NDSS

National Diabetes Services Scheme

An Australian Government Initiative

NDSS Helpline 1800 637 700

ndss.com.au

diabetes australia

The NDSS is administered by Diabetes Australia

Developed in consultation with young people living with diabetes.

Our voices, our lives, our choices
NDSS Youth and Youth Transition Project report.
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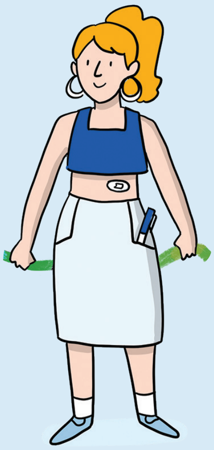

About the Project Coordinator

Siobhan Johnston

Siobhan brings over 13 years of type 1 diabetes lived experience to her role as the NDSS *Youth and Youth Transition Project Coordinator* (based at Diabetes Victoria).

Siobhan has a *Science Bachelor of Nutritional Therapy* and *Graduate Certificate in Health Promotion* and *Consumer & Community Engagement*. Siobhan found her niche working in consultation with consumers at Diabetes Victoria.

Having received her type 1 diabetes diagnosis on her first day of year 11, Siobhan is all too familiar with the numerous challenging transitions that take place for young people in this age group. At the age of 16, she was no longer a child, but she was not yet an adult either. To assert her growing desire for independence, it made sense that Siobhan learned how to manage her own diabetes from day one.

Siobhan is extremely thankful for the unwavering patience and support that she received from her immediate family and husband Travis as she learned to accept and manage her diabetes as part of her everyday routine.

Siobhan is a strong advocate of peer support and describes it as "something you stumble across unintentionally and don't know how much you benefit from it until it hits you". She is an avid member of the *Type 1 Facebook* peer support community because they "just get it!" The days of high glucose levels and blocked cannulas do not seem so daunting anymore. You feel less alone and very normal in your approach to the daily challenges with type 1."

Siobhan jumped at the chance to work on this project and hopes that she can help to facilitate further change in the NDSS program and service offerings for young people with type 1 diabetes moving forward.

Foreword

Siobhan's type 1 diabetes diagnosis at 16 influenced her young adult years and shaped the person she is today. Her parents, as her most avid supporters, remember this time vividly. This is their perspective of Siobhan's diabetes journey.

By Craig and Jenny Walker (Siobhan's parents)

In February 2007, Siobhan's life was to change forever after receiving the diagnosis of type 1 diabetes from our local GP. We were becoming very concerned with Siobhan's rapid decline in health. We took Siobhan to the doctor and requested they test for diabetes which was initially denied. Instead, the GP suggested it may be a case of glandular fever and sent us home.

A few days later we took Siobhan back to the doctor and insisted they test for diabetes. Siobhan was feeling extremely unwell, losing weight and unable to quench her thirst. Two hours after Siobhan had the blood test done, our doctor rang and we rushed back to receive the diagnosis of type 1 diabetes.

We were all shocked and relieved at the diagnosis. The doctor suggested we book an appointment with an endocrinologist. However, Jenny advocated that she take Siobhan straight to the Royal Children's Hospital and we were very glad that we did! As it turned out, Siobhan's blood glucose level (BGL) was 34 mmol/L and she had high ketones.

The Royal Children's Hospital provided excellent support for Siobhan and the whole family for the two years that she was under their care. Upon admission, Siobhan spent the following seven days in the hospital learning how to inject herself with insulin, test her blood glucose levels and the importance of regular meals and carbohydrate counting. Siobhan, as a very reliable and organised young lady, took the learning on board to ensure she was looking after herself. However, she worried if she would ever be able to play netball again.

Diabetes comes with its challenges. The sleepless nights managing high and low blood glucose levels and hours spent worrying about Siobhan when she returned to school and part-time work. And now as a mother of a young child, we continue to support her the best we can when her diabetes requires some extra attention.

Type 1 diabetes has shaped Siobhan into a strong and determined woman.

A girl who, due to her diagnosis of type 1 diabetes, was unsure if she could finish high school went on to study at university and is now pursuing her passion, working for Diabetes Victoria, helping to support all people living with diabetes.

Acknowledgements

This report forms part of the NDSS *Youth and Youth Transition Priority Area* and details the findings of *Our voices, our lives, our choices*, a national co-designed and consumer-led initiative with young people aged 18 to 29 years, living with type 1 diabetes, across Australia.

The idea for this national consultation came to fruition through informal discussions with four young people, all living with type 1 diabetes, who identified that a need existed for the NDSS to better engage with them. It was their idea and advice that led to the development of a successful NDSS proposal.

The report was compiled in collaboration with two groups:

- **The *Expert Consumer Consultation Group* (ECCG):** Consisted of 13 empowered young people, representing all states, with strong links to the diabetes community. The ECCG volunteered their time to ensure their own voice and their communities' voices were heard.
- **The *Expert Reference Group* (ERG):** Made up of nine national health professionals, researchers and diabetes advocates providing their advice and professional insights.

We would also like to take this opportunity to acknowledge:

- **The interviewees:** The 12 young people from across Australia who committed their time to being interviewed and providing their stories to enrich the outcomes. They were selected for their diverse experiences and insights into life with diabetes. We have incorporated their comments and stories throughout this report, while maintaining their privacy. Their stories provided a voice for some of the identified priority communities.
- **The 2384 survey participants:** We appreciate their time taken to complete the survey and the insights they provided.

Finally, we would like to acknowledge the work of the team:

Project Coordinator:

- **Siobhan Johnston** – NDSS *Youth and Youth Transition Project Coordinator, Diabetes Victoria*

Support team:

- **Carolyn Jones** – *NDSS National Youth and Youth Transition Priority Leader and Consumer Engagement Manager, Diabetes Victoria*
- **Kim Hider** – *Head of Evaluation, Evidence and Quality, Diabetes Victoria*
- **Matthew Ross** – *Projects and Evaluation Officer, Diabetes Victoria*
- **Jane Cheney** – *Consumer Engagement Officer, Diabetes Victoria*
- **Nino Soeradinata** – *Publication Designer, Diabetes Victoria*

Executive summary

The *Our voices, our lives, our choices* report formed part of the National Diabetes Services Scheme (NDSS) *Youth and Youth Transition Priority Area* 2019-2020. It was a consumer-led and co-designed project that aimed to further understand the current experiences of young Australians (18 to 29 years) living with type 1 diabetes. The overall objective was to hear from young Australians regarding their awareness of and interactions with the NDSS, and how the NDSS could better support them.

To our knowledge, this was the largest national consultation undertaken with young people aged 18–29 years, reaching 13% of the overall population of young people with type 1 diabetes registered with the NDSS.

Demographic of respondents

Young people can be a difficult group to reach.[1] For young people with type 1 diabetes, this can be a challenging time of recognised legal independence combined with sole responsibility for their own diabetes management. Transition from paediatric diabetes services to adult healthcare services or adapting to a new diagnosis in early adulthood can compound the challenges.[2] It can be a time when optimal diabetes self-management is compromised.[3]

Method

A review of existing resources and studies was completed between June and August 2019. The national online survey was developed in consultation with a group of young people from across Australia, who were selected to become the *Expert Consumer Consultation Group* (ECCG). *An Expert Reference Group* (ERG) consisting of health professionals, researchers and diabetes advocates provided support during the project. The national online survey was open from 2 March to 22 March 2020. In addition, interviews with young people were conducted from 6 April to 14 April 2020.

Reach

13,140 young people, who were registered with the NDSS, were sent the link to the online survey, and 2384 responded. Additionally, 12 phone interviews were conducted to highlight views of those from identified priority communities.

Results

This report presents the data of the 2384 young people who responded to the survey and 12 interviewees who provided their stories.

Responses were received from all Australian states and territories, and included metropolitan, regional, rural, remote and very remote areas. There was a widespread response across the age range with 14% (n=334) of respondents aged 18-19 years and 21% (n=501) of respondents aged 28-29 years. Fifty-one percent (n=1215) of respondents reported being diagnosed between the ages of 6 and 13 years. A total of 3.2% (n=78) identified as Aboriginal and/or Torres Strait Islander and 2.7% (n=60) spoke a language other than English at home. More than 30 different languages were identified as those being spoken at home.

Technology and devices used

Young people were asked to indicate which technology/devices they use to manage their diabetes:

- 94% (n=2160) used a blood glucose meter
- 64% (n=1469) administered their insulin via injections (pen or syringe)
- 42% (n=970) administered their insulin via an insulin pump
- 35% (n=800) used a continuous glucose monitoring (CGM) system
- 26% (n=604) used a Flash glucose monitoring (Flash GM) system and
- 13% (n=293) managed their diabetes using a DIY technology system.

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[1] Hicks J & Flamez B.N (2016) *Young adulthood: Physical and cognitive development* in Capizzi D. & Staufter M (Eds) *Human growth and development across the lifespan: Applications for counsellors, p. 389 – 414 John Wiley & Sons Inc*

[2] 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.

[3] Ventura AD, Browne JL, Holmes-Truscott E, Hendrieckx C, Pouwer F, Speight J (2016) *Diabetes MILES-2 2016 Study*. Diabetes Victoria, Melbourne.

Executive summary

Barriers to using particular technology and devices included the burden of cost when not eligible to access fully subsidised products through the Australian Government's Continuous Glucose Monitoring Initiative (CGM Initiative) as part of the NDSS. Other challenges raised included psychological barriers, limited knowledge about the device or a previous negative experience with the technology. The most common reason for not using Do It Yourself (DIY) technologies was a lack of information about devices or concerns about safety.

Accessing diabetes products through pharmacy

A total of 69% (n=1645) did not experience problems accessing diabetes products from NDSS Access Points (usually a community pharmacy) in the last 12 months, however 31% (n=739) had experienced problems.

Variation existed between pharmacies. Many respondents raised concerns about the limited knowledge some pharmacy staff had about the NDSS ordering system and different diabetes products.

Limited stock of non-NDSS diabetes products such as blood ketone strips and NDSS products such as needles created difficulty in sourcing diabetes products.

Connection, mental health and support

- Thirty-nine percent (n=930) were connected to other young people with diabetes while 61% (n=1454) were not.
- Twenty-nine percent (n=691) found connections with others with diabetes important or extremely important.
- Preferred engagement methods with other young people included Facebook, Instagram, phone/text and peer support (face-to-face).
- For those who indicated being connected was important, nearly 11% (n=125) identified mental health support as highly desired.

Awareness and communication of NDSS offerings

- There was a low awareness and use of NDSS programs, services and resources. For example, less than 5% were aware of, or had taken part in, the OzDAFNE program.
- Only 13% (n=310) were aware of and had accessed the NDSS Helpline. 53% (n=1264) were aware of but had not accessed the NDSS Helpline.
- Young people had low levels of awareness of existing NDSS resources. Between 48-83% were not aware of eight key diabetes resources available to them on the NDSS website (*Diabetes Annual Cycle of Care* fact sheet and checklist, *Moving on Up: Guide for young adults with diabetes, Diabetes and driving, Alcohol and type 1 diabetes, Drug use and type 1 diabetes, Travel and type 1 diabetes and CGM and Flash GM device summary & compatibility chart*).
- The preferred engagement methods when receiving communication from the NDSS about offerings and subsidised products included email, text messages, the respondent's health professional and social media.

Education and information

- The preferred methods for participating in diabetes education included online self-paced learning modules, face-to-face individual sessions, YouTube videos, apps, podcasts and face-to-face group sessions. Webinars were the least preferred method.
- The most common ways young people look for diabetes information included through their health professional, doctor, internet browser searches (i.e. Google and Yahoo), diabetes education sessions and through other people with diabetes. The NDSS website was the sixth preferred option and the NDSS Helpline was the eleventh preferred option out of fifteen options provided. The preferred education topics of interest included new and emerging treatments and technologies, mental health, burnout and diabetes distress, diabetes research opportunities, insurance and income protection options, and a low carbohydrate lifestyle.

How can the NDSS continue to improve its support?

- More tailored and accessible mental health support services
- Better and cheaper access to health professionals
- Better access to services and information in rural and remote areas
- Promotion of consumer empowerment, connection and collaboration.

Key opportunities

The following nine key opportunities have been developed based on the results of the national survey, interviews conducted, consultations with people living with diabetes and healthcare professionals. Key opportunities are displayed in logical sequence as presented in the survey results.

Key opportunity 1

Continue to support the need of young people with type 1 diabetes for information and resources about CGM and CGM devices.

Key opportunity 2

Improve access to subsidised NDSS products by providing information and resources to pharmacies about the products and the ordering processes.

Key opportunity 3

Expand NDSS Helpline access to accommodate young people connecting to diabetes healthcare professionals.

Key opportunity 4

Provide opportunities for young people to connect with diabetes related mental health support.

Key opportunity 5

Assist young people with type 1 diabetes to meet and support others.

Key opportunity 6

Enhance NDSS connections with young people to ensure offerings are developed and evaluated with them.

Key opportunity 7

Include young people in the development of campaigns and share on platforms they prefer to use.

Key opportunity 8

Deliver NDSS educational materials via methods preferred by young people.

Key opportunity 9

Provide information to young people about diabetes research and clinical trial opportunities.

Introduction

Young people with type 1 diabetes in Australia today

Early adulthood is an important time in a young person's life as they strive to find their place in the world. Childhood is defined as 'anyone under 18 years of age'[4] while adulthood is legally defined as 'a person who is at least 18 years old.'[5] Major changes occur during these early adult years; including greater cognitive and emotional capacity and relationship skills.[6] Legally, they are recognised for the first time as independent. This often occurs while also navigating the commencement of higher education, an apprenticeship and/or work, voting, moving out of home and travel.[7,8]

Throughout this report we will use the term *'young people'* which we have defined as *'any adult between the ages of 18 to 29 years (inclusive)'*. There are 18,420 young people, aged 18-29 years, living with type 1 diabetes in Australia and registered with the NDSS.[9]

Young people with type 1 diabetes face additional challenges.[10] They must navigate the usual transitions to adulthood, while also assuming the increasing responsibility for their diabetes care and overall health.[11,12,13,14] Disengagement from health services is well recognised in this group as some navigate the transition from the supported paediatric health service to adult care, and others face being newly diagnosed.[15] Optimal diabetes self-management can be compromised during this time.[16]

An important objective of this national consultation was to obtain a baseline understanding of young people's awareness and use of NDSS programs, services, resources and information. Congruent to this, the content of this report is informed by their experiences.[17]

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[4] *Australian Human Rights Convention* 1990 for definition of a child

[5] *Children and Young People's Act* 2008, (ACT) refers to the *Legislation Act* 2001 (ACT) for definition of an adult

[6] Hicks J & Flamez B.N (2016) *Young adulthood: Physical and cognitive development* in Capizzi D. & Stauffer M (Eds) *Human growth and development across the lifespan: Applications for counsellors*, p. 389 – 414 John Wiley & Sons Inc.

[7] Australian Institute of Health and Welfare, 2015 *Transitions to independence*, Australia's welfare 2015 Australia's welfare series no 12. Cat. No. AUS 189. Canberra: AIHW

[8] Monaghan M, Helgeson V, Wiebe D. *Type 1 diabetes in young adulthood*, Curr Diabetes Rev. 2015;11(4):239-250. doi:10.2174/157339981166150421114957 https://www.ncbi.nlm.nih.gov/pmc/articles/PMC4526384/

[9] *Figures* (NDSS registrations) correct at March 2020 when the online survey commenced

[10] 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.

[11] Ibid

[12] Diabetes Australia, *Young Adults with diabetes needs analysis*, (2006) Diabetes Australia, Canberra, ACT

[13] Monaghan M, Helgeson V, Wiebe D, *Type 1 diabetes in young adulthood*, Curr Diabetes Rev. 2015;11(4):239-250.doi:10.2174/157339981166150421114957 https://www.ncbi.nlm.nih.gov/pmc/articles/PMC4526384/

[14] Ng AH, Crowe TC, Ball K, Rasmussen B, *Transitional Needs of Australian Young Adults With Type 1 Diabetes*, JMIR diabetes. 2017;2(2): e29-e.

[15] Elders V, Keen A, Gold A, *Adults with type 1 diabetes: what factors are associated with disengagement from health services?* Diabetes Centre, Practical Diabetes, (2014) UK, Vol. 31 No 3

[16] Ventura AD, Browne JL, Holmes-Truscott E, Hendrieckx C, Pouwer F, Speight J (2016) *Diabetes MILES-2 2016 Study*. Diabetes Victoria, Melbourne.

[17] National Diabetes Services Scheme - ndss.com.au/about-the-ndss.

Background to this project

From June to August of 2019, a desktop literature review was completed. This included a review of national research and existing NDSS resources available to young people with diabetes.

Specifically, the result of the desktop review relating to young people with type 1 diabetes identified:

- The primary focus of the NDSS *Youth and Youth Transition Priority Area* in the past was focused on the paediatric space and the transition of young people moving from paediatric to adult healthcare services.[18][19][20][21]
- In 2019, the NDSS announced a $6 million national investment with the launch of the *Diabetes in Schools* program.[22] Therefore, it was concluded that children of school age are currently supported through this initiative and the existing NDSS camps programs.
- There is now an opportunity to investigate and focus on the specific needs of young people with type 1 diabetes.[23]

The result of the desktop literature review relating to young people with type 2 diabetes identified that:

- The needs of this group are different to that of young people with type 1 diabetes. Four previous Australian studies or literature reviews recognised that a wide-ranging consultation with young people from the type 2 diabetes community would be a solid investment.[24][25][26][27] However, this group has proven difficult to reach by past engagement methods.[28] A considered and tailored engagement strategy, developed in partnership with young people with type 2 diabetes, that identifies and addresses specific issues for this group is needed.
- Investigation of the specific needs of this demographic may be considered further in the future.[29]

A review of existing NDSS resources developed for young people with type 1 diabetes identified that this audience is currently catered for by the availability of the following resources:

- *Youth transition pack* (birthday card program)
- *Alcohol and type 1 diabetes*
- *Drug use and type 1 diabetes*
- *Travel and type 1 diabetes*
- *Moving on Up*
- *Continuous glucose monitoring: a guide to using CGM for children and young people with type 1 diabetes.*

Each of these resources can be found on the *Young People's* resource page of the NDSS website.

