



Diabetes
MILES Youth
Study

2014 Survey Report

Suggested citation: Speight J, Hagger V, Trawley S, Hendrieckx C, Browne JL, Cheney J, Pouwer F, Cameron F, Skinner TC, Scibilia R on behalf of the Diabetes MILES Youth reference group (2015). Diabetes MILES Youth Study 2014 Survey Report. Diabetes Victoria, Melbourne.

ISBN 978-0-9873835-0-1 (print)

ISBN 978-0-9873835-1-8 (online)

The Diabetes MILES Study is an international collaborative, first launched in 2011 jointly by Prof Jane Speight, Foundation Director of The Australian Centre for Behavioural Research in Diabetes (ACBRD) and Prof Frans Pouwer from Tilburg University, The Netherlands.

This report details the first findings of the Diabetes MILES Youth Study 2014 survey, which is part of the NDSS Young People with Diabetes National Development Program. The NDSS is an initiative of the Australian Government administered by Diabetes Australia.

The survey report was compiled as part of the NDSS Young People with Diabetes – National Development Program (NDP), in collaboration with researchers at The Australian Centre for Behavioural Research in Diabetes (ACBRD), a partnership for better health between Diabetes Victoria and Deakin University.

For further information about:

- the NDSS, visit: www.ndss.com.au
- the ACBRD, visit: www.acbrd.org.au.

Research Team

The survey was led by:

- Renza Scibilia, NDSS National Development Program Leader for Young People with Diabetes
- Professor Jane Speight, Foundation Director of the ACBRD.

The research team includes:

- Dr Steven Trawley (Research Fellow, Project Manager)
- Ms Virginia Hagger (Research Fellow)
- Dr Christel Hendrieckx (Research Fellow)
- Dr Jessica Browne (Research Fellow).

Reference Group

We would like to thank all those who have been instrumental in the development of the Diabetes MILES Youth Study. The design of this survey was informed by two reference groups (both listed in Appendix 1):

- the NDSS NDP Young People with Diabetes Expert Reference Group (ERG)
- the Diabetes MILES Youth Study reference group, comprising 12 multi-disciplinary, national and international experts who were invited to share their expertise in paediatric / behavioural diabetes research.

Both reference groups were consulted on the content of the survey, and will continue to collaborate with the research team in the preparation of peer-reviewed publications arising from the Diabetes MILES Youth Study.

Survey Respondents

Last, but certainly not least, we would like to thank our survey respondents:

- young people (aged 10-19 years) with type 1 or type 2 diabetes
- parents of young people (aged 10-19 years) with diabetes.

We hope you find this report of interest.

The findings from this survey will be used by Diabetes Australia to identify priorities and opportunities to expand and/or improve the support services provided to young people with diabetes and their families through the National Diabetes Services Scheme.

Foreword

The developmental period of adolescence opens up exciting new opportunities for young people to engage differently with family, friends and the world around them. It can also be a period of great challenge and personal stress and many young people struggle to find a path through adolescence unscathed. For young people with diabetes, finding a path through adolescence can be particularly challenging; they must learn to negotiate the direction and shape of their personal path with the added responsibility of diabetes self-management.

This report describes the findings of the first Diabetes MILES Youth Study that was undertaken in 2014 as part of the NDSS Young People with Diabetes National Development Program, an initiative of the Australian Government administered by Diabetes Australia. The Diabetes MILES Youth Study set out to understand how adolescents with diabetes and their parents are managing. Its aim was to explore the well-being and quality of life of young people with diabetes and their parents and to investigate self-reported diabetes care and health outcomes. This report provides challenging information about young people with diabetes, including concerns about body image, mental health and diabetes self-management. It also provides important insights about how parents are managing. Here again, the results are sobering.

The Diabetes MILES Youth Study was undertaken in collaboration with researchers at The Australian Centre for Behavioural Research in Diabetes (ACBRD), a partnership for better health between Diabetes Victoria and Deakin University. All involved are to be congratulated for their efforts at starting to make visible the types of challenges that too often remain hidden by young people living with diabetes and their families. An ongoing challenge for researchers is understanding how best to recruit a study sample that is nationally representative of young people with diabetes and their parents.

As great a challenge is how to respond to the health issues experienced by young people with diabetes and their families. These data provide a particular challenge to health services, from primary care through to specialist child and young adult diabetes services, about how to ensure that health services are appropriately comprehensive in their ability to respond to the diversity of issues experienced by young people with diabetes – and their families. It is hoped that these data provide a trigger to health services and other support services that target adolescents with diabetes about how they might better meet young people's needs.

We also have a responsibility to engage young people in finding solutions that resonate with them. We need to ensure that young people with diabetes are not viewed as 'a problem' but embraced equally as experts in their own lives, their own diabetes, and their own healthcare - this is the least we can do.



Professor Susan Sawyer MBBS MD FRACP
Chairman, NDSS NDP Young People with Diabetes Expert Reference Group

Table of Contents

Acknowledgements	1
Table of Contents	3
List of Figures	4
List of Tables	4
Abbreviations	5
Executive Summary	6
Introduction	9
Method	10
Demographics	12
General Quality of Life	18
General Emotional Well-being	19
Depression and Anxiety	20
Diabetes-Related Distress	21
Disordered Eating	22
General Health	24
Diabetes Self-Care and Management	25
Access to Healthcare	28
Family Support	29
General Emotional Well-being and Anxiety: Parents	32
Diabetes-Related Distress: Parents	33
Fear of Hypoglycaemia & Hyperglycaemia: Parents	34
Discussion	36
References	40
Appendix I: Reference Groups	43
Appendix II: Variables included in survey (Youth version)	44
Appendix III: Variables included in survey (Parent version)	46
Appendix IV: Summary of scales included in this report	47

List of Figures

List of Figures

Figure 1. Device on which survey was completed by youth and parent respondents	11
Figure 2. Youth and parent respondents' location (by postcode).....	13
Figure 3. Youth general quality of life by gender and age group (N=780)	18
Figure 4. General emotional well-being of youth by gender and age group (N=779).....	19
Figure 5. Youth depression symptoms and severity by gender and age group (N=551)	20
Figure 6. Youth anxiety symptoms and severity by gender and age group (N=551)	20
Figure 7. Youth diabetes-related distress by gender and age group (N=537).....	21
Figure 8. Average eating problem score by age and gender (N=510)	22
Figure 9. Self-rated health over the past four weeks (N=493)	24
Figure 10. General health by diabetes duration and co-morbidity	24
Figure 11. Diabetes treatment type by age group (N=763).....	25
Figure 12. Frequency of blood glucose checks per day reported by youth age group (N=751).....	26
Figure 13. Parents' general emotional well-being by child's age group and child's gender (N=825).....	32
Figure 14. Parents' anxiety symptoms by child's age group and gender (N=821)	32
Figure 15. Parents' diabetes-related distress by child age group (N=776)	33
Figure 16. Top hypoglycaemia concerns by history of hypos in the previous 12 months (N=740).....	34

List of Tables

Table 1. Youth response rate compared to invitations sent and total NDSS Registrant population aged 10-19 years with type 1 diabetes (by state).....	12
Table 2. Age and state / territory of youth (N=781) and parent respondents (N=826)	12
Table 3. Socio-economic status and area for youth (N=781) and parents (N=826).....	13
Table 4. Youth education/employment status (N=781).....	13
Table 5. Age and gender of youth respondents (N=781)	14
Table 6. Parental report of age and gender of child with diabetes (N=826)	14
Table 7. Top 3 problem areas in diabetes for youth by gender	21
Table 8. Binge eating over the past 14 days	22
Table 9. Top 2 items most frequently reported by gender	22
Table 10. Additional medical conditions most commonly reported by youth (N=314).....	24
Table 11. Visits to healthcare professional during past 12 months (N=772)	28
Table 12. Responsibility for diabetes care, according to parent respondents (N=744)	29
Table 13. Youth perceptions of responsibility for diabetes care (N=759)	29
Table 14. Frequency of arguments about diabetes between youth and parents, according to youth respondents (N=759)	29
Table 15. Parents' concerns about hyperglycaemia (N=813).....	35

List of Abbreviations

ACBRD	The Australian Centre for Behavioural Research in Diabetes
BMI-SMT	Body Mass Index Based Silhouette Matching Test
DEPS-R	Diabetes Eating Problem Survey-Revised
DA	Diabetes Australia
DA–Vic	Diabetes Victoria
DKA	Diabetic ketoacidosis
GAD-7	Generalised Anxiety Disorders 7-item Questionnaire
GP	General practitioner
HbA1c	Glycosylated haemoglobin (a measure of average blood glucose over 8-12 weeks)
HCCQ	Healthcare Climate Questionnaire
HCP	Healthcare professional
HFS	Hypoglycaemia Fear Survey
MILES	Management and Impact for Long-term Empowerment and Success
MY-Q	Mind Youth Questionnaire
NDSS	National Diabetes Services Scheme
PAID-T	Problem Areas In Diabetes – Teen version
PAID-PT	Problem Areas in Diabetes – Parents of Teens version
PHQ-8	Patient Health Questionnaire (8-item version)
QoL	Quality of Life
SMBG	Self-monitoring of blood glucose
WHO-5	World Health Organization Wellbeing Index (5-item version)

Executive Summary

There are 10,580 young Australians aged 10-19 years living with diabetes and registered with the NDSS (type 1: 9,842; type 2: 738)ⁱ. This survey was undertaken to better understand the motivators, behaviours and psychological well-being of young people with diabetes to inform improvements in services and resources for supporting self-management.

For young people with diabetes, management of the transition from paediatric to adult care is vital to optimise diabetes self-management and to prevent / delay long-term complications, and yet is a time when many young people do not manage their diabetes optimally.

The aim of the Diabetes MILES Youth Study was to explore the well-being and quality of life of young people with diabetes and their parents, and to investigate self-reported diabetes care and health outcomes.

Method

The survey was conducted entirely online. Six versions of the survey were developed for different sub-samples:

- for young people aged 10 to 12 years with:
 - a) type 1 diabetes, and b) type 2 diabetes
- for young people aged 13 to 19 years with:
 - a) type 1 diabetes, and b) type 2 diabetes
- for parents of young people (aged 10 to 19 years) with: a) type 1 diabetes, and b) type 2 diabetes.

In August 2014, an invitation to complete the online survey was posted to 5,928 NDSS Registrants with type 1 diabetes and 417 Registrants with type 2 diabetes (or their parents, if they were less than 18 years old) in the relevant age group, who had previously consented to be contacted for research purposes. The survey was also advertised via flyers in diabetes clinics, social media postings and notices in relevant publications (e.g. Diabetes Australia magazines).

Due to the very low number of responses from young people with type 2 diabetes (N=11) and their parents (N=8), their data were excluded from this report. The remainder of this report focuses on young people with type 1 diabetes, and parents of young people with type 1 diabetes.

Sample

This report presents data from 781 young people with type 1 diabetes (aged 10 to 19 years) and 826 of their parents.

Respondents were from all states and territories, including metropolitan, regional and remote areas.

Young people

- 61% girls, 39% boys
- Mean age: 14 years.

Most young people were born in Australia (91%) spoke English at home (97%), lived with both parents (80%) and were still at school (87%).

Parents

- 88% were mothers, 12% were fathers
- Mean age: 46 years.

Most parents were born in Australia (80%), spoke English at home (98%), were married (79%), had a university education (53%) and were in paid employment (69%).

Emotional Well-being

- Most young people (67%, n=526) reported good quality of life (QoL), but QoL was higher in boys (77%) than girls (61%)
- 28% of young people reported impaired general emotional well-being; 74% of these were girls
- 25% of young people aged 13-19 years reported moderate-to-severe depressive symptoms
- 23% of young people aged 13-19 years reported moderate-to-severe anxiety symptoms
- Girls were more likely to report severe anxiety and depressive symptoms, and girls reported more diabetes-related distress than boys; for girls, such symptoms tended to increase with age, while there were no differences for boys by age group
- In terms of diabetes-related distress, the most common concern for girls aged 13-19 years was 'worrying about their weight', whereas boys were most concerned about 'friends or family not understanding how difficult living with diabetes can be'.

ⁱ Figures correct at August 2014 when surveys were conducted online

Parental Well-being

- 34% of parents reported impaired general emotional well-being (for themselves)
- 8% of parents experienced severe anxiety symptoms
- Parents worried most frequently about 'the future and the possibility of their child developing complications', and 'feeling upset when their child's diabetes management is off track'
- Almost half of the parents surveyed (48%) were frequently worried about their child experiencing hypoglycaemia.

General Health

- Girls (aged 13-19 years) perceived their health to be poorer than boys
- 42% of young people lived with another medical condition as well as type 1 diabetes.

Diabetes Self-Care and Management

- 52% of young people used an insulin pump. In the 18-19 years age group 40% used an insulin pump compared to 60% of the 10-12 years group
- 82% of young people reported checking their blood glucose at least 4 times per day
- On average, young people reported their most recent HbA1c was 64 mmol/mol (8.0%); which is above the target range of <58 mmol/mol (<7.5%)[1]
- 50% of young people forgot to administer their insulin dose at least once during the previous two weeks, and 19% missed (at least) one insulin dose on purpose
- 29% reported having four or more hypoglycaemic events (also referred to as 'hypos' or low blood glucose) during the past week, while 33% of young people had experienced at least one severe hypo in the past 12 months
- 17% reported impaired awareness of hypoglycaemia symptoms, increasing their risk of severe hypoglycaemia
- 54% reported using an 'app' to help them manage their diabetes, with the most common use being for carbohydrate counting.

