes of diabetes, various treatments, advice on diet and exercise, and even chat sites for people with diabetes where they can come together and talk. Yet, several of the young adults who took part in the research felt hopelessly ill-informed.

- 66% of young adults say that the advice they get from health professionals is conflicting
- 53% say that dealing with diabetes is all too confusing
- 51% of young adults say they know quite a bit about diabetes, but could do with a refresher from time to time
- 52% of young adults with diabetes have found that arming themselves with information about diabetes has helped them to cope better.

One of the issues for young adults with type 1 diabetes who were diagnosed when they were very young was that information and advice was targeted almost exclusively at their parents. They complained that no-one ever took the time to really explain to them what diabetes is all about.

***“They talk to your parents, and don’t tell you anything. They think you know it all, but you don’t.”***

***“The time comes when need to take care of yourself, but you don’t know anything because no-one really told you.”***

***“There’s a need for constant, on-going education.”***

Many also complained of getting different (sometimes conflicting) advice on how to best manage diabetes from the many different doctors, specialists and educators who have been involved in their care.

***“There’s no standard care.”***

***“It’s confusing.”***

## The public ‘just doesn’t get it’

A further cause of frustration and grief for young adults who have diabetes is the lack of understanding and insight within the general public.

This was a particularly significant gripe for young adults with type 1 diabetes, who complained that while there is a lot of (generally negative) media attention on diabetes these days, it has focussed almost entirely on type 2 diabetes. It was felt that the public, including many health professionals, has a poor grasp of the differences between type 1 and type 2 diabetes. They perceive diabetes as a condition that strikes people who are older, overweight, and haven’t been taking care of themselves (and only have themselves or their parents to blame for getting sick).

- 74% of young adults with diabetes are embarrassed about having diabetes
- 25% of young adults with diabetes find that the attitudes and prejudices of people who don’t have diabetes is one of the three biggest challenges they face

***“I get so annoyed when people ask if I ate too much sugar when I was a child. It drives me nuts.”***

***“They think it’s your fault. That you’ve brought it on yourself.”***

***“They don’t understand that there’s a difference between type 1 and type 2 diabetes.”***

***“I get sick of the questions and misconceptions.”***

People can be, and often are, judgemental of young adults who have diabetes. This is frustrating and hurtful, and damaging to their self esteem. On occasion, public misperceptions can also be downright dangerous. Some high school students, for example, reported having teachers who refused to allow them to eat during class or confiscated their supply of jelly beans. Others complained about been thrown out of pubs and nightclubs by security staff for drunk and disorderly behaviour, when they were actually having a serious hypoglycaemic attack.

***“I would love a little information card you could just hand out to people so you didn’t have to explain yourself over and over to everyone you meet.”***

***“A role for Diabetes Australia could be to distinguish between type 1 and type 2. Even GPs hardly know the difference.”***

People with diabetes who require insulin injections also face public condemnation, due to a lack of understanding about diabetes within the general community. Some young adults feel embarrassed and ashamed about injecting, and feel obliged to do so in private.

***“I once got told I was disgusting and should be ashamed of myself, by this woman in the toilet who assumed I was a junkie.”***

## Finding the right support team is key to survival

As we discuss in detail in Chapter 13 of this report, a good support team includes health professionals who are well informed, understanding, and are willing to take a holistic view of the issues faced by young adults who have diabetes. Indeed, finding the right health professional can make a world of difference to a young adult's outlook and approach to managing diabetes.

- *43% of young adults believe that having support and encouragement from health professionals has helped them to cope*

***“If they listen, instead of nag, they just might be able to help you back on the right track. But making you feel bad doesn’t help. They just make you feel like you don’t even deserve to be helped.”***

***“They really should encourage young people to see a psychologist, even if they think they’re fine. Especially, if they think they’re fine. You’ve got to deal with it early, don’t leave it until it’s too late.”***

However, the support team also includes other young adults who have diabetes, with whom they can exchange stories and experiences, and provide emotional support and guidance. Camps and forums for young adults with diabetes are considered tremendously important, particularly for those living in rural and remote parts of Australia.

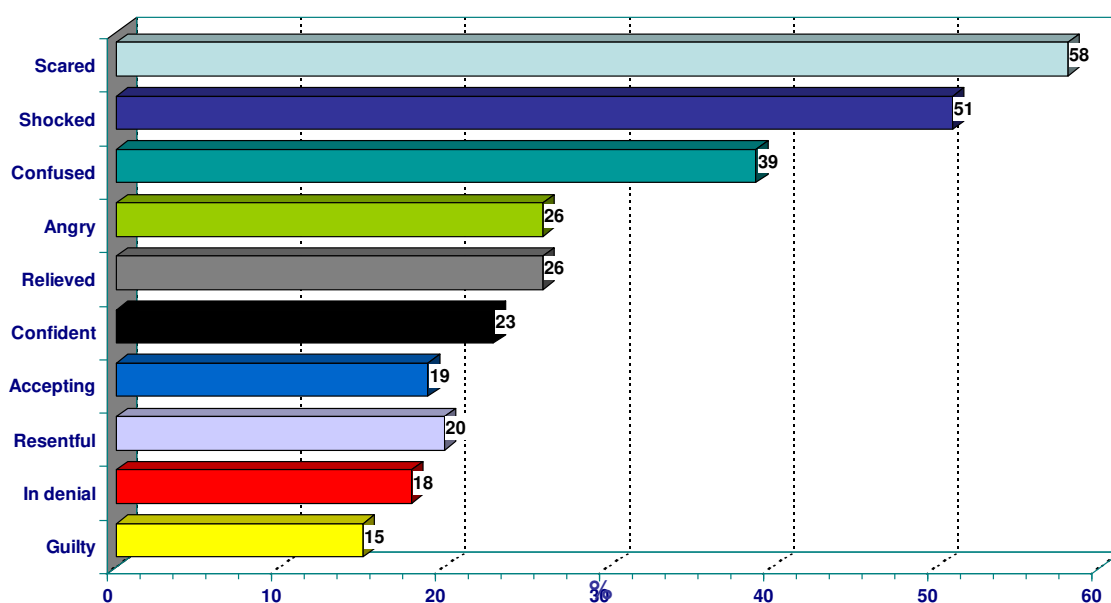
## 6. On being diagnosed

### 6.1 Reactions

Fear, shock and confusion were by far the most common reactions to being diagnosed with diabetes. However, the experience can be quite different depending on when they were diagnosed and the type of diabetes they have, the age they were diagnosed, and the level of support provided by the people around them at the time.

Figure 1:

QA9: Please select which, if any, of the following words describe how you felt at the time you were diagnosed with diabetes



Base: n=376 diagnosed at age five +

## **It's a different experience, depending on the type of diabetes people have**

For young adults with type 1 diabetes, the day they were diagnosed with diabetes was a day they will probably never forget. Confusion and fear were the dominant emotions. However, often they were so unwell that it took a while for it to sink in that their life would never be quite the same again.

***"I have a vivid memory. It was a Sunday. I didn't know anything about it, and then suddenly I'm in hospital and had to have two needles a day."***

***"Too sick to think much about it."***

***"I can pinpoint the exact moment. I was at the movies, it was the day before my 13<sup>th</sup>. I drank two of those huge cups of Coke, and was still parched. Something was clearly wrong."***

***"I had all of these emotions at different times but mostly I was scared and not knowing if I was doing things right."***

***"It was so sudden. I never really got upset about it. It didn't really ever sink in. I just learnt to do it. I felt so sick and the needles made me feel better, so it was good really."***

***Young adults with type 2 diabetes***, who tended to be in their twenties or early thirties when they were diagnosed, recalled the experience as being long and drawn out, rather than something that happened all of a sudden. For some, there were no discernible symptoms, and the diagnosis was almost by chance, as part of a routine health check, rather than in response to a specific set of symptoms.

***"My first memory was when I was about 14 years old, I had an upset stomach – some days I didn't feel right. I think I might have had it then but not known."***

Compared with young adults with type 1 diabetes, those who were diagnosed with type 2 diabetes were more likely to say they felt relief upon being diagnosed, and being able to move forward with their lives. They were also more likely to be left feeling confident that they could handle the treatment.

***"I had lunch in a food court and a guy pulled out an insulin pump. I asked him 'are you diabetic?' He said he was type 1. I consider myself lucky not having to use the insulin injection and pumps."***

***“It was conditional ‘confidence’ that I could handle it: only after clarifying with the Doc that I could still play sport, travel and drink alcohol. Then I knew I could cope with whatever the hell I had.”***

**Women with gestational diabetes** recalled feeling more concerned for their baby, than for their own health. However, their reaction depended a great deal on how they were presented with the news by their obstetrician or GP. Some said that their health care practitioner had tried to ‘scare them into submission’, with threats that their baby would die if they didn’t comply.

***“They told me I was going to have a dead baby. Imagine telling a first time mum those things just to scare you into submission.”***

Others said that health professionals had gone to great efforts to provide them with reassurance, advising them not to worry, and just to take one day at a time.

***“I had a great obstetrician. He said that it’s not my fault, don’t panic, that we could start by looking at diet and exercise and take it from there.”***

## **Age when diagnosed appears to be a factor that influences how well people cope**

For young adults with type 1 diabetes, the age at which they were diagnosed with diabetes was felt to have a big impact on how they coped with the diagnosis as well as how they are managing now. In the qualitative research, young adults who were diagnosed with type 1 diabetes as a child often said that they felt that they were lucky being diagnosed when they were young (despite the fact that they have had to deal with diabetes for longer and are now far more susceptible to serious complications). The way they saw it, they were lucky because they can hardly remember what it was like to not have diabetes. Their parents were far more concerned than they were about it.

***“My parents were far more traumatised than I was.”***

***“I suppose it was easier being diagnosed when I was really young. I can’t even remember when I didn’t have diabetes.”***

***“I was lucky getting diagnosed when I was six. I’m not missing anything.”***

***“I feel so sorry for people get it at 24 and have to change everything.”***

This is supported by the online survey, in which people who were diagnosed between the age of 11 and 14 were significantly less likely to report feeling scared than people who were diagnosed later in life, and more likely to report acceptance (see Table 3 below).

Interestingly, some also considered themselves lucky that they were diagnosed at a young age due to the high level of support available for children with type 1 diabetes and their families. Conversely, being diagnosed with diabetes as a teenager was considered a major disruption to a young person's life. Typically, this is a time when young people are already facing an enormous amount of change and upheaval in their lives, and they already have so many issues to deal with. Moreover, there is limited support and information available specifically for teenagers and young adults who are newly diagnosed.

***“Because I was diagnosed later, I didn’t get a chance for camps. I spent the first six years on my own.”***

***“It was like someone pulled the rug out from underneath me. Everything suddenly changed.”***

***“Just as I was starting to get some freedom, diabetes came along and took it all away from me. Mum starts telling me you can’t do this, and put me on this strict regime.”***

***“Getting diagnosed at 14 is huge ... I told mum I’d rather die than have diabetes and have needles.”***

Young adults diagnosed between the ages of 19 and 25 were significantly more likely than people diagnosed as children and teens to report feeling shocked, but also relieved and confident that they could handle it.

Table 3: Reactions to being diagnosed as a function of type of diabetes and age diagnosed

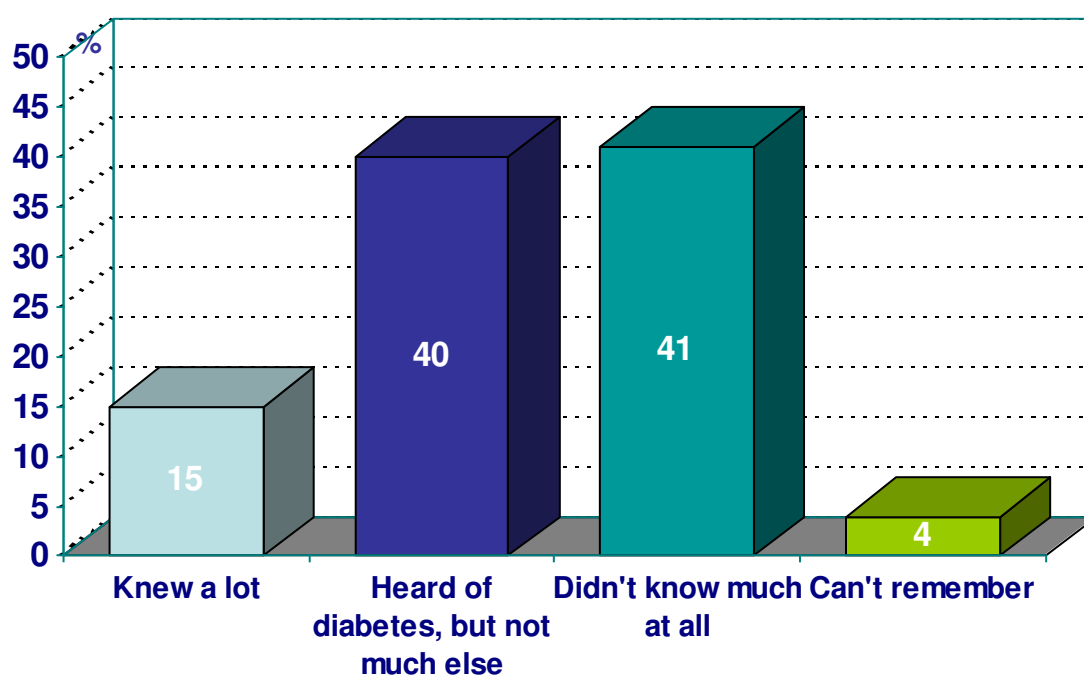
QA9: Please select which, if any, of the following words/phrases describe how you felt at the time you were diagnosed with diabetes?									
	Total	Type of diabetes			Age Diagnosed				
		Type 1	Type 2	GDM	<10 yrs	11-14 yrs	15-18 yrs	19-25 yrs	26+ yrs
Base	(376**)	(320)	(49)	(7*)	(86)	(71)	(63)	(84)	(72)
Scared	58%	59%	55%	57%	51%	48%↓	63%	65%	64%
Shocked	51%	49%	53%	86%	19%↓	54%	56%	69%↑	60%
Confused	39%	39%	35%	71%	42%	44%	48%	33%	32%
Angry	26%	25%	35%	14%	14%↓	25%	43%	26%	28%
Relieved	26%	25%↓	37%↑	14%	7%↓	18%	35%	39%↑	35%
Confident	23%	22%↓	33%↑	29%	8%↓	18%	27%	36%↑	28%
Resentful	20%	20%	22%	29%	7%↓	23%	27%	25%	24%
Accepting	19%	19%	18%	14%	8%↓	30%↑	19%	26%	14%
In denial	18%	17%	20%	14%	9%↓	15%	24%	19%	22%
Guilty	15%	13%↓	31%↑	14%	6%↓	11%	21%	19%	19%

↑↓ indicates that the differences between these two figures are statistically significant  
 \* Caution: small sample size. Care is required when interpreting these results  
 \*\* Excludes those diagnosed before the age of 5.

## 6.2 Knowledge of diabetes when initially diagnosed

Excluding those who were diagnosed as a young child (and cannot expect to remember or understand much about the diagnosis), only 15% said they *knew a lot about diabetes* when they were diagnosed. Forty percent said that they had *heard of it, but not much else*, whilst 41% said that they *didn't know much at all*.

Figure 2:  
QA6: Thinking back to when you were initially diagnosed with diabetes,  
how much do you feel you knew about diabetes then?



Base: n=376 (diagnosed at age five +)

As shown in Table 4 below, knowledge was significantly higher for those who were diagnosed in their late twenties and early thirties (usually with type 2 diabetes) than it was for those who diagnosed in their childhood or teens (one in four people who were diagnosed after the age of 26 said they knew a lot about diabetes when they were diagnosed, compared with only 5% of people diagnosed as children). However, the vast majority still did not have much insight into diabetes when they were diagnosed, even as adults.

Table 4: Knowledge of diabetes as a function of type of diabetes and age diagnosed

QA6: Thinking back to when you were initially diagnosed with diabetes, how much do you feel you knew about diabetes then?									
	Total	Type of Diabetes			Age Diagnosed				
		Type 1	Type 2	GDM	<10 yrs	11-14 yrs	15-18 yrs	19-25 yrs	26+ yrs
Base	(376*)	(320)	(49)	(7)	(86)	(71)	(63)	(84)	(72)
I knew quite a lot about diabetes	15%	12%↓	33%↑	14%	5%↓	14%	13%	17%	26%↑
I'd heard of it but not much else	40%	39%	47%	57%	10%↓	25%↓	57%↑	58%↑	54%↑
I didn't know much at all	41%	45%↑	18%↓	29%	69%↑	61%↑	29%↓	25%↓	18%↓
Can't remember	4%	5%	2%	0	16%↑	0	2%	0	1%

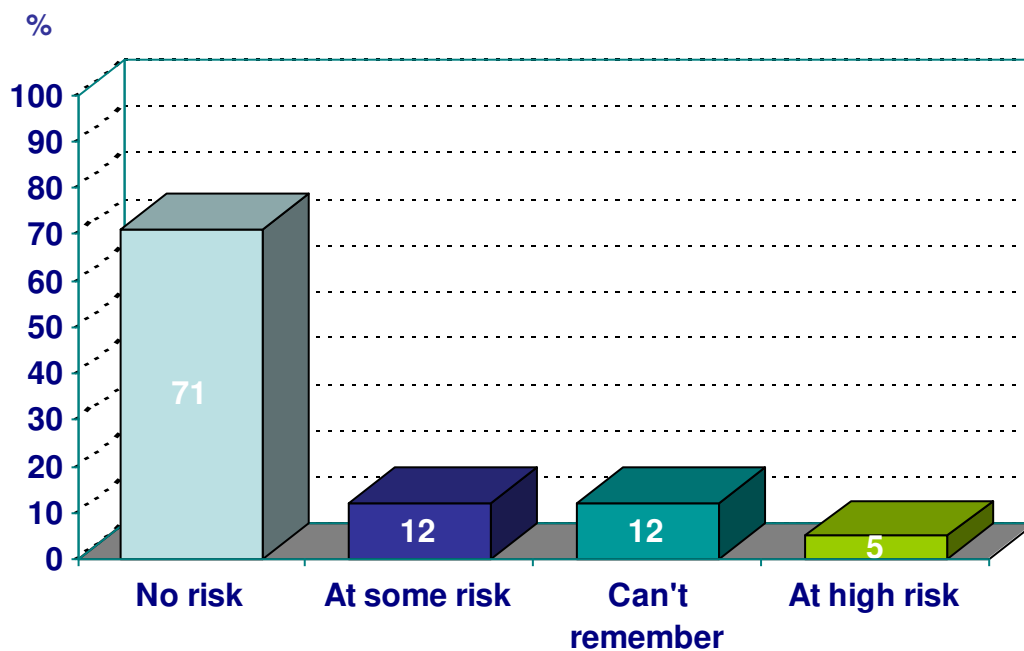
↑↓ indicates that the differences shown are statistically significant  
 \*Excludes those diagnosed before the age of 5.

