

# BMJ Open Mapping care provision for type 1 diabetes throughout Australia: a protocol for a mixed-method study

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## ABSTRACT

**Introduction** Type 1 diabetes (T1D) is a chronic and incurable autoimmune disease, diagnosed in early childhood and managed initially in paediatric healthcare services. In many countries, including Australia, national audit data suggest that management and care of T1D, and consequently glycaemic control, are consistently poor. This can lead to adverse outcomes such as cardiovascular disease and nephropathy. T1D treatment is complex, multidisciplinary, multiagency and life-long and should involve patient-centred, developmentally appropriate care. Although an emerging body of literature describes T1D models of care, their components, implementation determinants and associated outcomes are poorly understood.

**Objectives** To provide a study protocol to describe methods to map existing models of care for children and young adults living with T1D. It will identify the gaps and needs in care delivery as viewed by healthcare providers and by children, young people and their families accessing care in metropolitan and rural or remote regions throughout Australia.

**Methods and analysis** A mixed-method study that includes provider and consumer-specific surveys and interviews about current T1D care provisions. Data will be analysed thematically (qualitative) and statistically (quantitative) and synthesised to describe the key characteristics of effective and sustainable models of care for T1D and to identify gaps.

**Ethics and dissemination** Ethics approval was granted by the Macquarie University Human Research Ethics Committee in July 2022 (#520221154439676). Results will be disseminated via publication in peer-reviewed journals and at relevant conferences.

## BACKGROUND AND RATIONALE

Type 1 diabetes (T1D) is a chronic and incurable autoimmune disease that presents in early childhood and affects more than one million young people worldwide.<sup>1</sup> In many countries, including Australia, national audit data suggest that management and care of T1D are consistently poor, possibly leading to adverse impacts such as diabetic ketoacidosis and long-term effects including cardiovascular

## STRENGTHS AND LIMITATIONS OF THIS STUDY

- ⇒ This is the first national study to describe existing models of care for type 1 diabetes currently operating in Australia.
- ⇒ The study design was developed in collaboration with the healthcare providers working with, and individuals living with, type 1 diabetes.
- ⇒ The mixed-method approach will enable a rich synthesis of data from multiple sources.
- ⇒ The outcomes will support consultations with clinicians, hospital and health service executives, policy-makers and individuals and their families.
- ⇒ The survey questions may not capture service characteristics and participant experiences and needs outside of Australia, which may limit generalisability.

disease and nephropathy.<sup>2–3</sup> Critically, no change in mortality has been reported in recent years, and cardiovascular disease risk is strongly correlated with duration of T1D and therefore problematic for those diagnosed at a young age.<sup>4–6</sup> Children and adolescents with T1D have a reduced life expectancy of approximately 12–16 years.<sup>7–8</sup> An important modifiable factor to reduce these risks is maintaining optimal glycaemic control.<sup>9</sup>

Although individuals understand the importance of good glycaemic control, registries show that around 85% fail to achieve recommended glycaemic targets.<sup>10–11</sup> Additionally, the transition from paediatric to adult care is difficult to navigate, and treatment adherence rates reduce significantly due to competing life stressors such as higher education, career and social demands.<sup>12</sup>

Globally, despite standardised international guidelines, T1D management and outcomes among individuals, clinics, jurisdictions and countries vary significantly. This highlights the complexity of the condition, where clinical outcomes for people with T1D have failed to improve as much as expected with major advances in insulin delivery and technology.<sup>10</sup>



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Some observers suggest that failures in the translation of successful interventions into practice and in the implementation of comprehensive and sustainable models of care may contribute to these findings.<sup>13 14</sup>

Managing T1D is complex because its management on individual and population levels has multiple interactions and consequences. Individuals living with diabetes do so within families, the immediate community, and wider society. Models of care do not always adopt this broad view. Successful solutions need to consider the complexity of the socioecological system in which the individual lives, in addition to their medical condition.<sup>15</sup>

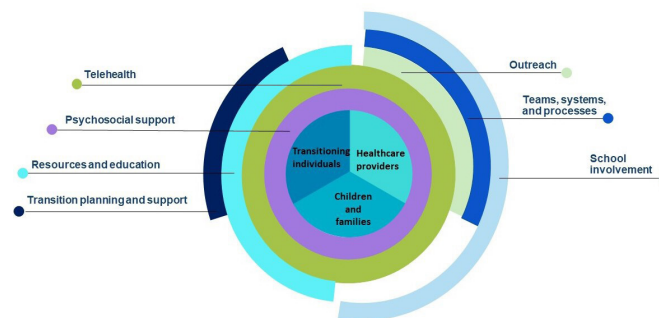
Our group have undertaken a scoping review of the literature to examine the evidence for T1D models of care. Some studies reported healthcare and psychosocial benefits for models that involved structured education programmes,<sup>16 17</sup> multidisciplinary teams<sup>18 19</sup> and capacity building for self-care.<sup>20 21</sup> We identified a significant gap in the literature: few studies addressed the implementation drivers or applied a guiding theoretical framework at the provider or health system level.

This study is part of an international collaboration to advance T1D care. In 2021, the Rio Tinto Children's Diabetes Centre; a JDRF Centre of Global Excellence, commenced with the following three objectives: (1) to formulate a framework to develop, implement and evaluate models of care that lead to improved health outcomes and reduced burden for young people living with T1D, (2) to promote effective transfer of research outcomes into health policy and/or practice and (3) to develop novel advanced economic frameworks that include the broad true costs of T1D to enhance access to novel therapies and shape policies.

This protocol describes the project that will address objective (1). It will scope and map the provision of paediatric and transitional T1D care and investigate model scope, components and resourcing of services in Australia. We will review clinics and currently implemented T1D models of care using a mixed-method approach to comprehensively describe the key model components and to identify gaps, strengths and context-informed barriers and enablers to implementation. Findings will inform the future improvement of healthcare in T1D.

## OBJECTIVES

The overall goals of this research are to map the current models of care for T1D and to formulate a framework to develop, implement and evaluate optimal models of care that lead to improved health outcomes and reduced burden of care for children and young people living with T1D and their families. To achieve this aim, the domains underpinning the provision of T1D care will be assessed on three levels: healthcare providers, children and their families, and young people who are transitioning from paediatric to adult services, using two methods of data collection (figure 1).



**Figure 1** Domains to be assessed through surveys and consultations.

Understanding what models of care have been implemented for T1D nationally will support a series of consultations with clinicians, managers, policy-makers, families and young people living with T1D. Ultimately, we will identify adaptable models and trial these in different contexts in a future project. The core aim is to codesign novel, personalised and integrated models of care that are fit for purpose and can be tested in the future.

## METHODS AND ANALYSIS

### Study design

This mixed-method, cross-sectional research consists of surveys and interviews with healthcare providers, children living with T1D and their families, and emerging adults. The design comprises collections of providers' and individuals' data gathered via surveys, including demographic information and specific questions about the provision of T1D care. Each survey was designed in collaboration with healthcare providers (endocrinologists), parents caring for a child with T1D, and emerging adults living with T1D. Qualitative interviews will be conducted to enable in-depth exploration of the information available through surveys, providing a more nuanced and comprehensive understanding of current models, needs, gaps, barriers and enablers experienced at the provider, consumer and system levels. Together, these methods of data collection will facilitate a thorough exploration of various domains to map current service provision for T1D in diverse contexts in Australia (figure 1).

### Quantitative methodology

Three online deidentified surveys will be widely distributed to three groups of participants throughout Australia using the REDCap platform,<sup>22</sup> which is hosted by Macquarie University: (1) healthcare providers who offer services for T1D, (2) children and families living with T1D and (3) emerging adults living with T1D who are transitioning or have recently transitioned from paediatric to adult care (transition group). Participants will have the option to indicate if they would like to take part in qualitative interviews.

### Qualitative methodology

We will invite participants who indicate an interest during the survey to participate in interviews where they will be asked a series of open-ended questions that will be designed based on the survey results. The purpose of these interviews is to expand on areas of interest and verify the findings from the questionnaire data. Interviews will be audio recorded and are expected to last approximately 45–60 min. The interview script commences with ‘Can you please elaborate on what you think is meant by ...’ and is deliberately open ended to allow participants to freely express their views.

### Study setting

The preference is to conduct interviews in person; however, we will also offer to conduct them electronically via Zoom meeting software due to participants’ locations and other commitments and the COVID-19 pandemic. We will follow all local health guidelines in terms of social distancing when conducting interviews in person. When interviews are conducted electronically, the researcher conducting the interviews will adhere to the following measures to always ensure security, as outlined by Macquarie University:

1. Enable waiting room (for all interview guests).
2. Enable meeting passwords.
3. Not share the Zoom link or code on social media or any public website.
4. Set screen sharing to ‘host’ only.
5. Turn off the annotation feature if not needed.
6. Restrict other features as needed in host controls.

### Length of study

We anticipate 12–24 months of data collection, followed by six months to prepare publications and disseminate findings.

### Study participants and recruitment

For providers, all T1D services across Australia will be approached. These services will be identified through the Australian Paediatric Endocrinology Group (APEG) and through the network of clinical chief investigators on the JDRF grant. It is anticipated that approximately 3–4 services will respond in the larger states and 1–2 services to respond from the smaller states and territories, for a total sample of 16–24 services.

Children, families and young people will be recruited through the clinical services as well as the National Diabetes Services Scheme (NDSS), which registered 4090 people with T1D over a 12-month period before September 2022.<sup>23</sup> In addition, we will recruit through Diabetes Australia and JDRF Australia including their newsletter subscribers and social media networks; and snowball effect social media, newsletters and flyers. We will turn comments and tagging off on the Facebook posts. Emails will be distributed via the existing networks of JDRF, Diabetes Australia and the Australasian Diabetic Data Network.

A sample of approximately 400 children/families and another sample of 400 young people (16–25 years) is expected to ensure geographical representation across the 8 states and territories of Australia. This number is considered adequate based on previous research in a similar context<sup>24</sup> and takes into consideration participant loss to follow-up.

Regarding recruitment for interviews the aim is to recruit 12–24 participants from each of the three participant groups (providers, children and families, and young adults). Purposive sampling will be used to ensure broad representation across geography, socioeconomic status (based on the Australian Bureau of Statistics, Index of Relative Indexes for Areas; ABS IRSAD), ethnicity and age. Based on experience of the authors and according to Braun and Clark (2021),<sup>25</sup> data saturation is likely to be reached; however, if new themes continue to emerge, additional participants will be recruited and interviewed.