Prior to the formation of the ECCG and ERG, initial discussions were held with eight experts in this practice area; including health professionals, researchers and other diabetes advocates. In addition, six informal meetings were also held with young people living with type 1 diabetes or type 2 diabetes.

These informal stakeholder discussions involved a review of past relevant research completed and resources available in the youth transition space, and suggestions for further work were discussed.

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[18] 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.

[19] Diabetes Australia, LTD. *Youth Transition Survey*, (2012) Diabetes Australia: Canberra, ACT

[20] Diabetes *Australia, Young Adults with diabetes needs analysis*, (2006) Diabetes Australia, Canberra, ACT

[21] Speight J, Hagger V, Trawley S, Hendrieckx C, Browne JL, Cheney J, Pouwer F, Cameron F, Skinner TC, Scibilia R, *Diabetes MILES Youth Study* (2015) Diabetes Victoria, Melbourne.

[22] Diabetes Australia, *Schools across Australia get help to support children with type 1 diabetes*, Media release, 4 Sept, 2018)

[23] NDSS website, *Type 1 diabetes in young people* (2019) ndss.com.au/living-with-diabetes/about-you/young-people/type-1-diabetes

[24] J L Browne[1,2,] R Scibilia[3] and J Speight[1], *The needs, concerns, and characteristics of younger Australian adults with Type 2 diabetes*, (2012)

[25] Dunning T, Savage S, *Information needs of young adults with type 2 diabetes:* (2013) a literacy review

[26] Dunning T, Savage S, Dabkowski, Information *Needs of Young Adults with Type 2 Diabetes* (2019)

[27] Savage S, *The education and information needs of young adults with type 2 diabetes*, 2009, a qualitative study, (Sally Savage BA, PhD Deakin University and Barwon Health, C/- The Geelong Hospital, Geelong, Vic., Australia)

[28] Ibid (footnote 14,15,16,17)

[29] NDSS website, *Type 1 diabetes in young people* (as at 2019) ndss.com.au/living-with-diabetes/about-you/young-people/type-2-diabetes/

Background to this project

Meetings were held with four young people with type 1 diabetes and two with type 2 diabetes. The aims of these discussions included gathering what they identified were the needs for their community and identifying a proposed engagement approach.

The results of the discussions with young people living with diabetes and other stakeholders highlighted:

- that a national consultation focused on the current needs of the 18 to 29 year-old diabetes community, in relation to the NDSS, would be beneficial
- the consultation needed to be conducted in partnership with young people to gain a broader understanding of their needs and to enhance reach.

In summary, there was recognition that a national co-designed consultation with and led by young people, who have type 1 diabetes or type 2 diabetes, regarding their expressed needs for access to NDSS programs, support and services would be beneficial. However, all young people we engaged with and most stakeholders felt strongly that these consultations needed to be separate and tailored to meet the specific type 1 diabetes and type 2 diabetes communities' engagement needs as defined by them.

Previous low engagement from the young type 2 diabetes community in research highlighted that planning the engagement strategy requires significant investment to ensure meaningful reach. For these reasons, it was decided the current focus would be young people with type 1 diabetes, aged 18 to 29 years.

Purpose of this report

The purpose of this project was to hear from young people with type 1 diabetes regarding:

- Their NDSS program and service needs.
- Awareness levels and uptake of NDSS services and resources
- Opportunities to further their engagement with the NDSS

To enhance our engagement with this audience, we worked in partnership with them, using a co-designed strategy developed with young people living with diabetes.

This report will outline the method and specific steps taken to ensure young people led the project from the beginning. They identified the topics and issues important to them and their communities, and the appropriate promotion and communication methods necessary to engage young people nationally. They were consulted on the image and title to connect young people to the project, and reviewed content and the final report.

This report presents the findings from the national survey and interviews conducted, and serves to:

- provide an overview of the main themes and issues identified
- make the national results available to young people
- highlight that further analysis of this data set and reporting is possible, for example, population specific reports broken down into state/territory, Aboriginal and/or Torres Strait Islander or rural & remote
- provide key opportunities for future work with young people.

Method

Study design

A mixed-methods approach, that included a cross-sectional survey and semi-structured interviews, was utilised to understand the needs of this population.

Engagement strategy

One engagement approach does not suit all communities.[30] For this reason, a specific engagement strategy for young people was developed and used throughout the project. It was also for this reason that, within this demographic, a multifaceted engagement strategy was needed.

The *Our voices, our lives, our choices* consumer engagement matrix (refer to Appendix 1) was developed (with young people) and incorporated from the very beginning, in all the engagement work undertaken.[31] It was adapted from Diabetes Victoria's Consumer and Community Engagement policy that has a matrix attached, designed for engaging people with diabetes (ISO-433).[32]

The matrix:

- Places the young person at the centre.
- Identifies those 'at risk' of not engaging or being heard, and attempts to incorporate strategies to include them from the beginning.
- Provides young people with the opportunity to contribute in the way they wanted.
  - Empowered young people[33] were provided with opportunities to lead and guide the project.
  - Less empowered or supported young people[34] were provided with the opportunity to participate in the way in which they felt most comfortable.

Engagement method

Recruitment to the roles of Project Coordinator and to the ECCG/ERG

In September 2019, a young person from the target demographic was recruited to coordinate this project. This position was advertised and recruited to using Diabetes Victoria's human resources (HR) recruitment processes.[35]

Additionally, two consultation groups were formed.

1. The *Expert Consumer Consultation Group* (ECCG) consisting of 13 representatives, covering each state. Fifty-six expressions of interest were received from young people across Australia following a national recruitment campaign. Selection was based on an applicant living with the condition, having strong connections to other young people with type 1 diabetes and an ability to represent not only their own views, but also those of the wider type 1 diabetes community.
2. The *Expert Reference Group* (ERG), consisting of nine health professionals, researchers and diabetes advocates, was established in November 2019 to support the ECCG. The role of this group was to draw upon their professional experience and knowledge to provide advice and act as a resource to the ECCG.

These two groups oversaw the survey's content and design, distribution strategy, online survey process, data analysis and review of this report.

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[30] Diabetes Victoria, *Consumer and Community Engagement Policy* (2018) ISO-433, Melbourne (V02) Adapted from IAP Spectrum of Public Participation in (2007) International Association for Public Participation

[31] ibid

[32] ibid

[33] ibid

[34] ibid

[35] Diabetes Victoria, *Recruitment policy and procedure* (2020) PC-263, Melbourne (V02)

Survey process

Survey content and design

The ECCG identified survey topics important to them and their communities.

These topics included:

- Importance of connection to others with type 1 diabetes
- Preferred communication methods for use by the NDSS
- NDSS education programs, services and resources
- Access to mental health services
- Access and availability to NDSS products through pharmacy
- Education topics of interest
- Future NDSS support offerings for young people.

The survey was then designed in line with these topics and the project objectives, and was hosted on the Qualtrics (survey) platform. The survey questions were shared with the ECCG to ensure they accurately reflected their feedback.

Final comments were sought from the ERG and approval was obtained from the ECCG before the final survey was submitted to the NDSS for sign-off.

Survey distribution strategy

The ECCG provided advice to ensure relevant survey dissemination and promotion methods were employed. Members provided feedback regarding most suitable communication methods. Suggestions included:

- Use of email and SMS communication via NDSS database.
- Avoidance of postal mail services
- Use of social media: Instagram, Facebook and Twitter
- Communication using a short, sharp and snappy message.
- Subject line suggestions that were incorporated into promotion included:
- *Have your say for a chance to win!*
- Provide an incentive with one major national prize preferred, rather than multiple smaller prizes.
- Use a relatable image as the consistent face of the project.

These suggestions were incorporated into the distribution strategy. Three electronic direct mails (eDM) and two text messages (SMS), containing a link to the online survey, were sent to all people within the target demographic, who had a current email address or mobile number at the time of the survey's release and who had consented to receive correspondence from the NDSS.

The final reminder eDM and SMS did not go out to the target population due to the COVID-19 pandemic. Specifically, on 18 March 2020 in response to the COVID-19 outbreak in Australia, the Governor General declared that a human biosecurity emergency existed.[36] It was decided that any communication coming from the NDSS to people registered with the Scheme at that time needed to be focused on issues relating to COVID-19.

The social media platforms the stakeholders used included Facebook, Instagram and Twitter. All members of the ECCG and ERG committed to sharing the survey link amongst their networks. Other stakeholder groups engaged to promote and share the survey included:

- Diabetes Australia.
- NDSS.
- Aboriginal and Torres Strait Islander Engagement, Diabetes Australia.
- State and territory diabetes organisations.
- Other diabetes support organisations (i.e. Type 1 Diabetes Family Centre and Type 1 Foundation).
- Peer support groups across Australia.

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[36] (https://www.aph.gov.au/About_Parliament/Parliamentary_Departments/Parliamentary_Library/FlagPost/2020/March/COVID-19_Biosecurity_Emergency_Declaration)

Method

Online survey

The online survey was live for a 3-week period, from Monday 2 March to Sunday 22 March 2020. The COVID-19 pandemic overlapped with the live survey for the last three days of the survey.

A short plain-language description of the project was displayed on the survey landing page. Respondents were then given the option to refer to the NDSS privacy policy that outlined the NDSS' obligation to maintain their privacy (Full survey available in Appendix 2).

Respondents took an average of 10 minutes to complete the survey, which comprised of 18 questions. Questions covered the following topics:

- respondent demographics
- diabetes management
- connecting with others
- awareness of NDSS programs, services and resources
- accessing information and education
- how the NDSS can better provide support.

An incentive of one national prize and one smaller prize for each state/territory was offered to respondents who completed the survey and provided their contact details. The survey clearly stipulated that contact details provided would only be used to notify the winners.

Survey sample

In total, **18,420** young people were eligible to participate in the survey.[37]

NDSS national database

Any young person aged 18 to 29 years (inclusive) with type 1 diabetes and registered with the NDSS was eligible to take part in this survey. The total number of young people with an email address or mobile number was **15,815**.[38] The following exclusions were made:

- Those with an incorrect email address listed.
- Those with an incorrect mobile number listed.
- Those who did not have either an email address or mobile phone number linked to their NDSS registration.
- Those who did not consent to be contacted about research.

Following these exclusions, a total of 13,140 young people were sent either the eDM or SMS from the NDSS which contained the link to the online survey.[39] Specifically, 8957 young people registered with the NDSS had an email address listed and 4183 that did not have an email address but had a mobile number listed at the time the survey was open.[40] This equated to 71% of the total population being reached via this engagement method.

Of the **13,140** who were sent the survey, **407** eDMs and **408** SMS bounced back.[41] This resulted in the overall potential reach of this method being **12,325** or 67% of the total target population.[42]

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[37] *Figures* (NDSS registrations) correct as at March 2020 when the online survey commenced

[38] Ibid

[39] *Figures* (NDSS registrations) correct as at March 2020

[40] Ibid

[41] Ibid

[42] Ibid

Examples of the NDSS eDM and NDSS SMS are shown below:

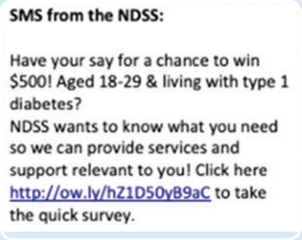
NDSS eDM

The National Diabetes Services Scheme (NDSS) has worked with young people living with type 1 diabetes to create a new survey.

As you are aged 18-29 years and living with type 1 diabetes, the NDSS want to know what you need so that we can provide services and support that is relevant to you!

Click here to take the survey. It contains only 18 questions and should take less than 10 minutes. For all of you who complete the survey, leave your details to go into the draw to win a $500 EFTPOS gift voucher. One winner from each state/territory will also receive a $50 EFTPOS gift voucher. (Drawn at random.

NDSS SMS



SMS from the NDSS:

Have your say for a chance to win $500! Aged 18-29 & living with type 1 diabetes?
NDSS wants to know what you need so we can provide services and support relevant to you! Click here http://ow.ly/hZ1D50yB9aC to take the quick survey.

Social media and other promotion

The consumer and community driven social media strategy, implemented via Facebook, Twitter and Instagram, complemented the NDSS distribution strategy and occurred at the same or similar times. These promotions (which were organic rather than paid) attempted to reach the additional **6095** young people who were yet to be reached by use of the NDSS database. This equated to 33% of the target demographic. The social media strategy also attempted to provide a secondary promotional source for those who did receive the eDM/SMS promotion but may not have completed the survey upon first receiving the communication.

Examples of social media promotion are shown below:

Facebook

Diabetes Victoria
Published by Hootsuite · March 11 at 11:00 PM

Calling all young adults (18-29 years old): Have your say and win $500!
If you're living with type 1 diabetes, the National Diabetes Services Scheme NDSS wants to know what you need so we can provide support services relevant to you!
Take part now: bit.ly/ndssyouthsurvey
#DiabetesVic #NDSS #type1diabetes #diabetessupport

Instagram

diabetes_australia

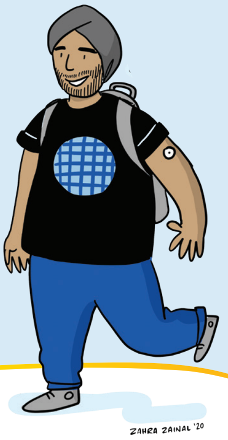
Liked by [redacted] and others

diabetes_australia Have your say for a chance to win $500... more

Twitter

NDSS
@NDSS_AUS

Have your say for a chance to win $500!
If you are aged 18-29 and are living with type 1 diabetes, tell us what you think and go into the draw to win $500!
ow.ly/3Liu50yB9j0



Method

Interview process

In addition to the survey, 12 individual interviews were conducted with young people from identified priority communities to further understand the needs and issues faced by these groups, and to ensure their voices were heard. Interview places were offered using a predetermined eligibility criterion to ensure a variety of experiences were heard. Priority groups of young people and communities were identified and recruited using the *Our voices, our lives, our choices* matrix (refer to Appendix 1).

Representation included:

- Nine interviewees identified as female and three as male.
- Most states and territories (except for Queensland as the interviewee cancelled).
- Culturally and linguistically diverse background.
- Newly diagnosed.
- Rural and remote communities.
- Those using various technology and devices.
- Living with complications relating to diabetes.
- Pregnancy and new parents.
- A range of age groups and duration living with diabetes.

Interviews were conducted via Zoom over a 2-week period from 6 to 14 April. and establishing rapport with interviewees was possibly assisted by the Project Coordinator opening up about her own experiences living with type 1 diabetes.

Utilising a young person as the interviewer was determined (by ECCG) as important for the interviewees to feel at ease with someone `*who just gets it!'*

Interviews took on average 30 to 60 minutes to complete.

The purpose of the project was explained to interviewees and they were advised that they need only answer those questions with which they felt comfortable.

Interviewees were assured that their answers would be de-identified and verbal consent was sought for the interviews to be recorded for the sole purpose of report write-up. Interviewees were provided with links to services available from the NDSS Agent in their state or territory or national services provided in case the interview brought up any issues for them.

A $25 gift voucher was sent to each of the 12 interviewees to thank them for their participation.

A total of 21 questions were asked of each interviewee (see Appendix 2). Many aligned with the survey, but the interviews also included the following questions:

- Current employment/study status.
- Current living situation.
- Living with disability or other health conditions.
- Reasons for period of reduced engagement with their diabetes healthcare team (where applicable).
- Diabetes complications.
- Completion of the NDSS national survey and provide reason if not.
- Survey communication method that most appealed to them.
- Interest in being contacted about future diabetes research opportunities.
- Access to NDSS subsidised products and impact on their diabetes management.

Survey results and findings

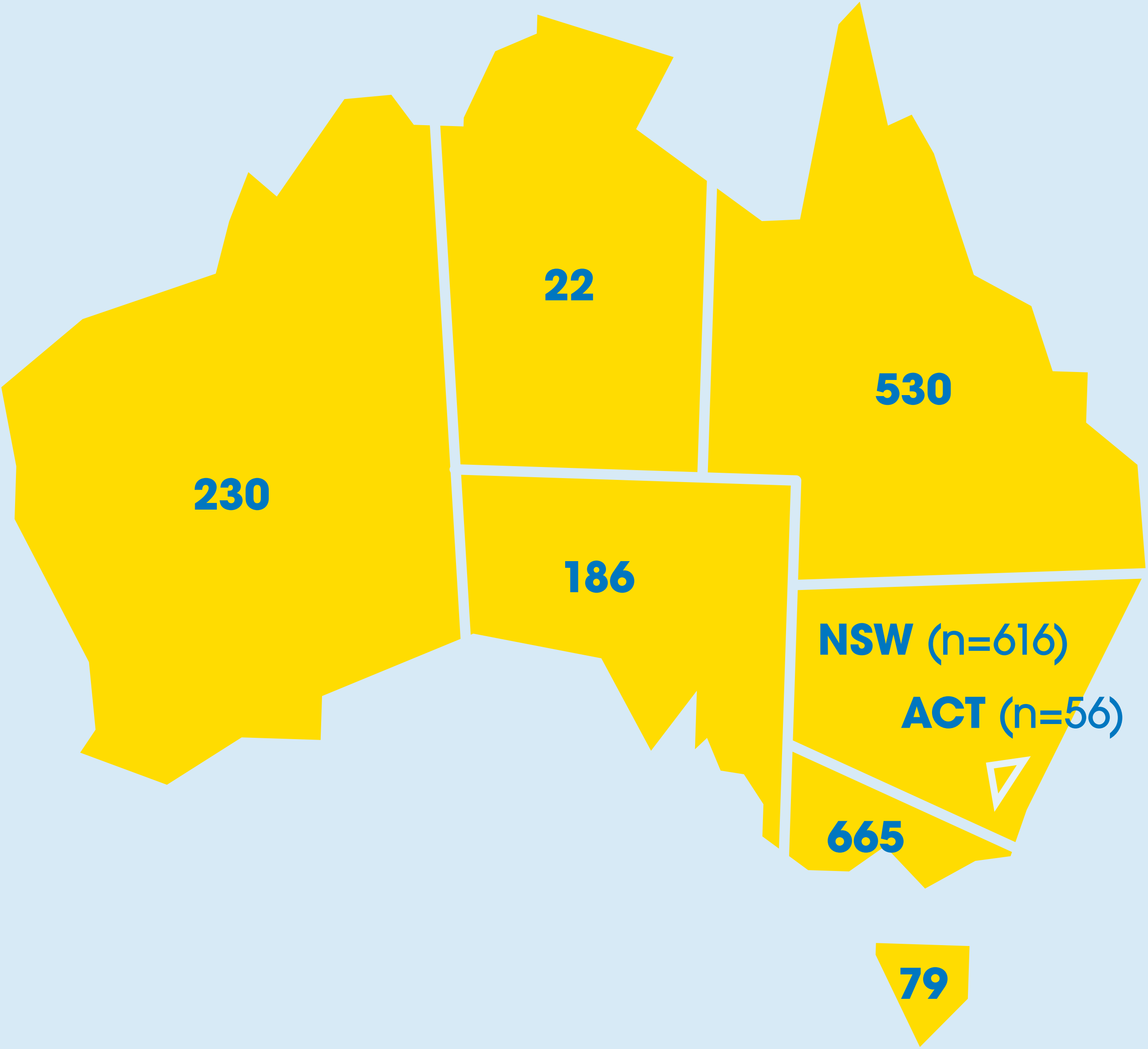
Demographics of respondents

2384 young people completed the survey during the 21 days that it was open. ***Figure 1*** shows the distribution of survey respondents by location. A 13% response rate was recorded when compared with the overall population of young people living with type 1 diabetes across Australia (***Table 1***).