## 6.3 Perceptions of risk

The vast majority (71%) of young adults with diabetes did not perceive themselves as being at risk of diabetes at around the time they were diagnosed. It is no wonder then, that their diagnosis came as a shock.

Figure 3:

QA7: Did you think that you were at risk of getting diabetes before you were first diagnosed?



Base: n= 376 (diagnosed at age five +)

Whilst young adults with type 2 diabetes were significantly more likely than those with type 1 diabetes to see themselves as being at least at some risk of diabetes (64%), the proportion of people diagnosed with type 2 diabetes who had no idea that they were at risk of diabetes was quite high. (see Table 5 below). Whilst not surprising, this is still a disconcerting finding. If young adults don't see themselves at risk, it is unlikely that they will seek assistance.

Table 5: Perceived risk as a function of type of diabetes and age diagnosed

QA7: Did you think you think that were at risk of getting diabetes before you were first diagnosed?									
	Total	Type of Diabetes			Age Diagnosed				
		Type 1	Type 2	GDM	<10 yrs	11-14 yrs	15-18 yrs	19-25 yrs	26+ yrs
Base	(376*)	(320)	(49)	(7)	(86)	(71)	(63)	(84)	(72)
High risk	15%	2%↓	27%↑	14%	1%	1%	2%	7%	15%↑
Some risk	40%	8%↓	37%↑	29%	2%↓	6%	11%	13%	29%↑
No risk	41%	76%↑	37%↓	57%	56%↓	85%↑	84%↑	77%	56%↓
Can't remember	4%	14%↑	0↓	0	41%↑	8%	3%↓	2%↓	0%↓

↑↓ indicates that the differences shown are statistically significant

\*Excludes those diagnosed before the age of 5.

## 6.4 Triggers for getting tested

The triggers for getting tested were different for young adults with type 1, type 2 and gestational diabetes.

For young adults with type 1 diabetes, (who were diagnosed after the age of five and can remember back that far), the key triggers were:

- frequent urination (89%)
- being incredibly thirsty all the time (88%)
- feeling tired (75%)
- weight loss (73%) and/or
- feeling generally unwell (62%).

For young adults with type 2 diabetes, the main triggers were:

- feeling tired (61%)
- feeling unwell (53%)
- thirst (47%)
- having a family history of diabetes (45%)
- frequent urination (43%)
- weight gain (29%), and/or
- ulcers or sores that wouldn't heal (27%).

Young women with gestational diabetes were mainly diagnosed as a result of a routine test during pregnancy (86%). Some were prompted by symptoms such as frequent urination (29%), an unquenchable thirst (29%), and/or a family history of diabetes (29%).

Table 6: Triggers for getting tested as a function of type of diabetes

QA8: As far as you can remember, what were the things that lead you (or your parents) to get tested for diabetes? [PLEASE SELECT ALL THE THINGS THAT WERE RELEVANT TO YOU]				
	Total	Type 1	Type 2	GDM
Base	(376**)	(320)	(49)	(7*)
Had to pee all the time	82%	89%↑	43%↓	29%
Was incredibly thirsty all the time	82%	88%↑	47%↓	29%
Tired	72%	75%↑	61%↓	14%
I'd lost a lot of weight	65%	73%↑	22%↓	0
Felt unwell	59%	62%	53%	0
Felt dizzy/faint	24%	23%	29%	0
Was having problems with my eyesight	22%	23%	18%	0
Parents/family made me get tested	19%	21%	14%	0
I have a family history of diabetes	18%	14%↓	45%↑	29%
Was having strange cramps	18%	19%	14%	0
Doctor suggested getting tested	14%	12%↓	27%↑	14%
Ulcers or sores that wouldn't heal	9%	8%	12%	14%
Got tested as part of general check-up	6%	4%↓	20%↑	0
I 'd gained a lot of weight	5%	2%↓	29%↑	0
Fell into a coma	5%	5%	2%	0
Got tested during pregnancy	2%	1%↓	2%	86%
Was having problems with my kidneys	2%	2%	2%	14%
Something else	23%	22%	35%↑	14%
Don't know/can't remember/ was too young	1%	1%	0	0
↑↓ indicates that the differences shown are statistically significant				
* Caution: sample size is small. Care is required when interpreting these results				
**Excludes those diagnosed with diabetes before aged five				

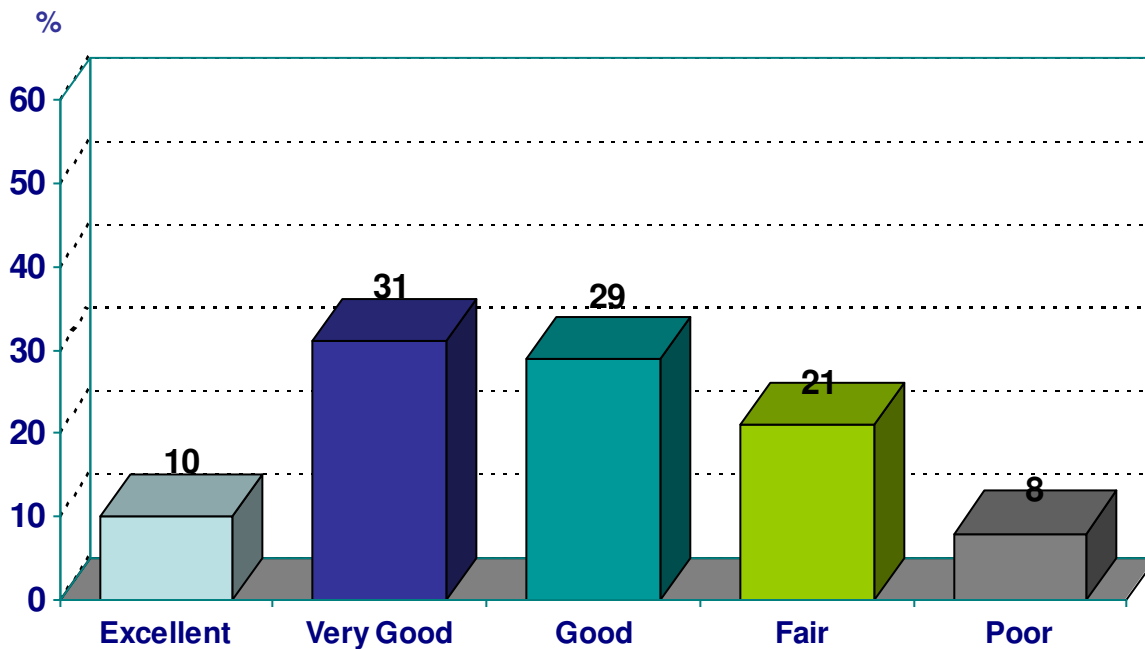
## 7. The current state of affairs

### 7.1 Health

The majority of young adults with diabetes rated their health as either good (29%), very good (31%) or excellent (10%).

Figure 4:

B1: Generally speaking, how would you rate your health now?



Base: n=414

As shown in Table 7 below, young adults with type 1 diabetes were more likely to rate their health as excellent or very good than young adults with type 2 diabetes. Males were also more optimistic than females.

Table 7: Health rating as a function of type of diabetes and gender

B1: Generally speaking, how would you rate your health <b>now</b> ?						
	Total	Type of Diabetes			Gender	
		Type 1	Type 2	GDM	Male	Female
Base	(414)	(358)	(49)	(7*)	(93)	(321)
Excellent	10%	11%	4%	14%	16%↑	8%↓
Very good	31%	33%↑	16%↓	29%	27%	32%
Good	29%	30%	29%	29%	30%	29%
Fair	21%	20%	29%	14%	20%	21%
Poor	8%	6%↓	22%↑	14%	6%	9%
Don't know/can't say	0	0	0	0	0	0

↑↓ indicates that the differences shown are statistically significant

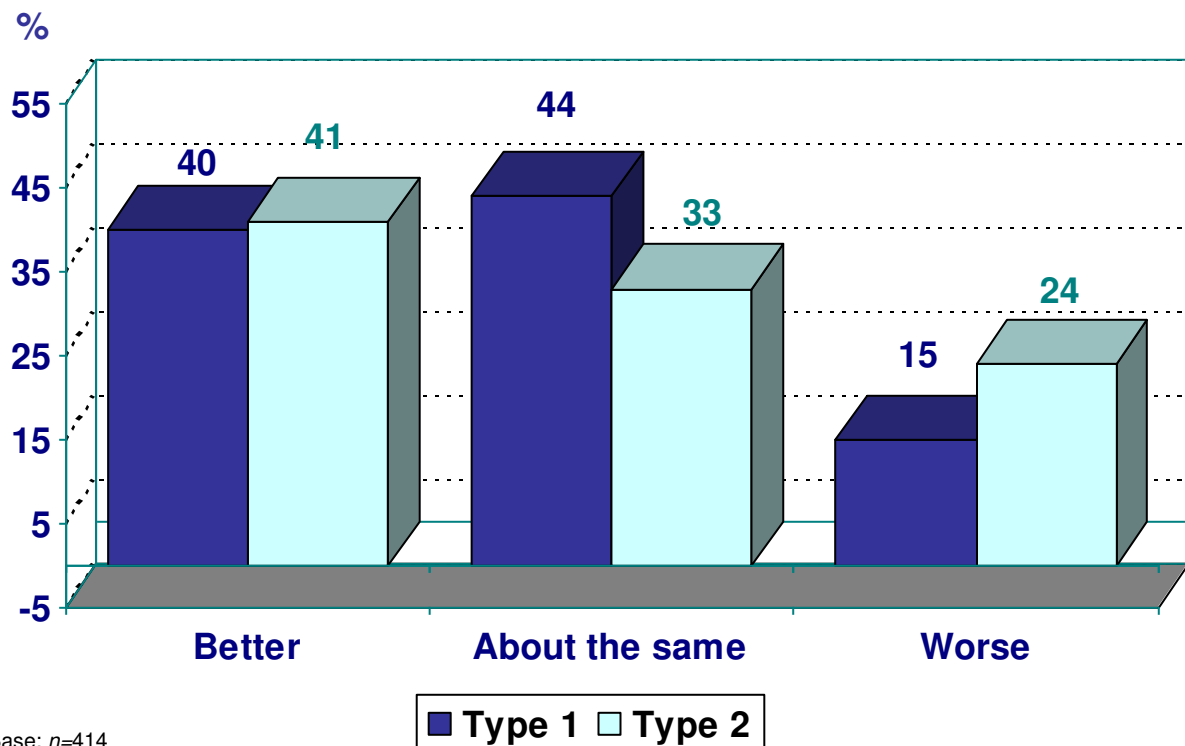
\*Caution: small sample. Care is needed when interpreting results

## 7.2 Health now compared to a year ago

Encouragingly, close to half of the online survey respondents reported that their health was better now than it was one year ago. However, there were differences between young adults with type 1 and type 2 diabetes. One in four young adults with type 2 diabetes felt that their health was getting worse.

Figure 4:

QB2: And how would you rate your health now compared to a year ago?



*B3: Apart from diabetes, do you have any other LONG TERM health conditions? (By a long-term condition we mean a condition that has lasted, or is expected to last for at least 6 months. It may be controlled through treatment or may not affect you all the time). PLEASE SELECT ALL THAT APPLY TO YOU [PLEASE TICK ALL THE THINGS THAT WERE RELEVANT TO YOU]*

	Total	Type of Diabetes			Gender	
		Type 1	Type 2	GDM	Male	Female
<i>Base</i>	(414)	(358)	(49)	(7*)	(93)	(321)
Depression	25%	25%	24%	14%	14%↓	28%↑
Asthma	15%	14%	20%	29%	14%	15%
Anxiety	12%	11%	18%	0	12%	12%
Obesity	9%	5%↓	37%↑	29%	9%	9%
High blood pressure, hypertension, poor circulation	8%	6%↓	24%↑	14%	9%	8%
Polycystic ovarian syndrome	7%	6%↓	18%↑	0	0	9%↑
Eye problems such as cataracts, glaucoma, retina problems, blindness	6%	7%	2%	0	3%	7%
Cancer	0%	1%	0	0	1%	0
Effect of stroke	0	0	0	0	1%	1%
Any other long-term condition not already mentioned	15%	17%↑	4%↓	0	11%	16%
No long-term condition other than diabetes	43%	45%	35%	29%	55%↑	40%↓

↑↓ indicates that the differences shown are statistically significant

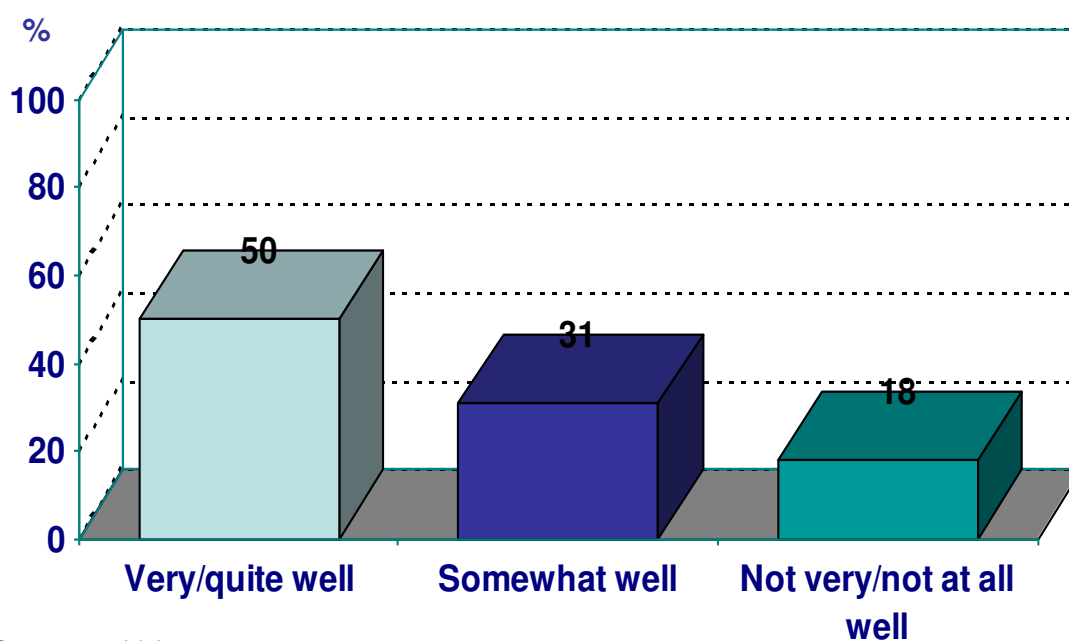
\*Caution: small sample. Care is needed when interpreting results.

## 7.4 How well are young adults with diabetes coping?

The majority of online survey respondents felt that they are coping at least somewhat well with having diabetes. However, only one in ten felt they are coping very well, whilst a proportion (18%) of young adults with diabetes is clearly struggling.

Figure 6:

QC1: Overall, how well do you feel you are managing your diabetes?



Base:  $n = 414$

As shown in Table 9 below, young adults aged 19-23 were more likely than other age groups to be struggling. Qualitative research found that early adulthood can be a particularly difficult time for young adults with diabetes as they take on major life transitions such as starting work, leaving home, and entering into relationships. Old routines are disrupted. Services designed to support for children and adolescents with diabetes are no longer available, whilst adult services are geared towards older people with type 2 diabetes. (See Chapter 14 for a more detailed discussion of the challenges around transition.)

Table 9: Managing diabetes as a function of type of diabetes and age

QC1: Overall, how well do you feel you are managing your diabetes?								
	Total	Type of Diabetes			Current Age			
		Type 1	Type 2	GDM	16-18	19-23	24-29	30-35
Base	(414)	(358)	(49)	(7*)	(39)	(90)	(130)	(155)
Very well	11%	12%	4%	0	18%	2%	12%	13%
Quite well	39%	40%	33%	57%	41%	34%	38%	43%
Somewhat well	31%	32%	29%	14%	28%	40%	32%	26%
Not very well	14%	13%↓	22%	29%	8%	16%	15%	14%
Not at all well	4%	3%	10%↑	0	3%	7%	3%	4%
Don't know	0	0	2%	0	3%	1%	0	0

↑↓ indicates that the differences shown are statistically significant

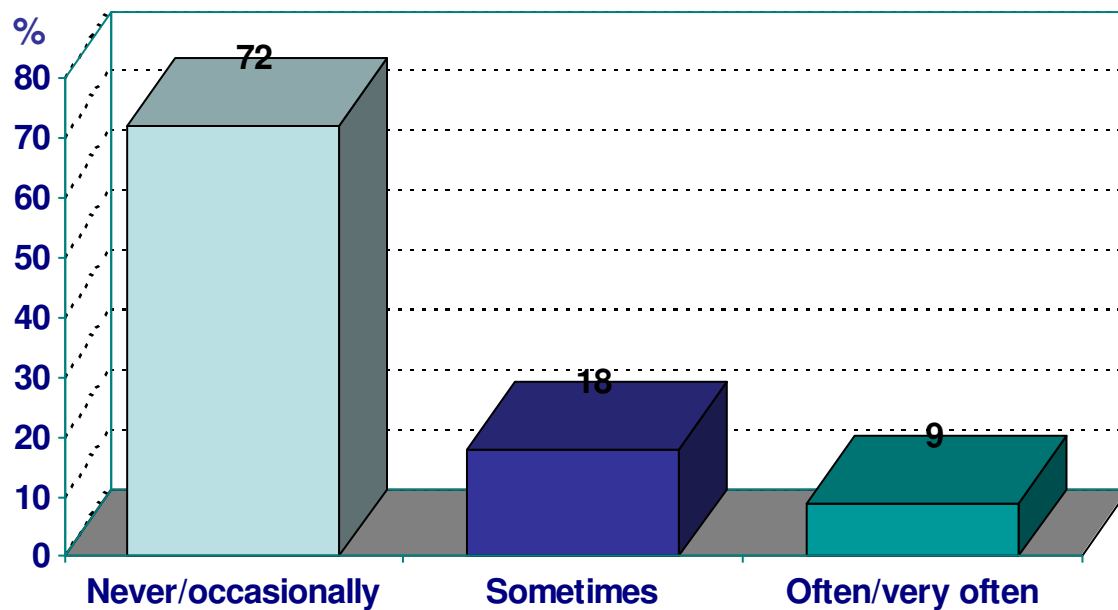
\* Caution: sample size is small. Care is required when interpreting these results.

## 7.5 Extent to which diabetes has kept young adults from normal daily activities

The good news is that only 9% of respondents in the online survey felt that having diabetes has often kept them from doing their normal daily activities in the past year.