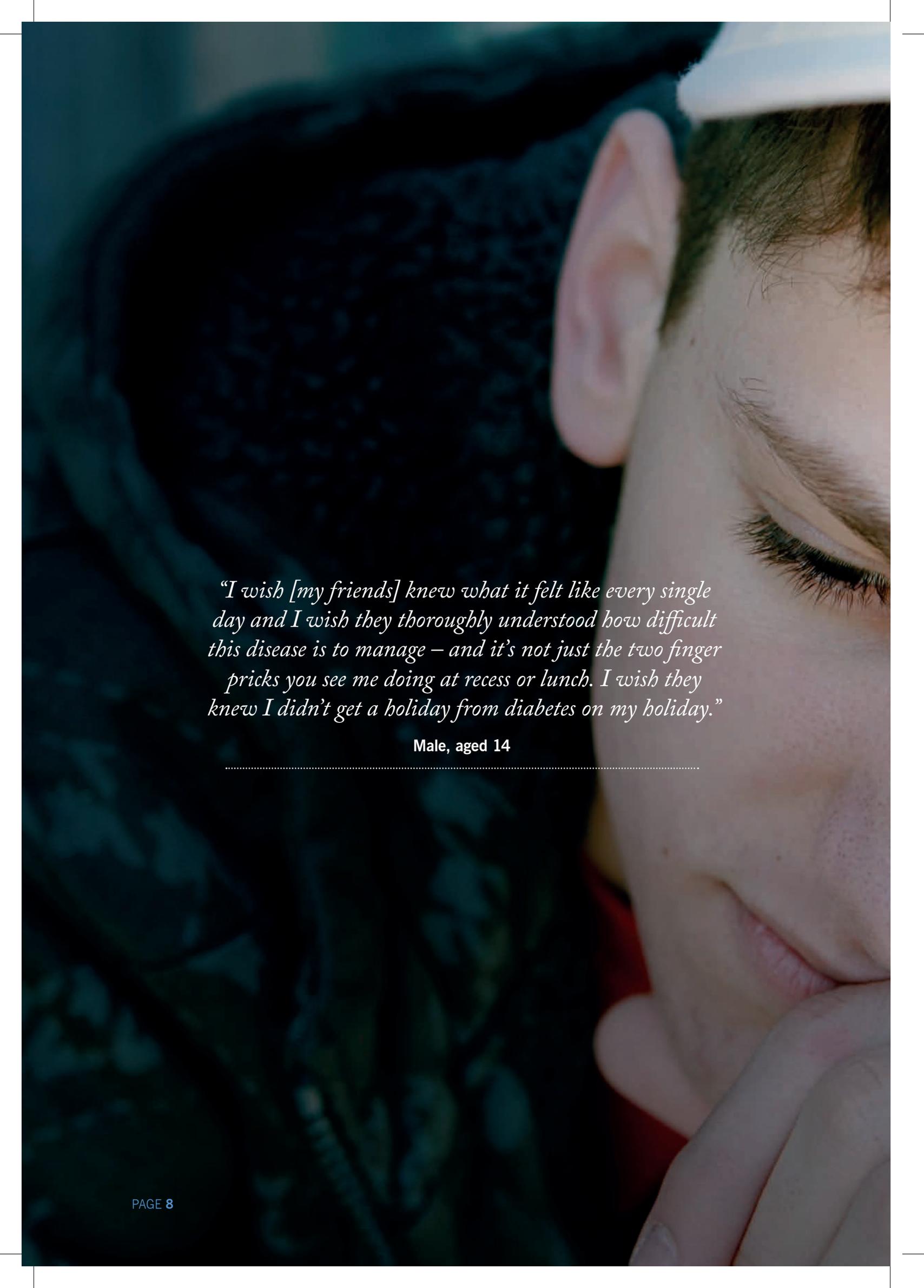
Family Support

- 18% of young people felt they often have too much responsibility for their diabetes care
- Remembering to check blood glucose and take insulin was a common argument between parents and young people with type 1 diabetes.

The Diabetes MILES Youth Study 2014 Survey Report aimed to provide a national 'snapshot' of the emotional well-being, general health and psychosocial issues facing young people with type 1 or type 2 diabetes and their parents. The lack of response from young people with type 2 diabetes and their parents indicates that more targeted methods are needed to engage this group in research.

Respondents (young people with type 1 diabetes and their parents) appear to be more socio-economically advantaged and have better access to healthcare services and resources than the average NDSS Registrant with type 1 diabetes. However, they reported high levels of psychological distress and poor emotional well-being. Thus, the findings reported here are likely to significantly under-estimate the level of distress experienced by young people with type 1 diabetes and their parents. While the burden of diabetes on young people is well documented, the adverse psychological consequences for parents needs greater recognition. The high levels of distress reported by respondents indicates that the psychological support needs of families living with diabetes are currently not being met by existing services.

Further analysis of these results is ongoing and will help to inform the NDSS and health service providers about the support needs of Australian families with young people living with diabetes.



“I wish [my friends] knew what it felt like every single day and I wish they thoroughly understood how difficult this disease is to manage – and it’s not just the two finger pricks you see me doing at recess or lunch. I wish they knew I didn’t get a holiday from diabetes on my holiday.”

Male, aged 14

Young People with Diabetes in Australia

There are 10,580 young Australians aged 10-19 years currently living with diabetes. The majority of these (93%, 9,842) have type 1 diabetesⁱⁱ.

Type 1 diabetes is an autoimmune condition and the most common chronic condition diagnosed in childhood. Type 2 diabetes is typically diagnosed in adulthood but incidence is increasing in young people (currently 738 aged 10 to 19 years in Australia) [2].

Living with diabetes is known to place significant self-care and psychological demands on young people and their families. Adolescence can be a challenging time even without diabetes. Optimal diabetes care is often compromised during this period, which can lead to early-onset of devastating long-term complications. Around one in three young people with diabetes are known to need mental health support [3, 4] and 30-40% of young people with type 1 diabetes are “lost in transition” from paediatric to adult diabetes care [5, 6].

Better understanding of young people’s perceptions about living with diabetes, their self-care behaviours, the support they receive and their unmet needs is required to inform future health policy and service provision, so that young people (and their families) can receive optimal care and support.

Background: The Diabetes MILES – Australia 2011 Survey

The Diabetes MILES (Management and Impact for Longterm Empowerment and Success) – Australia 2011 Survey (www.diabetesmiles.org.au) explored the psychosocial aspects of living with diabetes in a national sample of Australian adults with type 1 or type 2 diabetes. This dataset of over 3,300 respondents continues to provide a wealth of information about the well-being and support needs of adults with diabetes. Importantly, it has raised considerable awareness of these issues amongst Australian healthcare providers and, anecdotally, we know that it has encouraged adults with diabetes to seek out psychosocial support from their peers,

their families and their healthcare providers. Feedback following the 2011 survey indicated that there was a need to conduct a similar large-scale national survey of the impact of diabetes on young Australians with diabetes and their parents.

Diabetes MILES Youth Study

The aim of the Diabetes MILES Youth Study 2014 (henceforth ‘MILES Youth Study’) was to investigate diabetes care, support and emotional well-being of young people (aged 10 to 19 years) with type 1 and type 2 diabetes, and their parents. This national survey had a strong focus on diabetes care behaviours, emotional well-being, quality of life, family relationships and support, to identify the unmet needs of a large and diverse sample of Australian youth with diabetes and their parents.

The response to the MILES Youth Study was very positive. Those who took part were pleased to see that research was being focused on these issues. Their comments are included as quotes throughout this report.

This Report

This report presents a selection of findings, and serves a number of purposes:

- To provide an overview of the main themes and topics that were explored in the survey, and report the top-line results
- To make the initial results of the survey available to young Australians with diabetes and their parents.

Analysis of this large and rich dataset is ongoing. Further reports and peer-reviewed publications will be distributed in due course. For further information, please continue to visit:

- www.ndss.com.au and
- www.diabetesmiles.org.au.

ⁱⁱ Figures correct at August 2014 when surveys were conducted online

Method

Survey Design

The content of the survey was determined by an extensive literature review and consultation with experts (see Reference Groups listed in Appendix 1). Validated scales and items were selected carefully for inclusion. Where an appropriate measure did not exist, was too lengthy, or was not available, the research team developed items unique to the MILES Youth Study.

Six versions of the survey were developed for:

- young people (aged 10 to 12 years) with:
 - a) type 1 diabetes, or b) type 2 diabetes
- young people (13 to 19 years) with: a) type 1 diabetes, or b) type 2 diabetes
- parents of young people (10 to 19 years) with:
 - a) type 1 diabetes, or b) type 2 diabetes.

The questions for the youngest group (10 to 12 years) were similar to those for the 13 to 19 year olds. However, their survey was shorter and differed in some content to reduce burden and avoid inappropriate questions. All surveys were available in English onlyⁱⁱⁱ.

The survey versions were piloted with eight young people and five parents living in the state of Victoria (for convenience of recruiting participants). The feedback led to some minor amendments to the survey instrument. On average, participants took 20-30 minutes to complete the survey.

The variables included in the final survey are listed in Appendix II, and information about the scales included in this report is in Appendix III.

Recruitment

In August 2014, an invitation to complete an online survey was posted to 5,928 NDSS Registrants with type 1 diabetes and 417 young people with type 2 diabetes (or their parents if under 18 years) in the relevant age group. Only those who had previously consented to be contacted for research purposes and who met the study eligibility criteria according to their NDSS record (approximately 59% of NDSS Registrants in this age group) were contacted. The survey was also advertised via flyers in diabetes clinics, social media postings and notices in relevant publications (e.g. Diabetes Australia magazines).

Online Survey

The MILES Youth survey was made available online (www.milesyouth.com) for eight weeks from 11 August 2014. Registrants and parents were informed that they could complete a paper version of the survey if preferred (but no such requests were received).

Upon first entering the online survey page, respondents were immediately invited to read a plain language description of the study and indicate their consent. They then completed preliminary questions so that a tailored version of the survey could be presented according to their age and treatment regimen.

Ethical Approval

The MILES Youth Study received ethical approval from the Deakin University Human Research Ethics Committee, reference number 2014-060.

Study Sample

In total, 934 young people and 1,050 parents entered the survey website. However, 10% of the young people and 20% of the parents did not provide sufficient data (e.g., age and type of diabetes) to enable them to continue to the full survey. A small number of parents were also excluded as their child was not aged 10 to 19 years. An additional 4% of young people and 1% of parents were removed as they failed to complete important sections of the survey (e.g., demographic and well-being questions).

The majority of respondents answered all questions (89%; n=1432). 77% (n=1235) asked for a copy of the survey report and 55% (n=885) were willing to be contacted for further research.

Due to the very low number of respondents who were a) young people with type 2 diabetes (N=11) or b) parents of young people with type 2 diabetes (N=8), their data are excluded from this report.

The final eligible sample for the MILES Youth Study 2014 includes:

- 781 young people with type 1 diabetes
- 826 parents of young people with type 1 diabetes.

ⁱⁱⁱ Funding constraints meant that it was not possible to provide the survey in languages other than English.

Analyses presented in this report refer to this final sample of respondents.

Important note: the parents who responded to the survey are not necessarily the parents of the young people who responded to this survey. All respondents were asked to provide their (or their child's) NDSS number for the purposes of linking youth and parent responses^{iv}. In total, 258 youth/parent dyads were identified by matching the young person's NDSS number to a corresponding number reported by a parent. Data related to the youth/parent dyads will be included in future reports.

How was the MILES Youth Study completed?

Nearly three quarters of parents and young people completed the online survey using a computer (see Figure 1).

More than a quarter of all respondents used a mobile device (e.g., smartphone or tablet) to complete the survey. This demonstrates the importance of making online surveys suitable for completion using mobile devices.

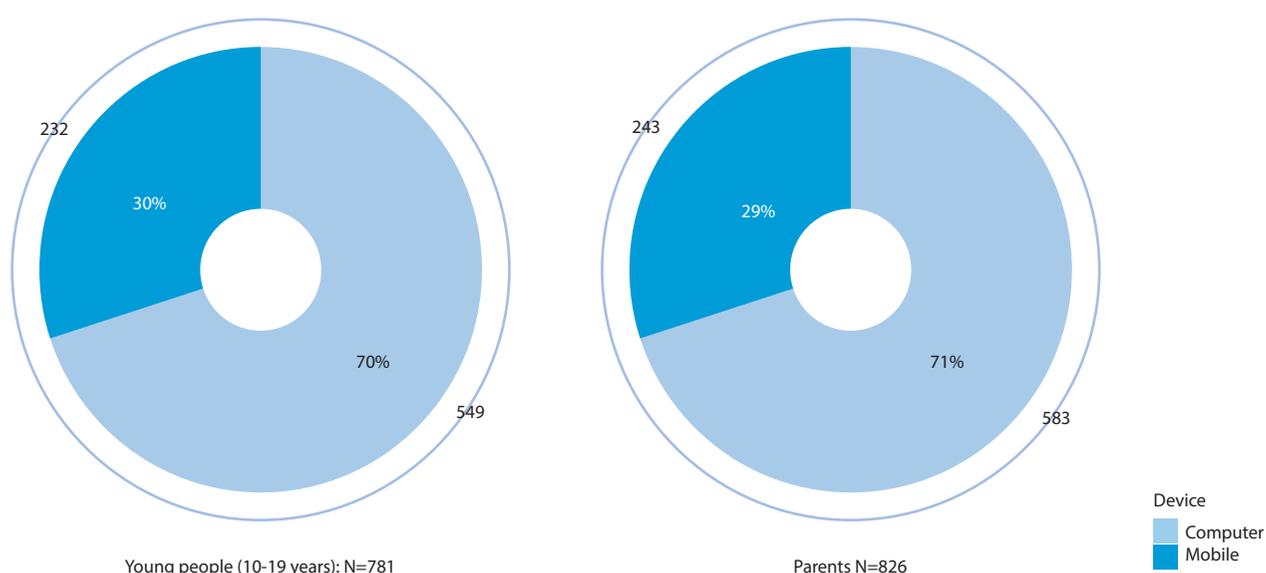
Interpreting data, tables and figures in this report

All data are presented as percentage (number) or mean \pm standard deviation. The mean is the average response. The standard deviation is the variability in scores. A low standard deviation tells you that most people scored quite close to the mean, while a high standard deviation tells you that scores were widely spread.

As mentioned previously, some items did not appear in every version of the survey. In addition, some respondents did not complete every item in the survey they received. As such, **the number of people who responded to each item varies, and is not always consistent with the total number of people who took part.** Each table and figure in this report is accompanied by an indication of the size of the sample (e.g. n=781) upon which the calculations are based. Please note that table percentages may not sum to 100 due to rounding.

For some questions, responses for young people are presented by age group: 10-12, 13-15, 16-17, and 18-19 years. Some questions were inappropriate for the youngest respondents, so data for the 10-12 year old group are not present. For questions asked of both youth and parents, where results are similar only youth responses are reported.

Figure 1. Device on which survey was completed by youth and parent respondents



^{iv} The researchers did not have access to the NDSS database or any personal registrant information.

Demographics

Locality of Respondents

Overall, 781 young people (aged 10-19 years) took part in the MILES Youth Study, representing 13% of those invited to the survey, and 8% of all NDSS Registrants in this age group (Table 1). The highest response rate (21%) was from Tasmania. Young people from all states and territories took part (Table 2 and Figure 2).

Table 1. Youth response rate compared to invitations sent and total NDSS Registrant population aged 10-19 years with type 1 diabetes (by state)

State / territory	YOUNG PEOPLE		NDSS Registrants aged 10-19 years	
	NDSS Registrants who received survey invitation N	Youth survey respondents % (N)	NDSS Registrants with type 1 diabetes N	Youth survey respondents as a percent of NDSS Registrants %
NSW	1,820	12% (211)	2,996	7%
VIC	1,372	13% (184)	2,504	7%
QLD	1,398	13% (182)	2,117	9%
WA	627	14% (87)	985	9%
SA	419	16% (68)	735	9%
TAS	156	21% (33)	264	13%
ACT	109	14% (15)	179	8%
NT	27	4% (1)	62	2%
TOTAL	5,928	13% (781)	9,842	8%

Table 2. Age and state / territory of youth (N=781) and parent respondents (N=826)

State / territory	YOUTH					PARENTS
	10-12 years	13-15 years	16-17 years	18-19 years	TOTAL state % (N)	TOTAL % (N)
NSW	66	66	45	34	27% (211)	25% (205)
VIC	59	71	24	30	24% (184)	30% (248)
QLD	50	64	44	24	23% (182)	20% (162)
WA	22	32	19	14	11% (87)	11% (92)
SA	17	29	10	12	9% (68)	8% (70)
TAS	10	11	6	6	4% (33)	2% (21)
ACT	6	4	5	0	2% (15)	3% (24)
NT	0	0	0	1	<1% (1)	<1% (4)
TOTAL	230	277	153	121	100% (781)	100% (826)

Socio-economic status

Socio-economic status (SES) was derived from the Australian Bureau of Statistics (ABS) Index of Relative Socio-Economic Advantage/Disadvantage (IRSAD)[7]. This measure summarises census data related to both advantage and disadvantage (e.g., income, education and unemployment) in an area. An IRSAD was calculated for each respondent using the postcode they provided (Table 3).