Figure 1**: Location of youth survey respondents by state and territory**

Total of 2384 survey responses received (13% of target population)

- 78 respondents identified as Aboriginal or Torres Strait Islander.
- 60 respondents spoke a language other than English.



Survey results and findings

***Table 1*: Percentage of young people with type 1 diabetes compared with state/territory and national response rates**

State/territory	Number of people aged 18 to 29 years with type 1 diabetes registered with the NDSS	Number of survey responses received	% of overall young people reached
VIC	4859	665	13.7%
NSW	5360	616	11.5%
ACT	349	56	12%
TAS	467	79	16%
QLD	3979	530	13.3%
NT	121	22	18.2%
WA	1909	230	12%
SA	1376	186	13.5%
Totals	18,420	2384	12.9%

Table 2 Provides the percentage of young people with type 1 diabetes who were sent the eDM or SMS, compared with the survey response rate.

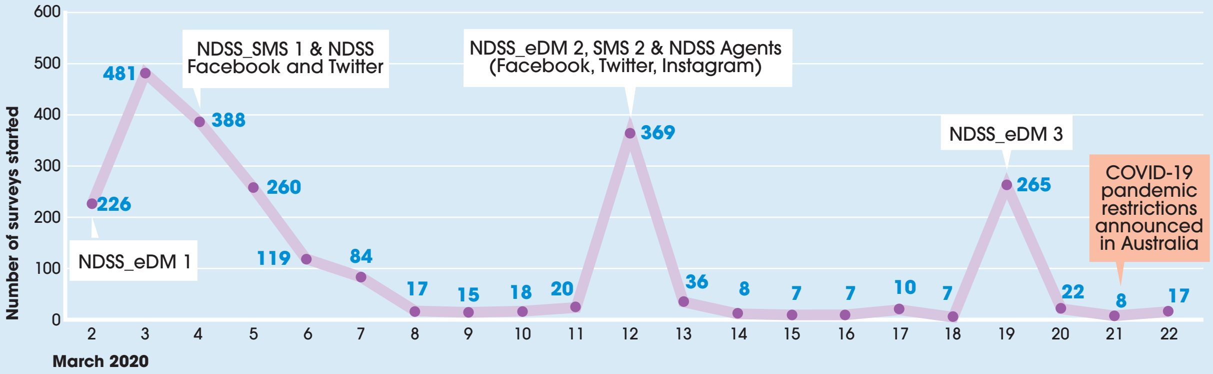
***Table 2*: Percentage of young people with type 1 diabetes, who were sent* an eDM or SMS, compared with the survey response rate.**

State/territory	Number of young people with type 1 diabetes sent eDM/SMS	Number of survey responses received	Survey response rate
VIC	3959	665	16.8%
NSW	4683	616	13.1%
ACT	308	56	18.2%
TAS	405	79	19.5%
QLD	3532	530	15%
NT	100	22	22%
WA	1631	230	14.1%
SA	1197	186	15.5%
Totals	15,815	2384	15.1%

* The total number of young people who actually received the eDM/SMS was 13,140. This difference was a result of invalidated emails, double ups or people who had not consented to being contacted by the NDSS for research purposes.

***Figure 2* Illustrates the distribution of eDM and SMS, as well as relevant social media posts, and the correlating peaks in survey participation rates.**

***Figure 2*: Survey responses by date and promotional campaigns (n=2384)**



Respondents' postcodes were matched to the Accessibility and Remoteness Index of Australia (ARIA). A full map of remoteness areas for Australia can be found in Appendix 4.

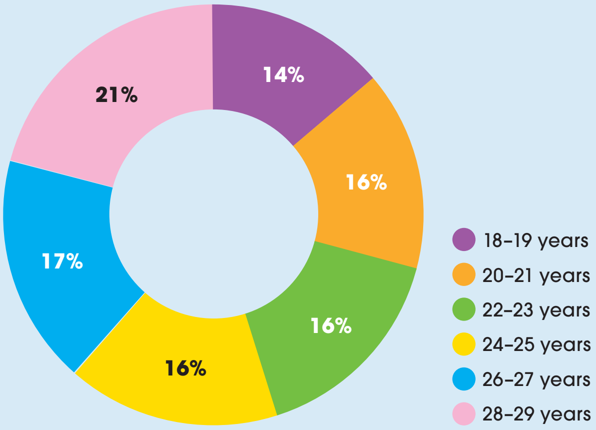
Each of the five ARIA categories were represented across the survey respondents with:

- 71% (n=1673) living in major cities in Australia.
- 21% (n=506) living in inner regional Australia.
- 7% (n=171) living in outer regional Australia.
- 1% (n=25) living in remote or very remote Australia.

NB: <5 respondents from very remote, therefore combined with remote respondents.

The age of respondents varied, with small increases in percentage of responses as age increased (***Figure 3***).

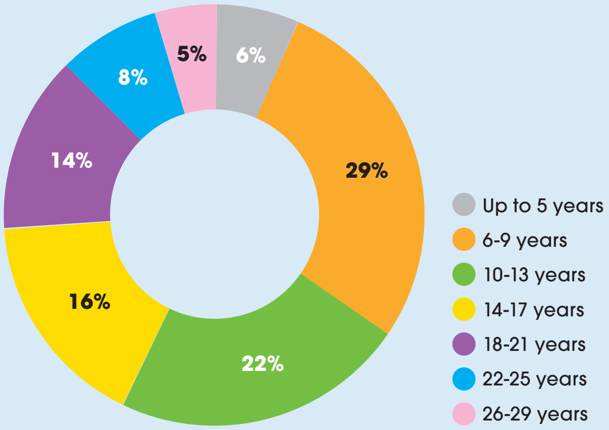
***Figure 3*: Age of respondents (n=2384)**



Survey results and findings

Respondents were asked at what age they were diagnosed with type 1 diabetes.

Figure 4: **Age of diagnosis of type 1 diabetes as a percentage**



There was representation of Aboriginal and/or Torres Strait Islander respondents across all states and territories, with 3.2% (n=78) identifying as Aboriginal and/or Torres Strait Islander.

Most respondents (97.3%, n=2319) stated that English was the main language they spoke at home. Only 2.7% (n=60) of respondents stated that they mostly spoke a language other than English at home.

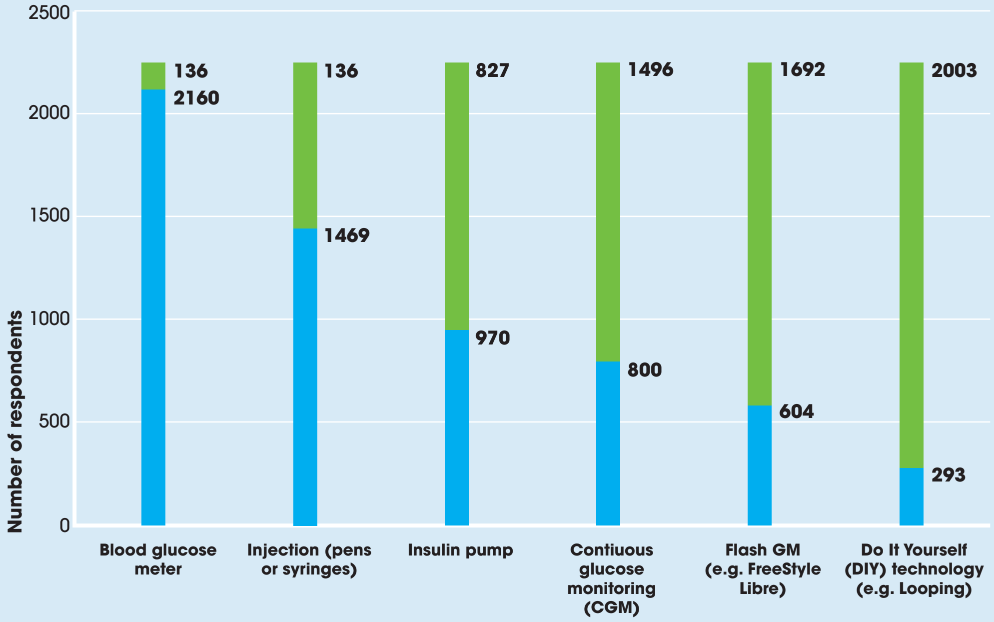
- Amharic
- Arabic (n=10)
- Afrikaans (n=3)
- Albanian
- Amharic
- Bengali (n=2)
- Cantonese (n=3)
- Chinese
- Croatian
- Filipino
- French
- Harari
- Hindi (n=3)
- Hokkien
- Italian (n=2)
- Macedonian (n=2)
- Mandarin (n=2)
- Nepali
- Portuguese (n=2)
- Samoan
- Serbian
- Sign language (Auslan) (n=2)
- Sinhalese
- Sindhi (n=2)
- Spanish (n=3)
- Swahili
- Tagalog (n=2)
- Telugu
- Thai
- Tigrinya
- Turkmen
- Urdu (n=3)
- Uzbek Russian

n=l for all other languages specified above without a number next to them.

Diabetes technology and devices

Respondents were asked to identify which technology and devices they used to monitor their blood glucose levels and administer their insulin.

Figure 5: **Diabetes technology and devices used (n=2296)**



The results outlined that:

- 94% (n=2160) used a blood glucose meter.
- 64% (n=1469) administered their insulin via injections (pen or syringe).
- 42% (n=970) administered their insulin via an insulin pump.
- 35% (n=800) used a CGM system.
- 26% (n=604) used a Flash GM.
- 13% (n=293) managed their diabetes through a DIY technology system.

Many respondents indicated that they had multiple options at their disposal. For example, those who used an insulin pump as their primary insulin delivery device, had insulin pens on hand as back-up for times when technology may fail them. This back-up system is encouraged by diabetes health professionals.

The same can be said for those who used CGM or Flash GM; people using this technology to measure their glucose levels still had a blood glucose meter to calibrate their CGM device, for times when technology is not working or to confirm results from their sensing device. The results clearly identified that the expense of CGM technology and/or Flash GM meant that many young people used these devices on a sporadic basis.

Young people also identified having planned `holidays' from technology for reasons such as feeling overwhelmed with the amount of data or financial strain. During these `holidays' they returned to managing their diabetes with insulin pens and blood glucose meters.

Young people reported various barriers to using particular devices for their diabetes management (***Table 3***).

Survey results and findings

Table 3: **Barriers to young people using technology and devices**

Technology and devices	Reasons respondents provided for not using this technology and devices.
Blood glucose meter (n=314) The main reasons given by young people for not using blood glucose meters were: 1. Using other devices 2. Physical and psychological barriers (e.g. pain, anxiety, finger scarring) 3. Cost 4. Inconvenience	▸ "Although it is reliable, I have a Freestyle Libre. I test more often with the Libre than what I did with the meter." ▸ "Pain and numbness in fingers. Used one for 10 years and fingers started to feel it a lot." ▸ "Sick of stabbing myself, painful, messy, have to carry more stuff around…" ▸ "I hate finger pricks and carrying a meter around with me all the time is too difficult, especially for males who don't carry handbags."
Injections (pens or syringes) (n=702) The main reasons given by young people for not using injections were: 1. Using an insulin pump 2. Physical and psychological barriers (e.g. fear, needle phobia, pain, scar tissue, embarrassed) 3. Forgetting to take insulin 4. Inconvenience	▸ "I moved from pens to an insulin pump just over a year ago and my control is exponentially better, insulin pumps take a lot of guess work out of dosing and make it a lot easier to control." ▸ "I don't like injections and doing it in public I feel embarrassed and people stare at me." ▸ "As an 18-year-old I am always out and about doing activities and it's easy to forget to inject them or forget the insulin itself, an insulin pump is a lot easier." ▸ "I developed bad bruising as a child on my arms as a result of insulin injections. I also prefer not having to manually insert a needle; I prefer pressing the button for pump site insertion."
Insulin pump (n=1241) The main reasons given by young people for not using insulin pumps were: 1. Cost 2. Physical and psychological barriers (e.g. bulky, fear, worry, scared) 3. Personal preference for insulin injections (pen or syringe) 4. Bad experience with past use	▸ "The cost. I'm not on any health insurance so it would be all out of pocket for me and being a Uni student, I don't have the cash to purchase one." ▸ "Lifestyle choices which may inhibit me from carrying a pump around all day (e.g. hiking) and a general fear of the pump and having a large box attached to my body." ▸ "I used to use an insulin pump, but I started to struggle having to be attached to it all the time. I found it very mentally taxing, so I went back to injections." ▸ "I do not like the idea of a machine being in control of my blood glucose management or insulin use. I feel much better using an insulin pen and it makes me less anxious."

Continuous glucose metering (n=1416)

The main reasons given by young people for not using CGM were:

1. Cost
2. Not eligible for government subsidy
3. Limited knowledge about this device
4. Physical and psychological barriers
5. Bad experience with past use

- "Currently using, however forced to make sensors stretch past their expiry (used for 14-28 days instead of 7)."
- "I am currently only using a CGM as it is subsidised since I just had a baby. In two months' time I will no longer have free access and won't be able to afford it."
- "No money. Not having one is impacting me significantly. I do not sleep enough (4-5 hours per night) due to not having a CGM that can alert me if I am low. It impacts my mental health too. I was told I am too old to get a subsidy."
- "I have used a CGM before and did not like it as it was unpredictable and often stopped working due to errors."

Flash glucose metering (n=1332)

The main reasons given by young people for not using Flash GM were:

1. Cost
2. Not eligible for government subsidy
3. Using another device
4. Limited knowledge about this device
5. Bad experience with past use

- "I really want to use the Freestyle Libre to save pricking my fingers every single day multiple times but, unfortunately, I cannot afford the $95 it costs a fortnight. I am a university student and am currently looking for part-time work."
- "I have used this once as a free trial. It was amazing and gave me so much insight and education as to what my blood glucose was doing overnight and how to prevent dangerous overnight lows. I cannot afford this product so had to stop using this."
- "I use a Libre when my family or partner buy one for me otherwise the cost is too expensive for me to continually use or purchase one for myself."

DIY technologies (n=1207)

The main reasons given by young people for not using DIY technologies were:

1. Limited knowledge about this device
2. Using other devices
3. Safety concerns
4. Cost

- "Lack of knowledge on availability and how to use."
- "Satisfied with insulin pump and CGM."
- "I have received mixed messages about looping from the diabetes community and healthcare professionals, and I have not researched too much into it to be fully confident in it."
- "I dislike the idea of using unofficial or untested methods."
- "Difficult to access information about DIY systems. Fear of safety issues."

Survey results and findings

In terms of more technological devices (e.g. insulin pumps, CGM and Flash GM) the most commonly identified barriers by young people living with type 1 diabetes were related to cost and, where relevant, not being eligible to access fully subsidised products through the CGM Initiative as part of the NDSS. Other common reasons for not using these devices included physical and psychological barriers, limited knowledge about the device and a negative experience with past use.

Comparatively, the most commonly identified reasons for survey respondents not using traditional management methods (e.g., blood glucose meters and insulin injections) were a preference for using newer technology and the physical and psychological effects associated with traditional management methods (e.g., pain, anxiety and scarring).

The most common reasons mentioned for survey respondents not using DIY technologies involved a lack of information about the systems, concern about safety and the preference to use other technology that did not raise these same concerns. This sentiment was shared by one interviewee who was very interested in DIY technology but discussed concerns regarding support available for people using DIY technology.

> "(DIY is) still considered taboo by health professionals. I would like to see it more accepted and trusted. This could be conveyed by stories promoted through blog posts made by reputable diabetes organisations."

Survey results that identified barriers to management were strengthened by findings drawn from the interviews.

Similar to the online survey respondents, approximately half of the interview participants were using multiple daily injections (MDI) to manage their diabetes, with the other half using an insulin pump. Several interviewees chose not to use an insulin pump due to possible restrictions it may place on their ability to carry out certain physical activities, such as exercise or work. The psychological aspect of being connected to a device 24/7 was also described as a barrier.

Many of the interview participants had tried one or more CGM and Flash GM devices but many had only been able to do so for a short time during a free trial period. Interviewees over the age of 21 expressed frustration at being ineligible for any of the current available subsidies, making them unable to afford a device which many considered would make managing their diabetes much easier as highlighted in the quotes below.