Figure 7:

QC2: How often has your diabetes kept you from doing your normal daily activities in the past year?



Base:  $n=414$

As shown in the table below, there was little difference in these results as a function of age or type of diabetes.

Table 10: Impact on daily activities as a function of type of diabetes and age

QC2: How often has your diabetes kept you from doing your normal daily activities during the past year (e.g. couldn't go to work or school, couldn't go out, couldn't get things done around the house etc)?								
	Total	Type of Diabetes			Current Age			
		Type 1	Type 2	GDM	16-18	19-23	24-29	30-35
Base	(414)	(358)	(49)	(7*)	(39)	(90)	(130)	(155)
Never	31%	30%	37%	43%	23%	23%	29%	39%
Occasionally	41%	43%↑	27%↓	43%	51%	39%	41%	39%
Sometimes	18%	18%	20%	0	15%	28%	19%	13%
Often	6%	6%	4%	14%	5%	7%	8%	5%
Very often	3%	3%	10%	0	5%	3%	3%	3%
Don't know	0	0	2%	0	0	0	0	1%

↑↓ indicates that the differences shown are statistically significant

\* Caution: sample size is small. Care is required when interpreting these results.

## 8. Challenges faced in caring for diabetes

Young adults with diabetes face many challenges in caring for their diabetes. Right at the top of their list of issues overall is *getting good control* (51%). This is followed by *getting enough exercise* (36%); *watching what they eat* (34%); *staying motivated* (33%); and the *cost of diabetes* (33%).

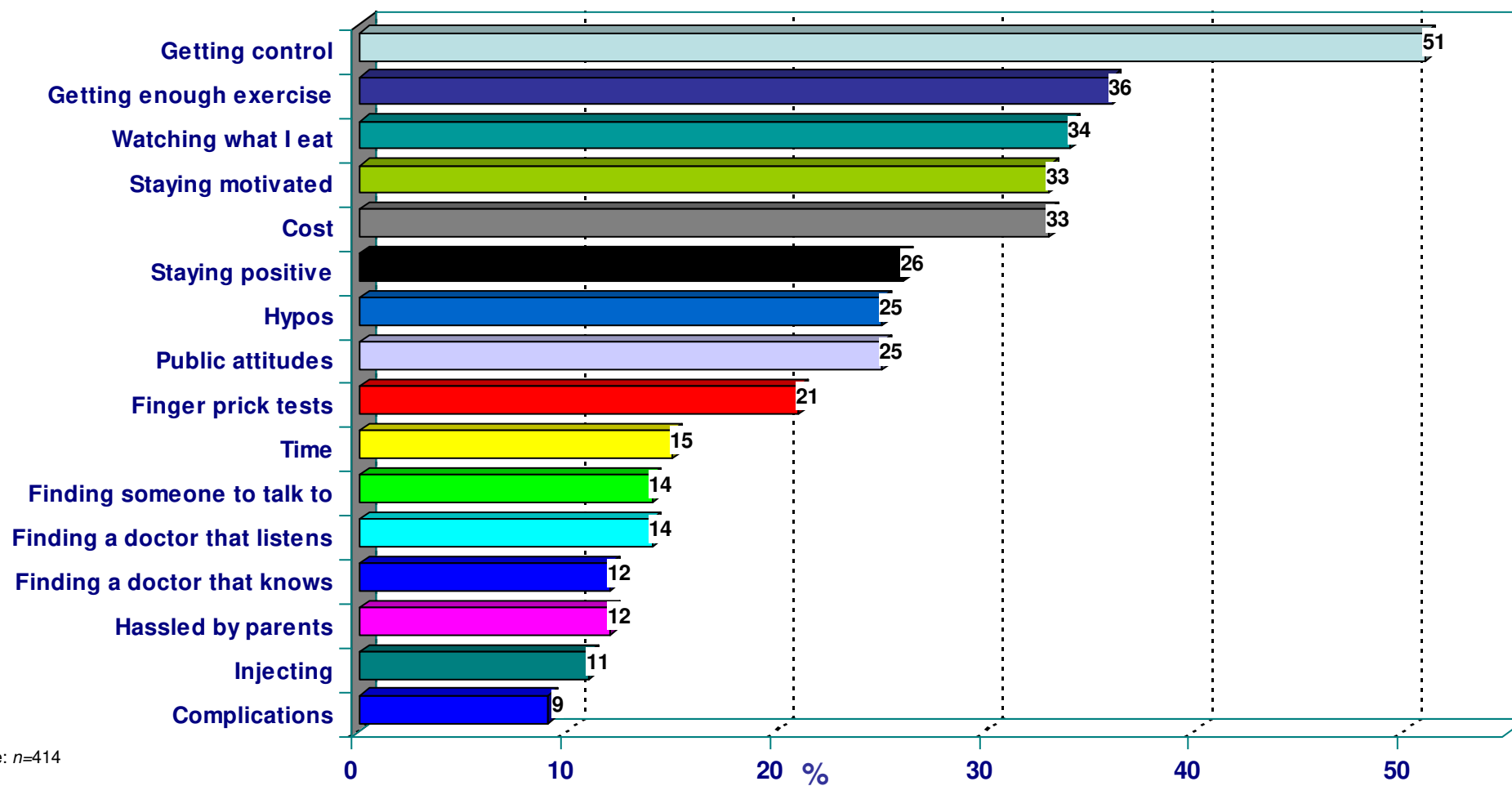
Interestingly, dealing with the day to day 'practical' issues associated with diabetes (such as finger prick tests and injecting) are not significant challenges once people have adapted. However, one in four (26%) struggle to stay positive. A similar proportion also finds dealing with public attitudes towards diabetes to be one of their 'top three challenges'.

Table 11 in the following pages lists these challenges as a function of the type of diabetes people have, and their age. Not surprisingly, it shows 'control' to be a particularly significant issue for young adults with type 1 diabetes (54%), along with dealing with hypoglycaemia (27%). Conversely, young adults with type 2 diabetes are more likely than young adults with type 1 diabetes to struggle with issues around diet (55%) and exercise (63%). Young adults with type 2 diabetes are also more likely to complain of being hassled by their parents (24%).

The results also show that 19 to 23 year olds are finding it harder than other age groups to stay positive (34%) and motivated (43%), whilst 16-18 year olds are the most sensitive to the attitudes and prejudices of people who don't have diabetes. Indeed, nearly half (41%) of 16-18 year olds cited dealing with the attitudes of others as one of their top three challenges.

Figure 8:

QC3: What would you say are the three biggest challenges you face in caring for your diabetes?



Base: n=414

Table 11: Challenges as a function of type of diabetes and age

QC3: What would you say are the three biggest challenges you face in caring for your diabetes?								
	Total	Type of Diabetes			Current Age			
		Type 1	Type 2	GDM	16-18	19-23	24-29	30-35
Base	(414)	(358)	(49)	(7*)	(39)	(90)	(130)	(155)
Getting good control	51%	54%↑	35%↓	43%	49%	57%	52%	48%
Watching what I eat	36%	34%↓	55%↑	29%	41%	39%	36%	33%
Getting enough exercise	36%	31%↓	63%↑	86%	41%	34%	29%	40%
Staying motivated	35%	34%	39%	57%	33%	47%↑	25%↓	35%
The cost of health care	33%	34%	33%	29%	23%	40%	35%	31%
Staying positive	26%	27%	22%	29%	33%	34%↑	25%	21%
Attitudes & prejudices of people who don't have diabetes	25%	26%	18%	0	41%	30%	20%	22%
Dealing with 'hypos' (sudden drops in low blood sugar)	25%	27%↑	8%↓	14%	26%	17%	30%	25%
Finger prick blood tests	21%	19%	39%↑	14%	26%	28%	16%	21%
Finding the time to fit in all the doctor's appointments	15%	16%	6%	14%	8%	17%	19%	12%
Finding someone to talk to, who really understands	14%	14%	16%	0	23%	19%	15%	9%↓
Finding a doctor that listens to me and is supportive	14%	14%	12%	0	15%	19%	15%	10%
Getting hassled by my parents/doctors/family	12%	10%↓	24%↑	14%	28%	18%	8%	8%
Finding a doctor that really knows about diabetes	12%	11%	14%	14%	13%	11%	12%	12%
Injecting insulin	11%	11%	8%	14%	33%↑	10%	9%	6%↓
Dealing with complications	9%	10%	4%	0	8%	11%	8%	9%
Getting hold of accurate information	7%	7%	10%	14%	5%	9%	6%	8%
Other	10%	11%	6%	0	8%	7%	12%	10%
↑↓ indicates that the differences shown are statistically significant								
* Caution: sample size is small. Care is required when interpreting these results.								

## 8.1 Barriers to coping

The main things that get in the way of young adults managing their diabetes better include:

- Finding it hard to stick to a routine (88% feel this way at least sometimes whilst 38% feel this way a lot).
- Just wanting to forget about having diabetes (83% feel this way at least sometimes whilst 34% feel this way a lot).
- Feeling scared (74% feel this way at least sometimes whilst 34% feel this way a lot).
- Not enough time in the day (81% feel this way at least sometimes, 31% feel this way a lot).
- Embarrassed (53% feel this way at least sometimes whilst 22% feel this way a lot).
- Get fed up and want to rebel (42% feel this way at least sometimes whilst 19% feel this way a lot).

A high 66% also said that receiving conflicting advice about how to manage their diabetes got in the way of them managing better, at least sometimes. (For more on the topic of information, please refer to chapter 15.)

Figure 9:

QC5: The following is a list of things that people with diabetes have said can sometimes get in the way of managing their diabetes better. To what extent, if at all, do you ever feel this way...?

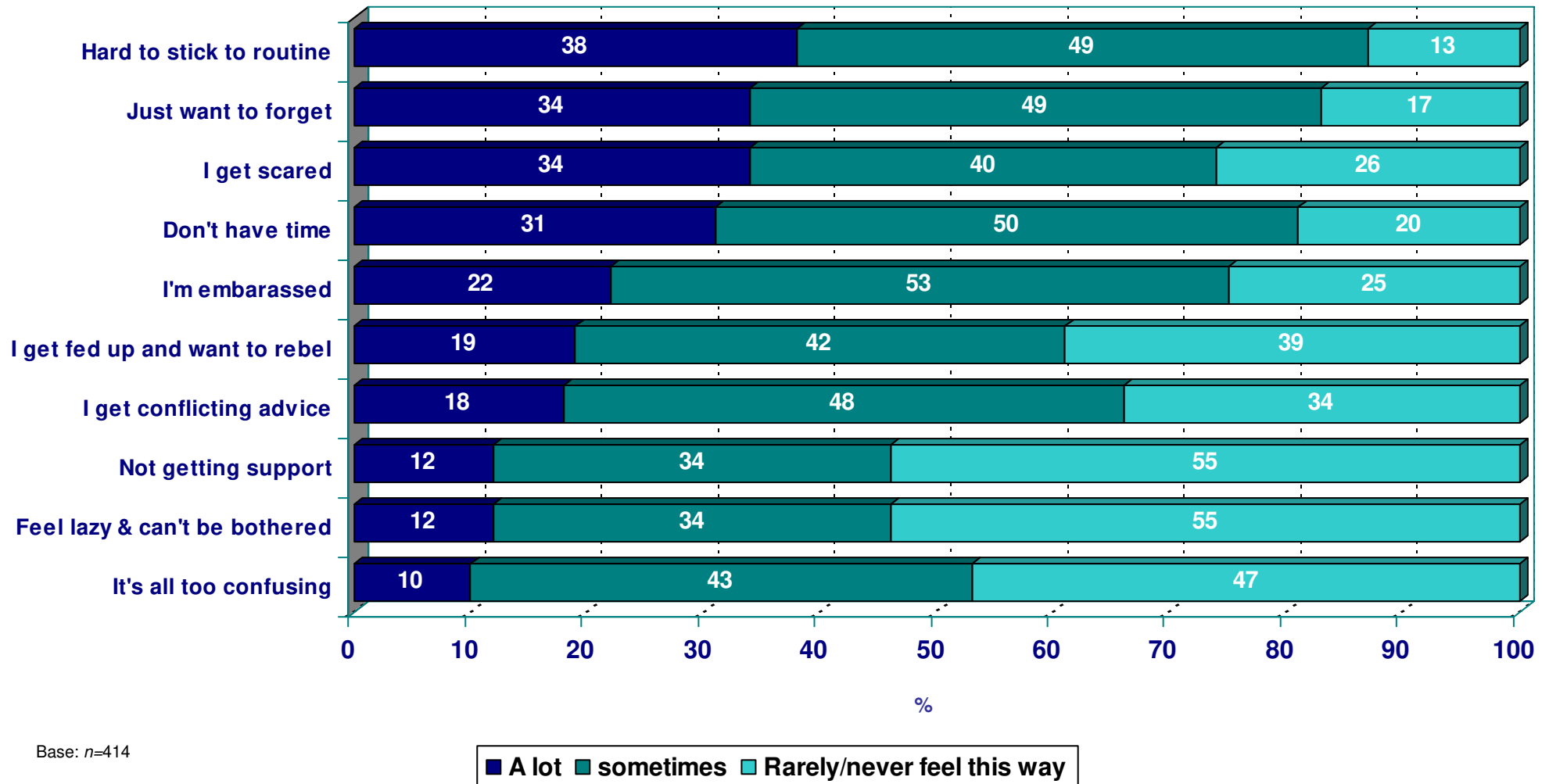


Table 12: Barriers as a function of type of diabetes and age

QC5: The following is a list of things that people with diabetes have said can sometimes get in the way of managing their diabetes better. To what extent, if at all, do you ever feel this way?

(% feel this way a lot/sometimes)

	Total	Type of Diabetes			Current Age			
		Type 1	Type 2	GDM	16-18	19-23	24-29	30-35
<i>Base</i>	<i>(414)</i>	<i>(358)</i>	<i>(49)</i>	<i>(7*)</i>	<i>(39)</i>	<i>(90)</i>	<i>(130)</i>	<i>(155)</i>
It's hard to stick to a routine because of work/study commitments	87%	86%	92%	100%	71%	89%	88%	88%
Just want to switch off and forget that I have diabetes	83%	82%	92%	71%	85%	88%	84%	79%
Don't have time to do all the things I know I probably should do to care for my diabetes	81%	81%	84%	57%	75%	84%	83%	77%
I'm embarrassed about having diabetes	75%	75%	78%	86%	80%	83%	68%	75%
I get scared	74%	75%	74%	57%	66%	82%	80%	67%
I get conflicting advice from health professionals	66%	66%	72%	71%	61%	70%	68%	63%
I get fed up with having diabetes and want to rebel	61%	60%	69%	43%	67%	69%	62%	53%
It's all too confusing. I don't really understand what I'm supposed to do	53%	55%	47%	29%	46%	63%	54%	49%
I'm not getting help or support from anybody	46%	45%	47%	43%	41%	46%	52%	41%
Sometimes I just feel lazy, and can't be bothered anymore	46%	46%	49%	14%	44%	59%	46%	38%
I get tempted by things that I know are not great for my health	35%	35%	38%	29%	26%	42%	40%	31%
There's no-one to talk to who understands what I'm going through	32%	30%	42%	29%	36%	35%	33%	29%
Nothing I do seems to make any difference, so I can't be bothered anymore	28%	23%	49%	71%	26%	32%	28%	24%

\* Caution: sample size is small. Care is required when interpreting these results.

## 8.2 Key issues as a function of life stage

Not surprisingly, both the quantitative and qualitative components of the research found that the specific challenges young adults face in managing their diabetes differ considerably as a function of their age, developmental stage, and life circumstances. The key issues for each life stage are described in more detail below.

### Mid teens

Compared to older age groups, 16-18 years olds find it especially hard to deal with the attitudes of people who don't have diabetes; to find someone who will listen to them; to cope with parents and doctors hassling them; and to inject and do finger prick tests.

Adolescence is a time of great change, when young people take on new roles and responsibilities, renegotiate their relationships, and experiment with things that are symbolic of adult life. Friends and peers start to overtake parents as being the most important and influential people in their lives. There is an overwhelming desire to 'fit in' and gain peer approval.

***"As a teenager, I felt so insecure. You just want to feel normal."***

***"The worst thing about having diabetes is that people might see you differently. Some people think you're a freak."***

By this age many adolescents seek independence and have taken on primary responsibility for caring for their diabetes. Whilst this is a healthy and normal part of their development, problems can occur if they are not adequately equipped to take on all of the challenges that go with it. Hormones rage out of control, and play havoc with blood sugar levels. Drugs and alcohol emerge on the scene, often well before young people have developed a full understanding of the risks, let alone the skills and courage to resist temptation and peer pressure.

***"When puberty hit, my levels went through the roof."***

***"I turned to drugs and alcohol to escape from it all."***

***"It's pretty hard when all your mates are going out drinking, it's socially isolating. It's hard not to go along with it. I ended up in hospital after a big night, it nearly killed me."***

At high school, teenagers with diabetes also face the difficult and embarrassing prospect of explaining their situation to new teachers they come into contact with. Some teenagers with diabetes have come against problems with teachers who don't know them, or understand their needs.

***“Teachers get shitty about you eating in class.”***

Disconcertingly, it is often around this time that information and support around diabetes for young people can start to taper off. Indeed, teenagers often complained that their knowledge of diabetes was poor, since much of the information available was developed for parents, rather than teenagers.

***“I couldn’t get into Diabetes Camp this year, because I’m too old, and it’s more for people who are new. I was devastated.”***

***“They give the information to your parents, and assume that they’ll pass it on, I suppose. They don’t tell you anything.”***

## **Late teens/early twenties**

Key issues for young adults in their late teens and early 20s include: staying positive and motivated, sticking to a routine, maintaining control, avoiding temptation and the sheer cost of health care.

Many young adults recalled their late teens as a particularly difficult period in their lives. Key events include leaving the relative safety and predictability of the school environment to embark on university or work. Some young adults also choose this time to move out of home (with or without their parents’ support), and suddenly find themselves responsible not only for caring for their diabetes but also managing finances, keeping house, and putting food on the table. Established routines are abandoned and diabetes can take a back step to other life issues.

***“Time management becomes a big issue when you start work. Finding time to eat. Finding time to cook.”***

***“At school, it was all pretty much routine. Breakfast, lunch and dinner at the same time. Mum cooked, no drama. I got to Uni and totally rebelled. I was all over the place.”***

***“Moving out of home is a big step, when you’re doing all the shopping and everything. The first thing I did was buy four huge boxes of Fruit Loops.”***

There are many practical challenges to deal with during this time. These include getting clearance to apply for a driver’s license, choosing a private health fund, stocking up on supplies, and paying bills. Money problems can be a significant cause of anxiety, particularly for those who have moved out of home.