Almost half the respondents were from a high socio-economic background.

Figure 2. Youth and parent respondents' location (by postcode)

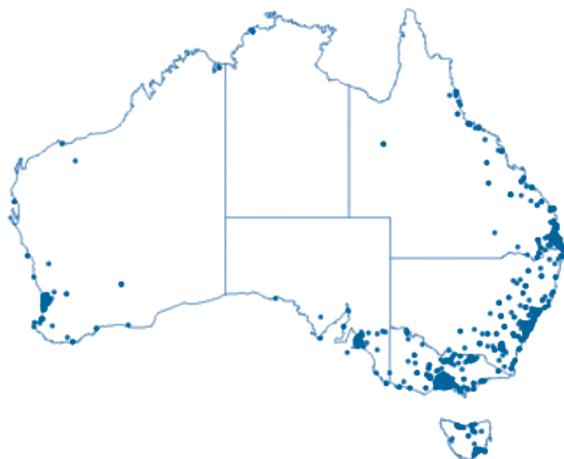


Table 3. Socio-economic status and area for youth (N=781) and parents (N=826)

SES	Low	Medium	High
Youth	17%	38%	45%
Parents	15%	39%	46%
NDSS Registrants invited	22%	42%	37%
Area	Metro	Regional	Rural
Youth	68%	31%	1%
Parents	67%	32%	1%
NDSS Registrants invited	68%	31%	1%

With regard to the sample of young people, the majority of school leavers (87%, n=85) were currently employed or undertaking further education (Table 4).

Table 4. Youth education/employment status (N=781)

Status /Age	10-12 years	13-15 years	16-17 years	18-19 years	TOTAL (N)	TOTAL (%)
At school (TOTAL)	230	277	140	34	681	87
School	228	275	138	31	672	86
Home school	2	2	2	3	9	<1
Left school (TOTAL)	0	0	12	86	98	13
University student			3	48	51	7
Working full or part time			4	17	21	3
Apprenticeship / TAFE / trade training			4	9	13	2
Looking for work			1	10	11	1
Home duties / carer				1	1	<1
Other				1	1	<1
TOTAL	230	277	152	120	779	100

Demographics

Age and Gender

Of the 781 young people who responded, 61% (n=474) were girls and 39% (n=307) were boys (Table 5). Parents also reported the age and gender of their child with diabetes (Table 6). Overall, there were more girls in the youth sample (61% vs 47%), suggesting a gender bias in the youth respondents.

Table 5. Age and gender of youth respondents (N=781)

	10-12 years	13-15 years	16-17 years	18-19 years	Total % (n)
Girls	57% (131)	58% (162)	65% (100)	67% (81)	61% (474)
Boys	43% (99)	42% (115)	35% (53)	33% (40)	39% (307)
Total	29% (230)	35% (277)	20% (153)	16% (121)	100% (781)

Table 6. Parental report of age and gender of child with diabetes (N=826)

	10-12 years	13-15 years	16-17 years	18-19 years	Total % (n)
Girls	50% (142)	44% (127)	46% (71)	47% (45)	47% (385)
Boys	50% (143)	56% (164)	54% (84)	53% (50)	53% (441)
Total	35% (285)	35% (291)	19% (155)	12% (95)	100% (826)

The mean age of youth respondents was 14±3 years. The proportion of young people in each age group was similar for youth and parent respondents. Among parent respondents, the mean age of the children with diabetes was 14±3 years.

Of the 826 parent respondents, 88% (n=727) were women and 12% (n=99) were men. 88% (n=722) identified themselves as the mother of the child, with fathers accounting for 12% (n=99), and 2% (n=13) other (e.g., grandparent, foster-parent). The mean parent age was 46±6 years.

Diabetes Duration

On average, young people had lived with diabetes for 5.8±4.2 years (range = 0 to 18 years). 19% (n=149) of young people had diabetes for less than one year.

Similarly, parents reported their child had lived with diabetes for 5.6±4.0 years (range = 0 to 16 years) and 18% (n=151) of parents had a child who had been diagnosed for less than one year.^v

Cultural Background

The majority of youth respondents were born in Australia; 9% (n=67) indicated that they were born overseas. While most spoke English as their primary language, 3% (n=23) indicated that they mainly spoke a language other than English at home. In total, 20 different languages were reported. A small minority (2%; n=14) of respondents reported being of Aboriginal and/or Torres Strait Islander (ATSI) descent.

In contrast, 20% (n=167) of parents reported being born in a country other than Australia. Only 2% (n=18) indicated that they mainly spoke a language other than English at home. A small minority (1%; n=9) of parent respondents reported being of ATSI descent.

Family Situation

80% (n=624) of young people reported living with both parents, 6% (n=50) lived with a parent and step-parent, 11% (n=85) lived with one parent only, and 2% (n=19) with another guardian (e.g., grandparent, foster-parent).

Parents were asked to indicate their marital status. The majority (79%, n=651) were married, and 7% (n=57) were in a de facto relationship. A minority were single parents: 10% (n=84) were separated, 3% (n=22) were either single or widowed and less than 1% (n=9) were in a steady relationship but not living with a partner.

^v Note that parent respondents are not necessarily the parents of the youth respondents.

50 parents (6%) indicated they also had diabetes; 5% (n=39) had type 1 and 1% (n=11) had type 2 diabetes. 24% (n=174) of parents reported that, in addition to their child with diabetes, another person in the household had special needs; 7% (n=57) reported 2 or more children with diabetes.

Education (parental reports)

Parents were asked to indicate, for both themselves and their partner (if applicable), the highest level of education attained. Of the 90% (n=740) who responded to this question, the majority (53%, n=389) had a university qualification, 9% (n=65) had attained year 12, and 7% (n=55) had completed year 10 or less.

Income (parental reports)

Of the 73% (n=604) who reported their income, 44% (n= 264) had a total household income above \$100,000, 21% (n=126) between \$80,000 and \$100,000, 14% (n=87) between \$60,000 and \$80,000, and 18% (n=127) below \$60,000. 80% (n=587) reported that they owned (or were paying a mortgage on) their home. 75% (n=554) of parents (or their partners) were in paid employment.

What adolescents had to say about diabetes

About diabetes...

“That it sucks! I hate it, I hate it, I hate it, I hate it!!! But I will have to learn to deal with it.”

“I rarely go out with friends because I hate injecting in front of other people and I feel as if I can’t have fun without being worried about diabetes.”

About the future...

“Thinking that I’m going to have this everyday until I pass away, and my children have a high chance of getting the disease too. It’s quite depressing. I don’t think I just talk for myself when I say how completely terrified I am of getting complications.”

About hypos...

“I worry about going low during activities, and when I sometimes don’t give myself as much insulin as I know I should just so I can protect myself.

I am scared I will never wake up. Mum and dad say they will check me that doesn’t help with the fear of never waking up!!!!!”

What I want my parents to know...

“I don’t forget to manage my diabetes on purpose. Secondly, when you are high, you don’t want to be told off for forgetting to bolus, because you don’t feel well, and that is enough of a consequence.”

What I want my parents to know...

“I wish they knew how grateful I am to them for being so brilliant in helping me out. I know they sometimes over analyse not out of blame, but out of worry and love.”

What I wish my friends knew about diabetes...

“Having lollies all the time does not make it fun.”

.....

What I wish my teachers knew...

“How much I’d rather do a whole year of homework than have diabetes and I would like them to know what I have to compete with and I am just 11 and they’re about 40.”

“How I feel when I am high or low and sometimes I can’t concentrate.”

.....

What would help support you...

“Maybe we should come up with ways to help stop us from feeling isolated. I think diabetes camps really help with that.”

.....

What I wish the public knew...

“Sometimes, we really grieve. The media concentration of type 2 makes it very hard for type 1 to be properly understood. Too many people write it off as something that can be controlled easily. While it might not be cancer, it is still awful, terrifying and very saddening.”

.....

What I wish the world knew about hypos...

“It’s hard, very stressful, having to wake up in the middle of the night knowing that you’re having a hypo and knowing that you can barely move because of it, it feels like getting suffocated by the world as you try to get up and get to your [blood glucose] monitor and to get some food.”

.....

General Quality of Life

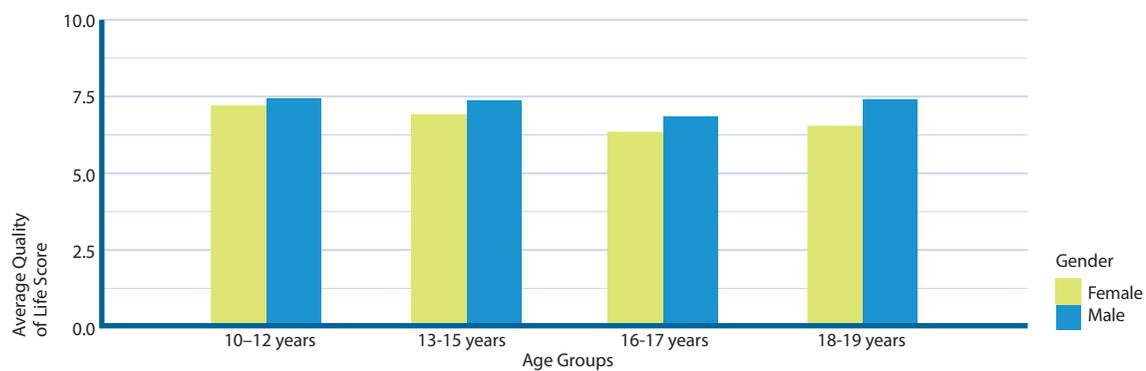
General quality of life (QoL) was assessed by asking respondents to indicate 'how good or bad you feel your life is right now', on an 11-point scale, where 0 = 'worst possible life' and 10 = 'best possible life'.

Of the 780 young people who answered this question, 67% (n=526) rated their general QoL as 7 or above, which is considered to be indicative of good general QoL.

Overall, more girls (39%; n=183) than boys (23%; n=71) reported scores below 7.

The difference between genders in general QoL scores increased markedly in the older age groups (Figure 3). The pattern of scores shows that general QoL is at its highest among 10-12 year olds and at its lowest for 16-17 year olds. This pattern is consistent for both genders.

Figure 3. Youth general quality of life by gender and age group (N=780)



"Living with diabetes is definitely a difficult and stressful task but as long as you manage it well you can do and be whatever you aspire to be."

Female, 13 years

General Emotional Well-being

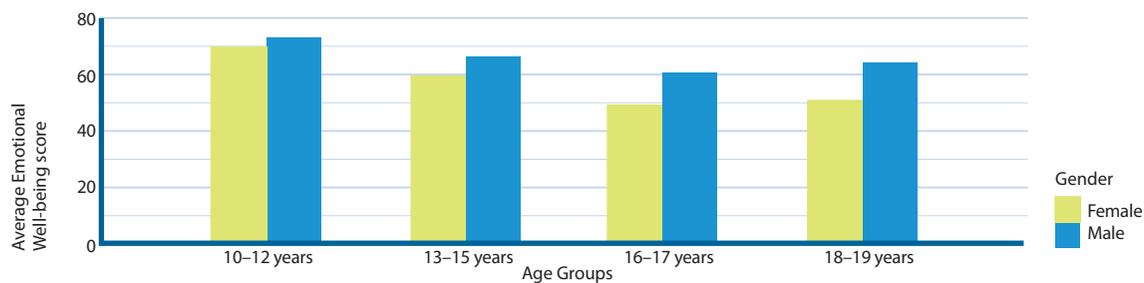
General emotional well-being was measured with the WHO-5 scale [8], which comprises 5 positively-worded items, related to positive mood (good spirits, relaxation), vitality (being active and waking up fresh and rested), and being interested in life.

Of the 779 respondents, 28% (n=217) scored <50, which indicates impaired well-being, and further screening for depression is recommended [9]. Of the 217 respondents who scored <50, 74% (n=160) were girls.

Participants who fell into 'impaired' categories, were offered information about seeking further support, as is recommended by the paper cited here.

The difference between genders in general emotional well-being increased markedly in the older age groups (Figure 4). The pattern of scores shows that general emotional well-being is at its highest among 10-12 year olds and at its lowest for 16-19 year olds. This pattern is consistent for both genders.

Figure 4. General emotional well-being of youth by gender and age group (N=779)



“I can say diabetes has obviously changed my life in so many ways I couldn’t count. But that doesn’t mean all of those changes have been bad. I am proud of being a diabetic, it has made me stronger and actually supplied me with many opportunities. I wish young diabetics could learn to be proud of what they have rather than wanting to hide the needles, the lows and the rest of it. It’s not something to be ashamed of.”

Female, 17 years old

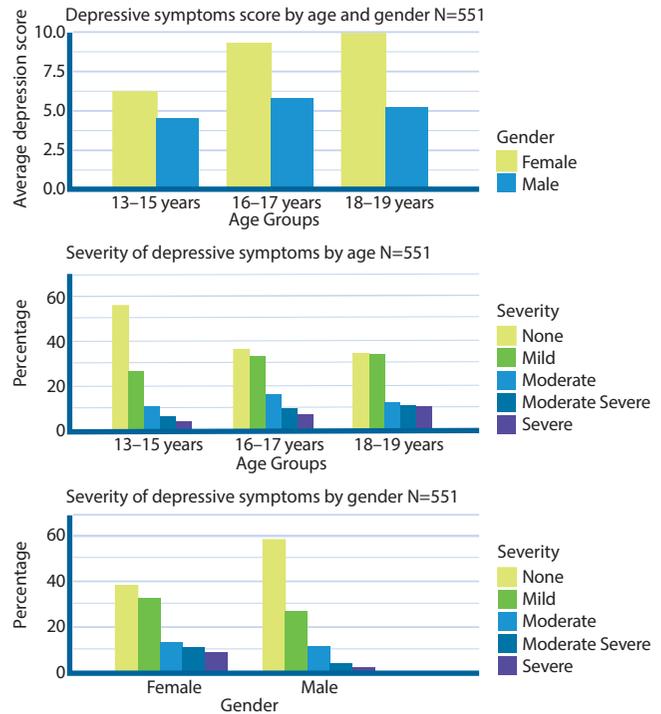
Depression and Anxiety

Depressive Symptoms

Depressive symptoms were measured using the eight-item Patient Health Questionnaire for Adolescents [10, 11]. Respondents rated the frequency with which they had experienced depressive symptoms over the past two weeks on a scale of 0 (not at all) to 3 (nearly every day), and item scores were summed to form a total score (range: 0 to 24). Severity of depressive symptoms was assessed using the cut-off scores of 5, 10, 15, and 20 representing mild, moderate, moderately severe and severe depressive symptoms respectively.