> "I'm on the last month of CGM due to coming to the end of my post-natal eligibility for the CGM subsidy. I found out about the pre-pregnancy subsidy on social media. We have made other budget cuts so we can afford the $200+ CGM expense each month. My diabetes management has been much better controlled on CGM and I'm anxious about the unknown, particularly my ability to continue to afford it."

> "When I could afford it, I used the Libre for two weeks on and two weeks off due to it being so expensive. Since moving out of home for study I can no longer afford it. My diabetes control went out the window, I gained lots of weight and my mental health decreased. I am using a Libre sensor this week and am feeling positive, conscious of regular blood glucose checks and eating better."

Interviewees who were self-funding (some through assistance from their parents or partner) often needed to selectively limit their use of these devices to times of absolute necessity (i.e., overseas holidays and during illness) in order to reduce the cost burden.

Suggestions were offered by survey respondents on how the NDSS could help to reduce these barriers.

When asked how the NDSS can better support young people living with type 1 diabetes in an open-ended question, 80% (n=948) of responses included a suggestion to provide **more product subsidies** to alleviate financial strain of living with type 1 diabetes. Some respondents stated that they had to make difficult choices between managing their diabetes and being able to afford other necessities as highlighted in their statements below.

> "I have had to give up things to be able to afford my medical supplies."

> "Some weeks I simply don't test my blood sugar as I cannot afford strips."

> "Allow access to subsidised schemes, such as CGM, before we become sick and have complications/hospital admissions. It makes no sense to work from a treatment model when we should be working from a preventative model."

From those suggesting **more product subsidies**, many requested increased subsidy eligibility for those over 21 years of age, specifically for **CGM** (n=533), **Flash GM** (n=156) and **insulin pumps** (n=56) which is further highlighted in the statement below.

> "Equal access to all technology. It's not about money, it's about people's health and wellbeing."

Respondents specifically mentioned that **increasing the age eligibility to over 21 years** (n=180) and/or **changing the eligibility requirements for a healthcare card** (n=139) would be greatly beneficial. There was discussion that young people with type 1 diabetes often struggle when they turn 21 years old and lose their access to the CGM subsidy. Additionally, respondents reported falling outside of the eligibility to hold a healthcare card, but not making enough money to comfortably afford the products necessary to manage their diabetes safely and optimally.

Some of the struggles faced by respondents are highlighted in the quotes below.

> "Type 1 diabetes doesn't stop at 21, why does the funding for CGM?"

> "I was diagnosed nine months before my 21st birthday and when I received the email on my birthday saying I was no longer covered for CGM it was devastating. My BGLs fluctuated and my mental health took a huge dive."

> "Just because we earn enough not to get a healthcare card, doesn't mean we earn enough to cover CGM supplies."

Survey results and findings

Another suggestion for **more product subsidies** included greater subsidies on **glucose monitoring strips** (n=24) as echoed from interviews highlighted below.

> "It is unfair that one minute a box of glucose strips is $1.20 and the next they are over $15. This is not a luxury. All diabetics need access to these products."

Accessing diabetes products through pharmacies

Barriers were identified in some instances when young people tried to access diabetes products through NDSS Access Points (usually community pharmacies).

Survey respondents were asked if they had experienced any problems in the past 12 months with accessing their diabetes products through their local pharmacy. Sixty-nine percent (n=1645) of respondents stated they had not experienced any problems while 31% (n=739) stated that they had.

Additional information provided by respondents about their experiences was grouped into four themes:

- Pharmacy staff's knowledge about the NDSS order process and diabetes products available.
- Product availability – rural and remote communities.
- Communication between pharmacy staff and customers with diabetes.
- Variations between pharmacies.

Many young people raised concerns about the **limited knowledge pharmacy staff** had of NDSS processes, the ordering system and lack of knowledge about different diabetes products. These resulted in **ordering delays or inability of pharmacy staff to process and provide the correct products** (n=49). Some of the challenges faced by respondents are highlighted in their statements below.

> "They often get my order wrong, then forget to re-order or give my products to someone else who comes in for pump supplies. They never have what I regularly use for pump supplies in stock."

> "The pharmacist made the wrong order because they used the wrong NDSS code. We didn't realise as the box looks exactly the same, so they refused to give us a refund."

> "The pharmacist was unaware of how to get the product through the NDSS and told me to order online myself."

When problems arose with the NDSS ordering system, there did not appear to be an alternate arrangement in place. This disadvantaged people, with some **having had to pay more for their products** (n=6) when the pharmacy could not register a young person's NDSS and concession benefits.

Several respondents preferred the previous arrangements of **ordering online for either pharmacy pick-up or home delivery** (n=6), stating that it was more convenient.

Respondents from **rural and remote areas** frequently identified **limited or no stock of ketone strips** (n=54) and **glucose monitoring strips and needles** (n=42). They reported having difficulty trying to access these products. Some also discussed experiences of pharmacies having low supplies of insulin and needing to reorder more in to fill scripts or having no pump consumables in stock as highlighted in their statements below.

> "Strips are always hard to get in rural areas."

> “I travelled to 4 pharmacies before finding ketone strips in stock.”

> “I had no pump supplies. They took 2 weeks to order it in so I had to go back on injections.”

Some respondents identified **miscommunication between pharmacy staff and themselves** as an issue; including subsidy eligibility (n=3) and products being out of stock for an unspecified time (n=5) or no longer supplied (n=6). Respondents in rural and remote areas spoke of their difficulties accessing supplies in their area.

> “It was much more convenient when they could be ordered and delivered directly to my home. It feels like a step backwards.”

> “I live in a small town 2 hours away from the nearest city and more often than not my products aren’t available.”

Others provided comments about **variations between pharmacies**. Some did not stock their type of insulin or pump supplies and discontinued or limited certain products (n=20). This required them to either having had to order them in or try other pharmacies.

> “The pharmacist told me I wasn’t allowed to buy strips for my blood kit without a doctor’s letter. I went to another pharmacy where I was able to buy strips.”

The issue of accessing diabetes supplies was discussed when respondents were asked what the NDSS could do to better support this demographic. Providing **online access** (n=65) for ordering diabetes products was suggested.

Online access linked to the theme of **improved service and access to supplies at NDSS Access Points** (n=6). While this theme was not widely discussed, it highlighted significant issues that some respondents were having when visiting NDSS Access Points.

> “I would find it helpful if there was some way to order products online rather than going to a pharmacy.”

> “Make it easier to access test strips, insulin and pump consumables through a simple online shop/ordering system.”

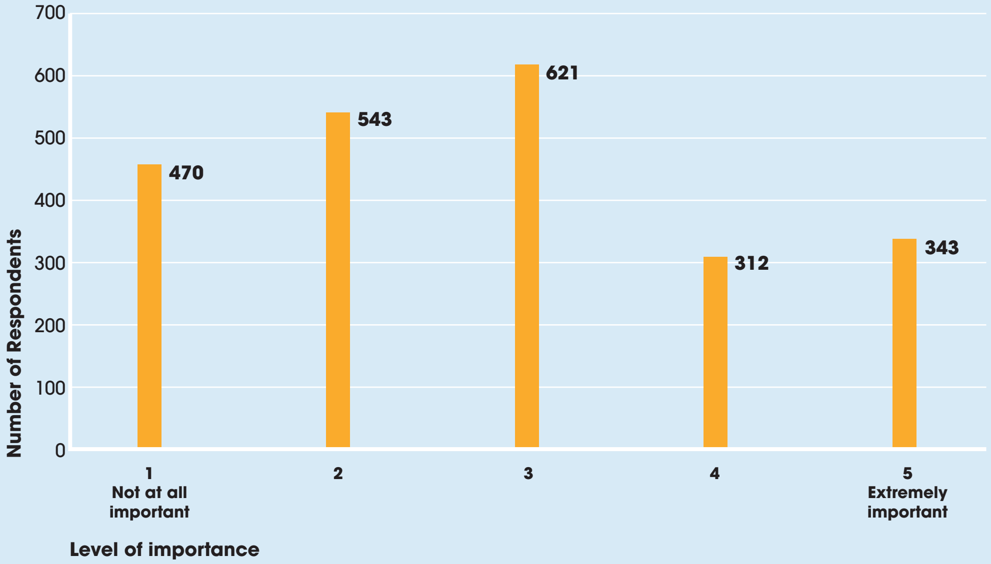
Survey results and findings

Connection, mental health and support

The importance of connection and peer support was investigated. A 5-point Likert scale was used to ask survey respondents how important it was for them to be connected to other young people with type 1 diabetes.

Twenty-one percent of respondents (n=470) stated that it was not important at all while 29% (n=655) provided a rating that it was important to them or very important to them (***Figure 6***).

Figure 6: **The importance of connecting with other young people with type 1 diabetes**



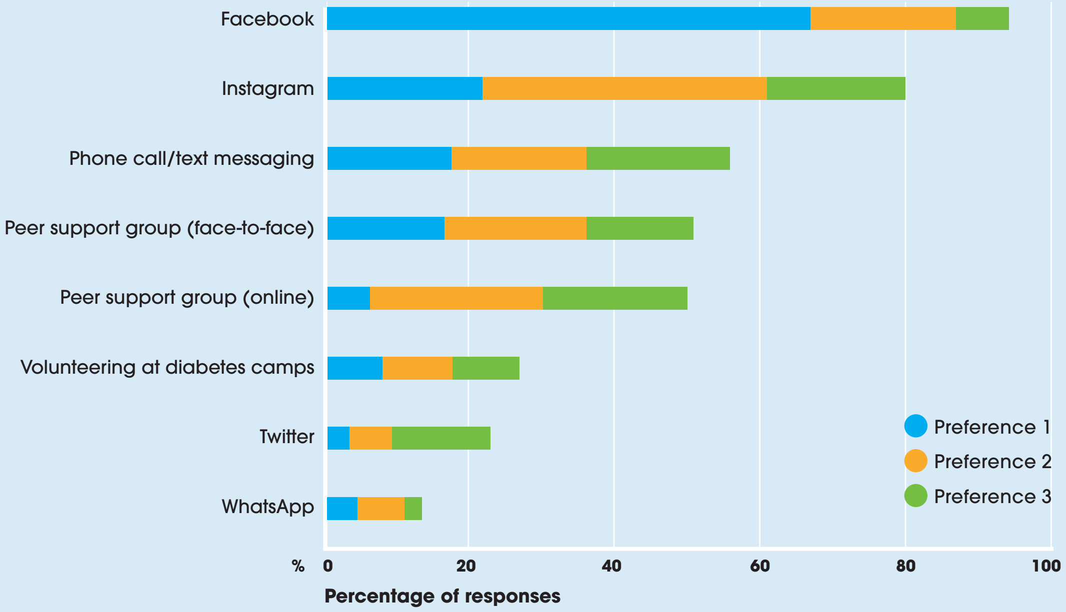
Age was a factor regarding the importance of connecting with others. There was a 6% incremental increase from respondents aged 18-19 years to 28-29 years, from 14% (n=64) to 20% (n=95), to this response.

Young people appeared to value connection to others with type 1 diabetes at around 22-23 years of age and again at 28-29 years. There was less importance for connection between 24-27 years and a mixed level of importance by 28-29 years.

The level of importance for connection was similar based on years of diagnosis with type 1 diabetes. The highest period of importance for many was associated with having lived with diabetes for 10-13 years. As people lived longer with type 1 diabetes the level of importance to be connected with others declined. Thirty-nine percent (n=897) of respondents stated that they were currently connected to other young people with type 1 diabetes while 61% (n=1395) were not. Reflecting on the survey and interview results, it is evident that one size does not fit all people living with diabetes and their preferences regarding peer support.

Those who indicated being currently connected to other young people with diabetes were asked to outline how they most frequently interacted (***Figure 7***). These responses identified Facebook (94%, n=677) and Instagram (81%, n=371) as the main social media platforms young people preferred to use to connect to others with type 1 diabetes. This was followed by phone calls or text messaging (66%, n=237) and peer support groups (both face-to-face and online) with 50-51% of responses.

Figure 7: **Top 3 ways respondents identified to connect to other young people with type 1 diabetes**



Respondents were also given the opportunity to add other ways they connected. Other online platforms mentioned included:

- Snapchat
- Reddit
- Discord
- TikTok
- Skype
- Tumblr
- YouTube.

Many of the 'other' responses provided relate to the respondent's relationship with the person/people they connected with, who also have type 1 diabetes, rather than the medium through which they did it. A reason for this could be that they did not identify what they were doing as relevant to any of the options provided. For example, catching up with a friend or friends who also have type 1 diabetes may not have been viewed as peer support by the respondents.

Friends (n=63) who also have type 1 diabetes was the most common response outside of those mentioned previously. Face-to-face and online contact were the preferred ways for these young people to catch up. In some instances, it was discussed that some people had been friends with others before any of them had received a diagnosis of type 1 diabetes (n=8), and this friendship had continued after each of their diagnoses.

Family (n=34) was commonly referenced as being important for connection, often with siblings who also had type 1 diabetes (n=16).

Face-to-face (n=29) catch-ups were referenced as a way to connect, as well as meeting **through the workplace and/or place of study** (n=27).

Survey results and findings

Many of the young people interviewed expressed their interest in finding connections with others living with type 1 diabetes, with most showing a preference for meeting at face-to-face events and then continuing to connect online. Interviewees from rural and regional areas expressed concern that this was much harder to do if you lived outside a capital city.

Interviewees diagnosed over 18 years of age reported that they struggled to find information that could lead them to connect with diabetes communities and other people with diabetes. It was also noted that peer support offerings were inconsistent depending upon their state of residence.

> "Peer support can offer advice you don't even know you need!"

> "The NDSS really need to focus on the mental health aspect of diabetes and therapy lessons. So many times in support groups people have said they don't want to take their insulin, that they're very unhappy/not the person they used to be, and have been hospitalised due to needing further mental healthcare. We are taught to scrutinise our bodies, to lose weight, to do less of everything, and we feel like we aren't alive."

When asked how the NDSS could help young people better manage type 1 diabetes, respondents' answers supplied several themes related to mental health and connection.

Of the 1179 responses to this question, 10.6% (n=125) discussed **mental health** support as being highly needed for the demographic. Some respondents suggested that people with type 1 diabetes receive free or subsidised visits to psychologists. Others discussed the need for better education in recognising mental health issues and being able to seek help themselves.

> "Push for mental health support (i.e., regular psychology sessions) to help cope and not feel so helpless and overwhelmed."

> "We need more help for mental health problems, but so many of us don't know how to access help or even if there is any help."

Peer support (n=132) was discussed as being important for emotional support as well as discovering tips and suggestions for diabetes management.

Having **diabetes camps for young people** (n=33) and **events for young people** (n=56) available to provide further support and connection was discussed. These suggestions could both be considered as forms of peer support and important to building supportive networks for young people living with type 1 diabetes.

> "There are camps for children but nothing for adults. Being diagnosed as an adult is really hard."

Other themes relevant to increased support included **one-on-one** check-ins (n=22) and **access to information and resources** around topics like workplace rights (n=20). Some suggestions made are outlined in the following quotes.

> "Organise meet-ups in multiple areas across the country, not just major cities."

> "Build a better support network for young people to confide, network and collaborate ideas on how to best manage diabetes or just rant about the autoimmune condition."

Survey results and findings

Awareness and communication of NDSS offerings

Survey respondents were asked about different NDSS programs, services and resources, and whether they were aware of and/or had accessed them (***Table 4***). The NDSS education programs included OzDAFNE and other programs/or activities (e.g., Med SMART, Carb SMART, supermarket tours). The NDSS information and resources mentioned in this question were designed specifically for young people with type 1 diabetes and are all available on the NDSS website.

***Table 4*: Awareness and access of NDSS programs, services and resources (n=2158)**

	Not aware of	Aware of but not accessed	Aware of and have accessed
Subsidised diabetes products	9.45%	12.28%	78.27%
NDSS Helpline	33.64%	53.38%	12.97%
OzDAFNE program	78.59%	16.54%	4.87%
NDSS education programs	79.15%	17.98%	2.87%

Respondents were asked if they were aware of or had ever used a range of NDSS resources which had been designed for young people, all of which are available on the NDSS website.

***Table 5*: NDSS resources for young people with diabetes (n=2158)**

	Not aware of	Aware of but not accessed	Aware of and have accessed
Diabetes Annual Cycle of Care fact sheet and checklist	82.85%	10.94%	6.21%
Moving on Up: Guide for young adults with diabetes	79.70%	12.74%	7.55%
Diabetes and driving booklet	52.36%	18.67%	28.96%
Alcohol and type 1 diabetes booklet	51.25%	21.55%	27.20%
Drug use and type 1 diabetes booklet	60.70%	26.09%	13.21%
Travel and type 1 diabetes booklet	57.14%	19.14%	23.73%
CGM booklet	48.10%	23.86%	28.04%
CGM device summary & compatibility chart	64.78%	20.02%	15.20%

The results show low awareness and use of NDSS programs, services and resources from this demographic. This highlights a need for broader and more specific marketing and promotion of NDSS services, programs and resources to young people with type 1 diabetes to improve overall awareness and increase use and participation.

Results from both the online survey and the interviews suggested that fact sheets and booklets relevant to young people need to be promoted more widely. There is a general consensus amongst young people that the NDSS is purely a **"provider of diabetes consumables"**. Some interviewees stated that they had only become aware of the NDSS resources aimed at young people due to their work in a health professional role, work at a diabetes-related organisation or as a result of being part of this project.

A common view from interviewees was that in order to promote resources designed for young people, the promotion needs to be designed to appeal to the audience.