***“Dealing with bureaucracy is a nightmare. Vic Roads treated me as a criminal. It’d get good to get help with that.”***

***“Ordering supplies is a pain. You have to pay for it over the phone by credit card, then it takes 10 days. You can’t go into Diabetes Australia and buy it, and I don’t have a credit card.”***

## **Mid/late twenties**

The biggest challenge of all for young adults in their mid to late twenties and early thirties and finding the time to fit everything in. Many struggle financially. This is also a time when people start worrying a little more about the future.

By mid twenties, one of the big issues is time management and learning how to ‘juggle’ diabetes with a hectic work and/or life schedule. Many jobs do not follow a routine, or provide staff with the flexibility to eat when they need to, or take time off for doctor’s appointments. Some adults are torn between wanting to keep their diabetes a secret to avoid discrimination, and wanting colleagues and managers to know (and understand) what’s going on in their lives.

***“I don’t have time to see all these specialists.”***

***“Shift work messes you up so badly. If you’re in a routine, it’s so much easier to take care of my diabetes.”***

***“I have back to back clients, for hours on end. There’s no time to stop really. Sometimes I get carried away and just forget to take my insulin. Then you have to wait to eat. It’s a pain. It’s more than a pain.”***

***“I didn’t tell anyone at first. Then I realised I had to, or they’d start thinking I was really weird.”***

Similar dilemmas are experienced when embarking on new relationships. Young adults wonder how much they should tell their new partners, for fear of ‘freaking them out’.

***“Partners and spouses put up with a lot of shit, you know. There’s no way I’d ever go out with someone who has diabetes.”***

***“Relationships are hard. You don’t want to share the baggage. It’s easier on your own.”***

The cost of health care and diabetes supplies is key source of resentment. Even with NDSS subsidies, medical expenses are a significant burden.

***“I hate the fact that you have to get a script for insulin each time. You can’t get repeats. So that’s yet another trip back to the doctor, and another \$50 down the drain.”***

***“Costs a fortune, and that’s one of the biggest struggles. Sometimes it really is a question of, ‘do I get medication or do I put food on the table?’***

***“Now that I’m working, I’ve lost my health care card. Half my money goes on taking care of diabetes.”***

By now, many young adults are starting to worry about the future. Can they have children? How will their condition progress? By the time they reach their mid twenties, young adults with type 1 diabetes are already experiencing significant health complications, and concerns about their health and personal safety are starting to have a bigger influence on their decision making.

***“It was really demoralising at age 30 that I had to go and live with my parents, because I was scared of living alone.”***

***“Mum’s got a spare set of keys, and she calls me every morning to check that I’m okay.”***

## 9. Coping mechanisms

Young adults cope with having diabetes in vastly different ways. Some build a life and career out of having diabetes. They join support groups, read books, and go out of their way to seek out and help other people in the same situation. Their diagnosis gives them automatic entry into a tight knit community, and they wear the label with pride.

***“In some ways, I’m quite glad that I’ve got diabetes. It means that I can help people.”***

***“The best thing about having diabetes is going to Diabetes Camp. Like it almost makes you want to have diabetes, just so that you can be part of it.”***

***“I tell everyone I meet that I’ve got diabetes. It’s good that they understand.”***

Others invest considerable energy into pretending that diabetes is not really there. They inject in private, and rarely discuss diabetes with friends and colleagues. They carry on, publicly at least, as if life was entirely normal. To some extent, this may be seen as quite positive. It may also seem, on the surface, that they are coping well. However, there is recognition that there’s a danger in bottling up feelings, and that by disconnecting from the diabetes community, some young adults with diabetes may be missing out on important information that could markedly improve their lives.

***“I haven’t told anybody, except maybe a few friends that I’ve known a long time. I just don’t want anyone making an issue out of it, or treating me differently.”***

***“On the whole, I don’t like thinking about it. I don’t like talking about it. Every now and then, I’ll force myself along to things, like this, just to touch base. Like it’s good to talk to others who’ve got diabetes too. But I generally avoid it like the plague.”***

***“It’s very beneficial to have contact, although it’s hard because it raises things you don’t really want to think about.”***

***“I’ve put myself in danger sometimes, but not telling anyone I have diabetes.”***

***“I didn’t want to have any thing to do with the associations.”***

Some young adults, from time to time, use their diabetes as an excuse for underachieving. They reach a point when they feel like giving up, and blame their illness for the events taking place in their life.

***“There was a time when I got all these complications and I was so sick and I kind of just gave up. I blamed my diabetes for everything ... not having a job. Not having a***

***boyfriend. It was like, diabetes is the reason why my life sucks. It wasn't very helpful."***

***"There are some people, me sometimes, who just bitch and whinge all the time. Like we all feel 'woe is me', some of the time."***

To a certain extent, the way people respond to having diabetes is linked to their core personality and outlook on life. However, it is not uncommon for people to shift in and out of these different mindsets, and adjust their coping mechanisms accordingly. Periods of denial, avoidance, anger, rebellion and sadness are all a normal response to having a life threatening, chronic health condition. However, if left unchecked for too long, these feelings can lead to clinical depression, long-term neglect and irreversible health problems. Unfortunately, for some young adults it can take a significant health crisis to get them to stop and take notice of what's going on.

These findings suggest just how important it is that young adults are given the opportunity and encouragement to fully explore and understand their response to having diabetes, and to get help and support well before they reach crisis point. As discussed in Chapter 13 of this report, however, young adults felt that many health professionals (including diabetes educators and endocrinologists) are not well equipped to provide the type of support and guidance they both yearn for and need to keep them motivated and on track.



## 9.2 Things that help

Qualitative research suggests that the way parents react to their child's diagnosis can have a big influence on their child's response to having diabetes, particularly if they were diagnosed as a child or young adolescent. Parents who are confident and reassuring help their children maintain a positive, resilient attitude towards their situation, whilst parents who are fearful and overprotective can diminish confidence in young person's ability to cope.

***"Mum carries this burden that it's all her fault, so she wants to control it. She wants to take over."***

***"I didn't inject until I was 18. I don't blame her, but my mum was so dominating that she made me doubt myself, I guess. I'm not sure it was the best way to handle things."***

Whilst, the majority of young adults (66%) said that the support of family or partners had played a big role in helping them to cope better with having diabetes, they also felt it would be useful if parents were shown how they can be supportive, without taking over the lives of their children.

***"Educating parents is really crucial. It would be good for them to talk to other teenagers, or get some training or support, so that they don't try and take over your life."***

***"Honestly, my mum knows nothing."***

Also important was being informed (48%), websites for young adults with diabetes (43%), the advice and support of health professionals (40%), and their friends (36%).

Finding a good team of health professionals who understand diabetes has made a world of difference to the lives of some young people. Better still, if the team includes a counsellor or psychologist to help work through the many emotional issues associated with having a chronic illness. Interactions with health care providers are discussed in more detail in Chapter 13.

***"They really should encourage young people to see a psychologist, even if they think they're fine. Especially, if they think they're fine. You've got to deal with it early, don't leave it until it's too late."***

The introduction of new technology, such as pumps, or new medication had also been influential in the lives of around one in three participants (33%). This is reflected in the following discussion between focus group participants.

***Person 1: "Going on a pump made the world of difference. I hate taking needles to other people's houses."***

***Person 2: "Same here, I can't bring myself to inject in public. It freaks everyone out. I hate it. I'm so much more independent now."***

Whilst diabetes camps and forums for young adults with diabetes did not rate highly overall as a source of support and information, qualitative feedback from those who had been on a diabetes camp organised by Diabetes Australia was tremendously positive. Not only were camps considered a great source of information for people who are newly diagnosed, the opportunity to meet people the same age in the same situation is extremely important to adolescents. It helps normalise diabetes, and create a sense of community and belonging.

***"Knowing that there are other people in the same boat, and that they normal and fun and cool, that's so reassuring."***

***"Diabetes Camp makes you feel like you're normal, like you're part of a community. You realise that people don't look at you funny because you have diabetes."***

***"There are groups at the hospital, but that is more for learning things. There wasn't much time to speak or to socialise or share stories."***

***"Diabetes Camp is the best thing ever. People live for camps. I'm not joking."***

Meeting other young adults with diabetes and sharing stories and experiences can be just as important for people in their late teens and twenties. However, opportunities to do this are few and far between. Whilst not everyone is keen on the idea of taking part in a support group, websites, such as Reality Check, were seen as a valuable and effective way of connecting young adults with diabetes with other people in the same situation, to exchange ideas and offer support.

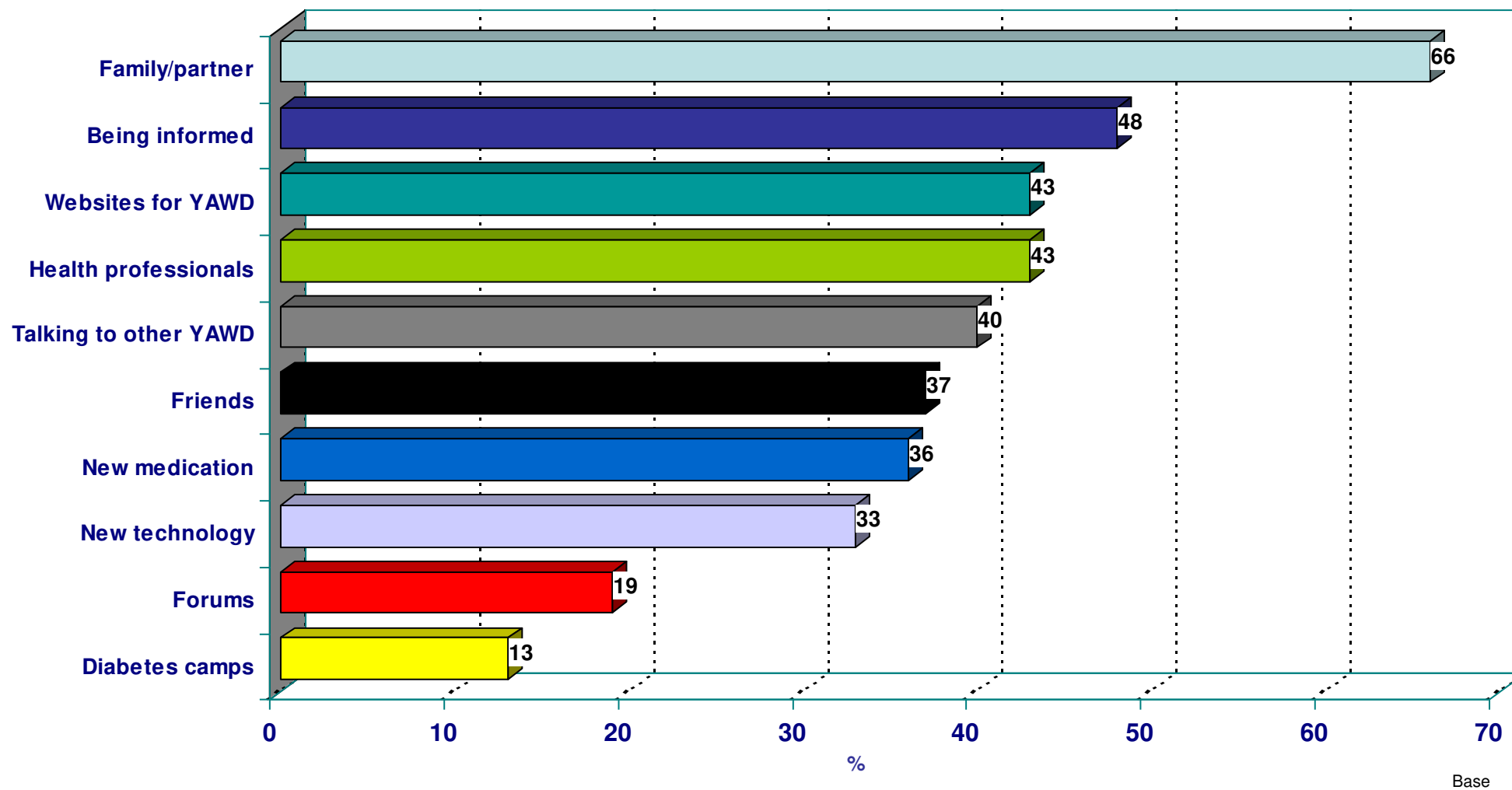
***"Just meeting other people with diabetes, is really important. I can't tell you how important that is."***

***"I don't want stuff out of a book. I want to talk to people who understand, to learn from other people who have diabetes and who get it."***

***"It's impossible to talk to someone who doesn't have diabetes about this stuff. They just don't get it."***

Figure 10:

QC4: What are the things that have helped you to cope better with having diabetes?



Base



Table 14 below shows the value of various types of support as a function of age. Compared to older age groups, 16-23 year olds rely more strongly on support from their friends, going to diabetes camps, and their parents. Older age groups, on the other hand, are more likely to value getting as much information about diabetes that they can lay their hands on, logging onto websites and chat rooms, and support from their spouse or partner.

Table 14: Things that help as a function of type of diabetes and age

QC4: What are the things that have helped you to cope better with having diabetes?								
	Total	Type of Diabetes			Current Age			
		Type 1	Type 2	GDM	16-18	19-23	24-29	30-35
Base	(414)	(358)	(49)	(7*)	(39)	(90)	(130)	(155)
Support and encouragement from family/partner	66%	66%	57%	100%	79%	61%	64%	67%
Finding out as much as I possibly can about diabetes	48%	48%	45%	71%	26%↓	44%	47%	57%↑
Websites/internet chat rooms for young adults with diabetes	43%	46%	27%	14%	18%	39%	48%	48%
Support and encouragement from health professionals	43%	45%	33%	14%	44%	37%	42%	47%
Talking to other people who have diabetes	40%	42%	31%	14%	33%	41%	41%	41%
Support and encouragement from friends	37%	38%	31%	29%	62%	39%	37%	29%
New medication (i.e. changing over to a different type of insulin or medication)	36%	40%	18%	0	33%	33%	35%	41%
New technology (i.e. pumps)	33%	38%	4%	0	28%	31%	31%	38%
Forums/conferences for young adults with diabetes	19%	22%	2%	0	5%↓	18%	25%↑	18%
Diabetes camps	13%	15%	0	0	44%	13%	12%	6%
Nothing has helped	4%	3%	12%	0	8%	6%	2%	4%
Other	4%	5%	0	0	3%	4%	3%	6%
Don't know	2%	1%	6%	0	0	4%	2%	1%

↑↓ indicates that the differences shown are statistically significant

\* Caution: sample size is small. Care is required when interpreting these results.

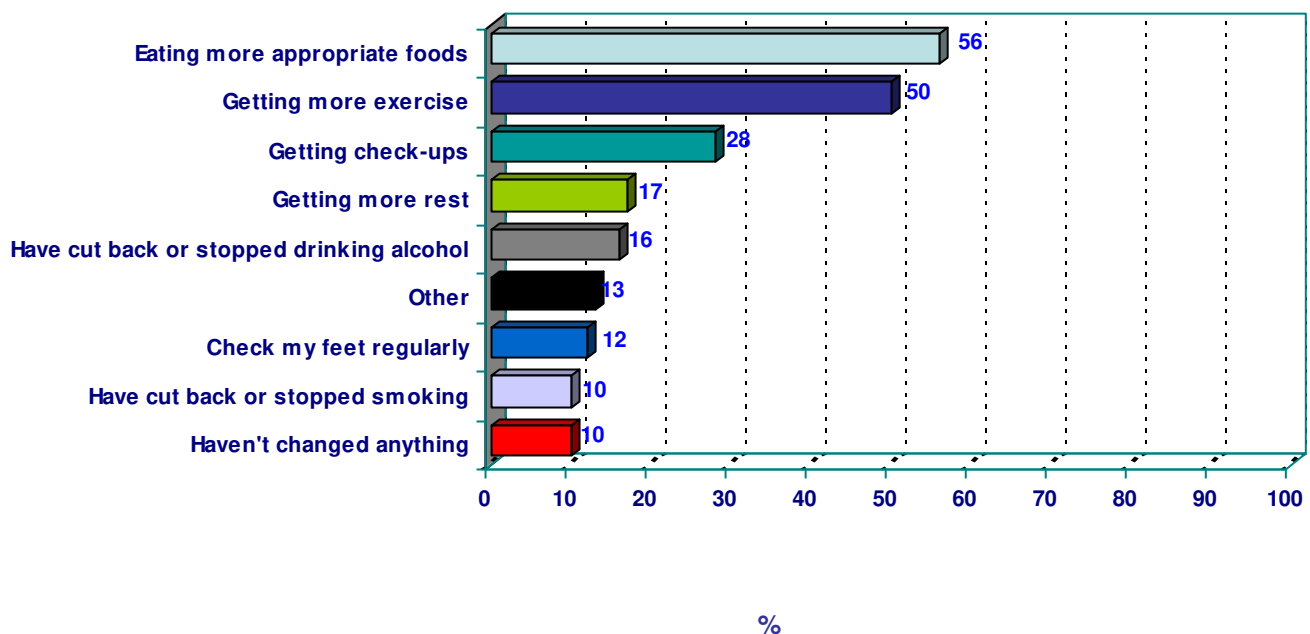
# 10. The practical side of managing diabetes

## 10.1 Efforts to improve overall health

In the last 12 months, around half of the sample had made an attempt to eat more appropriate foods (56%) and get more exercise (50%), in order to improve their overall health (higher again amongst those with type 2 diabetes).

Figure 11:

QC9: In the last 12 months, which (if any) of the following things have you been doing to improve your overall health?



Base: n=414

As shown in Table 15 below, around one in four had been getting check ups (higher amongst females – 31%), whilst 17% had been getting more rest and 16% had cut back or stopped drinking alcohol.

Eleven percent of young adults with type 1 diabetes had not changed anything in the last 12 months to improve their overall health.