The nature of the Australian population ensures that people from Aboriginal and/or Torres Strait Islander and culturally and linguistically diverse (CALD) backgrounds will be recruited if their English language skills are sufficient to complete the survey. We recently conducted a population-based study where the survey was offered in English, with >5000 respondents; 11% identified as Aboriginal and/or Torres Strait Islander and 25% were from CALD backgrounds, suggesting that appropriate representation is possible.<sup>26</sup>

For those accessing the research invitations electronically (via email or Facebook ads), the invitations will include a link to each of the surveys hosted on the RedCap platform at Macquarie University in Australia. The surveys are attached as online supplemental files 1–3 and the interview script can be found as online supplemental file 4. Participants will have the opportunity to contact the study investigators via email or phone for more information about the study. Participants will be informed that their experiences are very valuable, but they are not obliged to disclose personal details if they do not wish to.

### Inclusion criteria

Providers must provide T1D services in Australia. This will include, but is not limited to, paediatric and adult endocrinologists, nurse practitioners, clinical nurse consultants, diabetes educators, nutritionists, social workers and psychologists. Families must have a parent or carer of a child with T1D. A second adult family member or carer is also welcome to participate. The transitional group participants must have started or completed a transition to adult T1D care. They may include a family member if they desire.

### Reimbursement

Participants in the family and transitional groups will be offered payment in line with the New South Wales recommended remuneration for health consumers for participating in interviews as part of the project. Providers will

receive no financial reimbursement for survey completion or interviews.

### Data collection

Data in this project will include demographic information and experiences with T1D and qualitative interview data. Demographic data and experiences with T1D will be captured using REDCap. Qualitative data from interviews with consenting participants will be audio recorded and transcribed and last approximately 45–60 min. Adults in the family groups will be interviewed individually before children and young people (8–16 years) and then a family interview will be conducted with all consenting family members together. To ensure the questions for the children's interview schedule are sensitive, informed and insightful, children's interviews will take place after interviews with parents to seek guidance on how to conduct the children's interviews to facilitate their understanding and help judge how to conduct the interview.

Member checking or providing participants with an opportunity to review or edit their responses is not a common practice in qualitative research and will not be considered as part of this research study. Such practice is more common for studies where a misunderstanding of the study topic/interview is likely; however, we do not envisage this occurring in this study.

### Data analyses

The quantitative data that includes demographic and health-related data from the surveys will be analysed using SPSS V.22.0.<sup>27</sup> This analysis will include the frequency distribution of different components of services across Australia. For example, health professionals who contribute to a multidisciplinary team. Two members of the research team using an open coding process by NVivo<sup>28</sup> will independently analyse the qualitative data thematically. Themes will be extracted that characterise the provisions of T1D care for providers and consumers.

### Synthesis and integration of results

The literature review findings will highlight the barriers and enablers of existing global models of care. These findings will be compared with the outcomes from the surveys and interviews about models of care throughout Australia. Additionally, these results will be compared with barriers and enablers of existing global models of care, and a national or international clinical practice guidelines and recommendations regarding delivery of T1D care. For example, guidelines published by the APEG or the International Society for Pediatric and Adolescent Diabetes. Together these findings will be synthesised and integrated to describe the characteristics of an effective and sustainable T1D model of care.

### Patient and public involvement

Patients or participants will be directly involved in the current study.

## DISCUSSION

This research seeks to map the provision of care for T1D healthcare providers and young individuals living with T1D. We will undertake a survey and review of clinics and models of care for T1D using a mixed-method approach. This will involve considering various domains and the complexity of the socioecological system in which the individual lives. Given that morbidity has remained unchanged in young people and cardiovascular disease risk is strongly correlated with the duration of diabetes age at onset of T1D,<sup>6</sup> evaluating the current status of delivery of diabetes care in Australia is crucial for identifying gaps and addressing barriers. This can be achieved by utilising a conceptual framework such as the Consolidated Framework for Implementation Research.<sup>29</sup> The Consolidated Framework for Implementation Research provides a theoretical lens to understand the process of introducing and managing new models of care within a complex healthcare system.<sup>29</sup> We will gain a deeper understanding of the factors that help or hinder implementation in different settings,<sup>30</sup> allowing for personalised, integrated models of care that are fit for purpose.

The limitations of this study may include the following factors: the survey questions may not accurately capture findings of all participants and may not be generalisable to countries outside of Australia. A risk of selection bias towards those who are included in NDSS, subscribe to diabetes networks newsletters and social media also exists. Although we are making every effort to capture diversity across Australia, our research may not be inclusive of all areas and groups as surveys and interviews will be conducted in English.

### Expected outcomes

This research will determine the key drivers and characteristics of an effective and sustainable model of care for young people. Adopting an evidence-based approach, we will map the current models of care for T1D within Australian and identify sustainable models of care that integrate and implement new knowledge and technologies to achieve person-centred care. Ultimately, the outcomes will advance the understanding of how to reduce the morbidity and mortality of T1D and its burden on children, their families, the health service and the community.

## ETHICS AND DISSEMINATION

### Consent

No known health or safety risks are associated with participation in any aspect of the described study. Ethics approval for conducting the study was obtained from Macquarie University Human Research Ethics (# 520221154439676). The results will be actively disseminated through peer-reviewed journals, conference presentations and reports to stakeholders.

Should a survey participant decide not to complete the survey, or decline to answer some questions, their

submitted data may still be used in the analysis. Should a participant withdraw from an interview, or withdraw their consent after the interview, their data will not be used as part of the formal analysis. We do not anticipate participant withdrawal having any impact on the study; however, should it occur, some modification of results may occur.

### Managing risk/distress

Children and/or young people will have an adult family member present in the same location during the individual interviews to ensure they feel safe and supported by a familiar adult. Interview techniques will be used appropriately, according to age, and data anonymity and confidentiality will be upheld throughout. Interview questions will be crafted and presented according to the age of the person being interviewed, their disease state and their cognitive status.

Participants will be informed as part of the survey by interview participant information and consent forms (PICF) that potential for distress exists as the questions relate to issues around healthcare. They will be informed that they do not have to answer any question that makes them feel uncomfortable and that they are able to stop at any time. If participants do become distressed, researchers will be able to arrange for free counselling or other support. The research team will refer distressed participants to appropriate mental health services.

The lead investigator will also ensure all participants are aware of the duty of care to appropriately manage any clinical concerns that may arise and will use her clinical judgement and prior research experience with families facing challenges because of complex parental illness to provide up-to-date information on accessing support opportunities. Clinicians involved as associate investigators on this study and senior academics from Macquarie University will be available to offer the researcher and families involved expert advice and guidance if required.

Survey respondents will need to read and electronically agree to consent before proceeding to the survey. Interview participants will be sent, or provided with, the PICF before the interview and asked to provide informed verbal consent before the interview begins. All participants over the age of 18 years will be able to provide verbal informed consent. Those under the age of 18 years will be required to give verbal consent, and their parent or carer must also provide consent. Participants will also be reminded that participation is voluntary, that they do not have to answer any question they do not wish to, and they can revoke their consent at any time during the study. The research team will also explain and clarify that participation or refusal to participate will remain unknown to others outside of the study and will not affect their employment or future healthcare treatment.

### Confidentiality

The study protocol, materials and all data will be stored in password-protected electronic files. Once the potential participants have been contacted for the interviews, all

data will be de-identified with a study code assigned. All participants will be advised that any information shared that by law must be disclosed to a relevant authority will not be kept confidential.

In this project, audio recordings of interviews will be made. This is so qualitative data can be accurately analysed. Once transcriptions of audio recordings have been made, audio recordings will be destroyed. All data relating to this research project will be destroyed after a 5-year storage period. This is in line with General Retention and Disposal Authority University Records (GDA 23) (2005) and the Australian Code for the Responsible Conduct of Research (2007) requirements. All identifying information in typed transcripts will be edited to protect participant anonymity. A reidentification key/code will be securely stored elsewhere, as will participant consent forms. All data presented in publications and reports that arise from this research will only include deidentified data. Only Macquarie University researchers involved in this project will have access to identifiable data, following relevant Macquarie University ethics clearances. All results will be distributed in a deidentified manner. This research will not disseminate findings that could foreseeably cause harm or embarrassment to participants.

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**Contributors** YZ, ED, TJ, SZ, TH, JC, DB and JB conceptualised the study. AC, YZ, RL, ED, TJ and JB contributed to the design of the study. AC drafted the first iteration of the manuscript. All authors contributed to manuscript revisions and refinement and approved the final manuscript.

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**Competing interests** None declared.

**Patient and public involvement** Patients and/or the public were involved in the design, or conduct, or reporting, or dissemination plans of this research. Refer to the Methods section for further details.

**Patient consent for publication** Not applicable.

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Confidential

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# Healthcare Provider Survey

Participant Information and Consent Form  
Chief Investigator: Associate Professor Yvonne Zurynski  
Email: Yvonne.Zurynski@mq.edu.au  
Project Title: Investigating T1D Models of Care, Implementation Science and Research Translation  
Funding Body: Juvenile Diabetes Research Fund  
HREC Reference: 11544  
Chief Investigator: Associate Professor Yvonne Zurynski  
Co Investigators:  
Dr Ann Carrigan  
Professor Elizabeth Davis  
Professor Tim Jones  
Professor Sophia Zoungas  
Associate Professor Tony Huynh  
Professor Jenny Crouper  
Professor Jeffrey Braithwaite  
Ms Rebecca Lake  
Ms Leanne Cromb  
Ms Sophie Lumby

We ask that the most senior person from the service complete the survey, such as the clinical lead. You will have the options to save your responses and return at a later stage if required to.

You are invited to participate in this study exploring existing models of care for children and young people living with Type 1 Diabetes in Australia. This research will scope and map the services currently available for the management of T1D, including transitional care as young people move from paediatric to adult health services. By investigating model components, barriers and enablers, and resourcing of services in Australia - the research will guide future improvements to these healthcare services.

This survey focuses predominantly on Type 1 diabetes services. There are questions specific to Type 2 diabetes at the end of the survey.

The study is being conducted by Associate Professor Yvonne Zurynski and Dr Ann Carrigan from the Australian Institute of Health Innovation at Macquarie University. If you have any questions please contact Dr Ann Carrigan (phone: 0414692204 email: ann.carrigan@mq.edu.au). The research project has been funded by the Juvenile Diabetes Research Fund Global Centre of Research Excellence in Diabetes Research.