Results are shown in Figure 5. 25% (n=138) of young people aged 13-19 years reported moderate to severe depressive symptoms. Depressive symptoms increased with age in both girls and boys. The frequency and severity of depressive symptoms was markedly higher among girls than boys; 31% (n=105) of girls compared with 15% (n=33) of boys reported moderate to severe depressive symptoms (PHQ-A score ≥ 15).

Figure 5. Youth depressive symptoms and severity by gender and age group (N=551)

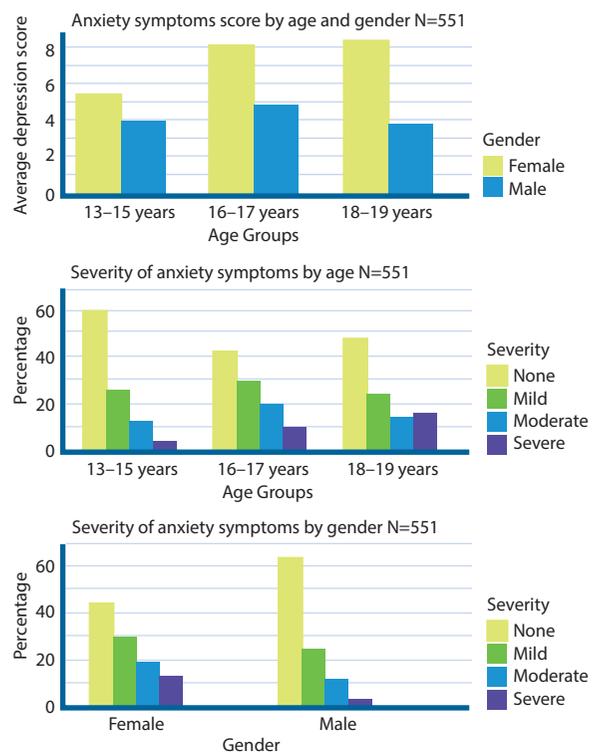


Anxiety Symptoms

Anxiety symptoms were measured using the seven-item Generalised Anxiety Disorder (GAD-7) scale [12]. Respondents rated the frequency with which they had experienced symptoms of anxiety over the past two weeks on a scale of 0 (not at all) to 3 (nearly every day), and item scores were summed to form a total score (range: 0 to 21). Severity of anxiety symptoms was assessed using cut-off scores of 5, 10 and 15 representing mild, moderate, and severe anxiety symptoms respectively.

Results are shown in Figure 6. 23% (n=125) of young people aged 13-19 years reported moderate to severe anxiety symptoms. There was a trend for higher anxiety scores among girls and among older youth. 29% (n=101) of girls reported moderate to severe anxiety symptoms, compared with 12% (n=24) of boys (GAD-7 score ≥ 10). The severity of anxiety symptoms also increased with age, particularly among girls.

Figure 6. Youth anxiety symptoms and severity by gender and age group (N=551)



Diabetes-Related Distress

The emotional distress caused by diabetes was measured using the Problem Areas In Diabetes-Teen (PAID-T) scale [13]. It includes 26 items, which are rated on a scale of 1 (not a problem) to 6 (serious problem). Item scores were summed to form a total score (range: 26-156), with higher scores indicating greater diabetes distress.

The PAID-T was completed by 97% (n=537) of the young people aged 13 to 19 years (Figure 7). The average PAID-T score was 77 ± 30 . Girls reported greater diabetes distress than boys, with an average score of 83 ± 31 compared to 66 ± 27 . While distress was stable across age groups for boys, it was higher among older girls. Top problem areas (which did differ by gender) are shown in Table 7.

Figure 7. Youth diabetes-related distress by gender and age group (N=537)

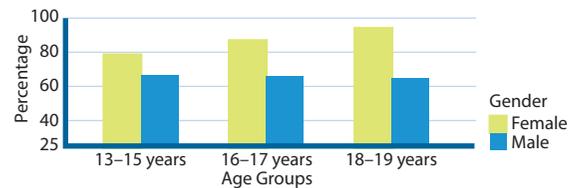


Table 7. Top 3 problem areas in diabetes for youth by gender

Problem area: Girls (n=334)	%	Problem area: Boys (n=203)	%
(1) Worrying about my weight	52	(1) Feeling that friends or family don't understand how difficult living with diabetes can be	31
(2) Feeling that friends or family don't understand how difficult living with diabetes can be	47	(2) Feeling that my friends and family act like "diabetes police"	23
(3) Feeling upset when my diabetes management is "off track"	39	(3) Worrying about getting low during sports activity	22

"My parents think I'm just being a 'typical teen' not wanting to look after myself because I think I'm 'invincible' but I'm not – I'm just trying to fit in and try and have a normal life."

Female, 16 years

Disordered Eating

Disordered eating is defined as an unhealthy eating pattern that can include restrictive dieting, compulsive eating and skipping meals or for people with diabetes, restricting or omitting insulin. The 16-item Diabetes Eating Problem Survey-Revised (DEPS-R) [14] was used to assess general and diabetes-specific aspects of disordered eating, e.g. 'After I overeat, I skip my next insulin dose'.

NB. The DEPS-R is a measure of disordered eating, not a measure of eating disorders per se. Respondents indicated the extent to which each item applied to them on a 6-point scale from 0 ('never') to 5 ('always'). Item scores were summed to a total score (ranging from 0 to 80), with higher scores indicating higher risk for disordered eating.

The questionnaire was completed by 93% (n=510) of young people aged 13 to 19 years. Girls scored higher than boys, with the difference between genders becoming more pronounced as age increased (Figure 8). The top two issues endorsed are shown in Table 9.

Figure 8. Average eating problem score by age and gender (N=510)

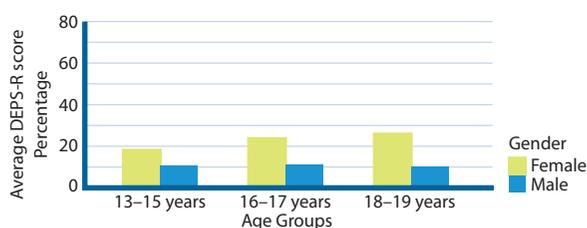


Table 9. Top 2 items most frequently reported by gender

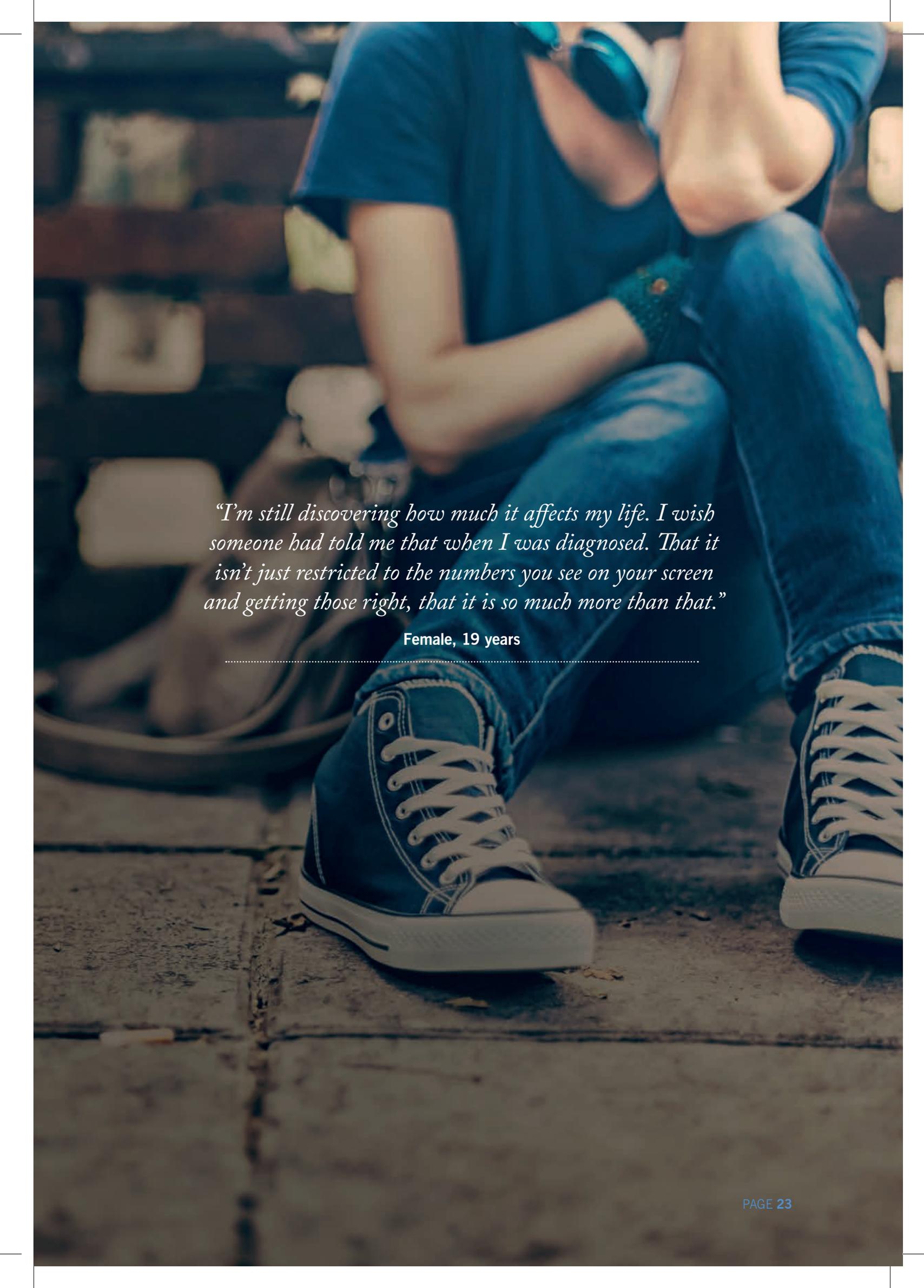
Eating concerns: Girls (n=314)	%	Eating concerns: Boys (n=196)	%
(1) Losing weight is an important goal to me	62%	(1) Losing weight is an important goal to me	21%
(2) I feel that it is difficult to lose weight and control my diabetes at the same time	59%	(2) I eat more when I am alone than when I am with others	20%

Losing weight was an important goal for both girls and boys but was more likely to be endorsed by girls (62% vs 21%). Girls were then most likely to endorse the dual challenge of managing diabetes and weight (59%) while one in five boys indicated they eat more when they are alone.

Young people were also asked to indicate on how many of the past 14 days, they had an eating binge (excluding hypoglycaemic events), ('feeling you cannot stop eating, and/or eating more than other people your age in a similar situation'). Girls were more likely than boys (25% vs 16%) to report bingeing on ≥ 4 days in the past two weeks (Table 8).

Table 8. Binge eating over the past 14 days

Binge days	0 days	1-3 days	4-7 days	8-11 days	12-14 days
Girls	41% (128)	34% (109)	17% (54)	3% (10)	5% (15)
Boys	50% (99)	34% (68)	9% (18)	5% (9)	2% (3)
Total	44% (227)	34% (177)	14% (72)	4% (19)	4% (18)



“I’m still discovering how much it affects my life. I wish someone had told me that when I was diagnosed. That it isn’t just restricted to the numbers you see on your screen and getting those right, that it is so much more than that.”

Female, 19 years

General Health

Additional Medical Conditions

A total of 42% (n=314) of young people indicated they had at least one additional health or medical condition other than type 1 diabetes, of whom 15% (n=111) reported more than one condition. The most commonly reported conditions are shown in Table 10.

Consistent with youth respondents, 42% (n=344) of parents reported that their child had an additional medical condition, with 15% (n=119) reporting more than one condition.

Table 10. Additional medical conditions most commonly reported by youth (N=314)

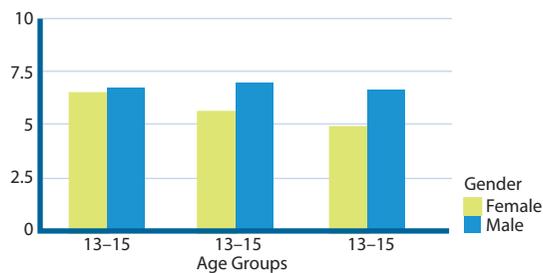
	Allergies	Coeliac disease	Asthma	Thyroid disease	Eczema	Autism Spectrum Disorders	Eating disorder
Youth	22% (69)	22% (68)	21% (65)	11% (33)	4% (13)	3% (8)	2% (6)

Perceived Health Status

Young people rated their health over the past four weeks on an 11-point scale, from 0 ('worst possible health') to 10 ('best possible health'). The mean score for self-rated health by gender and age are detailed in Figure 9.

Overall, 16% (n=77) reported they were in the 'best possible health' (rating 9 or 10) and 27% (n=132) rated their health as relatively poor (rating 4 or less).

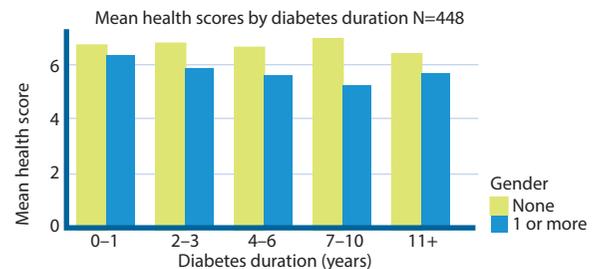
Figure 9. Self-rated health over the past four weeks (N=493)



Boys tended to rate their health more positively than girls. While boys' ratings of their health were similar across age groups, older girls rated their health as poorer than that of younger girls.

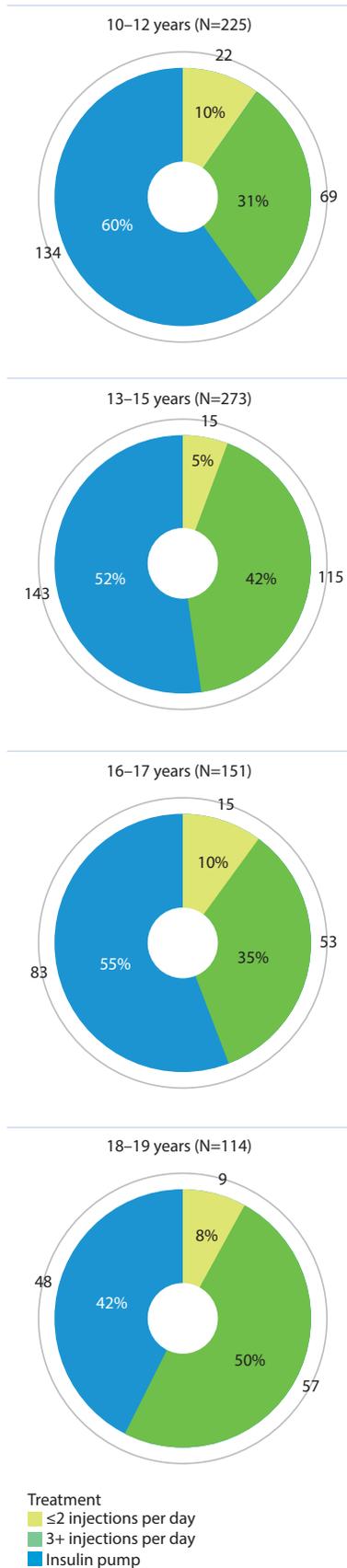
There was a trend for respondents who reported 1 or more additional medical conditions to report lower health status as their diabetes duration increased (Figure 10).