*Table 15: Efforts to improve health as a function of type of diabetes and gender*

QC9: In the last 12 months, which (if any) of the following things have you been doing to improve your overall health? [SELECT ALL THE THINGS THAT ARE RELEVANT TO YOU]						
	Total	Type			Gender	
		Type 1	Type 2	GDM	Male	Female
<i>Base</i>	(414)	(358)	(49)	(7*)	(93)	(321)
Eating more appropriate food	56%	53%↓	71%↑	86%	52%	57%
Getting more exercise	50%	48%	63%	71%	42%	53%
Getting check-ups more regularly	28%	27%	29%	43%	18%↓	31%↑
Getting more rest	17%	16%	16%	29%	15%	17%
Having cut back or stopped drinking alcohol	16%	16%	10%	14%	14%	16%
Check my feet regularly	12%	12%	12%	14%	11%	13%
Have cut back or stopped smoking	10%	10%	8%	14%	14%	9%
Haven't changed anything	10%	11%	0	0	8%	10%
Other	13%	9↓%	35%↑	57%	6%↓	14%↑
↑↓ indicates that the differences shown are statistically significant						

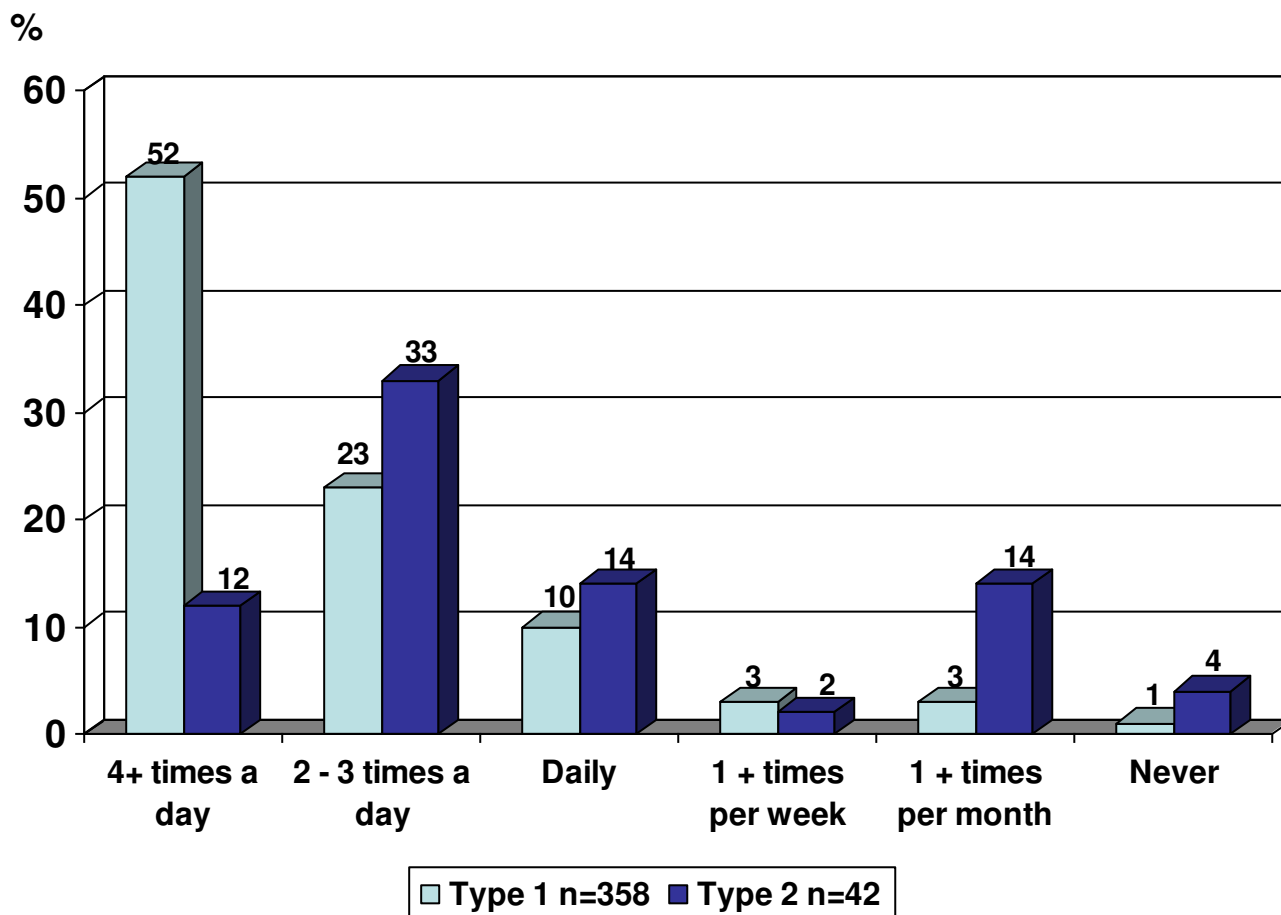
\* Caution: sample size is small. Care is required when interpreting these results.

## 10.2 Frequency test glucose levels

Almost all young adults with type 1 diabetes were testing their BGL at least daily (over 52% were testing four or more times a day). Young adults with type 2 diabetes tested less often, with one in five testing weekly or monthly, rather than daily.

Figure 12:

C10: How often, if at all, do you test your blood sugar levels  
(using a meter or finger prick test)?



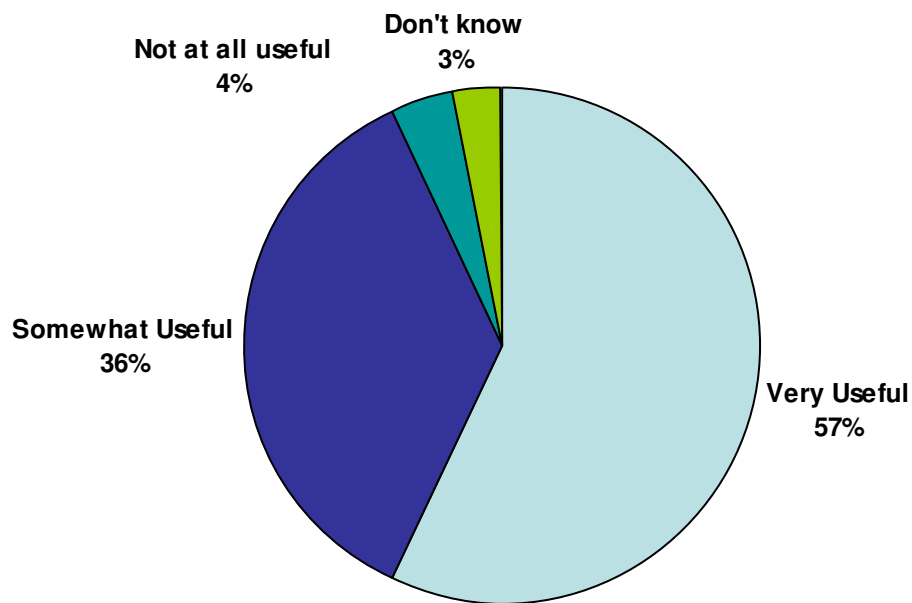
Base: n=400

## 10.3 Usefulness of testing BGL

The vast majority (93%) of young adults who test their BGL regularly felt that this was at least somewhat useful in managing their diabetes.

Figure 13:

C11: How useful is testing your blood glucose in helping you manage diabetes?



Base: n=253

## 10.4 Use of medicines/insulin

As would be expected, young adults with type 1 diabetes were taking insulin or insulin and tablets to manage their diabetes. Fifty five percent of young adults with type 2 diabetes were taking tablets or capsules prescribed by their doctor, 14% were taking insulin, and 10% were taking both. Eighteen percent of young adults with type 2 diabetes were not taking any type of medication to manage their diabetes.

Table 16: Use of medicines as a function of type of diabetes

C12 Are you currently taking either of the following for your diabetes?				
	Total	Type of Diabetes		
		type 1	type 2	GDM
Base	(414)	(358)	(49)	(7*)
Tablets or capsules prescribed by the doctor	8%	1%↓	55%↑	29%
Insulin	85%	96%↑	14%↓	0
I don't take any medication	4%	1%↓	18%↑	57%
Insulin and tablets or capsules prescribed by GP	3%	2%↓	10%↑	14%
Don't know	0	0	2%	0
↑↓ indicates that the differences shown are statistically significant				
* Caution: small sample size. Care is required when interpreting the results				

## 10.5 Compliance

Of those that take medicine, the majority (81%) always take the medicine as prescribed, but 19% do not. Asked why, the main reason was that sometimes they just forget. However, there was also some evidence of issues with inconvenience, and side effects.

*Table 17: Reasons Don't Comply*

<i>C12C What are the main reasons that you don't always take your medicines prescribed?</i>	
	<b>Total</b>
<i>Base*</i>	<i>(9)</i>
Sometimes I just forget	78%
It's inconvenient	33%
I find it embarrassing	22%
Can't always afford to buy it	22%
Don't like the side effects	22%
Doesn't seem to help	11%
I don't like taking medication	11%
<i>*Only asked if does not always take medications as prescribed by doctor. Caution, sample size is small..</i>	

## 10.6 Type of insulin used

The majority (62%) of insulin users were taking a combination of short-acting and long-acting insulin, whilst 34% were taking short-acting insulin alone.

Teens were significantly more likely to be taking combination therapy than young adults in their thirties, whilst males were more likely than females to be taking a combination.

Table 18: Type of insulin used as a function of age and gender

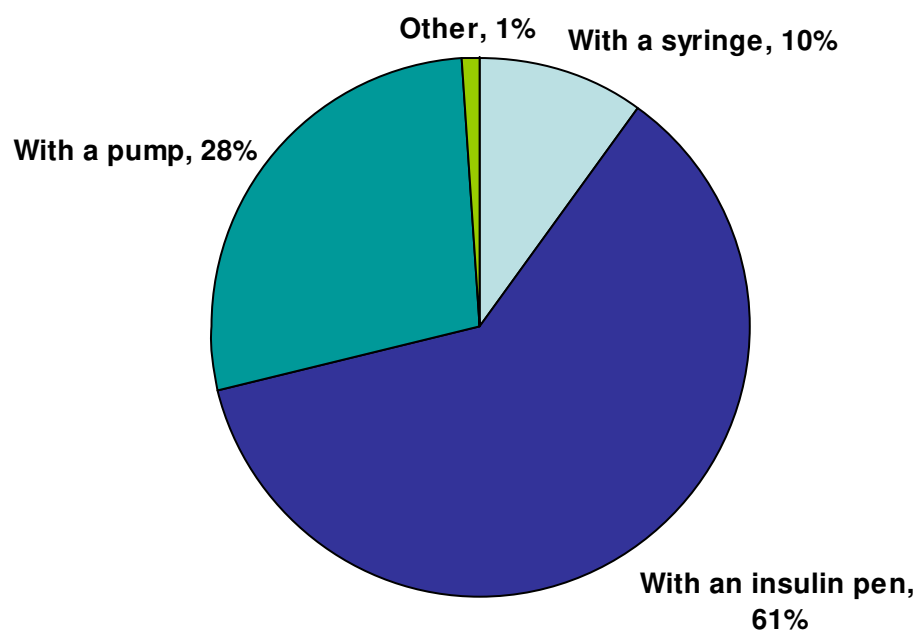
C12D: Which of the following Types of insulin are you currently using?							
	Total	Current Age				Gender	
		16-18	19-23	24-29	30-35	Male	Female
Base*	(365)	(37)	(80)	(122)	(126)	(77)	(288)
Short acting (such as Humalog, Novorapid, Humulin R or Actropid)	34%	19%↓	28%	30%	47%↑	22%↓	37%↑
Intermediate acting (such as Humulin NPH, Humulin L, Proaphane, Monotard)	1%	0	0	1%	2%	1%	1%
Long acting (Humulin UT, Ultratard, Lantus or Levemir)	2%	3%	1%	3%	2%	1%	3%
A combination of short acting and long acting	62%	78%↑	71%	66%	48%↓	75%↑	59%↓
↑↓ indicates that the differences shown are statistically significant * only asked if using insulin							

## 10.7 Insulin delivery

The majority (61%) of insulin users are injecting insulin with an insulin pen, whilst 28% use a pump and 10% use a syringe.

Figure 12: Method of insulin delivery

C12F How do you take your insulin?



Base: n=365

As shown in Table 19 below, there were significant differences in delivery method as a function of age and gender. Nearly one in three teenagers aged 16-18 said that they were using a syringe to (27%) – much higher than other age groups. Conversely, people in their thirties were more likely to be using a pump (42%).

Males were significantly more likely than females to be using a pen (74% vs 57%) whilst females were more significantly more likely than males to use a pump (32% vs 14%).

Table 19: Method of insulin delivery as a function of age and gender

Q12F: How do you take your insulin?							
	Total	Current Age				Gender	
		16-18	19-23	24-29	30-35	Male	Female
Base*	(365)	(37)	(80)	(122)	(126)	(77)	(288)
With a syringe	10%	27%↑	16%	7%	45↓	9%	10%
With an insulin pen	61%	54%	60%	71%↑	52%↓	74%↑	57%↓
With an insulin pump	28%	19%	24%	20%↓	425↑	14%↓	32%↑
Other	1%	0	0	2%	2%	3%	1%

↑↓ indicates that the differences shown are statistically significant  
 \* only asked if using insulin

## 10.8 Health care tests undertaken

Encouragingly, the study suggests that most young adults with diabetes are getting regular check ups and tests. However, foot care is an area that is widely neglected by young adults. The findings also suggest that some young adults may benefit from more regular discussions with health care providers around their overall health, and things that they could be doing to improve their health.

In the past two years:

- 95% of young adults with diabetes had taken a Haemoglobin A1c test
- 93% had their blood pressure tested
- 85% had a weight check
- 73% had a test to check for eye damage caused by diabetes
- 54% had a test for signs of feet problems
- 42% had a healthy living check
- 24% had a medication review.

Table 20: Health tests undertaken as a function of type of diabetes, age and gender

QD3: In the past 2 years, which (if any) of the following health care tests have you had in relation to your diabetes?										
	Total	Type 1	Type 2	GDM	Current Age				Gender	
					16-18	19-23	24-29	30-35	Male	Female
Base*	(365)	(358)	(49)	(7**)	(37)	(80)	(122)	(126)	(77)	(288)
A blood test	95%	96%	90%	86%	92%	96%	95%	96%	94%	96%
A test for blood pressure	93%	94%	86%	86%	77%	94%	93%	97%	91%	94%
Weight check	85%	86%	76%	86%	77%	83%	82%	90%	82%	85%
A test for an eye damage caused by diabetes	73%	76%	55%	43%	59%	69%	71%	81%	63%	76%
Medication review	72%	75%	55%	57%	69%	73%	71%	74%	73%	72%
A test for signs of feet problems	54%	56%	45%	29%	36%	51%	53%	61%	49%	55%
'Healthy Living' check	52%	51%	57%	29%	51%	54%	50%	50%	48%	52%

\* only asked if using insulin  
 \*\* Caution: small sample. Care is required when interpreting results.

# 11. Interactions with health service providers

## 11.1 When was the last visit to a health professional?

The vast majority of young adults with diabetes (84%) had been to see a GP in the last 12 months about their diabetes, and despite problems with access, most (70%) had seen an endocrinologist. Relatively few, however, had been to see a podiatrist or counsellor in the last five years.

Figure 18: Last visit to health professional

D1: When was the last time, if ever, that you saw the following types of health professionals in relation to your diabetes?

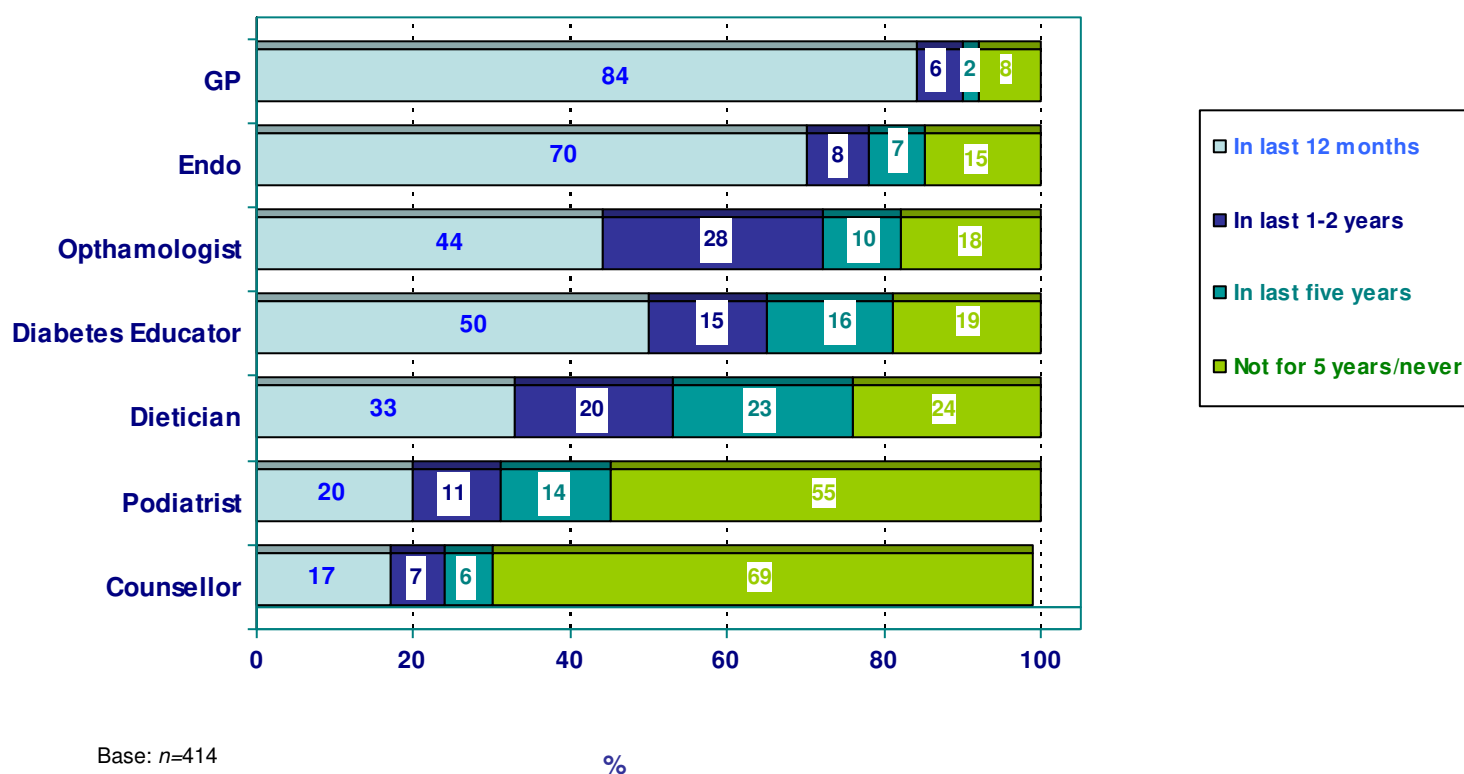


Table 21: Last visit to health practitioner by type of diabetes and location

*D1: When was the last time, if ever, that you saw the following types of health professionals in relation to your diabetes? [PLEASE TICK ALL THE OPTIONS RELEVANT TO YOU]*