As a healthcare provider you are being invited to participate in this survey, which should take no longer than 45 minutes to complete. Participation in this study is entirely voluntary: you are not obliged to participate and if you decide to participate, you are free to withdraw at any time. Information about your service will be confidential and de-identified and no information which is published or shared will identify you or your service in any way. Services will be identified by location (metro/rural) and whether hospital based, inpatients or outpatients or private clinic/rooms based. Your responses will only be used for the purpose of this research project and they will only be disclosed with your permission, except as required by law.

At the end of the survey, you will be asked if you would like to be part of a team reviewing the findings and developing a manuscript.

At the end of the survey you may elect to enter a draw to win a \$200 Booktopia voucher as a thank you for your participation.

A summary of the report after analysis and published papers can be provided after the research has concluded, if requested.

If you agree to participate, please select "I accept" below to continue to the survey.

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I have read and understood the above information, and any questions I have asked have been answered to my satisfaction. I agree to participate in this research, knowing that I can withdraw from participation in the research at any time without consequence.

- I accept  
 I do not accept

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- 
1. How would you describe your clinical role?
- General paediatrician
  - Paediatrician with special interest in T1 diabetes
  - Paediatrician with special interest in T1 diabetes and endocrinology
  - Paediatric diabetologist or endocrinologist
  - Adult endocrinologist consultant
  - Adult endocrinologist fellow
  - Adult endocrinologist registrar
  - Diabetes nurse practitioner
  - Diabetes nurse
  - Diabetes educator
  - Community nurse
  - Dietician
  - Psychologist
  - Exercise physiologist
  - GP (if linked to a paediatric diabetes team)
  - Other (please specify below)
- 

1a. If you selected "other" above, please enter your profession here.

---

- 
2. What is your age?
- < 31
  - 31-35
  - 36-40
  - 41-45
  - 46-50
  - 51-55
  - 56-60
  - >61
- 

3. What is your sex?
- Male
  - Female
  - Other/ Prefer not to say
- 

4. What is the location or postcode of your clinic?

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**The following questions are meant to determine details of routine Type 1 diabetes care services offered by your service.**

4a. In what setting(s) does your service see children or young adults with Type 1 diabetes? (select all that apply)

- Young adult diabetes service
- Paediatric diabetes outpatient clinic
- Paediatric inpatients in a paediatric hospital
- Paediatric inpatients in a general hospital
- General diabetes outpatient clinic in an adult hospital
- Community outreach outpatient clinic
- Large regional clinic (and inpatient setting)
- Rural clinic
- Private clinic
- In patient's home
- Other, please specify below

4b. If the location at which you treat children and young people with T1D was not listed above, please specify here.

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5. How often do you usually see your T1D patients per year in a formal clinic?

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**The following questions ask about your clinics' patient numbers and whether you share care with other services. Estimates are fine.**

6. Please estimate how many children and young people with T1D are seen each year in your service?

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7. What proportion of patients seen by your service are co-managed with other services? For example, GPs. (Please enter a percentage)

- 0-10%  
 10-20%  
 20-30%  
 30-40%  
 40-50%  
 50-60%  
 60-70%  
 70-80%  
 80-90%  
 90-100%

8. When patients come to the service, if they see the doctor, on average how long do they spend with them?

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9. When patients come to the service, if they see the diabetes nurse, on average how much time do they spend with them?

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10. When patients come to the service, if they see the dietician, on average how much time do they spend with them?

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11. When patients come to the service, if they see the diabetes educator, on average how much time do they spend with them?

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12. Are interpreter services available on-site in your clinic?

- Yes  
 No  
 Don't know

12a. Why not?

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13. Does the service offer children and young people with Type 1 diabetes and their families out-of-hours access (e.g., an advice line staffed by a member of the diabetes care team)?

- Yes  
 No  
 Don't know

13a. Please briefly describe the out-of-hours access that the service provides and who operates this service.

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13b. Why not?

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14. Do patients with T1D have access, if needed, to all team members at a clinic visit?

- Yes  
 No  
 Don't know

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14a. Why not?

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15. Does the service deliver care for T1D in other locations in addition to the main clinic, e.g. outreach clinics in rural regions or interstate?

Yes  
 No  
 Don't know

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15a. What is/are the name of the town/s where the clinic is held?

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15b. How regularly does your service conduct these in these locations?

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15c. Does the outreach clinic have a specific focus on complex cases of T1D?

Yes  
 No  
 Don't know

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15d. What is the total number of T1D patients seen per annum in the outreach service? (Estimates are fine)

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15e. Do you have access to a specialist team when needed if you are a regional service?

Yes  
 No  
 Don't know

---

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16. How many newly diagnosed T1D patients does your service educate at diagnosis and then return to their local area for follow up, per annum?

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17. In terms of population, how large is your catchment area? (e.g. state-wide service, Local Health District or Network, specific local region)

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**18. Who is routinely available in your diabetes service or via referral?**

	Allocated to your service full time (clinical staff)	Allocated to your service part time or casual	Need to refer out?	Not available / accessible
Endocrinologist	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Paediatric Endocrinologist	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Fellows/Registrars	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Hospital Nurse Practitioners	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Clinical Nurse Consultants	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Clinical Nurse Specialists	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Community Nurse Practitioners	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Podiatrist	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Orthodontist	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Psychologist	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Dietitian	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Social Workers	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Exercise physiologist	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Physiotherapist	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
General paediatrician	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

19. Do you try to ensure that your T1D patients see the same clinical team at each visit?

- Yes, always  
 Yes, when possible  
 No

20. Does your service link-in with the local Primary Health Network?

- Yes  
 No  
 Don't know

20a. How is your service linked to the Primary Health Network?

- Provide educational opportunities for GPs  
 Hold regular interdisciplinary meetings  
 We have a GP Health Pathway for T1D  
 Other (please specify below)

20b. Other (please specify)

\_\_\_\_\_

21. How does your service communicate with patients GPs?

- Regular letter from OPD and a discharge summary for admissions  
 Joint consult with GPs or regular/meetings/phone calls  
 No regular contact  
 Other (please specify)

21a. Please specify other ways that your service communicates with patient's GP?

\_\_\_\_\_

22. Do you offer T1D services specifically designed for the following populations? (Select all that apply)

- Rural and remote communities  
 Aboriginal and Torres Strait Island peoples  
 Pacifica  
 Culturally and linguistically diverse  
 Other (Please specify) below  
 None

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22a. Other (please specify)

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23. Does the Type 1 diabetes team liaise regularly with school staff who supervise children and young people to offer diabetes education and information?

Yes  
 No  
 Don't know

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23a. If your service does not liaise regularly with school staff, why not?

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24. Do you have access to the funded Diabetes Australia 'Diabetes In Schools' program?

Yes  
 No  
 Don't know

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24a. Why not?

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25. Do you use the Diabetes Australia 'Diabetes In Schools' program?

Yes  
 No  
 Don't know

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26. Does your service offer patient reported experience measures (PREMs)?

Yes  
 No  
 Don't know

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26a. Which PREMS does your service measure?

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27. Does your service offer patient reported outcome measures (PROMs)?

Yes  
 No  
 Don't know

---

27a. Which PROMS does your service measure?

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**The next set of questions asks about the use of telehealth in your service pre and post COVID.**

28. Pre-COVID, did your service use telehealth to conduct T1D consultations with patients / families? (select all that apply)

- Yes, mainly video consultations  
 Yes, mainly telephone consultations  
 Yes, we used video and telephone equally  
 Yes, we sometimes used a hybrid of telehealth and face to face (e.g., the patient is face-to-face but their GP or another health professional is online or on the phone)  
 No, we did not use telehealth

29. Currently, as part of your routine T1D care, on average across clinics, does your service use any of the following telehealth services to conduct consultations?

- Video consultations  
 Telephone consultations  
 Hybrid of video and telephone consultations  
 No, Face-to-face only

29a. Currently, as part of routine T1D care, on average across clinics, what proportion of consultations in your service are video consultations? (Please enter a percentage)

- 0-10%  
 10-20%  
 20-30%  
 30-40%  
 40-50%  
 50-60%  
 60-70%  
 70-80%  
 80-90%  
 90-100%

29b. Currently, as part of routine T1D care, on average across clinics, what proportion of consultations in your service are telephone consultations? (please enter a percentage)

- 0-10%  
 10-20%  
 20-30%  
 30-40%  
 40-50%  
 50-60%  
 60-70%  
 70-80%  
 80-90%  
 90-100%

29c. Currently, as part of routine T1D care, on average across clinics, what proportion of consultations in your service are telehealth as opposed to face-to-face? (please enter a percentage)

- 0-10%  
 10-20%  
 20-30%  
 30-40%  
 40-50%  
 50-60%  
 60-70%  
 70-80%  
 80-90%  
 90-100%

30. Please comment on the perceived advantages and disadvantages of using face- to-face and/or telehealth consultations

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31. Under what circumstances would you typically use telehealth for T1D care? (Select all that apply)

- Accessibility issues for patient or family (mobility problems or other disability)
- COVID-19 or another infectious disease
- Immunocompromised patient or family
- Rural/remote family location
- The family cannot access transport
- Out of hours services only
- Government recommendation
- Never use telehealth
- Other (please specify below)

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31a. Under what circumstances would you use telehealth? (Other)

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**Psychological support**

32. Do you have a dedicated internal psychologist on site as part of your service?

- Yes  
 No  
 Don't know

32a. What is the average waiting time to see the psychologist in your service?

\_\_\_\_\_

32b. What is the average waiting time for patients to see a mental health professional that you refer them to?