Figure 10. General health by diabetes duration and co-morbidity



Diabetes Self-Care and Management

Figure 11. Diabetes treatment type by age group (N=763)



Diabetes Treatment

Just over half of youth respondents (52%, n=408) used an insulin pump to manage their diabetes, while 48% (n=371) used insulin injections (Figure 11). Insulin pump usage was lower among those aged 18 to 19 years. The majority (83%, n=294) of young people not using a pump managed their diabetes with multiple daily insulin injections (MDI) (i.e. three or more injections of short-acting insulin per day). The rate of insulin pump use was higher than the national average for youth aged 10-19 years (41%) [15] particularly among the younger age groups.

Insulin Use

Young people aged 13 to 19 years (N=526) were asked on how many of the past 14 days they had forgotten to take their insulin, and on how many days they missed taking insulin on purpose.

Although 50% (n=262) indicated that they never forgot, 36% (n=189) said they forgot on 1-3 days of the past 14 days; while 15% (n=75) indicated they forgot on at least 4 of the previous 14 days.

The majority (81%, n=428) reported that they had not purposefully missed taking any insulin injections or pump boluses in the past 14 days. One in five (19%, n=98) indicated that they intentionally omitted their insulin on at least 1 day during the previous 14 days.

The most commonly reported reasons for purposefully skipping insulin doses were: 'I couldn't be bothered' (65%, n=62), 'I hate having to inject with everything I eat' (42% n=40), and wanting to avoid low blood glucose (39%, n=37). It is also notable that nearly a quarter (23%, n=22) who reported missing insulin doses, did so to manage their weight.

Diabetes Self-Care and Management

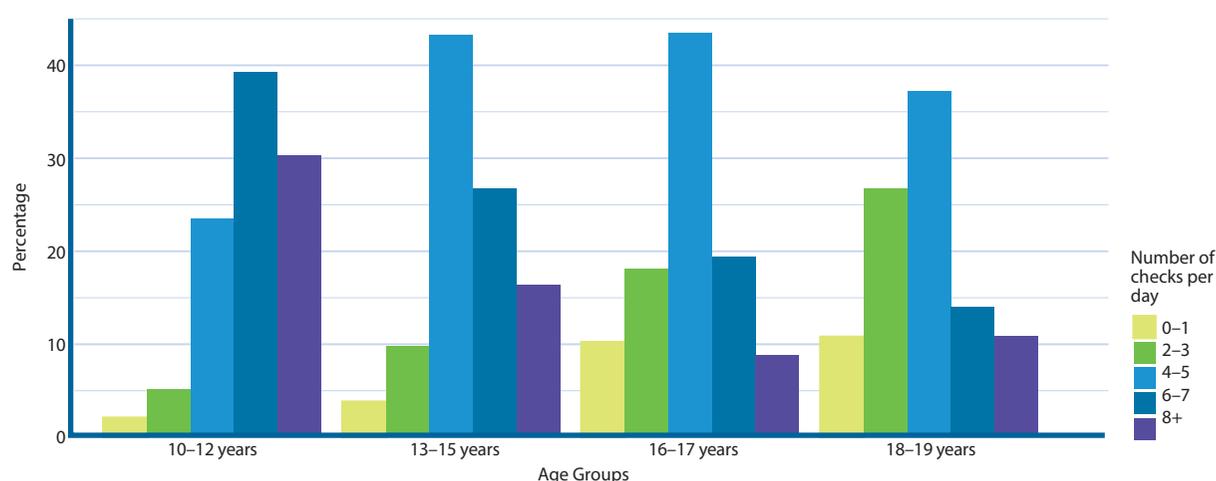
Self-Monitoring of Blood Glucose

Over one-third (37%, n=276) of young people indicated that they checked their blood glucose 4-5 times per day; while 18% (n=136) of respondents reported checking 8+ times per day and 5% (n=41) checked once or less than once per day. Parents reported very similar frequency of blood glucose monitoring for their children.

Figure 12 shows the number of blood glucose checks per day reported by youth respondents by age group. It shows a trend towards fewer blood glucose checks per day as the young person gets older.

Parents were asked how often does their child (or a parent / carer) usually check their blood glucose during the night after they have gone to sleep. Of the 816 respondents, 23% (n=191) indicated they/their child never checked their blood glucose during the night, while 25% (n=208) checked every night.

Figure 12. Frequency of blood glucose checks per day reported by youth age group (N=751)



HbA1c

Glycated haemoglobin (HbA1c) is a blood test result that indicates the average blood glucose over the previous 2-3 months and is checked approximately 3 monthly. Young people were asked to recall their most recent HbA1c result (n=650) and when it was last checked (n=754). They reported an average HbA1c of 64 ± 7 mmol/mol ($8.0 \pm 1.6\%$), with 71% (n=539) indicating it had been checked within the past 3 months.

HbA1c was higher among girls aged 18-19 years (average 73 ± 11 mmol/mol or $8.8 \pm 2.0\%$) than younger girls and boys. 38% (n=249) were in the target range of < 58 mmol/mol (7.5%). Reported HbA1c was higher for young people who used injections (average 66 ± 9 mmol/mol or $8.2 \pm 1.9\%$) compared to those who used an insulin pump (average 63 ± 6 mmol/mol or $7.9 \pm 1.3\%$).

Parents reported very similar results for their child's latest HbA1c (average 64 ± 6 mmol/mol or $8.0 \pm 1.4\%$). Parents were also asked to select which target range they would be happy with for their child's HbA1c:

- 63% (n=515) reported they would be happy if their child's HbA1c was within the recommended range of 48-58 mmol/mol (6.5-7.5%) [1]
- 9% (n=73) would be happy if the HbA1c was in the range 60-68 mmol/mol (7.6-8.5%)
- 23% (n=188) would be happy if the HbA1c was below 48 mmol/mol (6.5%)
- 5% (n=37) of parents were unsure of the recommended HbA1c range.

Hypoglycaemia: episodes

Young people aged 13 to 19 years (N=522) were asked about their experiences of hypoglycaemia (also referred to as 'hypos' or low blood glucose). Most respondents (80%; n=416) indicated they had experienced at least one episode of hypoglycaemia (mild or severe, day or night) in the past week. A substantial minority (29%; n=149) had experienced four or more such episodes in the past week.

Severe hypoglycaemia (defined as an event requiring someone to assist for recovery) had been experienced by 33% (n=171) in the past 12 months. A severe hypoglycaemic event that required hospital treatment was experienced by 11% (n=55). The parents' reported rate of severe hypoglycaemia (32%; n=246) and the frequency of hospital admissions for treatment of hypoglycaemia (9%; n=70) were similar.

Hypoglycaemia: awareness

Young people aged 13-19 years (N=523) were asked about their awareness of hypoglycaemic symptoms. This was assessed using the single-item Gold score [16], which asks respondents to rate on a 7-point scale the extent to which they know when their hypos are commencing with scores of 1 ('always aware') to 7 ('never aware'). A total of 17% (n=90) of respondents had impaired hypoglycaemia awareness, as indicated by a score of 4 or more on this scale.

Hypoglycaemia: worries

Young people aged 13-19 years (N=515) were presented with a list of concerns they may have about low blood glucose and were asked to indicate how much each one applied to them [17]. The two most common concerns were:

- not having sugary foods available when feeling low (28%; n=142)
- having low blood glucose whilst asleep (27%; n=139).

Diabetic Ketoacidosis (DKA)

DKA is a serious complication of type 1 diabetes, which occurs as a consequence of insulin deficiency, such as, at the onset of type 1 diabetes, during acute illness or when insulin doses are not taken.

Of the 530 young people aged 13 to 19 years who were asked about DKA, 23% (n=124) reported one or more episodes in the past 12 months; a third of whom were diagnosed with diabetes in the previous 12 months (33%, n=41). 5% (n=24) had experienced DKA three or more times in the past 12 months, and most of these (83%, n=20) had lived with type 1 diabetes for longer than one year.

40% (n=324) of parents reported that their child has had an admission to hospital for DKA, with the majority (75%; n=244) indicating this had occurred at the time they were diagnosed.

'App' use

Young people (N=728) were asked about their use of mobile technology in the management of their diabetes. 35% (n=255) indicated that they used an 'app' for this purpose; the majority (86%; n=219) used the app for carbohydrate counting. Among those not using an app, nearly half (43%; n=204) reported that they did not think apps could help with diabetes management.

Treatment Satisfaction

Of the 737 young people who responded to this question, 72% (n=532) were 'happy' or 'very happy' with their treatment regimen; only 7% indicated that they were 'unhappy' or 'not at all happy' (n=53) [18].

Of the 774 parents who answered a similar question about their satisfaction with their child's treatment regimen, 78% (n=606) indicated that they were 'satisfied' or 'very satisfied'; only 9% (n=66) indicating they were 'dissatisfied' or 'very dissatisfied'.

Access to Healthcare

Diabetes Care Services

Parents were asked to indicate the main type of service their child attends for diabetes care. The majority reported attending a hospital diabetes clinic (61%, n=504) or private paediatrician / endocrinologist (20%, n=167). Only 3% (n=27) indicated their GP or family doctor was their main diabetes healthcare provider.

Parents were also asked how many times in the past 12 months their child had seen a range of healthcare professionals (Table 11). While 73% of parents (n=570) reported that their child had seen an endocrinologist or paediatrician three or more times, 5% (n=35) had not seen one at all. 40% of parents (n=307) reported that their child had visited a mental health professional in the previous 12 months.

Transition to Adult Care Services

Of young people aged 16-19 years (N=230), 3% (n=24) were attending a young adult clinic.

Parents with a child aged 16-19 years (N=229) were asked whether their child's doctor or diabetes educator had talked with them about their child's transition from paediatric to adult diabetes services:

- 45% (n=103) indicated their child did not have a transition plan
- 38% (n=87) had not discussed finding an adult care provider
- 43% (n=100) had not discussed how their child's healthcare needs might change as they move towards adulthood.

Table 11. Visits to healthcare professional during past 12 months (N=772)

	0	1-2	3	4+
Endocrinologist or Paediatrician (n=772)	5% (35)	22% (167)	26% (204)	47% (366)
Diabetes Nurse Educator (n=766)	9% (69)	33% (249)	23% (176)	36% (272)
GP / Family Doctor (n=764)	13% (96)	47%(361)	17%(128)	23% (179)
Dietitian (n=752)	34% (252)	45% (337)	12% (93)	9% (70)
Optometrist (n=756)	29% (223)	69% (523)	<1% (3)	1% (7)
Mental Health Professional (n=753)	59% (446)	23% (175)	5% (40)	12% (92)

NOTE: % calculated per row; % may not sum to 100 due to rounding up

Parents were asked who had primary responsibility for a range of diabetes management tasks at home over the previous month (Table 12). In the majority of cases, young people had the main responsibility for giving (71%, n=529) and/or remembering injections/insulin boluses (56%, n=422). Tasks that were more likely to be shared with parents were carrying sugary food/drink as a hypoglycaemia treatment (55%, n=410), remembering to check blood glucose (48%, n=357), and decisions about food and meals (56%, n=419).

Young people were asked about who has responsibility for their diabetes care [18]. 18% of young people felt they had too much responsibility, while 17% felt their parents or other people had too much responsibility (Table 13).

Young people were also asked how often they argued with their parents about diabetes self-care (Table 14) [18]. 25% (n=194) argued 'often' or 'all the time' about blood glucose checks or injections, and 22% (n=164) argued 'often' or 'all the time' about meals and snacks.

Table 12. Responsibility for diabetes care, according to parent respondents (N=744)

Responsibility for ...	Child	Shared	Parent(s)
giving insulin injections or boluses	71% (529)	25% (188)	4% (27)
remembering to take morning or evening insulin injection / bolus by pump	56% (422)	34% (253)	10% (74)
remembering times when blood glucose should be checked	42% (318)	48% (357)	10% (74)
deciding what to eat at meals and snacks	30% (227)	56% (419)	14% (103)
carrying some form of sugar (or sugary drink) in case of low blood glucose	33% (249)	55% (410)	12% (90)

NOTE: % calculated per row

Table 13. Youth perceptions of responsibility for diabetes care (N=759)

How often do you feel...	All the time	Often	Sometimes	Rarely	Never
you have too much responsibility for your diabetes care?	6% (46)	12% (95)	25% (191)	30% (235)	24% (190)
your parents / other people have too much responsibility for your diabetes care?	5% (38)	12% (90)	19% (152)	31% (242)	30% (236)

Table 14. Frequency of arguments about diabetes between youth and parents, according to youth respondents (N=759)

Arguments about ...	All the time	Often	Sometimes	Rarely	Never
remembering to check blood glucose / give injections	7% (54)	18% (140)	24% (184)	33% (247)	18% (134)
meals and snacks	6% (46)	16% (118)	26% (194)	34% (259)	19% (141)

What parents had to say about diabetes

“The longer we live with it, we are closer to further bad health prospects and no relief in sight for this ever going away. I personally will never totally ever be at ease again.”

“I find it emotionally difficult as a parent to watch my child live with and manage such a chronic and demanding disease, even though he is doing such a great job.”

“Glucose levels are constantly in your mind from when you open your eyes in the morning to when you turn in at night... I often think I'd better get up now I'm awake to test my daughter.”

“My daughter has been hypo unaware for nearly 9 months now and has been saved from dying thanks to the use of a CGM, however as a single parent this is well beyond my financial means for her to wear 24/7 which scares me. I am deathly afraid of missing an overnight hypo. I won't allow her to have a sleep over at anyone's house as a result.”

“That it does get easier. That you never stop worrying about them and their safety. When they get older how they are going to manage their diabetes. It has made her more mature and very independent. She has taken her diagnosis with maturity and amazing responsibility. Don’t underestimate what your kids can cope with and deal with.”

“Because of such a great organisation and the wonderful support we get from NDSS, our specialist and our GP, my son’s diagnosis has been a very smooth and positive experience/transition.”

“It is hard sometimes. We always encourage positivity and acknowledge things can be worse and are grateful they are not. Sleeping at night is sometimes tough and working with exercise and type 1 is challenging. It’s tough when friends talk about your child as if they are not there... I have always struggled with this level of ignorance.”