*[% In the last 12 months]*

	Total	Type of Diabetes			Location	
		Type 1	Type 2	GDM	Metro	Regional/ remote
<i>Base</i>	(414)	(358)	(49)	(7*)	(93)	(321)
GP/family doctor	84%	84%	86%	86%	85%	85%
Ophthalmologist	44%	46%	41%	14%	45%	45%
Endocrinologist	70%	75%↑	37%↓	29%	76%↑	55%↓
Podiatrist	20%	22%	12%	14%	18%	25%
Diabetes Educator	50%	52%↑	35%↓	43%	49%	54%
Dietician	33%	33%	31%	29%	30%	40%
Counsellor/Psychologist/ Psychiatrist/Social Worker	17%	18%	10%	0	17%	17%
<i>Base*</i>	(7)	(n/a)	(n/a)	(7*)	(3)	(4)
Obstetrician	29%	-	-	29%	67%	0
Midwife	29%	-	-	29%	67%	0

↑↓ indicates that the differences shown are statistically significant

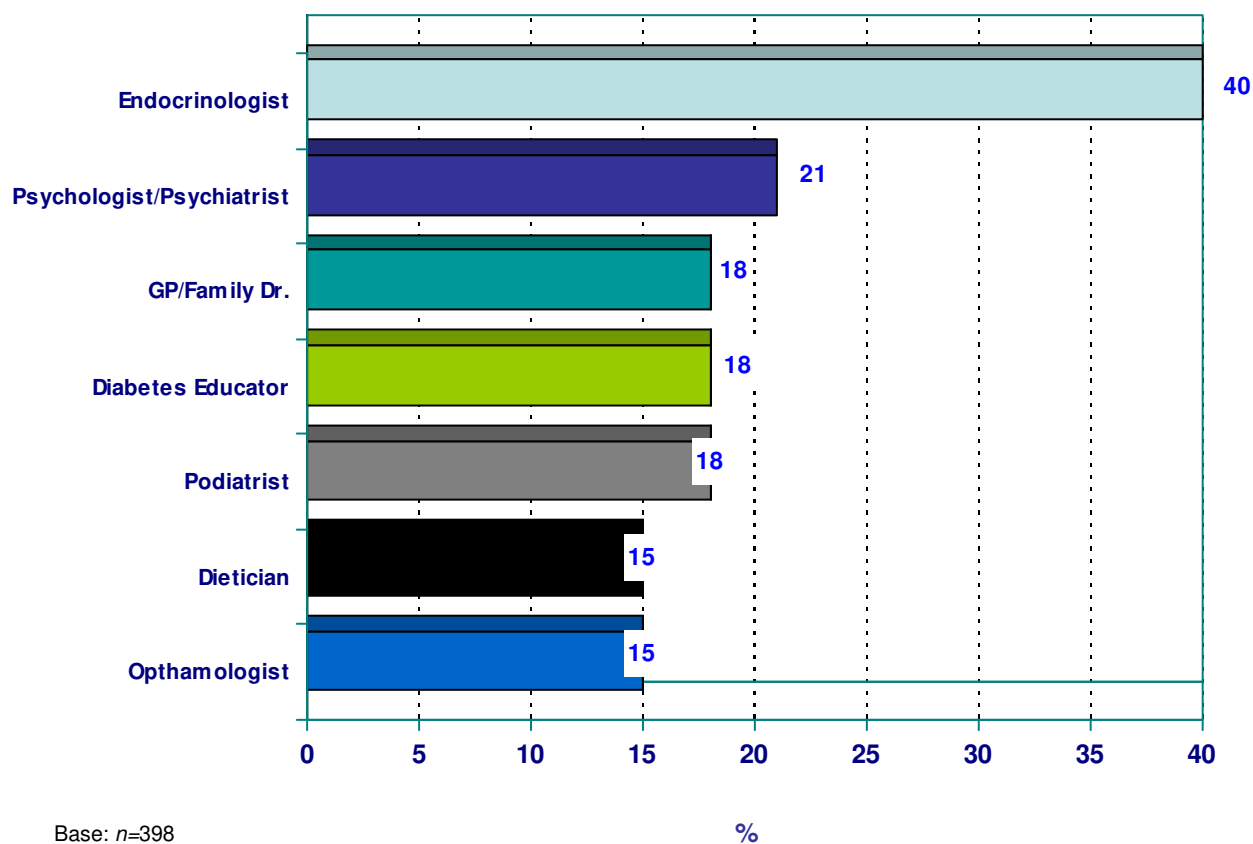
\*Caution: small sample. Care is needed when interpreting results.

## 11.2 Ease of access

Whilst most young adults with diabetes had no major difficulties getting in to see a GP or diabetes educator about their diabetes, a high 40% had experienced problems getting to see an endocrinologist.

Figure 19: Ease of access

QD2A: Have you ever had any problems getting to see any of the following health professionals about your diabetes?



As shown in Table 20 below, access was especially difficult for young people living in regional and remote areas of Australia, where just over half had trouble getting in to see an endocrinologist. Nearly a third of people in regional and remote parts of Australia also experienced some difficulties getting to see a counsellor or psychologist.

Table 20: Ease of access by type of diabetes and location

D2A: Have you ever had any problem getting to see any of the following health professionals about your diabetes as often as you would have liked? (% that had problems)						
	Total	Type of Diabetes			Location	
		Type 1	Type 2	GDM	Metro	Regional/ remote
Base	(398)	(345)	(47)	(6*)	(284)	(103)
GP/family doctor	18%	17%	26%	33%	17%	19%
Ophthalmologist/eye specialist	15%	15%	19%	0	13%	15%
Endocrinologist	40%	40%	43%	0	36%↓	51%↑
Podiatrist	18%	17%	28%	0	17%	15%
Diabetes Educator	18%	17%	22%	43%	16%↓	22%
Dietician	15%	12%↓	31%↑	50%	13%	16%
Counsellor/Psychologist//Social Worker	21%	21%	19%	0	16%	33%↑

↑↓ indicates that the differences shown are statistically significant

\*Caution: small sample. Care is needed when interpreting results.

### **11.3 Barriers to seeing health professionals as often as needed**

As shown in Table 23 on the following page, lengthy waiting lists were the biggest barriers to seeing an endocrinologist (50%). The simple fact is that there are not enough endocrinologists available to service the needs of young adults with diabetes, especially in rural areas.

Of those who experienced difficulties seeing a GP, the main reasons were getting time off work or study (46%), or long waiting lists to the GP of their choice (46%).

Amongst those who had trouble accessing an ophthalmologist, the main problems were time (45%) and cost (42%). Cost was also a barrier to seeing a psychologist (48%).

***“I have had to stop seeing my endo. I can’t afford to see her anymore.”***

Table 21: Reasons Why Couldn't Get to see the Health Professional

QD2B: Why can't you see this type of health professional as often as you would like?							
	GP	Ophthalmologist	Endocrinologist	Podiatrist	Diabetes Educator	Dietician	Counsellor/psychologist
Base	(71)	(53)	(148)	(47)	(64)	(49)	(44)
Can't afford it	37%	42%	32%	34%	8%	22%	48%
Had difficulty getting time off work/study to go	46%	45%	36%	51%	41%	35%	39%
Getting there is hard because I don't drive/there's no public transport	8%	9%	5%	13%	8%	6%	7%
There's a waiting list to see them/not taking new patients	46%	38%	50%	26%	44%	41%	27%
I was told I didn't really need to see them	4%	6%	4%	6%	3%	8%	11%
Other	24%	19%	28%	15%	25%	24%	27%
Don't know	0	2%	0	2%	0	2%	2%



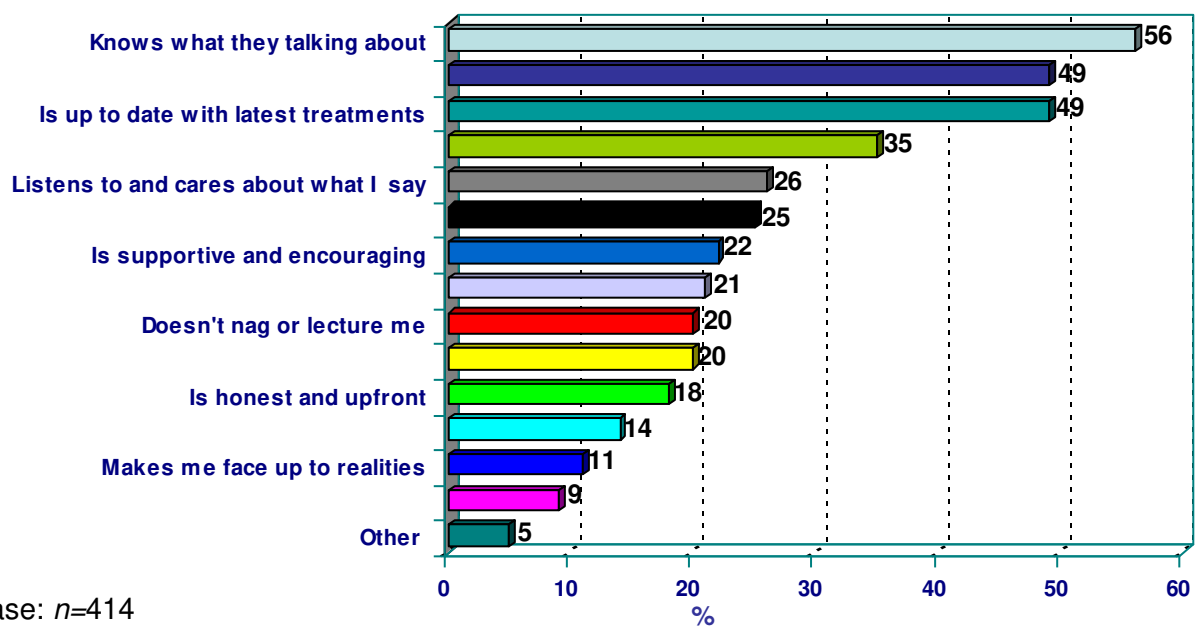
## 11.4 The qualities young adults look for in a health professional

Overall, the main qualities young adults hope to see in health care professionals that work with young adults who have diabetes are:

- knows what they're talking about (56%)
- doesn't expect me to be perfect (49%)
- is up to date with all the latest treatments and technologies (49%).

Figure 20: Qualities sought in health professional

D4: What are the top qualities you hope to see in a health care professional that works with young adults who have diabetes?



As shown in Table 22 below, knowledge, and the provision of clear and straightforward advice, is considered particularly important qualities by young adults with type 2 diabetes, along with an understanding of what they are going through. They also seek people who are honest, positive, realistic, and easy to get to.

***“I went to an endo who just made me feel bad. The result? I didn’t see another endo for two years.”***

***“You get conflicting information from different educators. It’s really frustrating.”***

These qualities are also important to young adults with type 1 diabetes. However, it is important to note that this segment is also especially keen to find health professionals who are up to date with the latest technologies. Listening to their point of view, and being treated as an individual were also extremely important.

***“They need to be holistic. To look at what else is going on in your life.”***

***“Some doctors act like it’s all my fault.”***

***“xxxx was the first person who bothered to listen to what I had to say, and not to what mum had to say. She is really helpful.”***

***“Each person is different, and needs to be managed differently.”***

***“I want GPs to realise that there’s no standard treatment anymore.”***

Table 22: Qualities sought in health professionals by type of diabetes and age

QD4: What are the top qualities you hope to see in a health care professional that works with young adults who have diabetes?								
	Total	Type of Diabetes			Current Age			
		Type 1	Type 2	GDM	16-18	19-23	24-29	30-35
Base*	(414)	(358)	(49)	(7*)	(39)	(90)	(130)	(155)
Knows what they're talking about	56%	54%↓	71%↑	43%	49%	44%↓	55%	65%↑
Doesn't expect me to be perfect all the time	49%	50%	43%	43%	54%	50%	45%	51%
Is up to date with all the latest treatments and technologies (i.e. pumps)	49%	52%↑	29%↓	43%	38%	36%↓	55%	54%
Provides simple, clear, practical advice	35%	30%↓	71%↑	43%	31%	33%	34%	39%
Listens to and cares about what I have to say	26%	25%	29%	14%	15%	26%	28%	26%
Is easy to talk to	25%	23%	31%	43%	28%	28%	26%	21%
Is supportive and encouraging	23%	22%	33%	14%	21%	21%	19%	28%
Understands what I'm going through	21%	19%↓	39%↑	14%	36%↑	19%	19%	21%
Doesn't nag or lecture me	20%	20%	18%	14%	26%	26%	23%	12%
Can get in to see them if I need to	20%	18%	29%	29%	18%	17%	22%	20%
Is honest and upfront	18%	15%↓	39%↑	0	26%	16%	14%	20%
Has a positive attitude	14%	12%↓	31%↑	14%	10%	18%	12%	15%
Makes me face up to realities	11%	10%↓	22%↑	0	13%	18%	8%	10%
Is easy to get to	9%	8%↓	22%↑	0	8%	11%	10%	8%
Other	5%	5%	2%	0	5%	7%	5%	3%

↑↓ indicates that the differences shown are statistically significant

\* Caution: small sample size. Care is required when interpreting results.

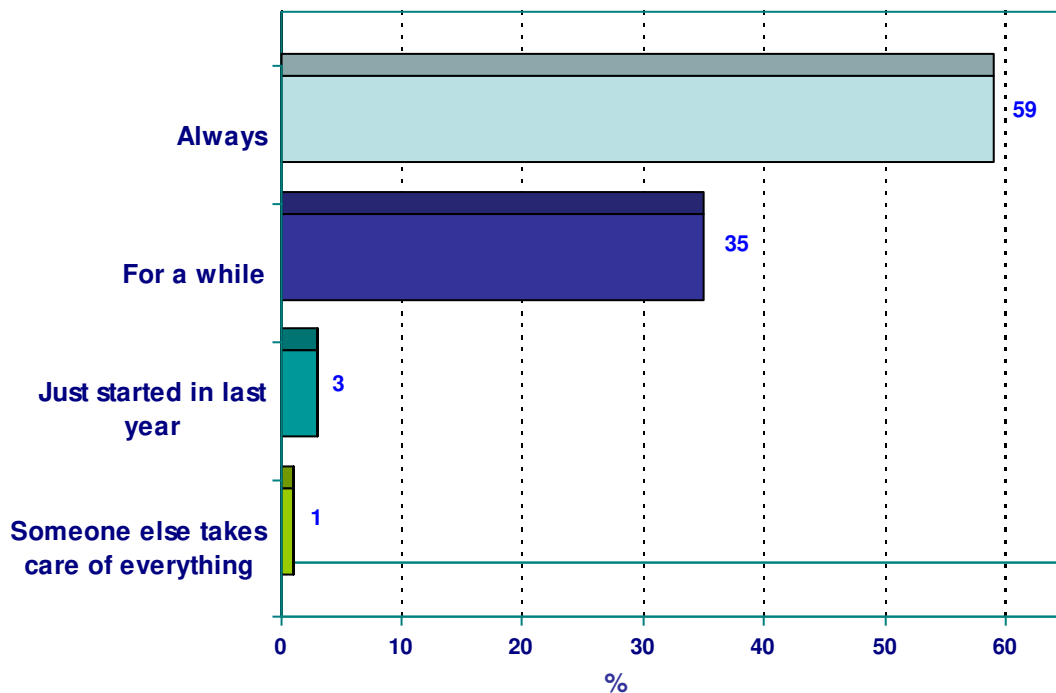
## 12. Transition

### 12.1 Responsibility for managing diabetes

Almost all of the young adults who were diagnosed during their childhood or teens were now taking full responsibility for managing their diabetes, and most had either always taken responsibility (59%) or had been doing so for a while (35%).

Figure 21: Responsibility for managing diabetes

QC7: For how long have you been taking responsibility for managing your diabetes?



Base:  $n=258$  (if diagnosed during childhood/teens)

	Total	Age Diagnosed			Current Age			
		<10 yrs	11-14 yrs	15-18 yrs	16-18	19-23	24-29	30-35
Base	(258*)	(124)	(71)	(63)	(39)	(69)	(78)	(72)
Have <b>always</b> taken responsibility for managing diabetes myself	59%	48%↓	56%	83%↑	26%↓	43%	65%	85%↑
Have been taking responsibility for most things <b>for a while now</b>	35%	47%↑	32%	16%↓	56%↑	49%	33%	13%↓
Have <b>just started</b> taking responsibility for most things in the last year or so	3%	2%	7%↑	2%	8%	4%	1%	1%
Someone else (parents, partner etc) takes care of just about everything	1%	1%	3%	0	5%↑	1%	0	0
None of these/don't know	2%	2%	1%	0	5%↑	1%	0	1%

↑↓ indicates that the differences shown are statistically significant

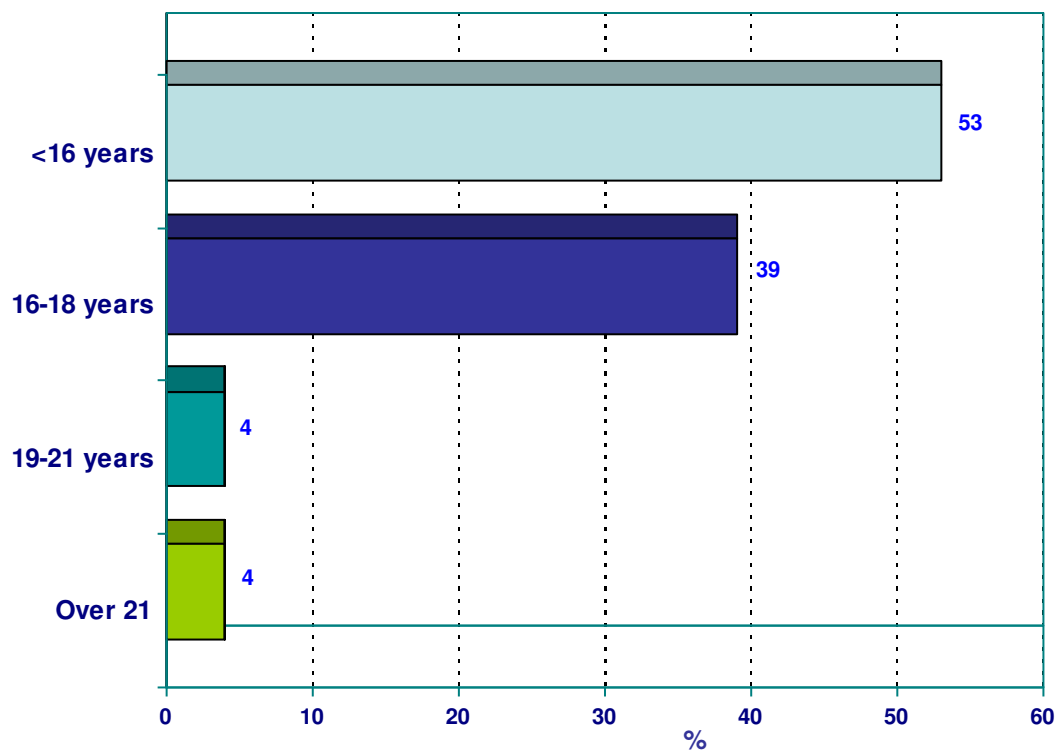
\* Only asked if diagnosed during childhood/teens

## 12.2 Age at which young adults start to take responsibility

Just over half (53%) of the online respondents who were diagnosed during their childhood or teens started to take responsibility for their own diabetes care by the age of 15, and almost all had done so by the time they were 18.