\_\_\_\_\_

32c. If there is no dedicated internal psychologist as part of the service, to whom are mental health referrals made? (Select all that apply)

- Clinical psychologist  
 Health psychologist  
 Psychotherapist  
 Psychiatrist  
 Counsellor  
 Mental health nurse  
 Social worker  
 Family therapist  
 Other (please specify below)

32d. Other (please specify)

\_\_\_\_\_



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**33. For what reasons do you refer patients to a psychologist?**

	Yes	No	I would if the service was available
Problems with self-management	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Recurrent DKA	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Low BMI	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Eating disorders (bingeing, bulimia, anorexia)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Disordered eating (e.g. skipping meals)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Body dysmorphia	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Morbid obesity	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Depression	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Needle phobia	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Anxiety	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Drug and alcohol problems	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Psychotic illnesses	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Psychosexual health	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Domestic violence and/or sexual abuse	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Suicidal thoughts or self harm	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Family stress or trauma	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Communication problems with the family/team	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Poor diabetes adjustment	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

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### 34. What protocols does the service follow for children and young people with Type 1 diabetes in the following situations? (Select all that apply)

	Our own locally developed	State based protocols e.g. from the Department of Health	National	Aligned with APEG
Diabetic ketoacidosis	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Hypoglycaemia	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Surgery	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Sick day management	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Diabetes complications assessment management	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Diabetes and exercise management for those on MDI and pumps	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Insulin pump and CGM usage protocols	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Diabetes in schools	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

35. If you use your own locally developed management protocols, are these? (Select all that apply)

- Local to your service
- Hospital-wide protocol
- Local health district/network
- State-wide protocol
- Does not apply

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**Diagnosis and initial management**

36. Does your service use electronic medical records?  Yes  
 No  
 Don't know

36a. Do all staff use the electronic medical records to make notes and store information on consultations and plans?  Yes  
 No  
 Don't know

36b. If not all staff, which staff use the electronic medical records?  Doctors  
 Nurses  
 Allied health professionals  
 Administrative staff

37. Does your service routinely enrol patients into a Type 1 diabetes registry?  Yes  
 No  
 Don't know

37a. Which diabetes registry does your service enrol patients into? (select all that apply)  Local  
 ADDN  
 SWEET  
 Other (please specify)

37b. Other (please specify)

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**Management from diagnosis**

38. Does the service develop Type 1 diabetes management plans or shared care plans?

Yes  
 No  
 Don't know

38a. Who is given access to the management/ care plans? (Select all that apply)

The team of health professionals at your service  
 Health professionals to whom you refer patients  
 The patient and/or family  
 The GP  
 The school  
 Other (please specify below)

38b. Other (please specify)

\_\_\_\_\_

39. If the plan is shared with the patient and/or family, how is this done? (Select all that apply)

Through a web portal or app  
 By email  
 Through MyHealthRecord  
 Printed and faxed/posted  
 Care plans are not shared  
 Other (please specify)

39a. Other (please specify)

\_\_\_\_\_

40. Are children and young adults newly diagnosed with Type 1 diabetes offered a structured diabetes education program?

Yes  
 No  
 Don't know

40a. Please provide details of structured education program

\_\_\_\_\_

40b. Why aren't children and young adults offered a structured diabetes education program?

\_\_\_\_\_

41. When do newly diagnosed T1D patients in your service usually commence on CGM?

The first week  
 Within the first 2 weeks  
 2 weeks to 3 months  
 After 3 months  
 It is up to the family

42. Are patients and/or families offered a choice of the CGM when first commenced?

Yes  
 No  
 Don't know

42a. Why aren't families offered choice of the CGM when first commenced?

\_\_\_\_\_

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43. Where do most children and young adults receive care at the time of their T1D diagnosis? (Select all that apply)

- At home  
 As an inpatient  
 As an inpatient until they have insulin injection, BGL monitoring and hypoglycaemia management, then OPD education  
 In ICU (DKA)  
 In ICU (not DKA)  
 Outpatient clinic  
 Community Health Service

43a. How many days on average are they an inpatient? (Enter number of days)

\_\_\_\_\_

44. Are patients and families routinely advised on how to obtain information about the following? (Select all that apply)

- Accessing NDSS  
 Health care card means tested Diabetes allowance  
 Medicare  
 Government subsidies - means tested Diabetes allowance  
 Government subsidies - means tested carers allowance  
 Government subsidies - essential medical equipment payment  
 Housing allowance  
 University entrance exam special conditions  
 Driver's license sign-off  
 Other (please specify below)

44a. Other (please specify)

\_\_\_\_\_

45. Are children and young people offered information and contact details of local T1D support groups?

- Yes  
 No  
 Don't know

45a. Why not?

\_\_\_\_\_

45b. Are the support groups accessible:

- Online or via social media  
 In person  
 Both  
 Don't know

46. Does the service offer children and young people with T1D and their families access to mobile health information technology from the diabetes care team?

- Yes  
 No  
 Don't know

46a. Which ones? (select all that apply)

- Apps  
 Text messages  
 Other (please specify below)

46b. Which apps do you use?

\_\_\_\_\_

46c. Why not?

\_\_\_\_\_

46d. Other (please specify)

\_\_\_\_\_

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**Ongoing diabetes care**

47. Does your service offer any of the following education sessions or programs for T1D patients/families? Note this is not for initial diagnosis, but for ongoing care. (Select all that apply)

- Diabetes and exercise
- Diabetes and transition to adult services
- Diabetes and smoking
- Drugs and alcohol
- Diabetes and driving
- Diabetes and pregnancy
- Diabetes and Sick day management
- Diabetes technologies
- Insulin adjustment
- Nutrition and carbohydrate counting
- Pre-school to school transition preparation
- Preparation for Schoolies and independent travel
- No education sessions or programs are offered
- We use programs offered by other organisations e.g. Diabetes Australia
- Other (please specify)

47a. Other (please specify)

\_\_\_\_\_

48. Do you regularly refer T1D patients to groups that offer patient education services, information and support?

- Yes
- No
- Don't know

48a. Which groups do you regularly refer patients to? (select all that apply)

- JDRF Australia or other JDRF state specific
- Diabetes Australia or other Diabetes Australia state specific
- Our own
- Online resources (not JDRF or Diabetes Australia)
- Other (please specify)

48b. Other (please specify)

\_\_\_\_\_

49. Does your service have its own patient management resources for the following?

- Diabetes and exercise
- Diabetes and transition to adult services
- Diabetes and smoking
- Drugs and alcohol
- Diabetes and driving
- Diabetes and pregnancy
- Diabetes and Sick day management
- Diabetes technologies
- Insulin adjustment
- Nutrition and carbohydrate counting
- Pre-school to school transition preparation
- Preparation for Schoolies and independent travel
- No education sessions or programs are offered
- We use programs offered by other organisations e.g. Diabetes Australia
- Other (please specify)

49a. Would you be interested in sharing your resources with others?

- Yes
- No
- Don't know

50. Would you be interested in having access to other services and resources for your patients?

- Yes
- No
- Don't know

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51. Does your clinic undergo regular evaluations such as audits and accreditation?

- Yes  
 No  
 Don't know

---

51a. Would you be happy to share your evaluation report?

- Yes  
 No  
 Don't know

---

51b. Which health outcomes are reported and how often?

\_\_\_\_\_

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51c. Why not?

\_\_\_\_\_

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**Insulin regimens**

52. Does your service manage T1D patients with the following insulin regimens? (Select all that apply)

- 1-2 a day insulin injections  
 3 times a day insulin injections  
 Multiple daily injections  
 Continuous subcutaneous insulin infusion  
 CGM and integration with hybrid closed loop pumps  
 DIY pumps  
 None of the above

52a. Do you have a service database documenting the insulin regimen for each patient?

- Yes  
 No  
 Don't know

53. Is there a trained specialist team available to initiate insulin pump therapy?

- Yes  
 No  
 Don't know

53a. Why not?

\_\_\_\_\_

54. What percentage of children and young people in the service are using an insulin pump but not in automode/ hybrid closed loop?

\_\_\_\_\_

55. What percentage of children and young people in the service are using a hybrid closed loop?

\_\_\_\_\_

56. What percentage of children and young people in the service are using DIY looping?

\_\_\_\_\_

57. What key clinical outcomes do you routinely measure and record during consultations? (Select all that apply)

- Weight, height  
 Blood pressure (systolic/diastolic)  
 BGL readings  
 HbA1c  
 CGM glycaemic metrics eg %hypoglycaemia/ TIR/ % high, %V high, CV, other  
 Pump settings and TDD  
 Complications assessment  
 None of the above  
 Other (please specify below)

57a. Other (please specify)

\_\_\_\_\_

58. Do you routinely download the data from patient's pumps or CGMs?

- Yes  
 No  
 Don't know

58a. Do you use the downloaded data in your clinical decision making?

- Yes  
 No  
 Don't know

58b. Why not?

\_\_\_\_\_



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58c. Does your service routinely or automatically download data from patient's pumps or CGMs?

- Yes  
 No  
 Don't know

---

59. Do you have standard ISPAD and NICE guideline congruent responses provided regularly to your patients on how to respond to out-of-range readings from pumps/glucometers/CGM regarding: (Select all that apply)

- Highs on sick days  
 Regular patterns of high BGLs  
 Hypoglycaemia on sick days  
 Regular patterns of hypoglycaemia  
 Ejection from auto mode  
 Pump failure disconnection doses  
 Screening for eating disorders of DE  
 Screening for T1D complications  
 Management for exercise  
 Other (please specify below)

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59a. Other (please specify)

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**Monitoring glycaemic control**

60. What target HbA1c ranges does your service aim for in patients aged: 0-5 years?

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61. What target HbA1c, ranges does your service aim for in patients aged: 6-11 years? (mmol/ml)

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62. What target HbA1c ranges does your service aim for in patients aged: 12-18 years? (mmol/ml)

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63. What target HbA1c ranges does your service aim for in patients aged: 18 years and over? (mmol/ml)

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**Optimal time in range**

64. Do you have a clinic target for the optimal time in range for CGM across a week in patients aged: 0-5 years?

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65. What is the optimal time in range for CGM across a week in patients aged: 6-11 years in your clinic?

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66. What is the optimal time in range for CGM across a week in patients aged: 12-18 years in your clinic?

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67. What is the optimal time in range for CGM across a week in patients aged: 18+ years in your clinic?

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**Hypoglycaemia targets**

68. What is the target % Hypoglycaemia < 3.9 mmol/l on CGM in patients aged: 0-5 years in your clinic? \_\_\_\_\_

69. What is the target % Hypoglycaemia < 3.9 mmol/l on CGM in patients aged: 6-11 years in your clinic? \_\_\_\_\_

70. What is the target % Hypoglycaemia < 3.9 mmol/l on CGM in patients aged: 12-18 years in your clinic? \_\_\_\_\_

71. What is the target % Hypoglycaemia < 3.9 mmol/l on CGM in patients aged: 18+ years in your clinic? \_\_\_\_\_

72. Does your service include specific age-related glycaemic targets in the diabetes care plans and share them with patients/ families and schools?  Yes  
 No  
 Don't know

72b. Why not? \_\_\_\_\_

73. Does your service have data on how many patients reach target levels (i.e., HbA1c)?  Yes  
 No  
 Don't know

73b. Why not? \_\_\_\_\_

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**74. For patients not on CGM, how often does the service recommend children and young people test their blood glucose level?**

	Testing for twice a day injections	Testing for three times a day injections	Testing for multiple daily injections	Testing for continuous subcutaneous insulin infusion
2-3 times	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
3-4 times	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
>4 times	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

75. What percentage of patients aged 0-5 years in the service are using Continuous Glucose Monitors?

- 0-10%  
 10-20%  
 20-30%  
 30-40%  
 40-50%  
 50-60%  
 60-70%  
 70-80%  
 80-90%  
 90-100%

75b. How often do they use the CGM?