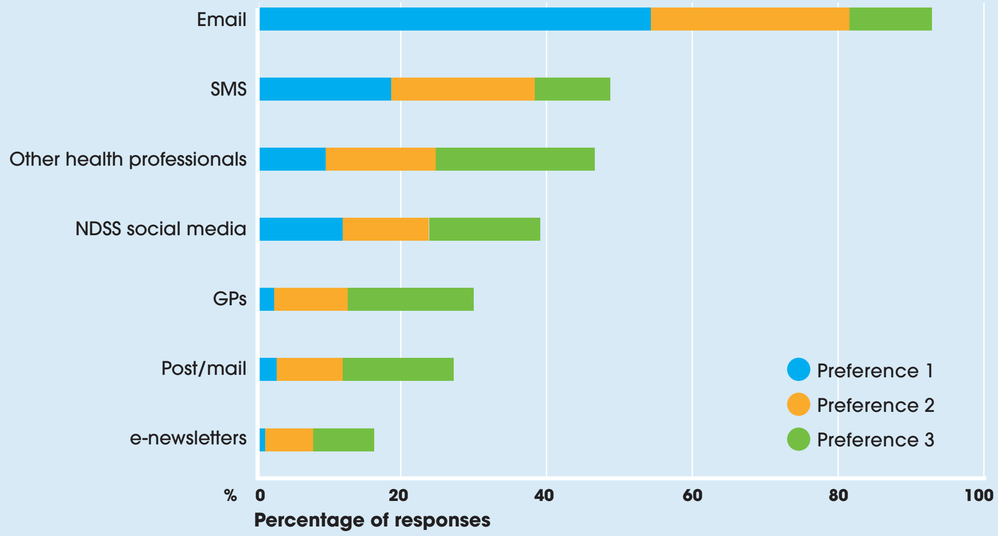
> "(The NDSS need) age-appropriate resources which are not focused on diabetes-related complications (i.e. not marketing or promoted for elderly people)."

Survey questions were used to investigate how the NDSS could better communicate with young people about NDSS offerings and newly subsidised products. Respondents were asked to rank, in order of most preferred, how they would like to find out about NDSS offerings and newly subsidised products.

As seen in ***Figure 8***, the top three options on how respondents wanted to find out more about NDSS offerings and newly subsidised products were via:

- **email** (93%, n=1690)
- **text messages** (49%, n=842)
- **health professionals other than their GP** (47%, n=744) such as endocrinologists, diabetes educators, dietitians and pharmacists.

Figure 8: **Preferred ways to be informed of NDSS offerings**



Survey results and findings

Social media posts were also considered a suitable way for the NDSS to communicate important information to young people. Some interviewees considered text messages a suitable channel, but only if the nature of the message is urgent and directly impacts young people and their access to insulin and consumables.

When asked how the NDSS could better provide support, survey respondents suggested through **better advertising of services, resources and products** (n=91). Some stated that they were unaware of many of the services, resources and products that the NDSS offered, and that uptake and use would be higher if people knew about them.

> "A lot of us don't know how much help is out there."

> "As of today, I just realised you have booklets on everything!"

Some felt that **better use of social media and technology to communicate, advertise and promote diabetes education** (n=82) could be particularly relevant to young people living with type 1 diabetes, potentially with a **centralised location of information** (n=13).

> "Podcasts and apps that are diabetes-related that all type 1s can have access to, especially those on hard topics like burnout and mental health."

> "Communicate with us. I have not received any communication or support via phone, email, text or post to let me know what is available to me as a young person with type 1 diabetes."

Education and information

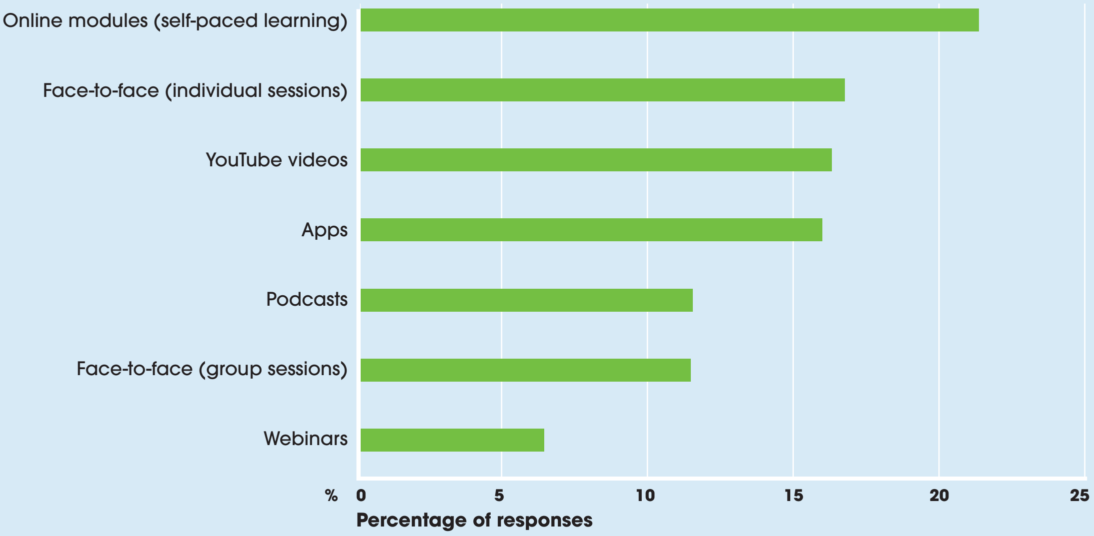
Participation in NDSS diabetes education

The survey asked young people how they would like to participate in NDSS education (***Figure 9***). Twenty-one percent (n=1100) rated online modules (self-paced learning) as the most preferred mode of education delivery. Other popular responses included:

- Face-to-face through individual education sessions (17%, n=862).
- YouTube videos (16%, n=840).
- Apps (16%, n=822).
- Podcasts (12%, n=594).
- Face-to-face via group education (12%, n=591).

Webinars were the least preferred education modality for this age cohort (6%, n=329) as seen in ***Figure 9***.

***Figure 9*: Survey respondents' NDSS education delivery preferences**



In some cases, an explanation was given for why the respondent was not interested in engaging in diabetes education. Some of these reasons given included feelings of guilt after consultation with health professionals, feeling confident that they did not need further education or willingness to ignore their diabetes.

Some respondents (n=10) stated that they wanted to receive diabetes education from their health professionals that they already visit, including their endocrinologist (n=4), GP (n=3) and credentialled diabetes educator (n=3). Participating in diabetes education online was suggested by 31 respondents. Having content emailed (n=18) was the most common preference for this theme.

"I work full-time so face-to-face options are difficult to attend – online material is easier to view after hours."

"When I was younger the diabetes educator made me feel like such a piece of shit and like I was worthless, so as soon as I turned 18 I have not seen anything to do with diabetes education. I have only seen the doctor about my diabetes twice since then."

Survey results and findings

In making suggestions for how the NDSS could offer better support, 16% (n=188) mentioned providing **more education for young people with type 1 diabetes**. This included education that was specific for, and catered to, young people with type 1 diabetes. Practical education with topics and approaches relevant to the lives of young people was preferred, rather than the notion of the `ideal' way to manage type 1 diabetes that may not be applicable to some people within this demographic.

> "I would appreciate resources with realistic approaches. Diabetes education usually has textbook rulings on drinking and diet (i.e., don't drink, eat only 30g carbs per meal), but young people in Australia will drink and eat junk food. It would be helpful to educate young people on how they can manage their diabetes when engaging with these activities."

> "Target NDSS programs to young people … A young person is unlikely to be interested in going on a tour of the supermarket, nor are they going to be able to attend at 2pm on a Wednesday."

It was important for respondents that there was **better availability and accessibility of programs** and information (n=72), as some reported wanting to increase knowledge of diabetes management but not having the opportunity to do so.

> "More information available online so people can access it outside of working hours."

In particular, there were suggestions for **better access to services and information for rural and remote areas** (n=34) as a way of providing better support.

> "By having information sessions and groups in rural areas, as well as big cities. We can't afford to take time off work, travel and find accommodation for information sessions."

> "Have more programs in rural areas. They always seem to be in the city."

> "Have programs such as OzDAFNE on the weekends and days where people who work full-time can also be able to access the class and information."

Where young people look for diabetes information

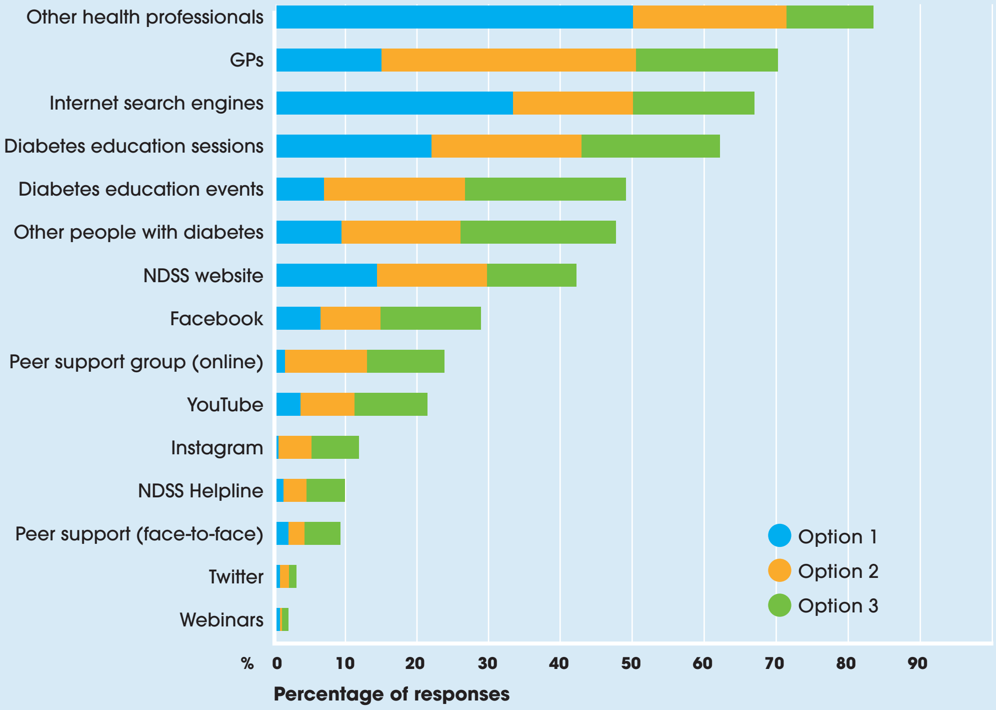
Survey respondents were asked to identify where they went for diabetes information. They were provided with 15 different options and asked to rank in order of most frequently used.

The top three options (***Figure 10***) included:

1. **Health professionals** such as endocrinologists, diabetes educators, dietitians and pharmacists (84%)
2. **GPs** (71%)
3. **Internet search engines** such as Google and Yahoo (67%).

The next options were at **diabetes education sessions/events** (62%, n=594) and then **other people with diabetes** (49%, n=510) and the **NDSS website** (48%, n=463).

***Figure 10*: Top 3 options for seeking information**



Respondents were also given the opportunity to add 'other' sources for diabetes information. Some stated that they did not access diabetes information for a variety of reasons; including feeling that they did not need it and not being able to afford to see health professionals to provide the information.

Family (n=36) was most commonly reported in 'other' sources of diabetes information. In some cases, it was because they had one or more family members with type 1 diabetes. Some also discussed receiving information from **friends** (n=6).

Survey results and findings

Accessing information **online** (n=31) was mentioned, with respondents getting information from diabetes organisations or companies **via their websites** (n=8) or **emails** (n=5). The **/r/diabetes sub-Reddit** was also discussed as providing valuable information (n=11).

> "Reddit is super helpful, with massive diabetes forums where people share experiences, tips, etc."

Respondents sought information from **published sources** (n=26), generally from **books** (n=8) and **peer reviewed research articles** (n=13).

Comparative to all of this, some people preferred to get information **from themselves** (n=9). In some cases, this was because the individual had lived with diabetes for so long that they felt they didn't need any further assistance. In others, it was because they were a health professional and had access to the information already.

Topics of interest

Survey respondents were asked to rank their top 5 topics of interest for receiving further information and education (*Figure 11*).

***Figure 11*: Topics of interest for survey respondents**

1. New and upcoming treatment & technologies (77%)
2. Mental health, burnout, diabetes distress (74%)
3. Diabetes research (62%)
4. Insurance and income protection (53%)
5. Low carbohydrate lifestyle (51%)

Survey results and findings

These responses are mirrored in suggestions for how the NDSS can provide better support, in which there were requests to better inform young people living with diabetes of emerging **technologies** (n=98) and **research** (n=57).

A breakdown of preferences for other topics of interest included:

- rights and responsibilities in the workplace
- travel (interstate and overseas)
- diabetes complications
- sexual health
- how to connect with others with type 1 diabetes
- diabetes education options for young people
- pregnancy and breastfeeding
- drugs and alcohol
- disordered eating
- driving
- starting at university/TAFE with diabetes
- peer support groups.

Some of these topics are already covered by the NDSS, with resources available online. This further highlights the need for more effective advertising of resources, services and programs to young people with type 1 diabetes.

> "Offer non-directive diabetes education programs, offer two-way conversation."

> "Offer different levels of online modules."

> "Lots of programs are geared towards beginners."

Several young women who participated in interviews were either contemplating pregnancy or had recently given birth. They expressed concern of the lack of advice available to women with type 1 diabetes around how to manage their diabetes during pregnancy, labour and breastfeeding. Other interviewees made comments about the diabetes education provided by the NDSS of which they were aware.

Suggestions not related to NDSS

Some suggestions of how the NDSS could better support young people with diabetes did not fit in above sections of the report as the specific products (such as insulin or blood ketone monitoring strips) or services (such as individual face-to-face consultations) are not available through the Scheme. However, as these suggestions have been expressed by the young people with type 1 diabetes, a brief discussion has been included in the report. Issues with health professionals were discussed, including the need for **easier, cheaper access to healthcare professionals** (n=23) and ensuring that healthcare professionals have **better knowledge about type 1 diabetes and treatment** (n=34).

> "The people who taught me about diabetes were quite judgmental and forceful, which led me to lying to, and distancing myself from, educators."

“Ketone strips should be added to the subsidy for when you need to use nearly 10 a day if ill.”

“Direct more funding to young adult diabetes clinics! 15 minutes with a different endocrinologist every 6 months doesn’t help anyone. Most young people need more support but can’t afford a private endocrinologist.”

“More public advertising so other members of the public understand diabetes further, such as signs and symptoms, and are aware of the differences between type 1 and 2 diabetes.”

Also mentioned in relation to healthcare professionals was the need for **better supporting transition from a paediatric clinic** (n=14).

There were requests for campaigns in **educating and raising awareness with the public** (n=40), including **how type 1 diabetes differs from type 2 diabetes** (n=15). Respondents reported feeling frustrated when people assumed that type 1 diabetes and type 2 diabetes were the same thing, as well as feeling embarrassed when needing to check blood glucose levels and inject insulin in public places.

Finally, it was requested that the NDSS **promote consumer empowerment and collaboration** (n=19) as it would help to ensure programs and services stay relevant while also giving the opportunity for the community to share information with one another.

“Listen to the needs of consumers.”

“After I left the paediatric clinic I felt a bit lost in who to turn to. I didn’t feel connected with healthcare services anymore, especially with my diabetes clinic, even though I was still attending the same centre. I lose a little bit of trust when I went because I felt like a number. Every time I would have to see someone new, every doctor would tell me something different and I couldn’t follow up with them to see if my care was working.”

Cost was cited as the biggest barrier preventing young people with type 1 diabetes from being able to access the technology and devices they would prefer.

Young people stated they were unable to continue use of CGM or Flash GM once they reached 21 years of age or passed the 3-month post-pregnancy period as they could no longer access the CGM Initiative through the NDSS. Young people also expressed concern that their inability to afford these technologies and devices would compromise the management of their diabetes, which consequently impacted their mental health.

“I am currently only using a CGM as it is subsidised since I just had a baby. In two months’ time I will no longer have free access and won’t be able to afford it.”

Discussion

Results of the online survey and interviews identified the following priorities and recommendations.

Summary of key findings

The two areas of greatest concern for young people, who responded to the survey or took part in the interview process, included:

- a lack of access to mental health support
- the financial burden encountered by use of insulin pumps and CGM and/or Flash GM by young people who were not eligible for subsidies.

Additionally, other identified themes included the fact that, while the NDSS provides information and support for all people living with diabetes, this information does not seem to be effectively targeted to reach young people. Many young people (particularly those in regional and remote areas) reported experiencing difficulty accessing diabetes products subsidised through the NDSS from their local pharmacy.

Access to information

The findings from the *Our voices, our lives, our choices* report (2020) demonstrate that most of the young people surveyed were not aware of, nor have ever accessed, the NDSS services, programs, resources and information available to them. There is a lack of awareness regarding the NDSS and the information and support the NDSS can provide to people living with diabetes. As a result, there is a very low uptake of programs and services offered to young people such as OzDAFNE. Additionally, there appears to be a discrepancy in the ways that young people seek diabetes information and the ways in which the NDSS currently makes it available to them.

In initial discussions with the 13 members of the ECCG, it was identified that none of them followed the NDSS or the state or territory diabetes organisations, as their NDSS Agent on social media. The overwhelming feedback coming from this group was that NDSS ‘provided subsidised products’ and they were unaware of any further assistance which they could access from the NDSS. Further work to align promotion channels with expressed preferences for receiving information may contribute to raising awareness of young people with type 1 diabetes of the programs, services and support available through the NDSS.

Diabetes technology and devices

Young people over the age of 21 years, who were not eligible for concessional benefits, found the financial and mental burden of struggling to fund the devices they felt were best for their diabetes management extremely difficult. Many were forced to use CGM and/or Flash GM on and off to lower the annual cost.

Accessing diabetes products through pharmacies

Almost one third of respondents indicated that they had experienced difficulty accessing diabetes products from their local pharmacy in the past 12 months. Of significant concern to young people was the lack of knowledge by pharmacy staff of NDSS products and how to use the NDSS Access Point ordering system. Some interviewees reported constantly having to visit multiple pharmacies in the search for a product when their local pharmacy was unable to assist.