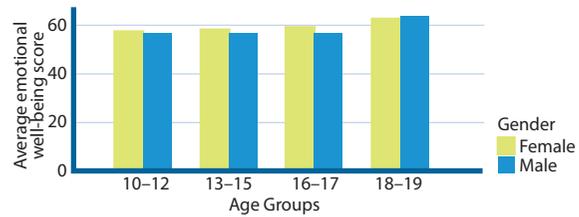
General Emotional Well-being and Anxiety: Parents

General Well-being

General emotional well-being was measured using the WHO-5 [8], which is a 5-item, positively-worded scale.

Of the 825 parent respondents who completed the WHO-5, 34% (n=279) scored <50, which indicates impaired well-being, and 12% (n=99) scored ≤28, which indicates likely depression [19]. Parents of older adolescents reported better emotional well-being (Figure 13). There were no apparent differences by child's gender.

Figure 13. Parents' general emotional well-being by child's age group and child's gender (N=825)

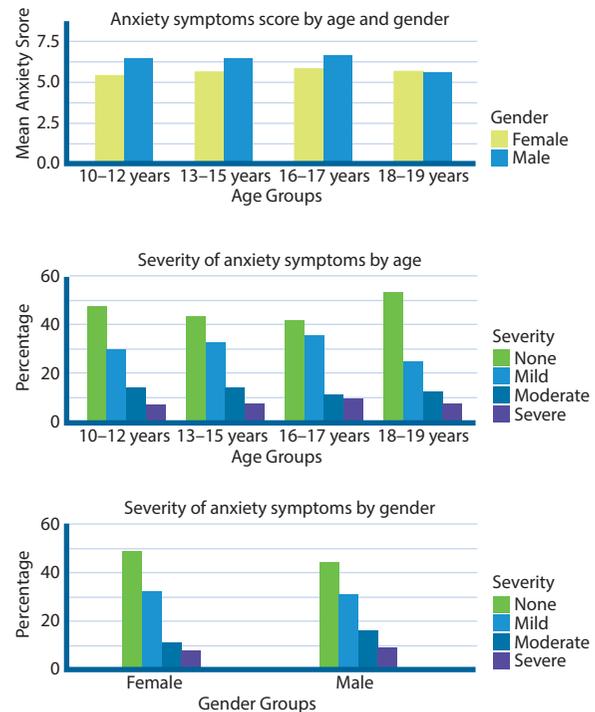


Anxiety Symptoms

Anxiety symptoms were measured using the seven-item Generalised Anxiety Disorder scale (GAD-7)[12]. 821 parent respondents rated the frequency with which they had experienced symptoms of anxiety over the past two weeks on a scale of 0 ('not at all') to 3 ('nearly every day'). Item scores were summed to form a total score (range: 0 to 21). Severity of anxiety symptoms was assessed using cut-off scores of 5, 10 and 15 representing mild, moderate, and severe anxiety respectively.

8% (n=67) of parents experienced severe anxiety symptoms. There was a trend for parents of boys to report higher anxiety scores than parents of girls (Figure 14).

Figure 14. Parents' anxiety symptoms by child's age group and gender (N=821)



Diabetes-Related Distress: Parents

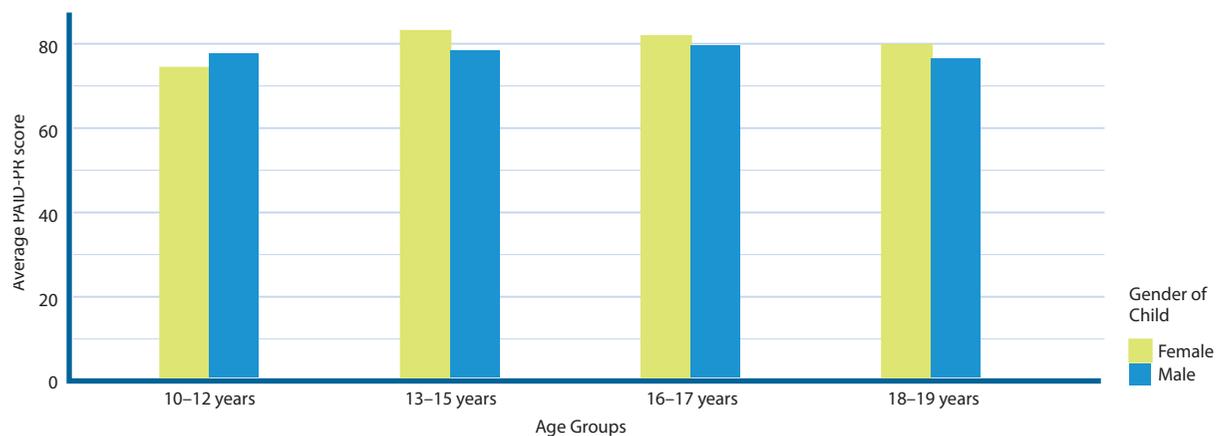
Diabetes-related distress, defined as distress resulting from living with diabetes and the burden of its management, was measured using the Problem Areas in Diabetes Scale – Parents of Teens version (PAID-PT) [20]. 776 parent respondents indicated the extent to which each of the 26 items (potential concerns) is a problem for them on a scale of 1 ('not a problem') to 6 ('serious problem'). Item scores were summed to form a total score (range: 26 to 156), with higher scores indicating greater diabetes-related distress.

The average diabetes-related distress score for parents was 79 ± 27 . In contrast to parents' anxiety symptoms, there was little difference in diabetes-related distress score according to the child's age or gender (Figure 15).

The top 3 problem areas for parents were:

- worrying about the future and the possibility of my child developing serious complications (42%; n=336)
- feeling that I act like the "diabetes police" (38%; n=298)
- feeling upset when my child's diabetes management is "off track" (38%; n=298).

Figure 15. Parents' diabetes-related distress by child age group (N=776)



Fear of Hypoglycaemia & Hyperglycaemia: Parents

Fear of Hypoglycaemia (low blood glucose)

Parents were presented with a list of concerns that parents of children with diabetes sometimes have about hypoglycaemia (low blood glucose) [17].

The top 3 areas most frequently rated 'almost always' or 'often' worrying to parents were:

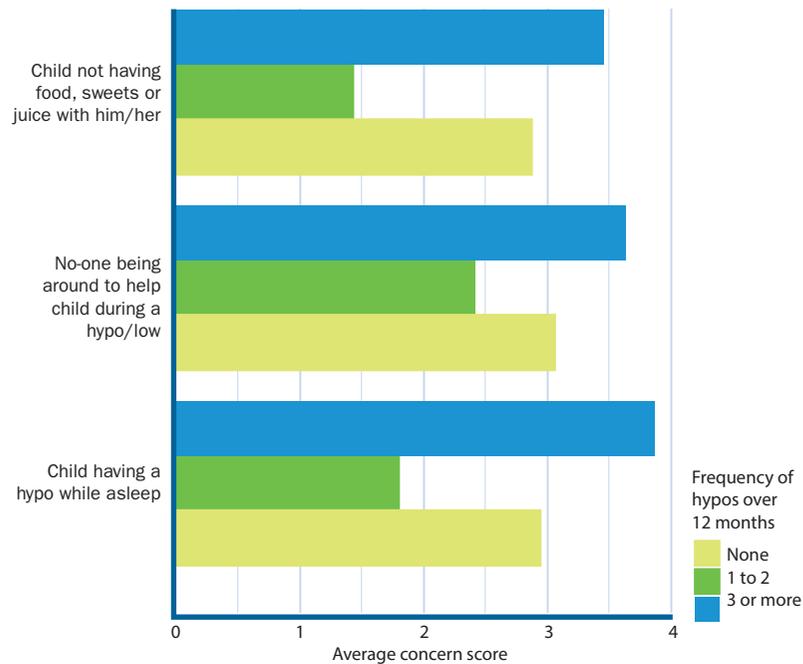
- their child having a hypo/low while asleep (49%; n=360)
- no-one being around to help their child during a hypo/low (41%; n=301)
- their child not having food, sweets or juice with him/her (37%; n=278).

These prominent concerns show a clear trend for higher concern scores with 3 or more hypoglycaemic events over the previous 12 months (Figure 16).

Parents were asked what actions they take to avoid their child having a low blood glucose. The top 3 actions most frequently rated as 'almost always' or 'often taken' were:

- having their child carry fast-acting glucose (86%; n=642)
- asking their child to check their blood glucose when they think they are having a hypo/low (83%; n=619)
- having their child eat something as soon as he/she feels the first sign of low blood glucose (65%; n=486).

Figure 16. Top hypoglycaemia concerns by history of hypos in the previous 12 months (N=740)



Fear of Hypoglycaemia & Hyperglycaemia: Parents

Fear of Hyperglycaemia (high blood glucose)

Parents were asked to indicate their concerns and feelings about high blood glucose (Table 15).

The majority of parents were often or always worried about their child having high blood glucose, and the risk of developing long term complications. Fewer parents worried about their child developing DKA.

Table 15. Parents' concerns about hyperglycaemia (N=813)

How often do you worry about ...	Always % (n)	Often % (n)	Sometimes % (n)	Rarely % (n)	Never % (n)
your child having high blood glucose? (N=813)	21% (175)	42% (345)	29% (236)	6% (50)	<1% (7)
your child developing complications of high glucose, e.g., blindness, kidney failure, amputation? (N=815)	24% (199)	30% (243)	32% (259)	11% (87)	3% (27)
your child going into DKA (diabetic ketoacidosis)? (N=815)	12% (100)	15% (125)	33% (270)	32% (259)	7% (61)

Discussion

The Diabetes MILES Youth Study 2014 was the first large-scale, national survey of young Australians living with type 1 diabetes (and their parents) focused on diabetes management, healthcare access and psychosocial outcomes (e.g., social support, quality of life, general emotional well-being, and diabetes-related distress).

During August and September 2014, NDSS Registrants aged 10 to 19 years (who had previously consented to being contacted for research) were invited to take part in the online survey. In total, 781 young people with type 1 diabetes completed the survey, which represents 13% of the 5,928 NDSS Registrants with type 1 diabetes invited to take part. In addition, 826 parents of young people aged 10-19 years with type 1 diabetes also responded to the survey.

Four hundred and seventeen NDSS Registrants with type 2 diabetes and their parents were invited to complete the survey. However, because of the low response from these Registrants and their families, the results were not included in this report. Type 2 diabetes is still uncommon in this age group so this response was not unexpected.

Young Peoples' Emotional Well-being

Most adolescents (67%) reported good general quality of life, but scores were lower among 16 to 19 year olds. One in 3 reported poor emotional well-being and there was a trend for emotional well-being to deteriorate with age. Almost 1 in 4 (23%) experienced moderate to severe anxiety symptoms, which is similar to the rate reported in a recent study among Australian adolescents with type 1 diabetes [21]. However, MILES Youth Study respondents reported much higher rates of moderate to severe depressive symptoms (25%) than young Australian adults with type 1 diabetes [21] (15%), US adolescents with type 1 diabetes (15.2%) [22], and a general population survey of Australian youth

in 2001 (5.2%) [23]. Different age groups and measurement instruments may explain some of the disparity.

The young people responding to this survey were most often distressed about: friends or family not understanding how difficult living with diabetes can be; worries about their weight; and becoming hypoglycaemic.

Gender Differences

Girls reported poorer emotional well-being, quality of life and perceived health than boys. Depressive and anxiety symptoms increased with age among girls and symptoms were more severe amongst girls than boys. Girls were more distressed about diabetes than boys, and reported more concerns about food and eating. While scores for general and diabetes-specific distress and disordered eating remained stable amongst boys across age groups, emotional distress increased with age among girls. The gender difference is consistent with a study finding similar levels of depressive symptoms among girls and boys until puberty, when girls' psychosocial well-being and mood begins to decline [24].

General Health

People with type 1 diabetes must deal with the demands of everyday life, in addition to the challenges of living with diabetes. Almost half of young people reported having another medical condition in addition to diabetes, and almost 1 in 4 reported two or more conditions; most frequently allergies and other autoimmune conditions, which increase the complexity of self-care and diabetes management.

Diabetes Self-care

The majority of young people appeared to be managing their diabetes well; checking blood glucose several times per day and taking insulin as recommended. However, the frequency of self-monitoring of blood glucose declined with age. One in 5 young people admitted missing insulin doses on purpose, which can have a major impact on blood glucose levels. One quarter (23%) of those missing insulin did so for weight-related concerns, although the most common reasons were related to the daily hassles of self-management.

Young people were most likely to be responsible for injecting and bolusing their insulin, whereas blood glucose monitoring and food-related decisions were more often shared responsibilities with parents. At the same time, remembering to inject insulin and check blood glucose was the subject of arguments with parents. Overall, 1 in 5 young people felt they had too much responsibility for their diabetes. Just over half of young people reported using technology to support self-management, including insulin pumps and 'Apps' for 'carb-counting'.

Diabetes Management

Young people reported frequent episodes of hypoglycaemia. Around 1 in 3 young people experienced four or more hypoglycaemic episodes per week; and one-third reported at least one episode of severe hypoglycaemia (requiring assistance for recovery) in the past 12 months. Impaired awareness of hypoglycaemia was reported by 17% which is considerably lower than the prevalence reported previously amongst Australian children and adolescents (29%) [25]. Approximately 1 in 4 often worried about having a hypoglycaemic event while asleep.

Young people were attending regular healthcare consultations, with 1 in 5 accessing private medical care. Satisfaction with healthcare was relatively high. Consistent with previous reports regarding transition from paediatric to adult care [26], just over half (55%) of the young people aged 16-19 years had a transition plan or had discussed future care as an adult, and few (only 8%) attended a young adult clinic. According to parents, over 1 in 3 young people with type 1 diabetes (40%) had visited a mental health professional at least once in the past 12 months. This suggests that mental health services are accessible for families, however, a national audit of paediatric diabetes services conducted in 2010 found psychological services under-resourced or unavailable [27]. Moreover, it does not mean that adolescents who most need psychological support are accessing these services or receiving adequate support. The high level of distress reported suggests otherwise.

The challenges of living with diabetes don't ease once a young person reaches adulthood, and young adults are not faring any better regarding their psychological well-being after they transition

to adult care [28]. Transition and 'young adults' are key focus areas for the NDSS and the subject of ongoing research of the ACBRD.

Parental Well-being

Most parents reported only mild or no anxiety or depressive symptoms, though 1 in 12 parents experienced moderate to severe anxiety and 1 in 3 poor emotional well-being. There was a small trend for parents' emotional well-being to improve as their child's age increased.

Worry about hypoglycaemia was a major concern for parents, particularly during the night, and 1 in 4 parents reported checking their child's blood glucose every night after their child had gone to sleep. Parents worried most about their child developing complications and 'getting off track' with their diabetes management. An additional, and possibly related, concern was feeling like they had to act like the "diabetes police" with their child.