\_\_\_\_\_

76. What percentage of patients aged 6-11 years in the service are using Continuous Glucose Monitors?

- 0-10%  
 10-20%  
 20-30%  
 30-40%  
 40-50%  
 50-60%  
 60-70%  
 70-80%  
 80-90%  
 90-100%

76b. How often do they use the CGM?

\_\_\_\_\_

77. What percentage of patients aged 12-18 years in the service are using Continuous Glucose Monitors?

- 0-10%  
 10-20%  
 20-30%  
 30-40%  
 40-50%  
 50-60%  
 60-70%  
 70-80%  
 80-90%  
 90-100%

77b. How often do they use the CGM?

\_\_\_\_\_

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78. What percentage of patients aged 18+ years in the service are using Continuous Glucose Monitors?

- 0-10%  
 10-20%  
 20-30%  
 30-40%  
 40-50%  
 50-60%  
 60-70%  
 70-80%  
 80-90%  
 90-100%

---

78b. How often do they use the CGM?

---

---

79. What CGM device is being used?

---

---

80. Are patients given education/instructions on how to check and calibrate their CGM?

- Yes  
 No

---

80a. Is this done via? (Select all that apply)

- DE education session  
 Patients do it themselves online  
 Explanation during routine consultations  
 Provided with written materials / guides  
 Directed to a web resource  
 Other (please specify below)

---

80b. Other (please specify)

---

---

81. Are children and young people with HbA1c levels consistently above 9.5% offered additional support?

- Yes  
 No  
 Don't know

---

81a. What sort of support? (Select all that apply)

- More frequent visits  
 Telehealth with bloods  
 Additional social work or psychologist support  
 Ask patient to add weekly or 2 weekly CGM and pump uploads  
 Suggest going to a Diabetes Australia camp (for children only)  
 Admission for stabilisation  
 Other (please specify below)

---

81b. Other (please specify)

---

---

82. Does the service follow the Diabetes Australia guidelines for optimal targets for short-term glycaemic control (pre-prandial 4 - 8mmol/litre and less than 10 mmol/litre 2 hours post prandial) for patients aged:  
(Select all that apply)

- 0-5 years  
 6-11 years  
 12 years and over  
 18 years and over

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83. On average, what percentage of your T1D patients have HbA1c levels  $\leq$  7.0?

- 0-10%
- 10-20%
- 20-30%
- 30-40%
- 40-50%
- 50-60%
- 60-70%
- 70-80%
- 80-90%
- 90-100%

---

84. On average, what percentage of your T1D patients are on CGM?

- 0-10%
- 10-20%
- 20-30%
- 30-40%
- 40-50%
- 50-60%
- 60-70%
- 70-80%
- 80-90%
- 90-100%

---

85. On average, what percentage of your T1D patients are on twice a day (BD) insulin delivery?

- 0-10%
- 10-20%
- 20-30%
- 30-40%
- 40-50%
- 50-60%
- 60-70%
- 70-80%
- 80-90%
- 90-100%

---

86. On average, what percentage of your T1D patients are on three times a day (TDS) insulin delivery?

- 0-10%
- 10-20%
- 20-30%
- 30-40%
- 40-50%
- 50-60%
- 60-70%
- 70-80%
- 80-90%
- 90-100%

---

87. On average, what percentage of your T1D patients are on multiple daily injections or pump therapy?

- 0-10%
- 10-20%
- 20-30%
- 30-40%
- 40-50%
- 50-60%
- 60-70%
- 70-80%
- 80-90%
- 90-100%

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88. On average, what percentage of your patients are on automated insulin delivery?

- 0-10%  
 10-20%  
 20-30%  
 30-40%  
 40-50%  
 50-60%  
 60-70%  
 70-80%  
 80-90%  
 90-100%

---

89. On average, what percentage of your T1D patients have < 4mmol/l hypoglycaemia?

- 0-10%  
 10-20%  
 20-30%  
 30-40%  
 40-50%  
 50-60%  
 60-70%  
 70-80%  
 80-90%  
 90-100%

---

90. On average what percentage of your T1D patients have TIR >70%?

- 0-10%  
 10-20%  
 20-30%  
 30-40%  
 40-50%  
 50-60%  
 60-70%  
 70-80%  
 80-90%  
 90-100%

---

91. If an audit has taken place, on average, what percentage of your T1D patients get screened for complications?

- 0-10%  
 10-20%  
 20-30%  
 30-40%  
 40-50%  
 50-60%  
 60-70%  
 70-80%  
 80-90%  
 90-100%

---

92. After exclusion of coeliac disease, thyroid disorder, Addison's disease and eating disorder, do children with T1D with recurrent seizures associated with low BGLs have access to the following: (Select all that apply)

- Neuropsychological assessments  
 Screening for other disorders including psychological disorders  
 No, but I would refer if the service was available  
 No



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**Transition from paediatric to adult services**

93. At what age do you assess readiness for transition to adult services? \_\_\_\_\_

94. At what age does your service require the patient to have transitioned to an adult service? \_\_\_\_\_

95. If the patient is not ready to transition by the prescribed age, will the transition occur anyway?

Yes  
 No  
 Don't know

95a. Why? \_\_\_\_\_

96. Do you have any patients over 18 years in your service?

Yes  
 No  
 Don't know

97. Do you have a specific transition service/ program or transition pathway available to your patients?

Yes  
 No  
 Don't know

97a. Does your transition service include the following components: (Select all that apply)

Transfer referral letter to adult service only  
 Nurses in adult service meet patient before transfer  
 Transfer to GP care only  
 Structured education with acknowledgement of important knowledge bases before transition occurs  
 Structured follow-up for assessment and confirmation of retainment in the adult service  
 A young adult clinic  
 Joint clinics where the paediatric team and the adult team will see the patient at the same time  
 Group based, where a number of young people transition together as a cohort  
 It is a virtual program  
 Involves the family or other caregivers  
 Provides specific preparation and education for family or other caregivers  
 Case coordinator for each patient  
 Does the paediatric service make the first appointment for the adult service  
 A peer-mentor (or transition buddy) for each patient  
 Other components (please describe below)

97b. Other components (please describe) \_\_\_\_\_

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**Effect of the pandemic and natural disasters**

---

98. What issues do you foresee for your patients and your clinic now that we are living with COVID-19?

---

99. How have COVID-19 and the recent fires and floods influenced telehealth, telephone and face-to-face appointments in your area?

---

100. Please provide any other comments about your Type 1 Diabetes service here:

---

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**Type 2 Diabetes**

101. Does your service look after children and young people with T2D?

Yes  
 No  
 Don't know

102. Are patients with T2D seen in a separate T2D clinic at a designated time?

Yes  
 No  
 Don't know

103. Do you see patients with T2D remotely (i.e., via outreach)?

Yes  
 No  
 Don't know

104. How many patients with T2D does your service care for per annum?

\_\_\_\_\_

105. Do you have specific T2D resources for your paediatric patients?

Yes  
 No  
 Don't know

106. What percentage of these T2D patients do you provide full diabetes care to?

0-25%  
 26-50%  
 51-75%  
 76%-100%

107. Does your service provide expert advice to another healthcare professional or service for the ongoing care of patients with T2D?

Yes  
 No  
 Don't know

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**Final questions**

108. Would you be willing to be contacted for a 45-minute interview about your service? This would enable us to gain a more in-depth understanding of how your service works and to use that information to help propose new service models

- Yes  
 No

109. Would you be interested in contributing to a manuscript based on this survey? This would involve critically reviewing manuscripts.

- Yes  
 No

110. Would you like it to be acknowledged by name as a contributor to the survey?

- Yes  
 No

111. Would your service be happy to be contacted for any further surveys related to paediatric or transitional diabetes care?

- Yes  
 No

112. Do you provide data about your service to ADDN?

- Yes  
 No  
 Don't know

112a. Would you like to be contacted by someone from ADDN?

- Yes  
 No

113. Are there any services in your network that you would recommend taking this survey? If so, please provide their name and/or contact information.

\_\_\_\_\_

114. Would you like to go into the draw to win a \$200 book voucher?

- Yes  
 No

114a. To go in to the draw please provide your email address here:

\_\_\_\_\_

## **Survey for paediatrics and their families living with T1D**

### **PART A: Questions for the carers of individuals living with T1D**

#### **General demographics**

- 1. In what year was your child born?**
- 2. What is your postcode?**
- 3. What is your child's gender?**
  - Male
  - Female
  - Non-binary
  - Prefer not to answer
- 4. Was your child born in Australia? y/n**  
If no, where were they born? \_\_\_\_\_
- 5. Were their parents born in Australian? Y/N**  
If no, where were they born? \_\_\_\_\_
- 6. Are you or your child of Aboriginal or Torres Strait Islander origin?**
  - Aboriginal origin
  - Torres Strait Islander origin
  - Both Aboriginal and Torres Strait Islander origin
  - No
- 7. Do you speak any language(s) other than English at home? If so, please list below:**
- 8. How old was your child when diagnosed with T1D?**
- 9. Who lives at home with you /you and your child? select all that apply with parents / siblings/ grandparents/ housemates etc**

### **PART B: Management from diagnosis**

- 10. Was your child offered the choice of the Continuous Glucose Monitoring (CGM) when first diagnosed? Yes/no/ If no, why not?**  
If yes, how long did it take to receive CGM?
- 11. When your child was first diagnosed with type 1 diabetes, where did you receive your care? Select all that apply.**

• At home	Yes/No
• As an inpatient in a hospital	Yes/ No
• As an inpatient until have insulin injection, BGL monitoring and hypoglycaemia management, then OPD education	Yes/ No
• In ICU	Yes/No
• If inpatient initially, how many days on average are they inpatient?	Yes/No

- Outpatient clinic Yes/ No
- Community Health Service Yes/ No

**12. Were you and your child offered information and contact details of local diabetes support groups and organisations e.g. ? Yes/ No/Unsure**

If yes, which ones?