Connection, mental health and support

As previously seen in research conducted with young people, mental health remains an issue of significant concern. The combination of burnout, diabetes distress and mental health proved to be of huge interest to this cohort (74.37%, n=1576). This could indicate either an increase in the pressure on young people living with a chronic condition or a lack of appropriate diabetes-specific mental health support.

Comparison to other NDSS consultations undertaken

There have now been four NDSS-funded consultations with young people living with diabetes in the past 14 years, and while all reports have provided similar findings, it must be noted that the demographic and purpose of each report were quite different.

1. The aim of the *Young Adults with Diabetes Needs Analysis* (2006) study was to discover concerns and issues faced by young adults who have diabetes, and identify areas of need in relation to information, health services and other types of support. This survey was conducted nationally with young adults (aged 16-34 years) living with type 1 diabetes, type 2 diabetes and gestational diabetes.
2. The *Youth Transition Survey* (2012) was conducted to provide baseline evidence about the issues faced by young people with diabetes as they move from paediatric to adult healthcare. This survey presented findings from Victorian and Tasmanian young people aged 14-24 years living with type 1 diabetes or type 2 diabetes.
3. The *Diabetes MILES Youth Study* (2014) set out to explore the wellbeing and quality of life of young people with diabetes and their parents, and to investigate self-reported diabetes care and health outcomes. This was a national survey encompassing young people (aged 10-19 years) with type 1 diabetes or type 2 diabetes and their parents.

Findings from the *Our voices, our lives, our choices* report (2020) have more similarities to the *Young Adults with Diabetes Needs Analysis* (2006) than the more recent *Youth Transition Survey* (2012) and *Diabetes MILES Youth Study* (2014).

The main themes which resulted from the *Young Adults with Diabetes Needs Analysis* (2006) were that more psychosocial support was needed, that young people with diabetes were not all the same, that strong support networks were wanted and that they would have liked to be better informed. While it had a similar purpose to the current study, it only provided a small sample of 356 young adults compared to the 2020 survey which received feedback from 2384 young people aged 18-29 years.

One similarity that was evident throughout all four studies conducted since 2006, however, was that young people's need for mental health support has increased. Further work to strengthen mental health support and resources for young people with type 1 diabetes should be considered. The 2012 survey reported that 51% of its cohort said they had discussed mental health issues with their health professionals. The *Diabetes MILES Youth Study* of 2014 reported that 28% of young people reported impaired general emotional wellbeing. The current survey highlights the increasing interest in accessing information on mental health, burnout and diabetes distress.

Interest in receiving up-to-date information on diabetes technologies was consistent in both the 2006 and 2020 surveys. There is also a consistent theme in the 2006 and 2020 surveys as to how and where young people sought diabetes information (e.g. the internet and health professionals which were the two main sources identified). The 2020 survey also identified that the preferred methods for this cohort to participate in diabetes education was definitively online learning in preference to face-to-face sessions which were more difficult to access in terms of time and location.

The similarities between the findings of the *Our voices, our lives, our choices* (2020) and those from the *Young Adults with Diabetes Needs Analysis* (2006) highlight that young people require their information in different formats, age-appropriate language and by way of different forums than those currently used to reach other groups of people in the diabetes community. Communication targeting this demographic should be written, designed and promoted in close consultation with young people in order for it to reach and activate them.

All four reports indicate that young people with diabetes require a very different method of engagement to other groups. Ongoing engagement and consultation with young people with type 1 diabetes can assist the NDSS in remaining relevant and ensure that programs, services and support meet their needs.

Key opportunities

The key opportunities were developed in consultation with the *Our voices, our lives, our choices* support team with involvement from the ECCG and feedback from the ERG. Key opportunities are displayed in logical sequence as presented in the survey results and a rationale for each opportunity is provided.

Diabetes technology and devices

The survey found that young people with type 1 diabetes identified limited knowledge about devices as a barrier to using CGM or Flash GM to manage their diabetes. Interviewees reported that they were not aware of the information and resources, including CGM and Flash GM specific content targeting young people with type 1 diabetes, available through the NDSS.

Key opportunity 1

Continue to support the need of young people with type 1 diabetes for information and resources about CGM and CGM devices.

Accessing diabetes products through pharmacies

Young people clearly identified a lack of knowledge by pharmacy staff in relation to NDSS products and systems. Further training for pharmacy staff is recommended to address the difficulties young people experience when accessing NDSS products required to manage their diabetes.

Key opportunity 2

Improve access to subsidised NDSS products by providing information and resources to pharmacies about the products and ordering process.

Connection, mental health and support

Young people have made it very clear that they would like to access information and support when and how they need it. They prefer online support as opposed to phone support. An afterhours online messaging service, not unlike the one provided by Lifeline, may provide this support. If required, a referral path for further emotional assistance could also be considered.

Key opportunity 3

Expand NDSS Helpline access to accommodate young people connecting to diabetes healthcare professionals.

Key opportunity 4

Provide opportunities for young people to connect with diabetes related mental health support.

The NDSS *Mental Health Priority Area* has the expertise and experience to lead development of mental health support programs and guide establishment of peer support forums.

Many young people want to be connected to others with type 1 diabetes. While online peer support is preferred by many, face-to-face is also a priority for some. Expanding and promoting peer support offerings to those who want them, while recognising that one option will not suit all could be considered.

Key opportunity 5

Assist young people with type 1 diabetes to meet and support others.

Awareness and communication of NDSS offerings

Young people had low-levels of awareness of existing NDSS resources with between 48-83% not aware of eight key diabetes resources available to them on the NDSS website. In initial discussions with the ECCG, most were not aware of, nor had ever used, the NDSS resources developed for young people. These resources had been developed in response to needs identified by young people and significant involvement with young people was undertaken in their production. Once these resources were presented to the ECCG, they were impressed with the content and wished they had been aware of the resources earlier.

It is apparent from all four NDSS surveys that young people should be involved in the production and promotion of information which is aimed at them. Consistent and ongoing consultation with young people can assist in ensuring information provided remains relevant to them.

Key opportunity 6

Enhance NDSS consultations with young people to ensure offerings are developed and evaluated with them.

Key opportunity 7

Include young people in the development of campaigns and share on platforms they prefer to use.

The *Youth and Youth Transition Priority Area* aims to provide young people with type 1 diabetes from all states/territories with the opportunity to partner with the NDSS in the work undertaken and support the promotion of NDSS information, services and resources.

Education and information

Young people wanting to access education and information about their diabetes management find face-to-face sessions difficult to access. Young people say they find it difficult to attend day-time sessions and those living in rural and remote areas find travel to their nearest capital city a barrier. Online learning is the preferred option and one which young people would be able to access in their own time, from their own home and when they felt they could benefit from further knowledge.

Key opportunity 8

Deliver NDSS educational materials via methods preferred by young people.

The NDSS *Youth and Youth Transition Priority Area* will continue work with young people to explore how NDSS education, information, resources and relevant research opportunities are best provided to them in their preferred formats.

Key opportunity 9

Provide information to young people about diabetes research and clinical trial opportunities.

Young people have expressed a strong desire to be kept up-to-date on the latest diabetes research and opportunities to take part in clinical trials. Invitations to participate in research should be communicated to young people in a format which is attractive to this group.

Strengths and limitations

The co-design and consumer-led methodology used throughout the project were significant components of achieving a high level of engagement. Involving young people was essential as identified in two previous studies undertaken; including *Young Adults with Diabetes Needs Analysis* (2006) and *Youth Transition Survey* (2012). It is worth noting that the engagement method took significant time to plan, prior to the initiative.

The timing of the survey was concurrent, for the final part of the survey period, to the COVID-19 pandemic state of emergency. This meant we were unable to send the final, planned SMS and social media posts, and this may have precluded some young people from participating.

If the period of the project had been a full 12 months, further opportunities to enhance the engagement between the ECCG and the ERG could have occurred.

The survey was made available to all young people (18 to 29 years) with type 1 diabetes nationally. The results indicated that a diversity of responses was achieved. While we attempted to ensure responses from priority groups, the survey was developed, promoted and delivered only in English. It was not translated into other languages. This may have limited the engagement with the survey to young people with type 1 diabetes who speak or read English.

It is important to note the number of Aboriginal and/or Torres Strait Islander people and those who spoke a language other than English at home, who took part in the survey. Given the diversity of respondents' backgrounds, additional data analysis and reporting may provide insights into how to ensure the breadth of voices and needs of young people can be heard and considered in the future.

The online format was an effective and economical approach for engagement. However, while every effort was made to reach all young people with type 1 diabetes, the survey was only available online which limited survey participants to those who have access to the internet. The primary method of engagement was with young people with type 1 diabetes registered with the NDSS. This data (at time of survey release) only reached a maximum of 67% of this total population. Those whose NDSS registration did not include up-to-date contact details may have missed the opportunity to take part.

The survey was also promoted on social media. It is difficult to determine the reach of this strategy in isolation, as the social media promotions occurred at the same or similar times as the NDSS eDM/SMS distribution and reminders. Survey respondents were not asked where they had heard about the survey.

Engagement of priority groups required more time than anticipated. This was evident in our inability to reach certain sections of the community, such as the Aboriginal and/or Torres Strait Islander group when conducting interviews.

To ensure the survey only included eligible participants, data from those who were not within the required age group or those who failed to complete the whole survey were removed from the analysed data. Privacy was maintained and the survey was anonymous, so it was not possible to know if respondents attempted the survey more than once. The platform which hosted the survey, Qualtrics, has a function that does not allow participants to complete the survey more than once on the same device. However, it was possible for participants to complete the survey more than once using a different device, although this seems unlikely.

In question seven of the survey, consideration needs to be given to the fact that, on 1 March 2020, the eligibility to access fully subsidised products through the CGM Initiative as part of the NDSS were streamlined.

Conclusion and next steps

Based on the feedback received from consumer engagement strategies utilised throughout the NDSS *Youth and Youth Transition project*, we (in consultation with the ECCG and ERG) have developed a set of **nine key opportunities** that should be considered in the NDSS's future engagement with young people living with type 1 diabetes.

Whilst some of the key themes from the survey and issues raised through interviews fall outside the scope of the NDSS, they have been included in the report as they represent the experiences and the views of young people living with type 1 diabetes.

Our goals are to contribute to ongoing improvement of the provision of relevant, timely and supportive NDSS programs, resources and services, and to ultimately achieve the flow-on effects of:

- Increased engagement and uptake of NDSS-funded programs by young people.
- Increased awareness of and satisfaction with NDSS programs, information and services provisions by young people.

Next steps

This report will help to inform future NDSS service provision for young people with type 1 diabetes. The *Our voices, our lives, our choices* national findings will be widely disseminated to young people with diabetes, other stakeholders, Diabetes Australia, NDSS publications, relevant conferences and forums.

We recognise the importance of maintaining momentum in regard to progressing the *Youth and Youth Transition* Priority *Area* recommendations we have put forward. We envisage using a best practice model involving high levels of community input to inform planning future NDSS information, resources, programs and services. A draft action plan will be developed with the ECCG to operationalise opportunities highlighted above. This will be divided into short, medium and long-term goals.

Expert Consumer Consultation Group (ECCG) members

Siobhan Johnston
NDSS *Youth and Youth Transition Project Coordinator* as Chair (attendee) of the ECCG.

Alyssa Caputo – South Australia
I am 28 years old and a trained massage therapist. I was diagnosed with type 1 diabetes in year 12, which was challenging to say the least! My younger sister also has type 1 diabetes and we are each other's biggest support. I joined the ECCG to help other young people with type 1 diabetes to have a voice in the future of diabetes in Australia. It was also fantastic to expand my resource and support network by connecting with like-minded individuals who know exactly what I'm going through every day!

Brooke Mills – Queensland
I was diagnosed with type 1 diabetes at age six. I never felt limited by my diabetes during my secondary education. I was part of many sporting teams as well as a committee member for the college art and student representative council. I went on to complete a Master of Architecture in 2016 at QUT. I work full-time and recently became registered as an Architect. I am passionate about helping improve the lives of people with diabetes and was honoured to be chosen as a voice for our community.

Cale Hutchins – Queensland
I've been living with type 1 diabetes since I was eight years old. My diabetes story has the same common threads that I hear from others with type 1 diabetes; balancing the stress of living a normal life and responsibly managing a very serious medical condition, managing the stigma associated with diabetes and living with the cost burden is a continuous learning process. I was excited by the opportunity to contribute to the ECCG and to meet others with type 1 diabetes from across Australia.

Elvin Lam – Victoria
I have type 1 diabetes, diagnosed at the age of 19.

I completed a Bachelor of Commerce double degree and a Bachelor of Business Information Systems at Monash University, and am currently working as an IT Audit Professional.
I am also a consumer representative to the Patron Data Governance Committee for the Melbourne Medical School. Being part of the NDSS ECCG enables me to represent the consumer group in Victoria living with diabetes.

Ellen Olzomer – New South Wales
I have been living with type 1 diabetes for 19 years. I am passionate about my work in the field of medical research, and also love being active. I enjoy hiking and running and have even completed a 100km trail run. I was eager to become a member of the ECCG as I have learned over the years to take a more holistic approach to my diabetes management, especially through education and connecting with others in the type 1 diabetes community.

I am grateful to be part of this process.

Emily Vuong – Western Australia

I am half-Vietnamese, half-Australian and I recently completed my Bachelor of Commerce at UWA. I've lived with type 1 diabetes for 22 years. I like to show people that people with type 1 diabetes can live a healthy and normal life just like anyone else – donuts included!

I was keen to join the ECCG because I wanted to be able to use my voice to action real change on a national level. I think the NDSS does an awesome job, but I was keen to be a part of making their resources more universally accessible.

Gabby Lane – Western Australia

I'm 23 years old and I was diagnosed with type 1 diabetes in 2011. After finishing my studies in Marketing and Management at UWA, I landed my dream job as the Adult Community Coordinator at the Type 1 Diabetes Family Centre in WA. I support people of all ages living with type 1 through program development, online connection, information and social events.

People know me for being passionate for the type 1 community and creating social impact. I applied for the ECCG as type 1 diabetes youth transition support lights me up and community is something I value immensely.

Georgie Peters – Victoria

I've been living with type 1 diabetes since 2010 and have been volunteering and advocating within the diabetes community for many years. I'm passionate about raising awareness to help people living with an eating disorder and diabetes. I have presented nationally and internationally, generating conversations and action around this issue and run a social media movement @bodyposibetes. I was interested in joining the group because I have a real interest in contributing to the dialogue around diabetes and the transition experience as a young adult and to represent my community in a way that affects change for a large amount of people!

Joseph Young – Victoria

I was diagnosed with type 1 diabetes at 19 years of age. Having been diagnosed 'later' in life, I have quickly found that supporting other people with diabetes is something that I want to dedicate my life to. Diabetes has shaped me into the person that I am. I have a Bachelor of Psychology and have been accepted into a Bachelor of Nursing and plan to complete a postgraduate in Diabetes Education. I was very interested in joining the ECCG to communicate with government bodies to fill the current gaps that we have in our services and expand education on type 1 diabetes.

Krystal Leane-Silva – South Australia

I am 25 years old. I was diagnosed with type 1 diabetes and coeliac disease in April 2018. I am currently studying a Bachelor's in Human Resource Management and work in recruitment. My hobbies include finding new and exciting low-carb, gluten-free recipes and spending time with my German Shepherd. I was interested in joining the group to provide my insights from a newly diagnosed perspective. Having spent most of my life without type 1 diabetes, I wanted to help improve the transition and experience for others.

Expert Consumer Consultation Group (ECCG) members

Louisa Sikaris - Victoria

I was diagnosed with diabetes at 10 years old and have volunteered on Diabetes Victoria's camps and events for the past four years. I completed a Master's degree in Clinical Exercise Physiology and I'm now an accredited exercise physiologist with ESSA. I was interested in joining the ECCG because I believe there is a significant lack of support for young adults in Victoria and a gap in the care of young adults in the healthcare system with type 1 diabetes.

Matt Campbell - Tasmania

I am 22 years old with a passion for architecture. I have been living with type 1 diabetes for a little over 15 years. I help co-lead Diabetes Advocacy Group Tasmania (DAGt) where we help to improve diabetes care from a patient perspective, including engagement. Joining the ECCG provided an opportunity to explore diabetes care from a broader perspective than my local care centre, but it is also a space where I can provide insight into some of the activities that have been working from DAGt for the benefit of the wider diabetes community.

Rachel Duthie - Tasmania

I've been inhabiting our planet for about 25 years and for 16 of those years type 1 diabetes has tagged along. I work as a hiking guide in the Northern Territory over winter to escape the cold, and guide hikes around the desert and Kakadu. I also dabble in youth work and sometimes combine the two and work in Bush Adventure Therapy.

I run camps for teenagers with diabetes down in Tasmania and am passionate about youth, diabetes and nature.

I was interested in being a part of your ECCG because I felt it a great way to bring real and tangible change to the diabetes community.

Expert Reference Group (ERG) members

CHAIR

Renza Scibilia – Victoria
Manager - Type 1 Diabetes and Communities, Diabetes Australia,
Diabetes advocate

MEMBERS

Dr Ashley Ng – Victoria
APD, PhD, MDiet, BFS&N (Hons)
Lecturer Dietetics and Human Nutrition
Lives with diabetes

Cheryl Nankivell – New South Wales
RN Credentialled Diabetes Educator
Diabetes NSW & ACT

A/Prof Christine Rodda – Victoria
MBBS, PhD, FRACP
Associate Professor Paediatrics – University of Melbourne
Paediatric Endocrinologist – Western Health
Program Director Musculo-Skeletal Development AIMSS
North West Academic Centre
The University of Melbourne
Western Centre for Health Research and Education – Western Health Sunshine Hospital

Dr Jason Yates – Queensland
Medical Director HWBSG
Paediatric Endocrinologist/General Paediatrician
Health and Wellbeing Service Group
Townsville Hospital & Health Service

Dr Phoebe Cliff – South Australia
MBChB (Hons)
Flinders Medical Centre
Lives with type 1 diabetes

Bec Johnson – Western Australia
MPH LLB/BA Dip Bus (Gov)
CEO, Type 1 Diabetes Family Centre
Lives with type 1 diabetes

Expert Reference Group (ERG) members

Samantha Beattie – Tasmania

Acting Nurse Northern Integrated Care Service
Acting Nurse Unit Manager John Morris Diabetes Centre
Clinical Nurse Specialist – Diabetes (RN CDE)
Nurse Practitioner Candidate – Diabetes

Dr Virginia Hagger – Victoria

RN-CDE, PhD
Senior Lecturer in Nursing
Course Director, Graduate Certificate in Diabetes Education
School of Nursing and Midwifery, Faculty of Health Deakin University

Carolyn Jones – Victoria

Consumer Engagement Manager; National Youth and Youth Transition and Peer Support Priority lead, Diabetes Victoria

Jane Cheney – Victoria

ERG attendee, Diabetes Victoria

Glossary of terms

BGL: Blood glucose level

Co-design: The co-design approach enabled a wide range of people with type 1 diabetes to contribute to the initiative. This approach goes beyond participation by incorporating, building and deepening equal collaboration between people with diabetes and service providers. A key feature of the co-design approach is that the person with diabetes is the 'expert of their own lived experience' and therefore central to the process.