Parents of children with diabetes are at increased risk of anxiety and depression, which is associated with negative effects on their child's psychological well-being, quality of life and diabetes outcomes [29]. Assessment of parents' emotional well-being and access to psychological support is a critical component of comprehensive, paediatric diabetes care, although services are currently under-resourced to meet these needs [27].

Strengths and Limitations of the MILES Youth Survey

The proportion of NDSS Registrants that took part in the MILES Youth Survey was generally equivalent by state, with the exception of Northern Territory, where participation was very low. The majority of respondents were living in metropolitan areas in New South Wales, Queensland and Victoria, which reflects the geographic distribution of NDSS youth Registrants (Table 3). Among youth respondents, both genders and all age ranges were well-represented although there was an over-representation of girls.

Discussion

The online format was a successful and economical approach for engaging young people with type 1 diabetes and their parents. Not having access to a computer or the internet may have precluded some people from taking part, however, no-one requested a hard copy survey. While the online format provides greater confidentiality and therefore, potentially more candour with regard to moods and feelings [30], self-reported health information may be less reliable. Around 1 in 4 respondents used a mobile device to complete the survey, suggesting mobile-friendly platforms be used when designing future online surveys and initiatives.

The majority of respondents answered all questions (89%), and 77% asked for a copy of the survey report, indicating the survey was relevant and addressed important issues for young people with diabetes and their parents.

Response Rates and Representativeness of Sample

While the overall response rate of 13% appears low, it is similar to other large-scale online surveys of this nature [31].

To ensure the survey only included eligible participants, data for those who failed to complete the demographic section and the following set of well-being questions were removed. The survey was anonymous, so it is not possible to know whether people attempted the survey more than once, although this is unlikely because most participants provided their NDSS registration number.

Despite the fact that only 1 in 5 of the parent and child respondents were identified as being from the same family (N=258 dyads matched by NDSS registration number), parental responses were remarkably consistent with those of young people for the corresponding survey items, e.g., participant demographics, treatment type, frequency of self-monitoring blood glucose.

More mothers (88%) than fathers (11%) took part in the parent survey, which is consistent with the traditional and major role that mothers have in supporting their children with day-to-day diabetes self-management [32].

The MILES Youth survey respondents were self-selected, so may not represent the broader population of young people with diabetes and their families. This was a community-based sample, and included people recently diagnosed with diabetes, whereas many surveys of young people with diabetes are clinic-based, and limited to those with a duration of diabetes over one year. Based on parents' level of education, income and postcode, respondents were from a relatively advantaged socioeconomic background compared to the general population.

Consistent with this demographic, insulin pump use was higher among the MILES Youth Study respondents than the Australian average for this age group (53% vs 41% respectively) [15]. Most young people were managing their diabetes well, and self-reported HbA1c was lower, and fewer reported an HbA1c level above target (>58 mmol/mol (7.5%)) than among other Australian adolescent cohorts [21, 27]. These indicators suggest that respondents may have better diabetes self-management, health literacy and better access to healthcare services than young people with type 1 diabetes generally. Therefore, the impact of diabetes on psychosocial well-being and emotional distress reported by respondents may actually under-estimate the burden for young Australians with type 1 diabetes and their parents. Based on previous research [33], families living in disadvantaged circumstances are likely to have higher rates of distress, poorer well-being and healthcare access.

The survey was only available in English, due to the cost of translations. This may have prevented some people from completing the survey thus limiting the representativeness of the population surveyed. Only 11 young people with type 2 diabetes and 8 parents of young people with type 2 diabetes responded. Considering this very low response, it is evident that other approaches are needed to engage young people with type 2 diabetes and their families, many of whom are likely to be from culturally and linguistically diverse backgrounds (including ATSI) and/or be experiencing socioeconomic disadvantage.

Conclusions

The Diabetes MILES Youth Study has highlighted some significant psychosocial concerns of both young Australians living with type 1 diabetes and their parents. Most of those surveyed were managing their diabetes well, and reported good quality of life and emotional well-being. However, a substantial proportion of young people and parents were struggling with the burden of diabetes and experiencing serious psychological distress related to living with diabetes. Given the response bias already noted, this finding is likely to significantly under-represent the number of Australian families living with diabetes and in need of psychological support. It has been noted elsewhere that depression, anxiety and diabetes-related distress are unlikely to be detected without structured monitoring [34]. While the increased burden of diabetes on young people is well documented, the adverse psychological consequences for parents needs greater recognition. Psychological needs for families living with diabetes are not currently being met by existing services.

Next steps...

Analysis of the Diabetes MILES Youth Study 2014 results is ongoing, and will provide further insights into the psychosocial problems facing young people with diabetes and their parents. The findings will be widely disseminated through national and international conferences, scientific publications, Diabetes Australia and NDSS publications, and consumer forums. This report will help to advise the NDSS, national and state governments and clinicians about the support needs of Australian families living with diabetes to inform future service provision.

References

1. Rewers, M. J., Pillay, K., de Beaufort, C., Craig, M. E., Hanas, R., Acerini, C. L., & Maahs, D. M. (2014). Assessment and monitoring of glycemic control in children and adolescents with diabetes. *Pediatric diabetes*, 15(S20), 102-114.
2. National Diabetes Services Scheme. (2014) *NDSS Data Snapshots; 30 September 2014*. Accessed on 5.12.14. Available at www.ndss.com.au/en/Research/Data-Snapshots/
3. Anderson, B. (2009). Psychosocial care for young people with diabetes. *Pediatric diabetes*, 10(s13), 3-8
4. Northam, E. A., Matthews, L. K., Anderson, P. J., Cameron, F. J., & Werther, G. A. (2005). Psychiatric morbidity and health outcome in type 1 diabetes—perspectives from a prospective longitudinal study. *Diabetic Medicine*, 22(2), 152-157
5. Lang, E. (2008). *Best practice guidelines for health professionals for the effective transition of young people with diabetes from paediatric to adult care*. Brisbane: Queensland Health.
6. Kipps, S., Bahu, T., Ong, K., Ackland, F. M., Brown, R. S., Fox, C. T., ... & Dunger, D. B. (2002). Current methods of transfer of young people with Type 1 diabetes to adult services. *Diabetic Medicine*, 19(8), 649-654.
7. Australian Bureau of Statistics. The Index of Relative Socio-economic Disadvantage (IRSD) 2011 [cited 1 December 2014]; Available from: www.abs.gov.au/ausstats/abs@.nsf/Lookup/2033.0.55.001main+featu res100052011.
8. Bech P, Olsen LR, Kjoller M, Rasmussen NK. (2003) Measuring well-being rather than the absence of distress symptoms: a comparison of the SF-36 Mental Health subscale and the WHO-Five Well-Being Scale. *International Journal of Methods in Psychiatry Research*. 12: 85–91.
9. De Wit, M., Pouwer, F., Gemke, R. J., Delemarre-van de Waal, H. A., & Snoek, F. J. (2007). Validation of the WHO-5 Well-Being Index in adolescents with type 1 diabetes. *Diabetes Care*, 30(8), 2003-2006.
10. Johnson, J. G., Harris, E. S., Spitzer, R. L., & Williams, J. B. (2002). The patient health questionnaire for adolescents: validation of an instrument for the assessment of mental disorders among adolescent primary care patients. *Journal of Adolescent Health*, 30(3), 196-204.
11. Kroenke, K., Strine, T. W., Spitzer, R. L., Williams, J. B., Berry, J. T., & Mokdad, A. H. (2009). The PHQ-8 as a measure of current depression in the general population. *Journal of affective disorders*, 114(1), 163-173.
12. Spitzer, R. L., Kroenke, K., Williams, J. B., & Löwe, B. (2006). A brief measure for assessing generalized anxiety disorder: the GAD-7. *Archives of internal medicine*, 166(10), 1092-1097.
13. Weissberg-Benchell, J., & Antisdell-Lomaglio, J. (2011). Diabetes-specific emotional distress among adolescents: feasibility, reliability, and validity of the problem areas in diabetes-teen version. *Pediatric diabetes*, 12(4pt1), 341-344.
14. Markowitz, J. T., Butler, D. A., Volkening, L. K., Antisdell, J. E., Anderson, B. J., & Laffel, L. M. (2010). Brief screening tool for disordered eating in diabetes internal consistency and external validity in a contemporary sample of pediatric patients with type 1 diabetes. *Diabetes Care*, 33(3), 495-500.
15. National Diabetes Services Scheme, *Personal Communication*, November 2014.
16. Gold, A. E., Macleod, K. M., & Frier, B. M. (1994). Frequency of severe hypoglycemia in patients with type I diabetes with impaired awareness of hypoglycemia. *Diabetes care*, 17(7), 697-703.
17. Gonder-Frederick, L., Nyer, M., Shepard, J. A., Vajda, K., & Clarke, W. (2011). Assessing fear of hypoglycemia in children with type 1 diabetes and their parents. *Diabetes Management*, 1(6), 627-639.
18. de Wit, M., Winterdijk, P., Aanstoot, H-J., Anderson, B., Danne, T., Deeb, L., ... Snoek, F. (2012) Assessing diabetes-related quality of life of youth with type 1 diabetes in routine clinical care: the MIND Youth Questionnaire (MY-Q). *Pediatric Diabetes*. 13(8): p. 638-646.
19. Hajos, T. R. S., Pouwer, F., Skovlund, S. E., Den Oudsten, B. L., Geelhoed-Duijvestijn, P. H. L. M., Tack, C. J., & Snoek, F. J. (2013). Psychometric and screening properties of the WHO-5 well-being index in adult outpatients with Type 1 or Type 2 diabetes mellitus. *Diabetic Medicine*, 30(2), e63-e69.
20. Weissberg-Benchell, J., Hood, K.K., & Antisdell-Lomaglio, J. (2014) *Psychometric Properties of the Parent Version of the Problem Areas in Diabetes-Teens*. Poster, 74th Scientific Sessions, American Diabetes Association, June 13-17, San Francisco, CA.
21. Hackworth, N. J., Hamilton, V. E., Moore, S. M., Northam, E. A., Bucalo, Z., & Cameron, F. J. (2013). Predictors of Diabetes Self-care, Metabolic Control, and Mental Health in Youth with Type 1 Diabetes. *Australian Psychologist*, 48(5), 360-369.

References

22. Hood, K. K., Huestis, S., Maher, A., Butler, D., Volkening, L., & Laffel, L. M. (2006). Depressive Symptoms in Children and Adolescents With Type 1 Diabetes Association with diabetes-specific characteristics. *Diabetes Care*, 29(6), 1389-1389.
23. Rey, J. M., Sawyer, M. G., Clark, J. J., & Baghurst, P. A. (2001). Depression among Australian adolescents. *The Medical Journal of Australia*, 175(1), 19-23.
24. Twenge, J. M., & Nolen-Hoeksema, S. (2002). Age, gender, race, socioeconomic status, and birth cohort difference on the children's depression inventory: A meta-analysis. *Journal of Abnormal Psychology*, 111(4), 578.
25. Ly, T. T., Gallego, P. H., Davis, E. A., & Jones, T. W. (2009). Impaired Awareness of Hypoglycemia in a Population-Based Sample of Children and Adolescents With Type 1 Diabetes. *Diabetes Care*. 32(10): p. 1802-1806.
26. Diabetes Australia LTD. (2012) *Youth transition survey*. Diabetes Australia: Canberra, ACT
27. Cameron, F., Cotterill, A., Couper, J., Craig, M., Davis, E., Donaghue, K., ... & Sheil, B. (2013). Short report: Care for children and adolescents with diabetes in Australia and New Zealand: Have we achieved the defined goals? *Journal of Paediatrics And Child Health*, 49(4), E258-E262.
28. Kibbey, K. J., Speight, J., Wong, J. L. A., Smith, L. A., & Teede, H. J. (2013). (2013) Diabetes care provision: barriers, enablers and service needs of young adults with Type 1 diabetes from a region of social disadvantage. *Diabetic Medicine*. 30(7): p. 878-884.
29. Whittemore, R., Jaser, S., Chao, A., Jang, M., & Grey, M. (2012). Psychological experience of parents of children with type 1 diabetes a systematic mixed-studies review. *The Diabetes Educator*. 38(4): p. 562-579.
30. Van Gelder, M. M., Bretveld, R. W., & Roeleveld, N. (2010) Web-based Questionnaires: The Future in Epidemiology? *American Journal of Epidemiology*. 172(11): p. 1292-1298.
31. Heiervang, E. & Goodman, R. (2011). Advantages and limitations of web-based surveys: evidence from a child mental health survey. *Social Psychiatry & Psychiatric Epidemiology*, 46(1): p. 69-76.
32. Seiffge-Krenke, I. (2002). "Come on, say something, Dad!": Communication and coping in fathers of diabetic adolescents. *Journal of Pediatric Psychology*, 27(5), 439-450.
33. Everson, S. A., Maty, S. C., Lynch, J. W., & Kaplan, G. A. (2002). Epidemiologic evidence for the relation between socioeconomic status and depression, obesity, and diabetes. *Journal of Psychosomatic Research*, 53(4), 891-895.
34. Jones, A., Vallis, M., & Pouwer, F. (2014). If it does not significantly change HbA1c levels why should we waste time on it? A plea for the prioritization of psychological well-being in people with diabetes. *Diabetic Medicine*.
35. WHO, *Info package: mastering depression in primary care, version 2.2*, 1998, World Health Organisation Regional Office for Europe: Psychiatric Research Unit: Frederiksorg.
36. Cooper, H., Spencer, J., Lancaster, G. A., Titman, A., Johnson, M., Wheeler, S. L., & Lwin, R. (2014). Development and psychometric testing of the online Adolescent Diabetes Needs Assessment Tool (ADNAT). *Journal of advanced nursing*, 70(2), 454-468.
37. Speight, J. (2010) *The Hypoglycaemia Awareness Questionnaire (HypoA-Q)*, AHP Research.
38. Jung, J., & Peterson, M. (2007). Body dissatisfaction and patterns of media use among preadolescent children. *Family and Consumer Sciences Research Journal*, 36(1), 40-54.
39. Peterson, M., Ellenberg, D., & Crossan, S. (2003). Body-image perceptions: reliability of a BMI-based silhouette matching test. *American Journal of Health Behavior*, 27(4), 355-363.
40. Croom, A., Wiebe, D. J., Berg, C. A., Lindsay, R., Donaldson, D., Foster, C., ... & Swinyard, M. T. (2011). Adolescent and parent perceptions of patient-centered communication while managing type 1 diabetes. *Journal of Pediatric Psychology*, 36(2), 206-215.
41. Williams, G. C., Freedman, Z. R., & Deci, E. L. (1998). Supporting autonomy to motivate patients with diabetes for glucose control. *Diabetes Care*, 21(10), 1644-1651.
42. Bradley, C., The diabetes treatment satisfaction questionnaire: DTSQ, in *Handbook of Psychology and Diabetes: a guide to psychological measurement in diabetes research and practice*, C. Bradley, Editor. 1994, Harwood Academic Publishers p. 111-132.
43. Hilliard, M.E., Weissberg-Benchell, J., Hood, K.K. (2014) *Psychometric Properties of a Diabetes Resilience Measure for Adolescents*. American Diabetes Association 74th Scientific Sessions, June 13-17, 2014, San Francisco, CA.