If no, why do you think you were not offered these?

**13. Were you and your child offered contact with social media support or information groups? Yes/ No/Unsure**

**14. Were you and your child offered access to mobile health information technology (e.g. apps, text messaging service) from the diabetes care team e.g. Yes/No**

If yes, tick all that apply:

- Apps (e.g., Dexcom, G6, Clarity)
- Text messages
- Other

If no, why do you think you were not offered these?

**PART C: Routine Type 1 diabetes care services**

**15. What services does your child receive for Type 1 diabetes? (Please select all that apply)**

- Health services within the public health system (Y/N)
  - Children's hospital paediatric clinic
  - Paediatric diabetes clinic in a general hospital
  - Other: \_\_\_\_\_
- Health services within the private health system Y/N
  - Private hospital clinic
  - Private specialist
- Health services provided through NDIS funding Y/N
  - Which services do you get through NDIS?
- Other services, please specify

**16. In what setting does your child receive care for type 1 diabetes? (please select all that apply)**

- Paediatric diabetes outpatient clinic
- Paediatric hospital (inpatients)
- Paediatric inpatients in a general hospital (i.e. not a paediatric hospital)
- General diabetes outpatient clinic in an adult or general hospital
- Community outreach outpatient clinic
- Regional outreach paediatric clinic
- Regional outreach paediatric clinic and inpatient setting
- Rural clinic
- Private clinic
- In your home via telehealth or visiting clinician

- Other – please specify: \_\_\_\_\_

**17. Which health professionals do you routinely see to manage your diabetes? Please tick all that apply**

Health professionals	Yes	No
Endocrinologist (diabetes doctor)		
Paediatric endocrinologist (children's diabetes doctor)		
General paediatrician		
General practitioner		
Trainee doctors		
Ophthalmologist (eye specialist)		
General nurses		
Specialist diabetes nurse		
Community nurse		
Diabetes educator		
Podiatrist (person who looks after your foot health)		
Orthotist (person who looks after your medical supportive device such as a splint)		
Psychologist		
Dietitian or nutritionist		
Social Worker		
Exercise physiologist		
Physiotherapist		
Other (specify below)		

**18. How often does your child visit the T1D clinic? (including telehealth or visiting a health professional )**

- Once per week
- Once every 3 months
- Once every 6 months
- Other

**19. Has your child ever needed health care outside of regular hours? i.e. in the evening or at the weekend? Yes/No. If yes, where did you go?**

**20. How would you rate you and your child's knowledge about how to manage their Type 1 Diabetes?**

- Excellent

- Good
- Average
- Poor
- Very poor
- Unsure

**21. How involved do you and your child feel in discussions about your healthcare?**

- Very involved
- Only occasionally involved
- I left this to my parents or carer
- I did not want to be involved
- Not involved at all
- I didn't want to be involved
- Unsure

Optional: Any further comments? (comment box)

**22. Have you and your child used telehealth with your healthcare provider?**

- Yes, mainly video consultations
- Yes, mainly telephone consultations
- Yes, we used video and telephone equally
- Yes, we sometimes used a hybrid of telehealth and face to face (e.g., the patient is face-to-face but their GP or another health professional is online or on the phone)
- No, we did not use telehealth

**23. If yes, do you and your child like using telehealth or prefer seeing someone in person?**

- I prefer telehealth
- I prefer seeing someone in person
- I have no preference

**24. Has your child ever seen someone for mental health support with respect to T1D?**

Yes/no

If yes, please tick all that apply.

Clinical psychologist	
Health psychologist	
Psychotherapist	
Psychiatrist	
Counsellor	
Mental health nurse	
Social worker	
Family therapist	
GP	
Other	

**If yes, what is the average waiting time between referral and appointment with a mental health service?**



**If yes, has your child seen a psychologist for the following?**

	Yes	No	Would do if service was available
Problems with self-management			
Recurrent DKA			
Low body mass index (BMI)			
Eating disorders (bingeing, bulimia, anorexia)			
Disordered eating (e.g. skipping meals)			
Body dysmorphia (perceived defects in your appearance)			
Overweight or obesity			+ dietitian + Physio
Depression			
Needle phobia			
Anxiety			
Drug and alcohol problems			
Psychotic illnesses			+ Mental health
Psychosexual health			
Domestic violence and/or sexual abuse			SW
Suicidal thoughts or self harm			
Family stress or trauma			+SW
Communication problems with the family			
Communication problems with the team			

**PART D: Ongoing diabetes care and support****25. Was your child offered any information about any of the following education sessions or programs? Note this is not relevant for initial diagnosis, more relevant for ongoing care**

Please tick all that apply

- Diabetes and exercise
- Diabetes and mental health
- Dietary management of diabetes
- Diabetes and transition to adult services
- Diabetes and smoking
- Drugs and alcohol
- Diabetes and driving
- Diabetes and pregnancy
- Diabetes and Sick day management
- Diabetes technologies
- Insulin adjustments
- Carbohydrate, fat or protein counting
- Pre-school to school transition preparation

- Preparation for independent travel
- Other
- No education sessions or programs are offered
- We use programs offered by other organisations e.g. Diabetes Australia

**26. Have you and your child been told about groups that offer patient education services, information and support? Yes/No**

If yes, who?

- JDRF Australia or other JDRF state specific
- Diabetes Australia or other Diabetes Australia branch in your state e.g. Diabetes NSW and ACT
- Online resources (not JDRF or Diabetes Australia)
- Your diabetes service/team
- Other: Specify \_\_\_\_\_

If no, why do you think you were not offered these?

**27. How often do you seek support from them?**

- Everyday
- Once a week
- Once a fortnight
- Once a month
- Once every 3 months
- Once every 6 months
- Once a year
- Never

**28. Was information provided to you verbally, in hardcopy or electronically?**

**Insulin treatment**

**29. Do you or your child know what the HbA1c target level is? Yes/no. If yes, what is it? (a range is ok). Drop down they can tick.**

**30. What insulin treatment does your child use currently?**

Short acting?
Long acting?
Both?

**31. What insulin therapy does your child use currently?**

1-2 times a day manual insulin injections
---

Three times a day manual insulin injections
Multiple daily injections (MDI)
Insulin pump
CGM and integration with hybrid closed loop insulin pump
DIY insulin pump
CGM integration with DIY insulin pump (looping)

**32. If your child uses an insulin pump, do you feel it has made management of your child's condition easier?** Yes/No If no, why not?

**33. Does your child use a continuous glucose monitor (CGM)?** Yes/No

If yes, Which one?

If yes, do you feel it has made management of your child's condition easier? Yes/No

If no, why not?

If no, how often do they do a finger prick blood test? (please tick all that apply)

- Before meals
- 2 hours after meals
- Around exercise
- At bedtime
- Only when they feel hypoglycaemic
- Only when they feel unwell

**34. Was your child given help on how to check and calibrate your CGM?** Yes/No

If Yes, how was this done? (tick all that apply)

- diabetes education start up session?
- Directed to an online resource?

Explanation during routine consultations

- Provided with written materials / guides
- Directed to a web resource (Please specify which one): \_\_\_\_\_
- By product manufacturer (e.g., Medtronic and Dexcom after online training)

**35. If your child does not use a continuous glucose monitor and/or an insulin pump, do you have access to this technology?** Yes/No If no, why not?

**PART E: Questions about living with type 1 diabetes and exercise****36. Is exercise discussed with a health professional when your child visits their clinic?**

Y/N; if Y, do you feel you get enough information to stay active and safe with type 1 diabetes?

**37. Does your child participate in team sports or other fitness activities? Please select all that apply.**

Activity	How often
Casually with friends	
Casually with family	
At school	
Sporting clubs in the community	
National level activity	
International level activity	

Any further comments?

**38. How many days per week does your child get at least 30 minutes of activity/exercise?****39. How many days per week does your child get at least 1 hour of activity/exercise?****40. Regarding exercise intensity, please describe your child's understanding of what moderate-to-vigorous physical activity looks like.****41. What are some barriers that prevent your child engaging in physical activity?****42. In relation to Q41, what methods do you or your child think will help overcome these barriers?** (For e.g. tailored exercise program, provision of more information or a combination)**43. What information regarding physical activity and diabetes management do you or your child think is currently lacking?****44. Does your child feel as though you are treated differently at sport or in the playground because of your diabetes?**

Yes/no. If yes, please describe.

**45. Does your child feel as though you are treated differently at home because of your diabetes?** Yes/no. If yes, please describe.**46. Are there any physical activities or sports that your child avoids because of your diabetes?****47. Do you choose not to let your child exercise because of the fear of them having a hypo?**

48. Do you know how your child's blood glucose levels are affected by exercise?
49. Does your child have your CGM or a blood glucose meter always available to check your blood glucose during exercise? Y/N. If no, why not?
50. Does your child know if they are having a hypo whilst exercising?
51. Based on the resources and information available to you, how confident is your child in managing glucose levels around exercise by consuming appropriate meals and snacks & necessary insulin dose adjustments during exercise and sport? 1 to 5 Likert scale (1: Not confident at all; 5: Very confident)

### School

52. If your child goes to school, does the school allow at least one staff member to have access to monitoring technology to support your child in the classroom? Yes/No If no, do you know why they will not allow it? Please explain.
53. If your child goes to school, does your child's sport teacher check on them during a sports lesson? If so, how often? (every 5, 15, 30, 60 minutes or over an hour)
54. When your child is at school – who can they go to for help if you are feeling unwell?
55. If your child goes to school, does the school allow your child to participate in sporting activities?
56. When your child is at school, is there enough support provided about their diabetes management during exercise?
57. When your child is doing community sports, does your coach provide support about their diabetes management during exercise?
58. When participating in community sports or going to a gym or another sporting activity do you tell the organisers that your child has type 1 diabetes?

### PART F: Questions about Diet/nutrition, exercise and management of tests and monitoring

#### Nutrition

59. Do you find it difficult to manage healthy food choices for your child? Yes/No
60. Do you avoid or limit certain foods or food groups to try and control your child's diabetes? Yes/No. If yes, what foods or food groups do you avoid or limit? \_\_\_\_\_
61. Do you feel confident in accurately counting carbohydrate to help estimate insulin requirements? Yes/No

62. **Do you consider the amount of fat and/or protein when calculating how much insulin is required at meals or snacks?** Yes/No/sometimes

63.