Figure 22: Age at which taking responsibility

QC8: At what age did you begin to take over responsibility for your own diabetes care?



Base: n=99 (if diagnosed during childhood/teens)

As shown in Table 24 below, the younger they were diagnosed, the younger they generally were when they started to take over responsibility for their own diabetes care.

Table 24: Responsibility for managing diabetes as a function of age diagnosed and current age

QC8: At what age did you begin to take over responsibility for your own diabetes care?								
	Total	Age Diagnosed			Current Age			
		<10 yrs	11-14 yrs	15-18 yrs	16-18	19-23	24-29	30-35
Base	(99*)	(60)	(28)	(11)	(25)	(37)	(27)	(10)
Under 16 years	53%	62%↑	50%	9%↓	80%	41%	44%	50%
Between 16-18 years	39%	35%	32%	82%	20%	49%	44%	40%
Between 19-21 years	4%	0	11%	9%	0	8%	4%	0
Over 21 years	4%	3%	7%	0	0	3%	7%	10%

↑↓ indicates that the differences shown are statistically significant

\* Only asked if diagnosed during childhood/teens, and if taking responsibility

### 12.3 Usage of paediatric diabetes services

Online survey respondents were asked a set of questions about their usage of paediatric diabetes services, and the transition to adult care.

- Of those aged 16-18 years, 46% were currently attending a paediatric diabetes clinic, 23% were going through transition, 5% used to go to a paediatric clinic but are now using adult services, whilst 15% had always used adult services.
- By the aged of 19-23, only 3% were still going to a paediatric clinic, and 13% were going through transition. The majority (75%) were now using adult services.
- The vast majority (70%) of those diagnosed in their late teens (15-18 years) were directed straight to adult services.

Table 25: Use of paediatric diabetes services as a function of age diagnosed and current age

QD5A: The following question relates to the period when you are moving from child or adolescent services to adult diabetes care – the ‘transition’ period. Please tick the option more relevant to you								
	Total	Age Diagnosed			Current Age			
		<10 yrs	11-14 yrs	15-18 yrs	16-18	19-23	24-29	30-35
<i>Base*</i>	(258)	(124)	(71)	(63)	(39)	(69)	(78)	(72)
Currently going to a paediatric clinic	8%	7%	11%	5%	46%↑	3%	0	0
Used to go to a paediatric clinic but now using adult services	49%	70%↑	46%	10%↓	5%↓	61%↑	59%↑	50%
Currently going through transition	7%	7%	7%	6%	23%↑	13%	0	0
Always used adult services	30%	10%↓	28%	70%↑	15%↓	14%↓	33%	49%↑

↑↓ indicates that the differences shown are statistically significant  
 \* Only asked if diagnosed with type 1 diabetes during childhood/teens

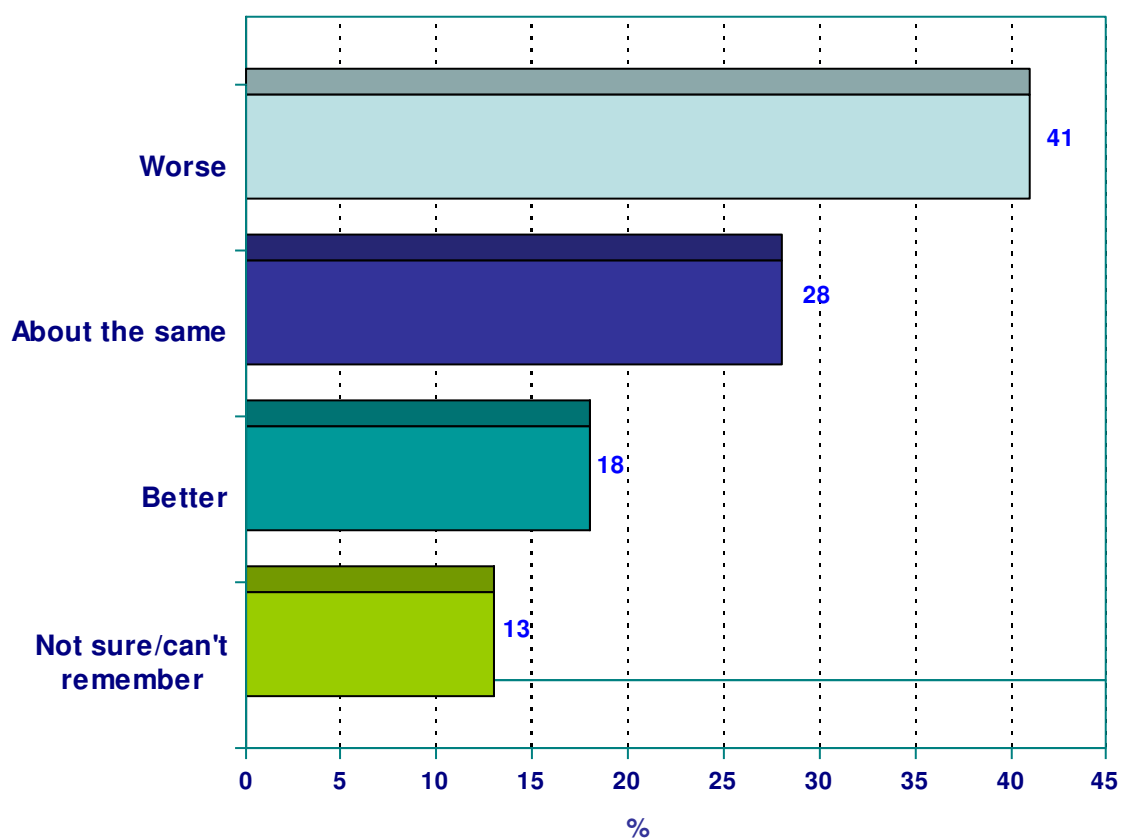
## 12.4 Rating of adult diabetes services

Nearly half (41%) of those who had attended both adult and paediatric diabetes services rated the treatment and care received at adult services as slightly or much worse. Eighteen percent felt the services were better.

***“You go from the RCH to Adolescent Health Services, and then suddenly you’re out on your own.”***

Figure 22: Rating of adult diabetes services

Q5B: How do you rate the adult diabetes treatment and care compared to those you received at the paediatric clinic?



Base: n=144 have been through transition

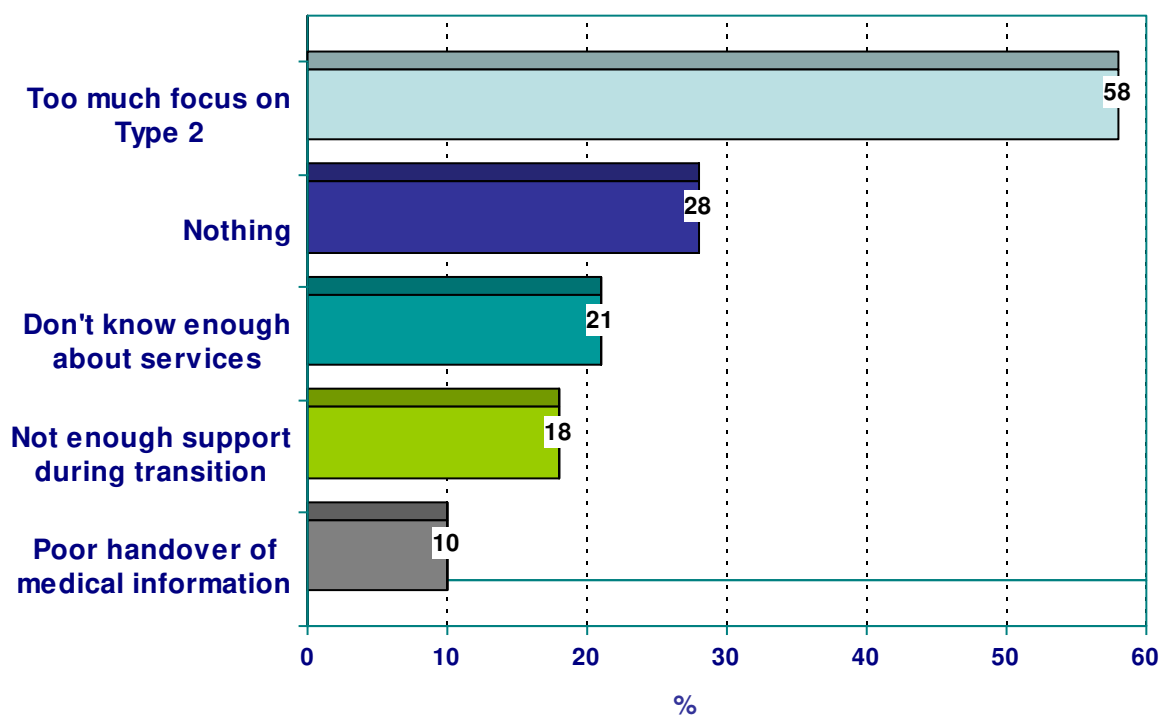
## 12.5 Barriers to using adult diabetes services

Asked what, if anything, was preventing or limiting use of adult services to manage diabetes, 38% said that there is too much focus on type 2 diabetes, 14% said that they don't know enough about where the services are and how to access them, and 12% said are not are not enough support services to help people through the transition period.

***“There aren’t any services for young people. It’s all for older people with type 2. Type 1s aren’t looked after. We’re rare.”***

Figure 23: Barriers to using adult diabetes services

QD5C: What, if anything, is preventing or limiting your use of adult services to manage your diabetes?



Base: n=221 have been through transition

Concerns about how to access adult services were particularly prevalent amongst young adults in their early to late twenties, as shown in the table below.

Table 26: Barriers as a function of age diagnosed and current age

QD5C: What, if anything, is preventing or limiting your use of adult services to manage your diabetes?								
	Total	Age Diagnosed			Current Age			
		<10	11-14	15-18	16-18	19-23	24-29	30-35
Base*	(221)	(109)	(58)	(54)	(17)	(61)	(72)	(71)
There is too much focus on type 2 diabetes/insufficient focus on type 1 diabetes	58%	61%	53%	57%	53%	54%	63%	59%
I don't know enough about where the services are and how I can access them	21%	22%	28%	13%	6%	21%	29%↑	17%
There are not enough support services to help people through the transition period	18%	27%↑	17%	2%↓	12%	25%	21%	11%
Poor handover of my medical information from the child/adolescent services to adult service	10%	15%	9%	2%	6%	16%↑	13%	3%↓
Other	12%	10%	17%	11%	12%	15%	14%	8%
Nothing, I'm currently happy with the adult service I am using	28%	26%	31%	28%	18%	18%↓	19%	46%↑
Not sure / can't remember	5%	5%	3%	9%	18%	8%	3%	3%

↑↓ indicates that the differences shown are statistically significant

\*Only asked if diagnosed with type 1 diabetes during childhood/teens and have gone through transition to adult services

## 13. Information Needs

### 13.1 Current knowledge

There is no shortage of information and advice available for people who have diabetes. The internet alone is a ready source of material on the medical causes of diabetes, various treatments, advice on diet and exercise, and even chat sites for people with diabetes where they can come together and talk. Yet, many of the young adults who took part in the research felt hopelessly ill-informed.

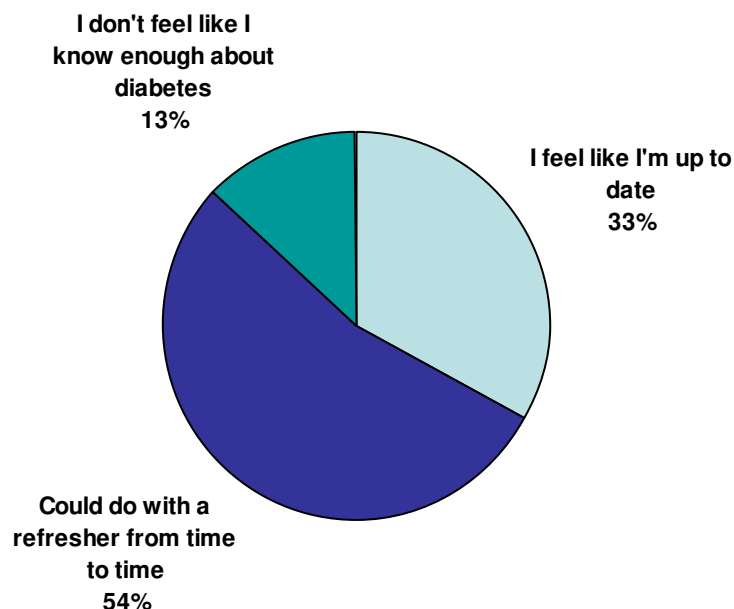
***“I went to see the diabetes educator last year and said ‘I don’t know anything at all because no-one bothered to explain it to me’”***

***“I have no idea what options are out there.”***

Just over half of the online survey respondents said that they know quite a bit about diabetes, but could do with a refresher from time to time. One in ten said they don’t know much at all.

Figure 24: Knowledge about managing diabetes

QF1 Which of the following best describes you in terms of how much you know about managing diabetes?



Base: n=414

Interestingly, the survey suggests that young adults with type 2 diabetes feel least knowledgeable about diabetes, with 35% saying that they don't understand much at all about the condition.

Whilst there were no differences as a function of current age, those who had been living with diabetes for many years felt more knowledgeable about diabetes than those who were diagnosed in their late twenties. However, those who were diagnosed as young children also complained that they were never completely educated about diabetes, as much of the information and support was targeted at their parents.

***“Because I was so young, no-one explained anything. It was a bit of a problem when I got old enough to manage myself.”***

Table 27: Knowledge of how to manage diabetes as a function of type of diabetes and age diagnosed

QF1: Which of the following best describes you in terms of how much you know about managing diabetes?									
	Total	Type of Diabetes			Age Diagnosed				
		type 1	type 2	GDM	<10 yrs	11-14 yrs	15-18 yrs	19-25 yrs	26+ yrs
<i>Base</i>	(414)	(358)	(49)	(7*)	(124)	(71)	(63)	(84)	(72)
I feel like I'm up to date with just about all there is to know	33%	35%↑	20%↓	0	40%↑	31%	30%	40%	17%↓
I know quite a bit about diabetes, but could do with a refresher from time to time	54%	55%	45%	43%	53%	58%	59%	42%↓	61%
I don't feel like I know enough about diabetes	13%	9%↓	35%↑	57%	6%↓	11%	11%	18%	22%↑

↑↓ indicates that the differences shown are statistically significant  
 \* Caution: small sample size. Care is required when interpreting the results

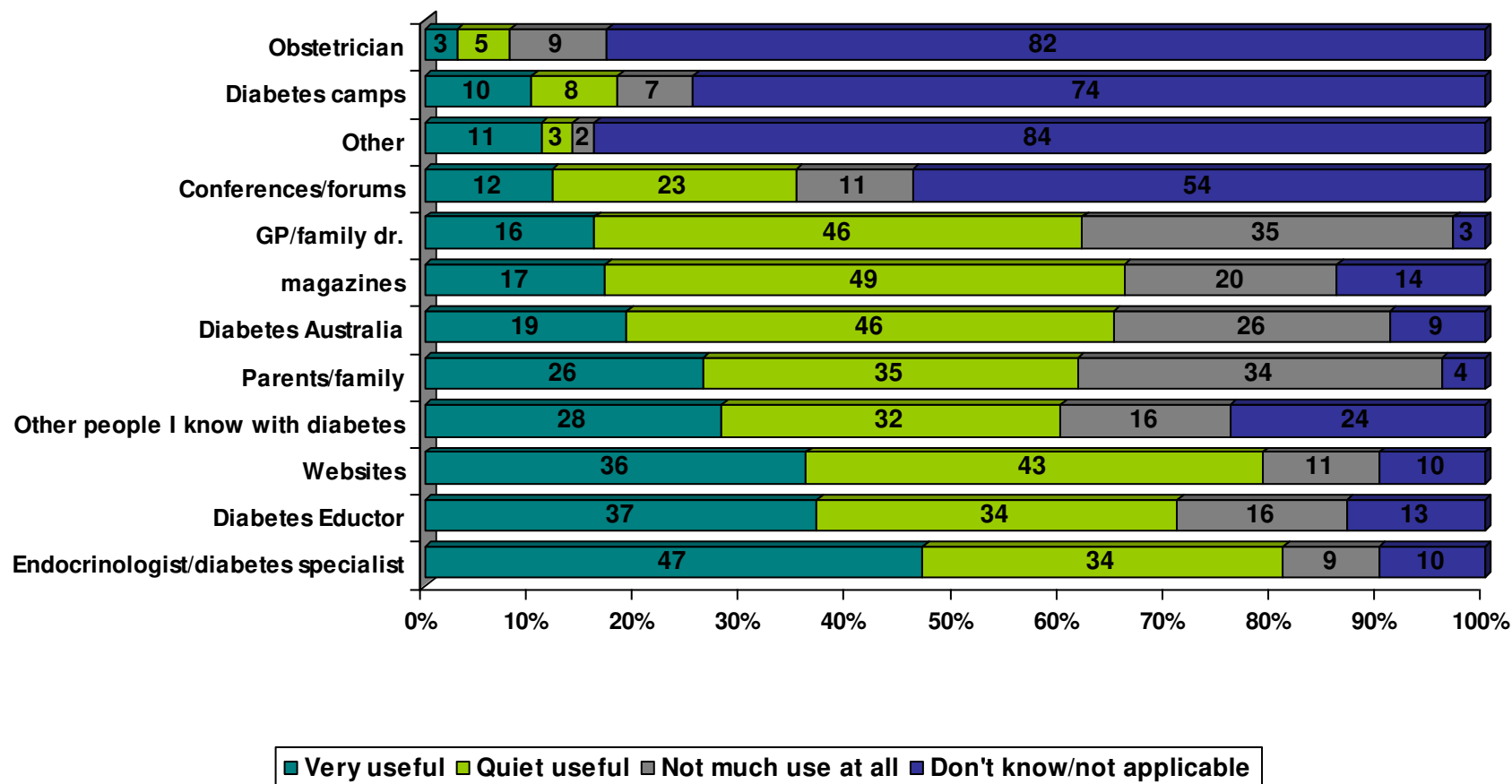
## 13.2 Sources of information

On-line survey respondents were asked to rate the usefulness of various sources of information and support. According to this analysis, the best sources of information for young adults are:

- endocrinologist and diabetes specialists (rated by 47% as very useful),
- diabetes educator (37% very useful),
- websites (36% very useful),
- other people who have diabetes (28% very useful).