CGM: Continuous glucose metering (CGM) continually measures and displays glucose levels throughout the day and night. CGM is made up of three parts: sensor, transmitter and receiver.

Consumer engagement: A commitment to meaningful and outcomes-driven consumer, community and workforce engagement that recognises that there is not a one size fits all engagement approach. No one consumer or community is the same, so their needs will vary and therefore the engagement strategies for these consumers/communities will vary.

Consumer-led: This approach moves beyond co-design principles of equal collaboration to also ensure people with diabetes had the opportunity to lead and drive the project. Specifically, the Project Coordinator was within the target demographic and coordinated the project, and the ECCG (13 people with lived experience) guided the project to completion. People with diabetes also identified and developed the idea and formed part of the ERG who supported the project to completion.

Consumer representative: A consumer representative is appointed to represent consumer and/or community perspectives. Consumer representatives may be connected to a community and must be confident to provide their own and their community's perspective or viewpoint.

Do It Yourself (DIY) Technologies: Technologies which are not commercially available in Australia and are 'build' by individuals with diabetes for their own use. 'Open source' technology solutions are developed and made available on the internet by people in the diabetes community. There are different methods of DIY technology including Looping, OpenAPS, Android APS and Nightscout.

ECCG: *Expert Consumer Consultation Group* – a group of 13 young people aged 18-29 years living with type 1 diabetes (representing all states and territories) who were selected to lead this project.

Empowered: To become stronger and more confident, especially in taking charge of one's life and claiming one's rights. An empowered consumer is confident in managing their diabetes and may want to advocate, support and/or provide information to their peers also living with diabetes. Empowered consumers may seek consumer representative opportunities.

ERG: *Expert Reference Group* – a group of 10 people consisting of health professionals and others who work with young people with diabetes.

Flash GM: The Freestyle Libre glucose metering system consists of a sensor worn on the back of the upper arm and a reader which displays glucose data with every scan. The sensor is designed to last for up to 14 days and provides glucose trends.

National Diabetes Services Scheme (NDSS): The NDSS is an initiative of the Australian Government that commenced in 1987 and is administered by Diabetes Australia. The aim is to enhance the capacity of people with diabetes to understand and self-manage their life with diabetes by providing access to services, support and subsidised diabetes products.

Type 1 diabetes: An auto-immune condition in which the immune system is activated to destroy the cells in the pancreas which produce insulin. The cause of this auto-immune reaction is unknown. There is no cure for type 1 diabetes.

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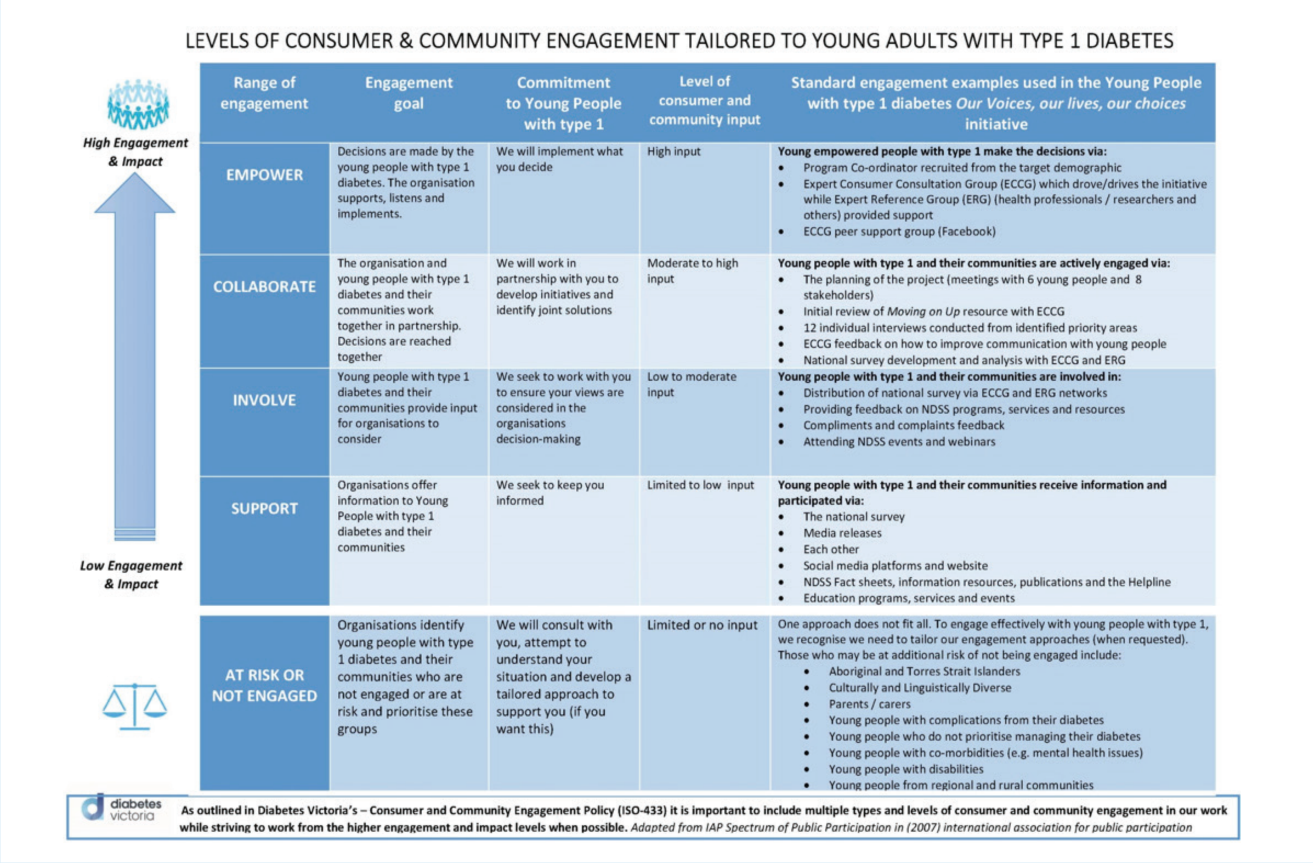
Appendix 1

Matrix

Levels of Consumer & Community Engagement tailored to young adults with type 1 diabetes



LEVELS OF CONSUMER & COMMUNITY ENGAGEMENT TAILORED TO YOUNG ADULTS WITH TYPE 1 DIABETES

High Engagement & Impact

Low Engagement & Impact

Range of engagement	Engagement goal	Commitment to Young People with type 1	Level of consumer and community input	Standard engagement examples used in the Young People with type 1 diabetes *Our Voices, our lives, our choices* initiative
EMPOWER	Decisions are made by the young people with type 1 diabetes. The organisation supports, listens and implements.	We will implement what you decide	High input	**Young empowered people with type 1 make the decisions via:** • Program Co-ordinator recruited from the target demographic • Expert Consumer Consultation Group (ECCG) which drove/drives the initiative while Expert Reference Group (ERG) (health professionals / researchers and others) provided support • ECCG peer support group (Facebook)
COLLABORATE	The organisation and young people with type 1 diabetes and their communities work together in partnership. Decisions are reached together	We will work in partnership with you to develop initiatives and identify joint solutions	Moderate to high input	**Young people with type 1 and their communities are actively engaged via:** • The planning of the project (meetings with 6 young people and 8 stakeholders) • Initial review of *Moving on Up* resource with ECCG • 12 individual interviews conducted from identified priority areas • ECCG feedback on how to improve communication with young people • National survey development and analysis with ECCG and ERG
INVOLVE	Young people with type 1 diabetes and their communities provide input for organisations to consider	We seek to work with you to ensure your views are considered in the organisations decision-making	Low to moderate input	**Young people with type 1 and their communities are involved in:** • Distribution of national survey via ECCG and ERG networks • Providing feedback on NDSS programs, services and resources • Compliments and complaints feedback • Attending NDSS events and webinars
SUPPORT	Organisations offer information to Young People with type 1 diabetes and their communities	We seek to keep you informed	Limited to low input	**Young people with type 1 and their communities receive information and participated via:** • The national survey • Media releases • Each other • Social media platforms and website • NDSS Fact sheets, information resources, publications and the Helpline • Education programs, services and events
AT RISK OR NOT ENGAGED	Organisations identify young people with type 1 diabetes and their communities who are not engaged or are at risk and prioritise these groups	We will consult with you, attempt to understand your situation and develop a tailored approach to support you (if you want this)	Limited or no input	One approach does not fit all. To engage effectively with young people with type 1, we recognise we need to tailor our engagement approaches (when requested). Those who may be at additional risk of not being engaged include: • Aboriginal and Torres Strait Islanders • Culturally and Linguistically Diverse • Parents / carers • Young people with complications from their diabetes • Young people who do not prioritise managing their diabetes • Young people with co-morbidities (e.g. mental health issues) • Young people with disabilities • Young people from regional and rural communities

diabetes victoria

As outlined in Diabetes Victoria's – Consumer and Community Engagement Policy (ISO-433) it is important to include multiple types and levels of consumer and community engagement in our work while striving to work from the higher engagement and impact levels when possible. *Adapted from IAP Spectrum of Public Participation in (2007) international association for public participation*

Appendix 2

Online survey

NDSS *National Youth and Youth Transition* Survey

The National Diabetes Services Scheme (NDSS) has worked with young people living with type 1 diabetes to create this survey.

If you are aged 18 to 29 years and living with type 1 diabetes, we would like to hear from you to find out how the NDSS can better support you to manage your diabetes. Your input will help us shape future NDSS offerings for young people.

The survey has 18 short questions and should take approximately 10 minutes to complete.

If you complete the survey, you will be able to enter your details to go into the draw for a chance to win a $500 EFTPOS gift voucher. We will also be awarding a $50 EFTPOS gift voucher to one participant in each state/territory. (* the same person cannot win the major prize and the individual state/territory prize).

All information collected within this survey is covered by the NDSS Privacy Policy. For more information, visit: ndss.com.au/privacy-policy/

Q1 What Australian state/territory do you live in?

▼ Australian Capital Territory... Western Australia

Drop down boxes for each state/territory

Q2 What is your postcode?

……

Q3 How old are you (in years)? (This survey is only for people 18 to 29 years with type 1 diabetes)

▼ Less than 18... More than 30

Drop down boxes for each age 18-29

Q4 How old were you when you were diagnosed with type 1 diabetes (in years)?

▼ Less than 1 ... 29

Drop down boxes for each age 1-29

Q5 Are you of Aboriginal or Torres Strait Islander origin?

☐ No
☐ Yes, Aboriginal
☐ Yes, Torres Strait Islander
☐ Yes, Aboriginal & Torres Strait Islander
☐ Prefer not to disclose

Drop down boxes for each age 1-29

Q6 What language do you speak mostly at home?

☐ English
☐ Other (Please state which language):

....

Q7 What tool/device do you use to manage your diabetes? (Please select a response for each listed below)

	Yes	No
Injections (pen or syringe)	☐	☐
Insulin pump	☐	☐
Do It Yourself (DIY) technology (e.g. Looping)	☐	☐
Blood glucose meter	☐	☐
Continuous Glucose metering (CGM)	☐	☐
Flash glucose metering (e.g. Freestyle Libre)	☐	☐

Appendix 2

Q8 What is stopping you from using any of the following? (If applicable, please outline any barriers that exist)

☐ Injections (pen or syringe)

....

☐ Insulin pump

....

☐ Do It Yourself (DIY) technology (e.g. Looping)

....

☐ Blood glucose meter

....

☐ Continuous Glucose metering (CGM)

....

☐ Flash glucose metering (e.g. Freestyle Libre)

....

Q9 How important is it for you to be connected to other young people with type 1 diabetes?

1	2	3	4	5
☐	☐	☐	☐	☐
(Not at all important)				(Extremely important)

Q10 Do you currently connect with other young people with type 1 diabetes?

☐ Yes
☐ No

Skip To: Q11 If you do currently connect with other young people with type 1 diabetes? = No

Skip To: Ways to connect If you do currently connect with other young people with type 1 diabetes? = Yes

Please tell us how you most frequently interact with other young people with type 1 diabetes? (Please rank the option/s that are relevant to you, with 1 being most frequently used)

☐ Facebook
☐ Twitter
☐ Instagram
☐ WhatsApp
☐ Peer support group (face-to-face)
☐ Peer support group (online)
☐ Volunteering at diabetes camps
☐ Phone call / text messaging
☐ Other

Validation rule: at least 1 must be identified

Q11 Please tell us where you get your diabetes information from when needed? (Please rank the option/s that are relevant to you, with 1 being most frequently used)

☐ Internet search engine (e.g. Google, Yahoo etc.)
☐ YouTube
☐ Facebook
☐ Twitter
☐ Instagram
☐ NDSS website
☐ NDSS Helpline
☐ Webinars
☐ Podcasts
☐ Peer support group (face-to-face)
☐ Peer support group (online)
☐ Diabetes education sessions or events
☐ General Practitioner (GP)
☐ Other health professionals (e.g. endocrinologist, diabetes educator, dietitian, pharmacist etc.)
☐ Other people with diabetes
☐ Other (please specify)

Validation rule: at least 1 must be identified

Appendix 2

Q11 Please tell us where you get your diabetes information from when needed? (Please rank the option/s that are relevant to you, with 1 being most frequently used)

☐ Internet search engine (e.g. Google, Yahoo etc.)
☐ YouTube
☐ Facebook
☐ Twitter
☐ Instagram
☐ NDSS website
☐ NDSS Helpline
☐ Webinars
☐ Podcasts
☐ Peer support group (face-to-face)
☐ Peer support group (online)
☐ Diabetes education sessions or events
☐ General Practitioner (GP)
☐ Other health professionals (e.g. endocrinologist, diabetes educator, dietitian, pharmacist etc.)
☐ Other people with diabetes
☐ Other (please specify)

Validation rule: at least 1 must be identified

Q12 Which of the following NDSS programs and services are you aware of, and have accessed? (Please select one response for each item)

Subsidised diabetes products	▼ I was not aware of this... I am aware and have accessed this
NDSS Helpline	▼ I was not aware of this... I am aware and have accessed this
OzDAFNE program	▼ I was not aware of this... I am aware and have accessed this
NDSS programs (e.g. Med SMART, Carb SMART, Supermarket tours etc.)	▼ I was not aware of this... I am aware and have accessed this

There are 3 choices presented in a drop-down option for Q12:

- *I was not aware of this*
- *I was aware and have not accessed this*
- *I was aware and have accessed this*

Q13 Which of the following NDSS resources are you aware of, and have accessed? (Please select one response for each item)

Subsidised diabetes products	▼ I was not aware of this... I am aware and have accessed this
Diabetes Annual Cycle of Care fact sheet & checklist	▼ I was not aware of this... I am aware and have accessed this
Moving on Up: Guide for young adults with diabetes	▼ I was not aware of this... I am aware and have accessed this
Diabetes and driving booklet	▼ I was not aware of this... I am aware and have accessed this
Alcohol and type 1 diabetes booklet	▼ I was not aware of this... I am aware and have accessed this
Drug use and type 1 diabetes booklet	▼ I was not aware of this... I am aware and have accessed this
Travel and type 1 diabetes booklet	▼ I was not aware of this... I am aware and have accessed this
Continuous Glucose metering (CGM) booklet	▼ I was not aware of this... I am aware and have accessed this
CGM device summary & compatibility chart	▼ I was not aware of this... I am aware and have accessed this

There are 3 choices presented in a drop-down option for Q13:

- *I was not aware of this*
- *I was aware and have not accessed this*
- *I was aware and have accessed this*

Appendix 2

Q14 In the last 12 months, have you had any problems accessing your diabetes products through your local pharmacy?

☐ No
☐ Yes (If yes, please briefly outline the issue you experienced):

……

Q15 How would you like to find out about NDSS offerings and newly subsidised products? (Please rank the option/s that are relevant to you, with 1 being most preferred)

☐ NDSS website
☐ NDSS social media (e.g. Facebook, Twitter, Instagram etc.)
☐ Text messages (SMS)
☐ Email
☐ e-newsletters
☐ Post/mail
☐ My General Practitioner (GP)
☐ Other health professionals (e.g. endocrinologists, diabetes educators, dietitians, pharmacists etc.)
☐ Other

Validation rule: at least 1 must be identified

16 What topics would you like the NDSS to provide in relation to education, information or resources? (Please select all that apply)

☐ How to connect to others with type 1 diabetes
☐ Peer support groups
☐ New and upcoming treatment & technologies
☐ Diabetes education options for young people (e.g. OzDAFNE)
☐ Diabetes complications
☐ Diabetes research
☐ Driving
☐ Mental health
☐ Drugs & alcohol
☐ Sexual health
☐ Pregnancy & breastfeeding
☐ Low carbohydrate lifestyle
☐ Diabetes distress
☐ Disordered eating
☐ Insurance and income protection (e.g. health, life, travel)
☐ Travel (interstate & overseas)
☐ Rights & responsibilities in the workplace
☐ Starting at University/TAFE with diabetes
☐ Burnout
☐ Other

………

Validation rule: at least 1 must be identified

Appendix 2

16 What topics would you like the NDSS to provide in relation to education, information or resources? (Please select all that apply)

☐ Face-to-face (individual sessions)
☐ Face-to-face (group sessions)
☐ Online modules (self-paced learning)
☐ Webinars
☐ Podcasts
☐ Apps
☐ YouTube videos
☐ Other

....