64. **Was the impact of fat and protein on blood glucose levels after meals and snacks explained to you?** Yes/No

65. **When your child was first diagnosed, was carbohydrate counting taught to you?** Yes/No If yes, how did you learn to do it? (i.e. friend, family member, self-taught)

66. **Where do you get nutrition information related to diabetes for your child?**

- Dietitians, diabetes educators or doctors at hospital
- Private Dietitians or Clinics
- Friends and family
- Social media
- Blogs
- Online community groups
- Other

Thank you very much for your time and comments. That is the end of the survey.

Are you interested in sharing your experiences further via an online interview? Please provide your contact details (only to be used for the purpose of contacting you about the interview).

If you would like a summary of the findings please provide your email or postal address so we can send you a copy of the report.

If participating in this survey raised any concerns about how you have been feeling, and you would like to talk to someone, there are a number of support options available to assist you. You can visit your regular GP, or if you have seen a health professional before to help with problems, you may wish to make an appointment to see them again.

For immediate support, contact Lifeline on 13 11 14, available 24/7, or online text chat from 7pm-4am (AEST) at: [lifeline.org.au/get-help/onlineservices/crisis-chat](https://lifeline.org.au/get-help/onlineservices/crisis-chat)

The beyondblue Support Service also provides free, immediate, short-term counselling advice and referrals to people in Australia via telephone and email 24/7, and web chat from 3pm to midnight (AEST), every day. The Support Service can be contacted on 1300 22 4636 or via email or web chat at: [beyondblue.org.au/get-support](https://beyondblue.org.au/get-support)

### Survey for emerging adults living with T1D

We know that many young people transition from paediatric care to adult care to several new doctors and services. When answering this survey, please think about the main doctor/s and service/s you see.

#### PART A: General demographics

**1. Which of the following best describes you?**

- Young person who has transitioned to adult health services
  - If you have transitioned, how old were you when you started seeing the adult health service? \_\_\_\_\_
- Young person who is currently transitioning to adult health services (go to A3)
- Other (please specify: \_\_\_\_\_)

**2. In what year were you born?**

**3. What is your gender?**

- Male
- Female
- Non-binary
- Prefer not to answer

**4. Were you born in Australia? y/n**

If no, where were you born? \_\_\_\_\_

**5. Do you speak any language(s) other than English at home?**

Y/N. If yes, please list below:

**6. What is your postcode?**

**7. Are you of Aboriginal or Torres Strait Islander origin?**

- Aboriginal origin
- Torres Strait Islander origin
- Both Aboriginal and Torres Strait Islander origin
- No

**8. How old were you when you were diagnosed with T1D?**

**9. Who lives at home with you?** select all that apply with parents / siblings/ grandparents/ housemates/ other – please list

#### PART B: Management from diagnosis

**10. Were you offered the choice of Continuous Glucose Monitoring (CGM) when first diagnosed? Yes/no/ I don't have CGM.**

If yes, how long did it take to receive CGM?

If no, why not?

**11. Where were you diagnosed with T1D?**

- At home
- At a GP Yes/No
- As an inpatient Yes/ No
- As an inpatient until have insulin injection, BGL monitoring and hypoglycaemia management, then OPD education Yes/ No
- In ICU Yes/No
- If inpatient initially, how many days on average are they inpatient? Yes/No
- Outpatient clinic Yes/ No
- Community Health Service Yes/ No
- Can't remember

**12. When diagnosed, were you offered information and contact details of local diabetes support groups and organisations? Yes/ No/Unsure**

If yes, which ones?

If no, why do you think you were not offered these?

**13. Were you offered contact with social media support or information groups? Yes/ No**

If yes, which ones?

If no, why do you think you were not offered these?

**14. Were you offered access to mobile health information technology (e.g. apps, text messaging service) from the diabetes care team Yes/No**

If yes, tick all that apply:

- Apps (e.g., Dexcom, G6, Clarity)
- Text messages
- Other

If no, why do you think you were not offered these?

**PART D: Ongoing diabetes care and support**

**15. Were you or your parents/carer offered any information by the clinic about any of the following education sessions or programs for patients? Note this is not relevant for initial diagnosis, more relevant for ongoing care**

Please tick all that apply

- Diabetes and exercise
- Diabetes and transition to adult services
- Diabetes and mental health
- Diabetes and smoking
- Diabetes and drugs and alcohol
- Diabetes and driving



- Diabetes and pregnancy
- Diabetes and Sick day management
- Diabetes technologies
- Insulin adjustment
- Nutrition and carbohydrate counting
- Preparation for Schoolies and independent travel
- Diabetes management at school
- Diabetes management on school camp
- Other
- No education sessions or programs were offered
- I use programs offered by other organisations e.g. Diabetes Australia. Y/N  
If yes, which ones?

**16. Have you been told about groups that offer patient education services, information and support? Yes/No**

If yes, who?

- JDRF Australia or other JDRF state specific
- Diabetes Australia or other Diabetes Australia branch in your state e.g. Diabetes NSW and ACT
- Other online resources (not JDRF or Diabetes Australia)
- Other: Specify \_\_\_\_\_

If no, why do you think you were not offered these?

**Insulin treatment**

**17. What insulin treatment do you use currently?**

Short acting
Long acting
Both

**18. What insulin therapy do you use currently?**

1-2 times a day manual insulin injections
Three times a day manual insulin injections
Multiple daily injections (MDI)
Insulin pump
CGM and integration with

hybrid closed loop insulin pump
DIY insulin pump
CGM integration with DIY insulin pump (looping)

**19. If you use an insulin pump, do you feel it has made management of your condition easier?** Yes/No If no, why not?

**20. Do you know what your average annual HbA<sub>1c</sub> target level is?** Yes/no. If yes, what is it? (a range is ok).

**21. Do you use a continuous glucose monitor (CGM)?** Yes/No

If yes, Which one?

If yes, do you feel it has made management of your condition easier? Yes/No If no, why not?

If no, how often do you test your blood? (please tick all that apply)

- Before meals
- Around exercise
- At bedtime
- Only when I feel hypoglycaemic
- Only when I feel unwell
- Around driving

**22. Were you given help on how to check and calibrate your CGM?** Yes/No

If Yes, how was this done? (tick all that apply)

- diabetes education start up session?
- Directed to an online resource?
  
- Explanation during routine consultations
- Provided with written materials / guides
- Directed to a web resource (Please specify which one): \_\_\_\_\_
- By product manufacturer (e.g., Medtronic and Dexcom after online training)
  
- Explanation during routine consultations
- Provided with written materials / guides
- Directed to a web resource (Please specify which one): \_\_\_\_\_
- By product manufacturer (e.g., Medtronic and Dexcom after online training)

### **PART C: Routine Type 1 diabetes care services**

**23. If you have transitioned to adult care, what services DID you receive for Type 1 diabetes before you transitioned? (Please select all that apply)**

- Health services within the public health system (Y/N)
  - Children’s hospital paediatric clinic
  - Paediatric diabetes clinic in a general hospital
  - Other: \_\_\_\_\_
- Health services within the private health system Y/N
  - Private hospital clinic
  - Private specialist
- Health services provided through NDIS funding Y/N
  - If yes, which services do you get through NDIS?
- Other services, please specify

**24. In what setting do you currently receive care for Type 1 diabetes? (please select all that apply)**

- Young adult diabetes service
- Paediatric diabetes outpatient clinic
- Paediatric hospital (inpatients)
- Paediatric inpatients in a general hospital
- General diabetes outpatient clinic in an adult or general hospital
- Community outreach outpatient clinic
- Young adult clinic
- Regional outreach paediatric clinic
- Regional outreach paediatric clinic and inpatient setting
- Rural clinic
- Private clinic
- In your home via telehealth or visiting clinician
- Other – please specify: \_\_\_\_\_

**25. Which health professionals do you routinely see to manage your diabetes? Please tick all that apply.**

Health professionals	Yes	No
Endocrinologist (diabetes doctor)		
Paediatric endocrinologist (children’s diabetes doctor)		
General paediatrician		
General practitioner (GP)		
Trainee doctors		
Ophthalmologist (eye specialist)		
Hospital general nurse		
Specialist diabetes nurse		
Community nurse		
Diabetes educator		

Podiatrist (person who looks after your foot health)		
Orthotist (person who looks after your medical supportive device such as a splint)		
Psychologist		
Dietitian or nutritionist		
Social Worker		
Exercise physiologist		
Physiotherapist		
Other (specify below)		

**26. How often do you visit the T1D clinic? (including telehealth or visiting a health professional )**

- Once per week
- Once every 3 months
- Once every 6 months
- Other

**27. Have you ever needed care outside of regular hours? i.e. in the evening or at the weekend? Yes/No. If yes, where did you go?**

**28. How would you rate your knowledge about how to manage your Type 1 Diabetes?**

- Excellent
- Good
- Average
- Poor
- Very poor
- Unsure

**29. How involved did you feel in discussions about your healthcare, before transition?**

- Very involved
- Only occasionally involved
- I left this to my parents or carer
- Not involved at all
- I didn't want to be involved
- Unsure

Optional: Any further comments? (comment box)

**30. How involved did you feel in discussions about your healthcare, during transition**

- Very involved
- Only occasionally involved
- I left this to my parents or carer

- Not involved at all
- I didn't want to be involved
- Unsure

Optional: Any further comments? (comment box)

**After transition**

- Very involved
- Only occasionally involved
- I left this to my parents or carer
- Not involved at all
- I didn't want to be involved
- Unsure

Optional: Any further comments? (comment box)

**31. Pre transition: Have you ever used telehealth with your healthcare provider?**

- Yes, mainly video consultations
- Yes, mainly telephone consultations
- Yes, we used video and telephone equally
- Yes, we sometimes used a hybrid of telehealth and face to face (e.g., the patient is face-to-face but their GP or another health professional is online or on the phone)
- No, we did not use telehealth

**If yes, do you like using telehealth or prefer seeing someone in person?**

- I prefer telehealth
- I prefer seeing someone in person
- I have no preference

**32. Post transition: Have you ever used telehealth with your healthcare provider?**

- Yes, mainly video consultations (skype, PEXIP, My Virtual Care, Zoom etc)
  - 
  - Yes, mainly telephone consultations
  - Yes, we used video and telephone equally
  - Yes, we sometimes used a hybrid of telehealth and face to face (e.g., the patient is face-to-face but their GP or another health professional is online or on the phone)
  - No, we did not use telehealth