References

44. Singh, H., Gonder-Frederick, L., Schmidt, K., Ford, D., Vajda, K. A., Hawley, J., & Cox, D. J. (2014). Assessing hyperglycemia avoidance in people with Type 1 diabetes. *Diabetes Management*, 4(3), 263-271.
45. Department of Public Health, State of Connecticut, USA. *Online Transition to Adulthood surveys for youth with chronic illness*. Available at www.ct.gov/dph/cwp/view.asp?a=3138&q=475012. Accessed on 2/3/2014.
46. Anderson, B. J., Auslander, W. F., Jung, K. C., Miller, J. P., & Santiago, J. V. (1990). Assessing family sharing of diabetes responsibilities. *Journal of Pediatric Psychology*, 15(4), 477-492.
47. Leonard, B. J., Skay, C. L., & Rheinberger, M. M. (1998). Self-management development in children and adolescents with diabetes: the role of maternal self-efficacy and conflict. *Journal of Pediatric Nursing*, 13(4), 224-233.
48. Cox, A. & Bentovim, A. (2000) *Framework for the Assessment of Children in Need and their Families. The Family Pack of Questionnaires and Scales*. Department of Health, Norwich, UK. Available at www.brown.uk.com/teaching/socialwork/familypack.pdf. Accessed on 1/6/2014

Appendix I: Reference Groups

NDSS Young People with Diabetes National Development Program - Expert Reference Group

Ms Renza Scibilia and Ms Jane Cheney from Diabetes Victoria were the program lead and coordinator, respectively. The following experts oversee the program that funded the survey and advised on its content

Name	Affiliation	State	Position
Prof Susan Sawyer (Chair)	Centre for Adolescent Health, Royal Children's Hospital	VIC	Chair of Adolescent Health
Ms Renza Scibilia (Leader)	Diabetes Victoria	VIC	NDSS NDP Young People with Diabetes Leader
Ms Jane Cheney (Co-ordinator)	Diabetes Victoria	VIC	NDSS NDP Young People with Diabetes Co-ordinator
Dr Jessica Browne	The Australian Centre for Behavioural Research in Diabetes	VIC	Research Fellow
Stephanie Cesile		TAS	Young person with diabetes
Assoc. Prof. Jane Holmes-Walker	Westmead Hospital	NSW	Endocrinologist
Prof Tim Jones	Princess Margaret Hospital	WA	Head of Diabetes & Obesity
Eunice Lang	Private practice	QLD	Credentialed Diabetes Educator
Sue Leahy	Diabetes New South Wales	NSW	Credentialed Diabetes Educator
Caroline Wells	Diabetes Tasmania	TAS	Chief Executive Officer

Diabetes MILES Youth Study Reference Group

The following experts advised on the content of the MILES Youth survey

Name	Affiliation	Country	Discipline
Prof Barbara Anderson	Baylor College of Medicine	USA	Paediatric Psychology
Dr Melanie Burkhardt	Fremantle Hospital	Australia	Health Psychology
Prof Fergus Cameron	Royal Children's Hospital, Melbourne	Australia	Paediatrics
Dr Maartje de Wit	VU University Medical Center	Netherlands	Medical Psychology
Dr Christel Hendrieckx	The Australian Centre for Behavioural Research in Diabetes	Australia	Clinical Psychology
A/Prof Marisa Hilliard	Baylor College of Medicine	USA	Paediatrics
A/Prof Michelle Jack	Royal North Shore Hospital	Australia	Paediatrics
Ms Brigid Knight	Queensland Diabetes Centre	Australia	Dietitian/Diabetes Educator
Dr Giesje Nefs	Tilburg University	Netherlands	Medical Psychology
A/Prof Elizabeth Northam	Royal Children's Hospital, Melbourne	Australia	Clinical Psychology
Prof Frans Pouwer	Tilburg University	Netherlands	Medical Psychology
Prof Timothy Skinner	Charles Darwin University	Australia	Health Psychology

Appendix II

Appendix II: Variables included in survey (Youth version)		
Concept	Measure or variable	Age group
About you		
Demographics	12 items - age, gender, family composition, occupation	10-19
Diabetes history	4 items - diabetes type, treatment, duration, family history	10-19
My mood		
General quality of life	Single item from MIND Youth Questionnaire (MY-Q) [18]	10-19
Well-being	WHO-5 Well-being Scale [8, 9, 35]	10-19
Depressive symptoms	8-items PHQ-A [10, 11]	13-19
Anxiety	GAD-7 [12]	13-19
My Feelings About Diabetes		
Diabetes distress	Problem Areas in Diabetes – Teen version (PAID-T) [13]	13-19
Family conflict	2 items from MIND-Youth Questionnaire (MY-Q) [18,46]	10-19
Responsibility for diabetes management	2 items (family responsibility) from MY-Q [18]	10-19
Parental support	2 free text boxes - developed for MYS (what I wish my parents knew about diabetes.. ; what my parent do to help me..)	10-19
My Health & Health Checks		
General health	5-items (other health conditions, HbA1c, weight, height)	10-19
Perceived health	1-item - self-rated health	13-19
Diabetic ketoacidosis (DKA)	1-item incidence of diabetic ketoacidosis	13-19
My Diabetes Care		
Blood glucose monitoring	3-items self-monitoring blood glucose frequency	10-19
Insulin management	4-items (Insulin treatment, insulin omission, adapted from MY-Q [18] and Adolescent Diabetes Needs Assessment Tool (ADNAT) [36]	13-19

Appendix II: Variables included in survey (Youth version)		
My hypos		
Hypoglycaemia frequency	6 items adapted from Hypoglycaemia Awareness Questionnaire (HypoA-Q) [37]	13-19
Hypoglycaemia awareness	Single-item Gold score [16] ; 1-item adapted from Hypoglycaemia Awareness Questionnaire (HypoA-Q) [37]	13-19
Fear of hypoglycaemia	Child Hypoglycaemia Fear Survey II [17] ; 15-item worry scale and 11-item behaviour scale	13-19
My eating habits		
Diabetes-specific eating disorders	16-items Diabetes Eating Problem Survey-Revised (DEPS-R) [14]; 1-item binge eating frequency adapted from MY-Q [18]	13-19
Body image	3-items, gender-specific body image silhouettes from BMI-based Silhouette Matching Test (BMI-SMT) [38, 39]	13-19
My Healthcare Team		
Patient-centred communication (PCC)	5-item PCC subscale of the Healthcare Climate Questionnaire [40, 41]	13-19
Treatment satisfaction	3-items from MY-Q (satisfaction with regimen, healthcare team and glucose control) [18]; derived from the Diabetes Treatment Satisfaction Questionnaire (DTSQs) [42]	10-19
Health professional support	Free text box	13-19
Support to manage my diabetes		
Resilience	12-items Diabetes Resilience Measure for Adolescents [43]	10-19
Social support	4-items – free text boxes (what I wish friends / teachers knew about diabetes; what my friends / teachers do to help me)	10-19
NDSS support	Free text box	13-19
Technology	5-study-specific items (diabetes ‘apps’)	10-19
Final comments	Free text box	10-19

Appendix III

Appendix III: Variables included in survey (Parent version)	
Concept	Measure or variable
About you	
Demographics	10 items - age, gender, family composition, occupation
My well-being	
Well-being	WHO-5 Well-being Scale [8, 35]
Anxiety	GAD-7 [12]
My child's diabetes	
Diabetes history and management	17 items - diabetes type, treatment, duration, family history, other health conditions, HbA1c, self-monitoring of blood glucose, diabetes ketoacidosis
Worry about hyperglycaemia	3 items from Hyperglycaemia Fear Survey II [17]
My Feelings About Diabetes	
Diabetes distress	PAID-Parent of Teen (PAID-PT) [20]
Diabetes awareness	2 free text boxes (what I wish family friends / general public knew about diabetes)
My Child's Diabetes Care	
Diabetes services	6 items (service providers)
Patient-centred communication (PCC)	5-item PCC subscale of the Healthcare Climate Questionnaire (parent version) [40, 41]
Treatment satisfaction	3 items from MY-Q adapted for parents (satisfaction with regimen, healthcare team and child's glucose control; derived from the Diabetes Treatment Satisfaction Questionnaire (DTSQs) [18, 42]
Transition	3 items adapted from Online Transition to Adulthood surveys for youth with chronic illness, US Department of Health [45]
Support from carers	2 open text boxes – (What I wish HCPs / teachers knew about diabetes)
My child's hypos	
Hypoglycaemia frequency	7 items adapted from Hypoglycaemia Awareness Questionnaire (HypoA-Q) [37]
Hypoglycaemia awareness	Single-item Gold score [16] adapted for parents; 1 item adapted from HypoA-Q adapted for parents [37]
Technical / medical support	4 items (beliefs about technology & hypos; discuss hypos with doctor)
Fear of hypoglycaemia	Hypoglycaemia Fear Survey II Parent version; 15-item worry scale and 11-item behaviour scale [17]
Managing My Child's Diabetes	
Diabetes Family Responsibility	5 items modified from the Diabetes Family Responsibility Questionnaire [46]
Self efficacy	Maternal Self-Efficacy for Diabetes Management Scale [47]
Personal Questions	
Demographics	8 items (education, employment, financial status)
Stressful life events	10 items adapted from Recent Life Events Questionnaire [48]
Support	
Support for managing diabetes	3 free text boxes (technology, other, NDSS support)
Final comments	Free text box

Appendix IV: Summary of scales included in this report

Name	Description
BMI-based Silhouette Matching Test (BMI-SMT) [38, 39]	The BMI-based-Silhouette Matching Test (BMI-SMT) uses gender-specific silhouette figures as reference points within a 27-point scale, each figure representing an increase (or decrease) of one BMI unit (a BMI score ranging from 14 to 40) to estimate the degree of body image dissatisfaction. Three sets of silhouettes were presented and respondents were asked to choose a point on the scale that (i) was 'closest to the weight they are now'; (ii) 'closest to the size they would like to be'; (iii) a study-specific item – 'closest to the size you would be without diabetes'.
Hypoglycaemia Fear Survey II (HFS-II) [17]	The 26-item child and parent versions of the HFS-II assess children's and parents' worries (15-item subscale) and behaviours (11-item subscale) related to hypoglycaemia. Items are rated on a five-point Likert scale (1=Never; 5= Always). Subscale and total scores are obtained by summing the items for the worry subscale (range 15–75), the behaviour subscale (range 10–50) and the total score (range 25–125). Higher scores indicate higher fear of hypoglycaemia.
Diabetes Eating Problem Survey-Revised (DEPS-R) [14]	A 16-item, diabetes-specific measure of disordered eating. Items are answered on a 6-point Likert scale (0= Never; 5=Always). Item scores are summed, with higher scores indicating more disordered eating.
Diabetes Family Responsibility Questionnaire (DFRQ) [46]	Five items from the DFRQ were used to identify parental perceptions about how diabetes self-care responsibilities are shared within the family. For each task parents chose: (i) child is mainly responsible, (ii) responsibility is shared, or (iii) the parent is mainly responsible.
Diabetes Resilience Measure for Adolescents (DRMA) [43]	A 12-item scale that measures diabetes resilience, defined as the achievement of positive outcomes despite experiencing significant risk or adversity. Items are rated on a 5-point scale (0=Never, 4=Almost always). There are slight wording variations between the 9-13 years and 14-18 years versions that were used for the 10-12 year and 13-19 year age groups of the MILES Youth surveys respectively. The results of the DRMA are not reported here.
Generalised Anxiety Disorder Scale (GAD-7) [12]	Generalised Anxiety Disorder scale (GAD-7) rates the frequency of anxiety symptoms over the past two weeks on a 7-point scale (0=Not at all, 7=Nearly every day). Item scores are summed to form a total score (range: 0 to 21). Severity of anxiety symptoms was assessed using cut-off scores of 5, 10 and 15 representing mild, moderate, and severe anxiety respectively.
Gold score [16]	The single-item Gold score measures hypoglycaemia awareness. The Gold score asks participants to rate on a 7-point scale the extent to which they know when their hypos are commencing (1 = Always aware, 7 = Never aware). A score of 4 or more implies impaired awareness.
Patient-Centred Communication (PCC) [40, 41]	A 5-item version of the Healthcare Climate Questionnaire modified for adolescents with diabetes and their parents, that measures adolescent and parent perceptions of collaborative decision-making with their diabetes healthcare professional. Items are rated on a 5-point scale (1=Strongly disagree; 5=Strongly agree). Scores are averaged across items with higher scores indicating higher PCC. The results of the PCC are not reported here.
Monitoring Individual Needs in Diabetes Youth Questionnaire (MY-Q) [18]	8 items from the MY-Q assessed general QoL (1 item), diabetes responsibility (2 items) and family conflict (2 items) and treatment satisfaction (3 items). Items were rated (QoL, 0=Worst possible life; 10=Best possible life); diabetes responsibility and family conflict (1=All the time; 5=Never) and treatment satisfaction (1=Not at all happy; 5=Extremely happy); Treatment satisfaction for parents was rated 1=Very dissatisfied to 5=Very satisfied.
Problem Areas in Diabetes – Teen (PAID-T) [13]	A 26-item scale which measures the perceived emotional burden of living with diabetes. The PAID-T was adapted from the adult version. Items are rated on a scale of 1 (not a problem) to 6 (serious problem). Item scores were summed to form a total score (range: 26-156), with higher scores indicating greater diabetes-related distress.

Appendix IV

Appendix IV: Summary of scales included in this report

Name	Description
Problem Areas in Diabetes – Teen Parent version (PAID-PT) [20]	The PAID-PT was adapted from the PAID-T to measure the perceived burden of caring for an adolescent with diabetes. The rating scale and method of scoring is the same as for the PAID-T.
Patient Health Questionnaire for Adolescents (PHQ-A) [10, 11]	An 8-items version (suicide ideation item was omitted) of the PHQ-9 scale, modified for adolescents, that assesses the presence and severity of depressive symptoms. Participants rate the frequency with which they have experienced symptoms of depression over the past two weeks on a 4-point scale (0= not at all; 3= nearly every day). Items scores are summed to form a total score out of 24. Scores of 5, 10, 15 and 20 represent cut-off points for mild, moderate, moderately-severe and severe depression respectively.
WHO-5 Wellbeing Scale [8, 9]	A positively-worded 5-item scale that measures general well-being. Each item is scored on a 6-point Likert scale (0=Not present; 5=Constantly present). The item scores are summed and higher scores indicate better well-being. A total score <50 suggests poor emotional well-being.
Maternal Self-Efficacy for Diabetes Management Scale (MSEDSM) [47]	A 17-item scale which assesses perceived parental confidence with specific diabetes management tasks. Each item is rated on 5-point scale (1= Not confident at all; 5= Very confident without help). Item scores are summed, with higher scores indicating greater self-efficacy. The results of the MSEDSM are not reported here.











2014 Survey Report