Figure 25: Sources of information and support

QF3 Up until now, how useful have the following been as a source of information and support?



Base: n=414

However, sources of information and support varied significantly by the type of diabetes and age of person with diabetes.

Table 27: Sources of information and support as a function of type of diabetes and age

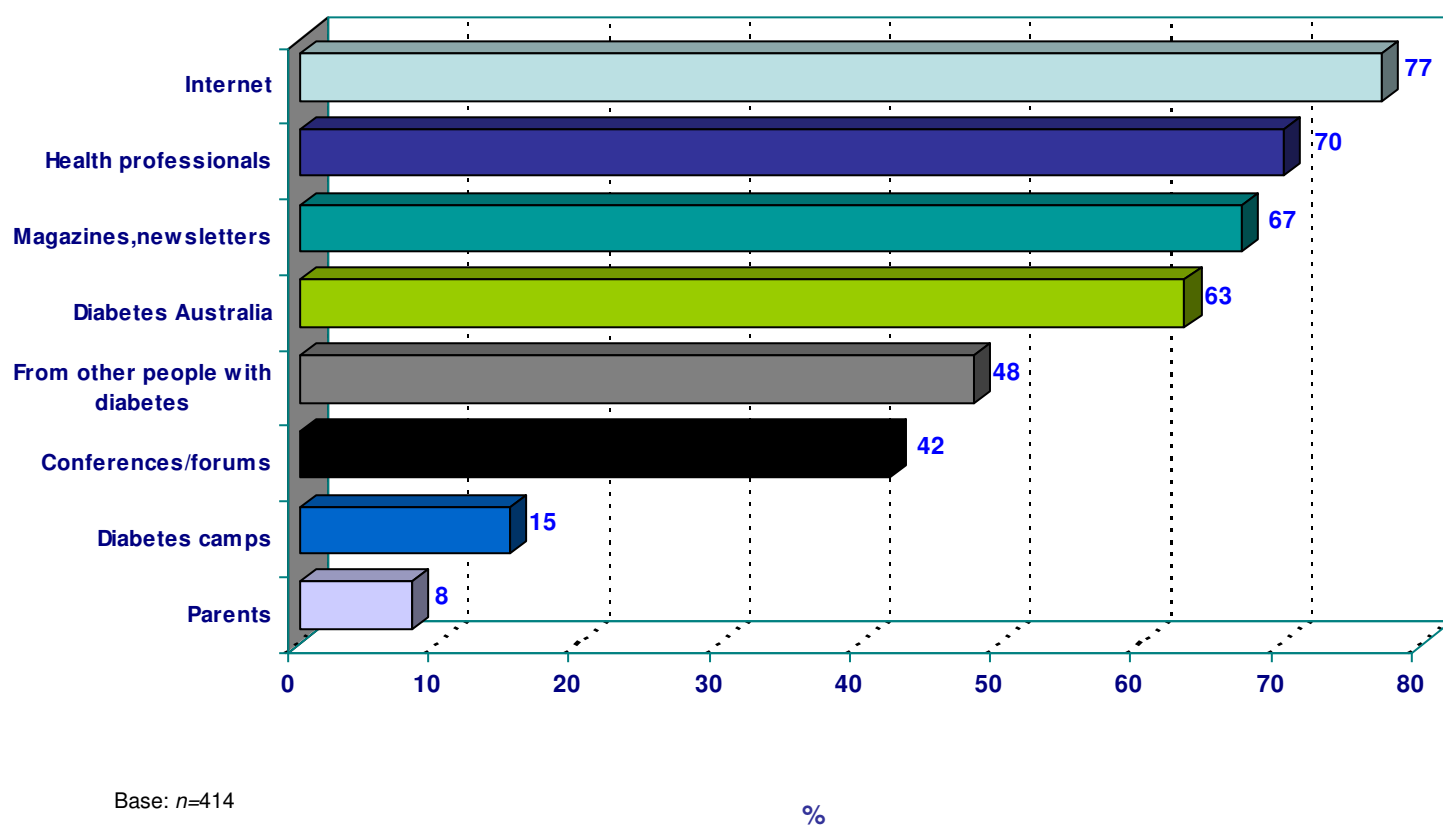
F3 Up until now, how useful have the following been as a source of information and support?								
	Total	Type of Diabetes			Current Age			
		type 1	type 2	GDM	16-18	19-23	24-29	30-35
Base	(414 )	(358)	(49)	(7*)	(39)	(90)	(130)	(155)
Endocrinologist/diabetes specialist	47%	51%↑	24%↓	14%	41%	42%	44%	54%↑
Diabetes educator	37%	39%↑	22%↓	29%	54%↑	41%	33%	34%
Websites	36%	38%↑	20%↓	43%	15%↓	33%	43%↑	37%
Other people I know who have diabetes	28%	30%↑	14%↓	29%	23%	18%↓	32%	32%
Parents/family	26%	26%	31%	29%	54%↑	32%	22%	20%↓
Diabetes Australia	19%	18%	24%	43%	26%	14%	22%	17%
Magazines/journals/newsletters	17%	17%	14%	14%	13%	16%	21%	15%
GP/family doctor	16%	15%↓	27%↑	43%	18%	18%	15%	16%
Conferences/forums	12%	14%↑	4%	0	8%	8%	18%↑	12%
Other	11%	14%	0	0	14%	8%	9%	12%
Diabetes camps	10%	11%	4%	0	31%↑	10%	12%	4%↓
Obstetrician	3%	3%	2%	0	0	2%	3%	5%
Midwife	0	0	2%	0	0	0	2%↑	0
↑↓ indicates that the differences shown are statistically significant								
* Caution: sample size is small. Care is required when interpreting these results.								

## 13.3 Preferred information channels

The most popular way to receive information on diabetes was via the internet (77%). However, young adults also value getting information from health professionals (70%), through magazines and newsletters (67%), and from Diabetes Australia (63%).

Figure 26: Preferred information channels

QF4: How would you like to receive information on diabetes?



As shown in Table 28 on the following page, young adults with type 1 and type 2 diabetes differed in their level of enthusiasm for forums and events that bring young adults with diabetes together. Clearly forums were valued more highly by young adults with type 1 diabetes. They were also more popular with young women.

Whilst camps did not rate highly overall, they are clearly an important channel of information for a large proportion of teenagers with diabetes (45%). Many teenagers also like their parents to give them information (41%).

People in rural and remote areas are less likely to want to get information from other young adults with diabetes. This is possibly because they don't know many people in their area. However, it might also be related to concerns about anonymity and privacy, which can be hard to achieve in small towns.

Table 28: Preferred information channels as a function of type of diabetes, age, gender and location

QF4: How would you like to receive information on diabetes?												
	Total	Type of Diabetes			Current Age				Gender		Location	
		Type 1	Type 2	GDM	16-18	19-23	24-29	30-35	Male	Female	Metropolitan	Regional/remote
Base	(414)	(358)	(49)	(7)	(39)	(90)	(130)	(155)	(93)	(321)	(292)	(110)
The internet	77%	79% ↑	63% ↓	86%	62% ↓	68% ↓	83% ↑	81%	75%	78%	77%	75%
Through health professionals	70%	71%	69%	57%	56% ↓	69%	71%	74%	68%	71%	72%	65%
Magazines/journals/newsletters	67%	67%	63%	57%	62%	68%	69%	65%	53% ↓	71% ↑	64%	71%
Diabetes Australia	63%	62%	67%	86%	54%	60%	63%	66%	57%	64%	62%	67%
From other people who have diabetes	48%	47%	51%	43%	49%	43%	48%	50%	43%	49%	50%	38% ↓
Conferences/forums for young people with diabetes	42%	45% ↑	20% ↓	29%	36%	47%	42%	40%	28% ↓	46% ↑	42%	44%
Diabetes camps	15%	16%	12%	14%	46% ↑	18%	14%	7%	12%	16%	15%	15%
Through parents	8%	8%	14%	14%	41% ↑	17%	6%	3%	10%	8%	9%	7%

↑↓ indicates that the differences shown are statistically significant  
 \* Caution: sample size is small. Care is required when interpreting these results.

## 13.4 Topics would like to know more about

Topics that young adults would particularly like to know more about include new developments in medication and technology (of especially high interest to young adults with type 1 diabetes). They would also like to know about: discounts and services available through the NDSS, travel advice, how to make appropriate food choices, how to minimize the chances of getting complications, support groups, how to exercise appropriately, what to do if planning a baby, and issues associated with drugs and alcohol. One in three would also like to know more about how to care of their feet.

Table 29: Topics would like to know more about as a function of type of diabetes and age diagnosed

QF2: On which of the following topics would you like to receive more information? (TICK AS MANY OPTIONS AS YOU'D LIKE)									
	Total	Type of Diabetes			Age Diagnosed				
		Type 1	Type 2	GDM	<10	11-14	15-18	19-25	26+
Base	(414)	(358)	(49)	(7*)	(124)	(71)	(63)	(84)	(72)
New developments in medication/technology	74%	79%↑	47%↓	43%	80%	75%	78%	70%	67%
Discounts and services available through the NDSS	58%	59%	51%	57%	60%	59%	63%	54%	54%
Travel advice	46%	47%	39%	29%	47%	46%	59%	45%	35%↓
How to make appropriate food choices	44%	41%↓	69%↑	71%	36%	41%	51%	46%	54%
How to minimise the chances of getting complications	45%	43%	53%	71%	42%	38%	35%	54%	54%
Support groups/activities for young people who have diabetes	43%	44%	37%	14%	44%	41%	48%	45%	38%
How to exercise appropriately	40%	36%↓	65%↑	57%	32%↓	37%	44%	43%	47%
Base	(414)	(358)	(49)	(7*)	(124)	(71)	(63)	(84)	(72)
What to do if you're pregnant or planning a	35%	35%	31%	43%	33%	37%	43%	36%	26%

QF2: On which of the following topics would you like to receive more information? (TICK AS MANY OPTIONS AS YOU'D LIKE)

	Total	Type of Diabetes			Age Diagnosed				
		Type 1	Type 2	GDM	<10	11-14	15-18	19-25	26+
baby									
Impact of diabetes on your baby (if pregnant)	32%	32%	31%	14%	31%	35%	38%	35%	22%
Issues relating to drugs and alcohol	31%	32%	31%	14%	32%	35%	32%	24%	35%
How to care for feet	30%	29%	41%	43%	31%	30%	32%	27%	32%
Complications of diabetes	25%	2%↓	41%↑	57%	20%	30%	19%	21%	39%↑
What to do if you have a hypo	12%	10%	24%↑	29%	10%	11%	10%	14%	17%
How and when to test your blood sugar	12%	9%	27%↑	29%	10%	10%	13%	11%	17%
How to take your medicines	9%	8%	16%	0	9%	6%	5%	12%	13%
Minimise the chance of getting type 2, if you've previously had gestational diabetes before	1%	0↓	4%↑	14%	0	0	0	2%↑	1%
Other	6%	6%	4%	0	6%	8%	3%	5%	6%

↑↓ indicates that the differences shown are statistically significant

\* Caution: sample size is small. Care is required when interpreting these results.

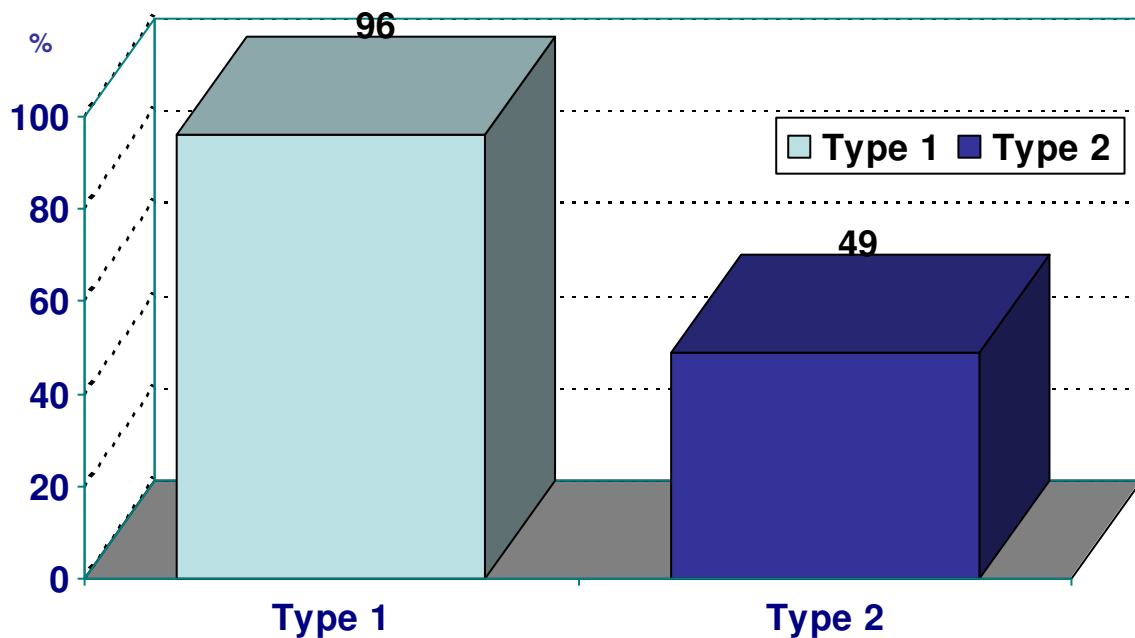
# 14. Dealing with hypoglycaemia

## 14.1 Incidence

Nearly all (96%) young adults with type 1 diabetes, and nearly half of those with type 2, have experienced a 'hypo' that made them feel unwell.

Figure 27: Incidence of hypoglycaemia

QE1: Since you've been diagnosed with diabetes, have you ever experienced a 'hypo' (a sudden drop in blood sugar levels) that made you unwell?



Base: :n=414

Overall, the average number of 'hypos' each week was 2.4, with an average of one serious hypo in the last six months, and 3.4 hypos whilst they were sleeping in the last six months.

Table 30: Frequency experience hypoglycaemia by type of diabetes and current age

Q2,3,&4: In the last week, how many times (if at all) have you had a 'hypo'? And in the last 6 months, how many times, (if at all) have you ever experienced a severe 'hypo' where you needed someone else's help to recover? And in the last 6 months, how many times (if at all) have you had a hypo while you were sleeping?

	Total	Type of Diabetes			Current Age			
		Type 1	Type 2	GDM	16-18	19-23	24-29	30-35
Base	(414)	(358)	(49)	(7)	(39)	(90)	(130)	(155)
Average number of hypos in last week	2.1	2.4	0.5	0.9	2.1	2.0	2.2	2.2
Average number of severe hypos in last 6 months	0.9	1.0	0.1	0.3	1.3	0.9	1.0	0.7
Average number of hypos whilst sleeping in last 6 months	2.8	3.1	0.5	0.0	2.2	3.0	3.0	2.6

⬆⬇ indicates that the differences shown are statistically significant

\* Caution: sample size is small. Care is required when interpreting these results.

## 14.2 Anxiety about hypoglycaemia

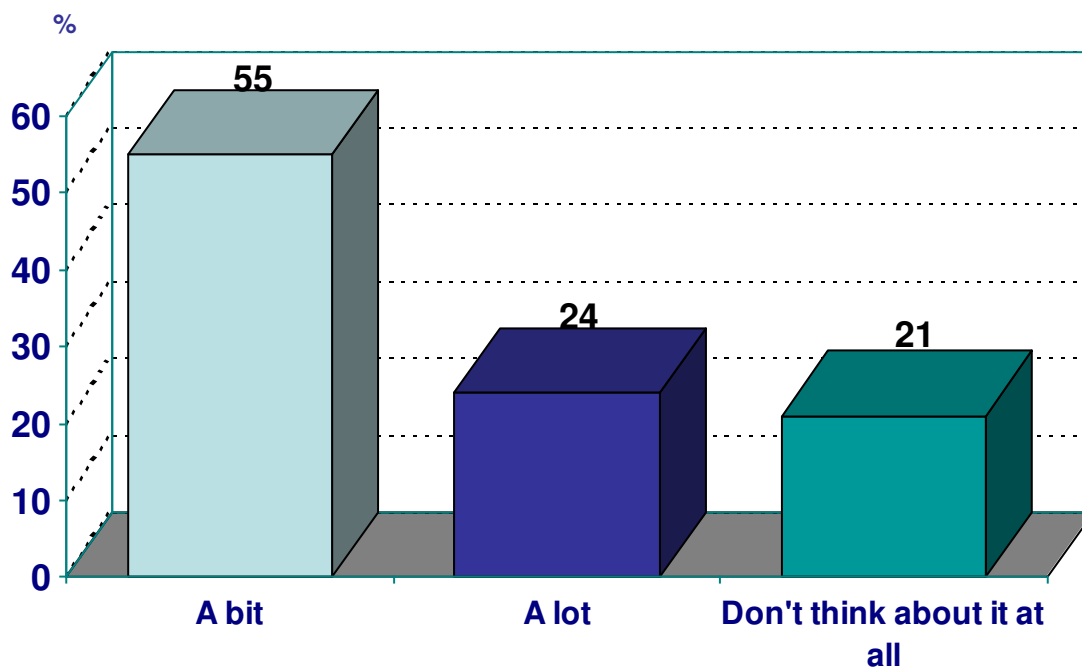
Over half of young adults with diabetes worry about having a hypo, whilst one in four (24%) worry a lot. For some, it is a cause of great anxiety than has impacted on their day to day lives and feeling of independence. Some fear sleeping alone, in case they have a serious hypo whilst they are sleeping.

***“Hypos are my least favourite thing. I feel really sick and it scares me.”***

***“I do really worry that I won’t wake up in the morning. I’ve had a couple of scares, and it freaks me out, and I don’t really like sleeping alone.”***

Figure 28: Anxiety about hypoglycaemia

QE5: To what extent do you worry about having a hypo?



Base: n=372

Anxiety about hypoglycaemia tends to increase as they get older, with almost one in three people over the age of 25 worrying about it a lot

Table 31: Anxiety about hypoglycaemia as a function of type of diabetes and age

QE5: To what extent do you worry about having a hypo?

	Total	Type of Diabetes			Current Age			
		Type 1	Type 2	GDM	16-18	19-23	24-29	30-35
Base**	(372)	(342)	(24)	(6*)	(34)	(77)	(120)	(141)
I don't think about it at all	21%	20%	29%	33%	29%	27%	16%	19%
It worries me a bit	55%	55%	63%	33%	53%	55%	57%	54%
I worry about it a lot	24%	25%	8%	33%	18%↓	17%↓	28%↑	27%↑
Don't know/can't say	0	0	0	0	0	1%	0	0

↑↓ indicates that the differences shown are statistically significant

\* Caution: sample size is small. Care is required when interpreting these results.

\*\*Base: have ever experienced hypo