**33. Did these consults meet your needs?**

- Yes
- No
- Unsure

Optional: Why do you say that? (comment box)

**If yes, do you like using telehealth or prefer seeing someone in person?**

- I prefer telehealth
- I prefer seeing someone in person
- I have no preference

**34. Have you ever seen someone for mental health support? Yes/no  
If yes, please tick all that apply.**

Clinical psychologist	
Health psychologist	
Psychotherapist	
Psychiatrist	
Counsellor	
Mental health nurse	
Social worker	
Family therapist	
GP	
Other	

**If yes, what is the average waiting time between referral and appointment with a mental health service?**

**If yes, have you seen a psychologist for the following?**

	Yes	No	I would, if the service was available
Problems with self-management of glucose control			
Recurrent DKA			
Low BMI			
Eating disorders (bingeing, bulimia, anorexia)			
Disordered eating (e.g. skipping meals)			
Body dysmorphia (perceived defects in your appearance)			
Morbid obesity			+ dietitian + Physio
Depression			
Needle phobia			
Anxiety			
Drug and alcohol problems			
Psychotic illnesses			+ Mental health
Psychosexual health			
Domestic violence and/or sexual abuse			SW
Suicidal thoughts or self-harm			
Family stress or trauma			+SW

Communication problems with the family			
Communication problems with the team			

### **PART E: Planning for your transition**

#### **35. When was the first time your healthcare team spoke about moving to new adult health services?**

- Before I was 16
- Between 16 and 18
- At my last appointment with the children's service
- Nobody spoke to me about moving
- I raised the issue with them

Optional: Any further comments? (comment box)

#### **36. How well prepared did you (do you) feel for moving to new adult health services?**

- Very well prepared
- Somewhat prepared
- Not prepared at all
- Unsure

Optional: Any further comments? (comment box)

#### **37. Were your wellbeing and social (psychosocial) needs taken into consideration when planning for your transition?**

- Yes
- No
- Unsure
- There was no planning

Optional: Any further comments? (comment box)

#### **38. Were your medical needs taken into consideration when planning for your transition?**

- Yes
- No
- Unsure
- There was no planning

Optional: Any further comments? (comment box)

#### **39. How confident were you when transitioning to the new adult health services that you had the knowledge and skills to manage your T1D? (Likert 5 point scale)**

- Excellent
- Good
- Average
- Poor
- Very poor
- Unsure

**40. How confident are you now, after transitioning to the adult health service that you have the knowledge and skills to manage your T1D? (Likert 5 point scale)**

- Excellent
- Good
- Average
- Poor
- Very poor
- Unsure

**41. Was anything done to help build your confidence or independence for managing your T1D before moving to new adult health services?**

- Yes
- No
- Unsure

**If yes, what was done to help build your confidence/independence?**

**42. How involved did you feel in discussions about your healthcare and transition to adult service? (choose as many as apply?)**

- Very involved
- Only occasionally involved
- I left this to my parents or carer
- Not involved at all
- I didn't want to be involved
- Unsure

Optional: Any further comments? (comment box)

**43. Were you given the healthcare information and letters you required when moving to new adult health services?**

- Yes they were provided without asking
- Yes but had to organise them myself
- No
- Unsure

Optional: Any further comments? (comment box)

**44. Did you have a GP/local doctor at the time of transition to the new adult health services?**

- Yes, I had one already
- Yes, I found one during the transition process
- No
- Unsure

**45. Was your GP involved in your transition process? (e.g., to help make a care plan and provide referrals to providers)**

- Yes



- No
- If, yes, how was the GP involved?

**46. Was there a transition co-ordinator available to help you?**

- Yes
- No
- Unsure

**47. Who would you say was your main transition coordinator/facilitator/organiser?**

**48. Were you referred to a specialist transition service designed for young people living with long term conditions transitioning to adult care? Y/N If yes, which one?**

**PART E: Your transition support**

**49. Were you assessed by a health professional for readiness for transition to adult services? If yes, at what age?**

**50. Were you given a choice on where you would access the new adult health services?**

- Yes
- No
- Unsure

Were you given any choice about which service you would transition to? (e.g. different options were offered) Y/N/not sure

**51. Were you provided with any peer support when preparing for transition or transitioning? (e.g. a group of young people transitioned together and supported each other) Y/N. Please Comment:**

**PART F: Planning for your transition and resources**

**52. Did you have a written or electronic transition plan?**

- Yes
- No
- Unsure

**53. Were you given a copy of the transition plan?**

- Yes
- Yes, my parents/carers were given a copy, but I wasn't
- No
- Unsure

**54. Have you visited the transition resources on a webpage? (e.g., Diabetes Australia)**

Yes/No/Didn't know they existed/Unsure/Other – please provide details

**55. Were these resources helpful?**

Yes

No

Unsure

Optional: Any further comments? (comment box)

**40. Have you used any apps or technology to help you through the transition process?**

Yes

No

Unsure

If yes, which ones?

If yes, did you find these resources useful?

**PART G: After your first appointments in the adult health service****42. Did anyone check in/follow up with you after your move to adult health services?**

Yes

Yes, checked in with my parents/carer but not with me

No

Unsure

Optional: Any further comments? (comment box)

**If yes, who followed up (e.g. diabetes nurse, doctor in the children's service?)**

If yes,

When did they check in with you?

- within a week of the first appointment in the adult service.
- within a month of the first appointment in the adult service.
- within 3 months of the first appointment in the adult service.
- Optional: Any further comments? (comment box)

**PART H: Your new adult health team****56. How many health care professionals did you see after transitioning to the new adult service? Please tick**

- 1
- 2
- 3
- 4
- 5
- 6 or more
- I transitioned to the care of my GP
- Unsure

**44. Does your new adult health service include the following components:**

- Structured education with acknowledgement of important information before transition occurs
- Structured follow-up for assessment and confirmation of retainment in the adult service
- A young adult clinic
- Joint clinics where the paediatric team and the adult team will see the patient at the same time
- Group sessions, where a number of young people transition together as a cohort
- A virtual program (please describe): \_\_\_\_\_
- Family or other caregiver involvement
- Specific preparation and education for family or other caregivers
- Case coordinator for each patient.
- Does the paediatric service make the first appointment for the adult service
- A peer-mentor (or transition buddy) for each patient?
- Other components (please describe): \_\_\_\_\_

**45. Did you meet your new adult health team before leaving the children's health service?**

- Yes in person
- Yes via telehealth
- No
- Unsure

**46. Did your adult health team have all the necessary paperwork, results and letters they needed for your first appointment?**

- Yes
- No
- Can't recall

**47. The wait time to see the new adult health team was?**

- Acceptable
- Too long
- Unsure

If too long, why do you say that? (comment box)

**48. How long did you wait before the first appointment with the adult doctors and other health professionals in the adult health services?**

**49. How would you rate your new adult health service's knowledge about your condition?**

- Excellent
- Good
- Average
- Poor

- Very poor
- Unsure

**60. Did your new adult health service feel welcoming to you?**

- Yes
- No
- Unsure

Optional: Why do you say that? (comment box)

**61. Did you feel your adult health team understood issues relating to adolescents and young adults?**

- Yes
- No
- Unsure

Optional: Why do you say that? (comment box)

**PART I: Questions about living with type 1 diabetes, exercise and nutrition**

**64. Do you participate in team sports or other fitness activities? Please select all that apply.**

Activity	How often
Casually with friends	
Casually with family	
At school	
Sporting clubs in the community	
National level activity	
International level activity	

Any further comments?

**65. What are some barriers that prevent you engaging in physical activity?**

**66. Do you know how to manage you blood glucose levels when exercising? Yes/No**

**67. Do you find it difficult to manage healthy food choices for yourself? Yes/No**

**68. Do you avoid or limit certain foods or food groups to try and control your diabetes? Yes/No. If yes, what foods or food groups do you avoid or limit? \_\_\_\_\_**

**69. How confident in accurately counting carbohydrate to help estimate insulin requirements? Likert 5 scale.**

**70. Do you consider the amount of fat and/or protein when calculating how much insulin is required at meals or snacks? Yes/No/sometimes**

**71. Was the impact of fat and protein on blood glucose levels after meals and snacks explained to you? Yes/No**

**72. . Where do you get nutrition information related to your diabetes?**

- Dietitians, diabetes educators or doctors at hospital
- Private Dietitians or Clinics
- Friends and family
- Social media
- Blogs
- Online community groups
- Other

**PART J: Feedback to improve the transition experience for others**

**73. What went well during your transition?**

**74. . Did anyone / anything particularly help? Can you share an example?**

**76. Have you experienced any other hurdles or issues that have affected your transition?**  
yes/no. if yes → What supports could have been given to help with this?

**77. What is one word that describes your transition journey?**

**78. Are there any specific areas you would like to be improved or changed to make the transition process smoother?**

**79. What advice would you give to other young people going through transition?**

Thank you very much for your time and comments. That is the end of the survey. Are you interested in sharing your experiences further via an online interview? Please provide your contact details (only to be used for the purpose of contacting you about the interview).

If you would like a summary of the findings please provide your email or postal address so we can send you a copy of the report.

If participating in this survey raised any concerns about how you have been feeling, and you would like to talk to someone, there are a number of support options available to assist you. You can visit your regular GP, or if you have seen a health professional before to help with problems, you may wish to make an appointment to see them again.

For immediate support, contact Lifeline on 13 11 14, available 24/7, or online text chat from 7pm-4am (AEST) at: [lifeline.org.au/get-help/onlineservices/crisis-chat](https://lifeline.org.au/get-help/onlineservices/crisis-chat)

The beyondblue Support Service also provides free, immediate, short-term counselling advice and referrals to people in Australia via telephone and email 24/7, and web chat from 3pm to midnight (AEST), every day. The Support Service can be contacted on 1300 22 4636 or via email or web chat at: [beyondblue.org.au/get-support](https://beyondblue.org.au/get-support)

Thank you for agreeing to allow us to contact you for a follow up call to talk about the findings of the survey. The purpose of this phone call is to expand on areas of interest and verify the findings. What we talk about today will continue to help us to map existing models of care for children and young adults living with T1D. It will identify the gaps and needs in care delivery as viewed by healthcare providers and by children, young people, and their families accessing care in metropolitan and rural or remote regions throughout Australia.

You are free to withdraw at any time without consequence.

Do you have any questions before we start? (pause for questions).

Can you please elaborate on what you think is meant by....