Validation rule: at least 1 must be identified

Q17 How do you like to participate in NDSS diabetes education? (Please select all that apply)

☐ Face-to-face (individual sessions)
☐ Face-to-face (group sessions)
☐ Online modules (self-paced learning)
☐ Webinars
☐ Podcasts
☐ Apps
☐ YouTube videos
☐ Other

....

Validation rule: at least 1 must be identified

Q18 What could the NDSS do to better support young people living with type 1 diabetes?

....

....

....

....

....

....

....

....

....

....

Incentive offer:
Thank you for taking the time to complete this very important NDSS national youth survey.

If you would like to go into the draw for a chance to win a **$500 EFTPOS gift voucher**, please enter your name and contact details below. We will also be awarding a **$50 EFTPOS gift voucher** to one participant in each state/territory.
This personal information will only be used for the purpose of notifying the winners. It will not be used to identify or link you to your responses and will not be shared with any third parties.

Name
....

Mobile
....

Email
....

Please share the survey

link https://diabetesvic.au1.qualtrics.com/jfe/form/SV_2f0UccqteaHIMBv and encourage other young people with type 1 diabetes in your network to complete the survey.

The more responses we receive, the stronger our voice for change!

Appendix 3

Interview questions disclaimer

Thank you for agreeing to be a part of the NDSS *Youth and Youth Transition project* interviews.

Your time and opinions are very valuable to us. We respect your privacy: all information you share today will be de-identified and therefore unable to be linked back to you.

*We would come back to you if we were wanting to use a particular quote in the final report.

Aim of interview: To explore some of the themes that resulted from the national youth survey (open from 3–23 March 2020) so we can provide a set of strong and relevant recommendations to the NDSS to guide future program and support delivery for young people.

Interview etiquette: Please don't feel pressured to answer anything if you are not comfortable doing so. If you would like to be linked with support services (DNE, dietitian, advocacy) I can do this for you.

A little bit about myself (interviewer): Type 1 for 13 years, diagnosed at age 16. I live in Melbourne and am married with a 16-month-old daughter. I have worked at Diabetes Victoria for over seven years and really enjoy working with others who also live with diabetes.

Now it's over to you (interviewee)! (Apologies if you already answered these questions in the online survey)

Please tell me a little bit about yourself:

- Do you identify as Aboriginal and/or Torres Strait Islander (or prefer not to say)?
- What is your main language spoken at home?
- Date of type 1 diabetes diagnosis?
- What technology/devices do you use a to manage your diabetes
- (MDI, pump, CGM, BG meter, Flash glucose monitoring)?
- Have you experienced any diabetes-related complications?
- Do you have a disability and/or other health conditions?
- Living situation (family/friends/partner)?
- Studying or working/not working currently?
- Did you complete the recent online NDSS *Youth Survey*? Why/why not?
- If yes, what method of survey promotion worked for you (NDSS email, NDSS text message, social media channels, word of mouth)?

1. **Loss/low level of engagement during transition**

   Supporting young people with diabetes is a national priority for the NDSS. It is estimated that 30-40% of young people in transition are lost from the healthcare system, which can lead to less desired diabetes management and diabetes-related complications.

   - Did this happen to you? If yes, could you please explain your experience?
   - What can NDSS do to keep young people like yourself, engaged with your healthcare team?

2. **Gaps in NDSS programs and support for young people (18-29 years)**

   Since your diagnosis, have there been any particular stages at which you would have benefited from additional NDSS program offerings and/or support (medical, emotional, device education, financial i.e. access to subsidised consumables) to help manage your diabetes? Yes / No

   - Please outline age and type of additional program/support which may have been beneficial? (During the ages 18-29 years)
   - How do you feel this would have benefitted your health/diabetes management?

3. **Access to technology**

   CGM was firstly approved on the NDSS for people with type 1 diabetes up to age 21, pregnant women (in Dec 2018), for women trying to conceive and three months post birth of a child. As of 1 March 2020, people with type 1 diabetes who are on a concession/pension card can also access CGM for free.

   - How have these changes affected your diabetes management (physically – lowered your HbA1c, mentally – positively or negatively)?
   - Were you once eligible and are no longer?

- Can you recall receiving communication from the NDSS about these newly introduced subsidies?
- Were you aware of any education re: how to use CGM? Did you find this supportive to your management?

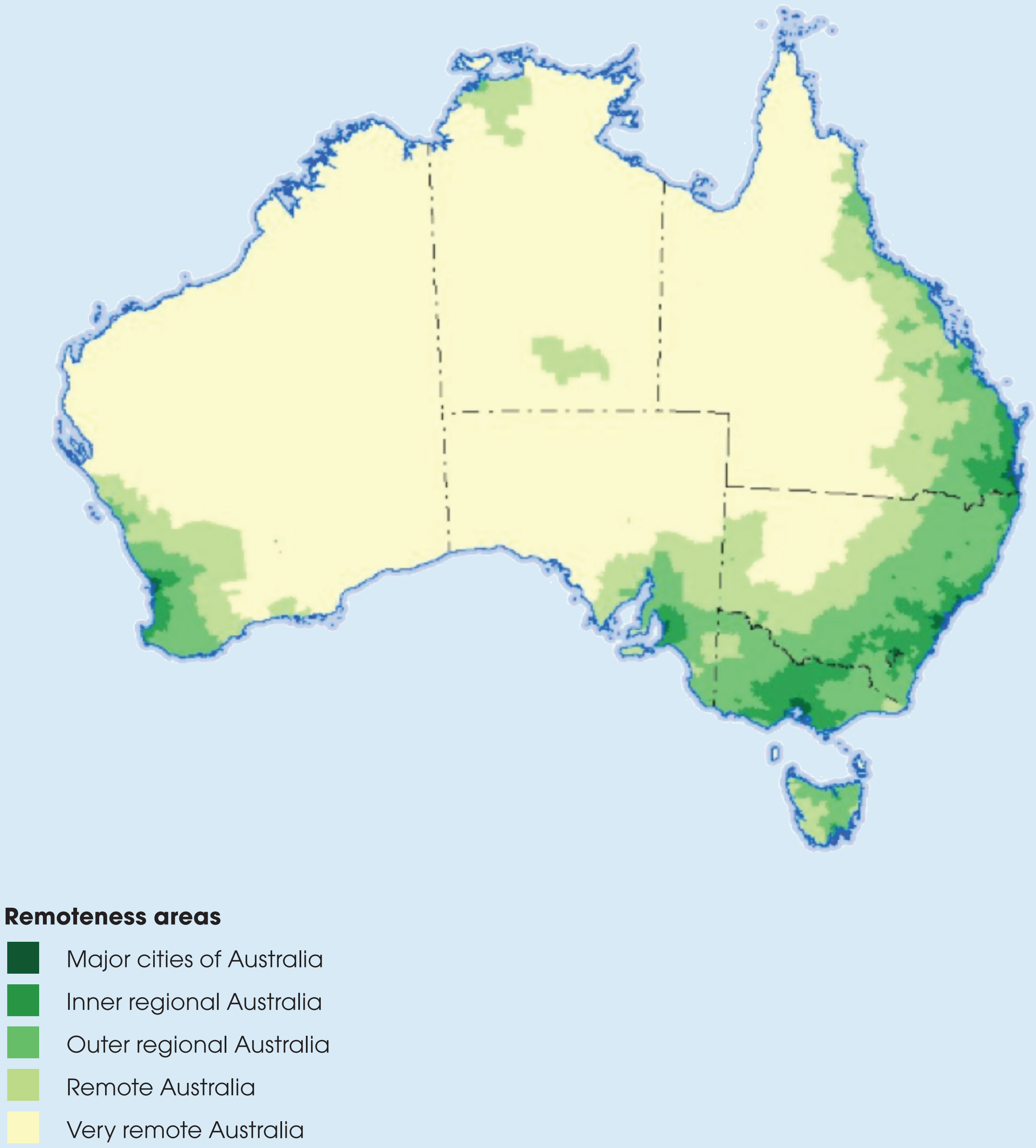
4. **NDSS program and service offerings**
   A large proportion of young people who completed the online survey, were not aware of NDSS programs such as the SMARTS series, supermarket tours or OzDAFNE (Dose Adjustment for Normal Eating) which are available to them.
   - Were you aware of OzDAFNE? If yes, what is your perception of the program?
   - (Delivery method 5 days straight or 1 session each week for 5 weeks).
   - Have you attended any of these programs? Yes / No
   - Why or why not (what barriers exist for you, if any)?
5. **NDSS resources (fact sheets)**
   An average of 50% (and in some cases higher rates) of young people were also unaware of NDSS resources which are available to help in managing type 1 diabetes, many of which have been designed for young people. A further 30% were not aware of the existence of the NDSS Helpline.
   - How could young people's awareness of these resources be improved?
   - Are these resources relevant to your needs? Please explain.
6. **NDSS Access Point/pharmacy issues**
   Have you experienced any issues ordering or accessing your diabetes supplies from pharmacies? *As these interviews were conducted during the COVID-19 lockdown, young people were asked to contain their answers to the 12 months prior to this)
   - And if so, what solution/s can you recommend?
7. **What is your preferred mode of delivery for diabetes Agent (i.e. Diabetes Victoria) organised events? Can you take me through this?**
   - Preferred day, time of day and reasons why you would or would not attend?
   - Duration?
   - Distance from home?
   - Mode of delivery (face-to-face, online – please be specific)?
   - Experience of speakers? (living with diabetes, health professionals)
8. **Peer support/connection with type 1 diabetes community**
   Connection online (Facebook groups/ Instagram/Twitter/WhatsApp) and face-to-face connection via volunteering on diabetes camps and social catch-ups.
   - What does this look like for you?
   - If you're not connected to others living with type 1 diabetes, do you choose not to be and, if so, why (if comfortable in sharing with me)?
   - Would you like an easily accessible peer support link in your state/territory? Please take me through what this might look like.

Thank you for your time, honesty and opinions as a young person living with type 1 diabetes. Your contribution to this project is much appreciated.

- As a token of appreciation, we are offering you a $25 Coles Myer Gift card.
- Are you interested in being contacted via email for future research opportunities?

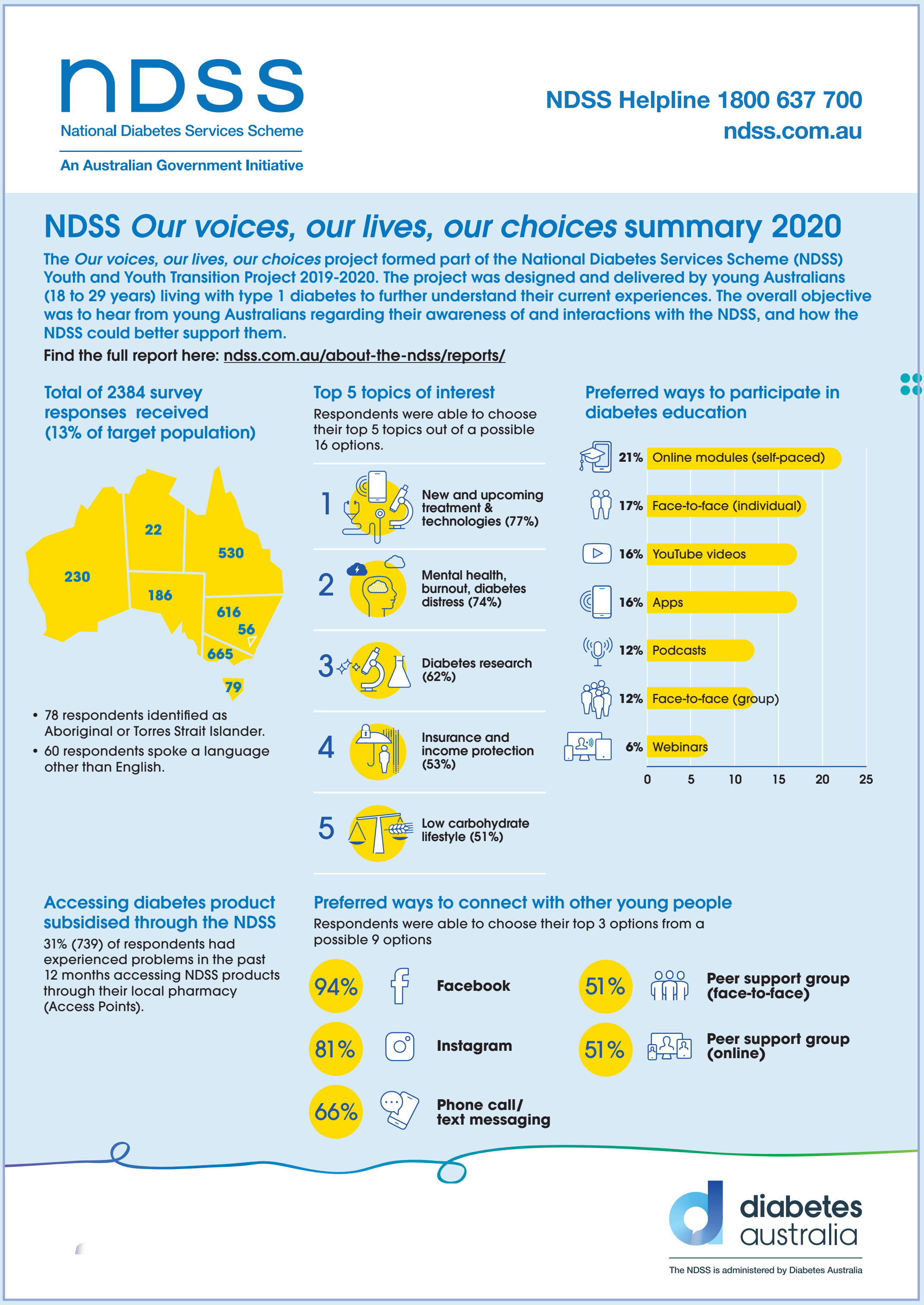
Appendix 4

Map of the 2016 Remoteness Areas for Australia



Appendix 5

Our voices, our lives, our choices summary 2020



NDSS National Diabetes Services Scheme

An Australian Government Initiative

NDSS Helpline 1800 637 700
ndss.com.au

NDSS *Our voices, our lives, our choices* summary 2020

The *Our voices, our lives, our choices* project formed part of the National Diabetes Services Scheme (NDSS) Youth and Youth Transition Project 2019-2020. The project was designed and delivered by young Australians (18 to 29 years) living with type 1 diabetes to further understand their current experiences. The overall objective was to hear from young Australians regarding their awareness of and interactions with the NDSS, and how the NDSS could better support them.

Find the full report here: ndss.com.au/about-the-ndss/reports/

Total of 2384 survey responses received (13% of target population)

- 78 respondents identified as Aboriginal or Torres Strait Islander.
- 60 respondents spoke a language other than English.

Top 5 topics of interest

Respondents were able to choose their top 5 topics out of a possible 16 options.

1. New and upcoming treatment & technologies (77%)
2. Mental health, burnout, diabetes distress (74%)
3. Diabetes research (62%)
4. Insurance and income protection (53%)
5. Low carbohydrate lifestyle (51%)

Preferred ways to participate in diabetes education

21%	Online modules (self-paced)
17%	Face-to-face (individual)
16%	YouTube videos
16%	Apps
12%	Podcasts
12%	Face-to-face (group)
6%	Webinars

Accessing diabetes product subsidised through the NDSS

31% (739) of respondents had experienced problems in the past 12 months accessing NDSS products through their local pharmacy (Access Points).

Preferred ways to connect with other young people

Respondents were able to choose their top 3 options from a possible 9 options

94%	**Facebook**
81%	**Instagram**
66%	**Phone call/ text messaging**
51%	**Peer support group (face-to-face)**
51%	**Peer support group (online)**

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The NDSS is administered by Diabetes Australia

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Our voices, our lives, our choices summary 2020

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Technology and devices

"I have a *Freestyle Libre*. I test more often with the Libre than what I did with the meter."

"I am currently only using a CGM as it is subsidised since I just had a baby. In two months' time I will no longer have free access and won't be able to afford it."

"I moved from pens to an insulin pump just over a year ago and my control is exponentially better, insulin pumps take a lot of guesswork out of dosing and make it a lot easier to control."

Key opportunities

The following nine key opportunities have been developed based on the results of the national survey, interviews conducted, and consultations with people living with diabetes and healthcare professionals.

Key opportunity 1

Continue to support the need of young people with type 1 diabetes for information and resources about CGM and CGM devices.

Key opportunity 2

Improve access to subsidised NDSS products by providing information and resources to pharmacies about the products and the ordering processes.

Key opportunity 3

Expand NDSS Helpline access to accommodate young people connecting to diabetes healthcare professionals.

Key opportunity 4

Provide opportunities for young people to connect with diabetes related mental health support.

Key opportunity 5

Assist young people with type 1 diabetes to meet and support others.

Key opportunity 6

Enhance NDSS connections with young people to ensure offerings are developed and evaluated with them.

Key opportunity 7

Include young people in the development of campaigns and share on platforms they prefer to use.

Key opportunity 8

Deliver NDSS educational materials via methods preferred by young people.

Key opportunity 9

Provide information to young people about diabetes research and clinical trial opportunities.

Disclaimer: *Key opportunities have been adapted for this document from the *Our voices, our lives, our choices* report.

Developed in consultation with people with diabetes.

NDSS *Our voices, our lives, our choices* summary 2020 is part of the NDSS Youth and Youth Transition Project.
This project engaged young people with type 1 diabetes to guide the delivery, development and design of this summary.
Illustrations by Zahra Zainal
NDSSA3BF011
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