



**JDRF** IMPROVING  
LIVES.  
CURING  
TYPE 1  
DIABETES.

100  
  
YEARS OF INSULIN

# THE CHALLENGES OF T1D

A JDRF REPORT

## A MESSAGE FROM OUR CEO, MIKE WILSON OAM



2021 marks the centenary of the discovery of insulin, a breakthrough that has had a lifesaving impact for millions of people living with type 1 diabetes (T1D) around the world. In the 100 years since, we have developed a much greater understanding of T1D. There have also been significant advances in technology that help people with T1D live a full life. However, 100 years on, insulin is still the only treatment option for millions of people living around the world with T1D. This means the needles, injections, finger pricks, bulky devices and constant monitoring remain part of our lives.

Yet we know the impact doesn't stop there, which is why we mustn't stop either. As this report shows, the impact of T1D touches every part of a person's life. From financial burdens through to the damage it can have on mental health and wellbeing, T1D casts a long and impactful shadow. This report, based on a survey of over 1,300 people, carers, patients and healthcare professionals, highlights the profound everyday struggles this condition creates and why we must continue to move the needle for people with T1D.

As well as presenting the findings, this report talks about how we are tackling some of the issues raised and how you can support us in our pursuit of a world without T1D. From advocating for improved access, through to a financial donation, or just educating friends or colleagues on the reality of life with T1D, you are playing your part in moving the needle in 2021.

Finally, my thanks to all of the survey respondents who, through their courage and honesty, have helped us build a true picture of the modern lived experience of T1D.

Mike Wilson OAM  
CEO and Managing Director, JDRF Australia

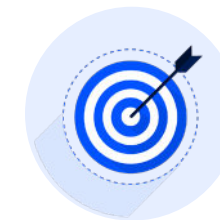
## SURVEY RESPONDENTS SNAPSHOT



### SURVEY

A 44-question online study was conducted amongst members of the T1D community.

Respondents qualified if they have type 1 diabetes or they are the caregiver of at least 1 person with type 1 diabetes. A small minority were health professionals or another family member of a person with type 1 diabetes.



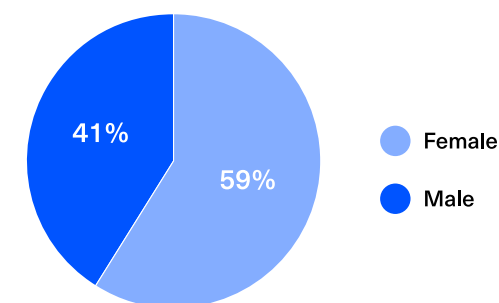
### OBJECTIVES

This study aimed to measure attitudes and behaviours of people with T1D or caring for someone with T1D on a variety of T1D-related topics.

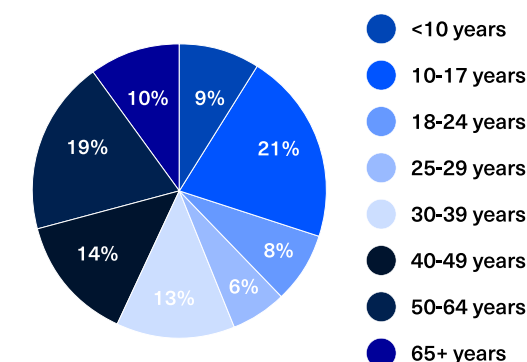
## DEMOGRAPHICS

Note: PWD = Person with Diabetes

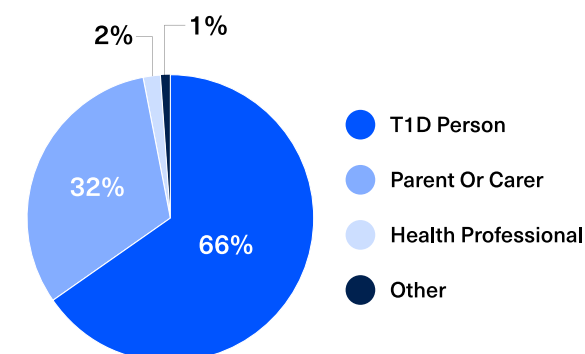
### Gender (PWD subject of the survey):



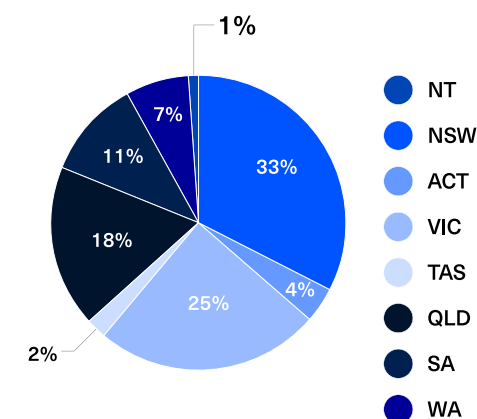
### Age (PWD subject of the survey):



### Survey completed by:



### Location:



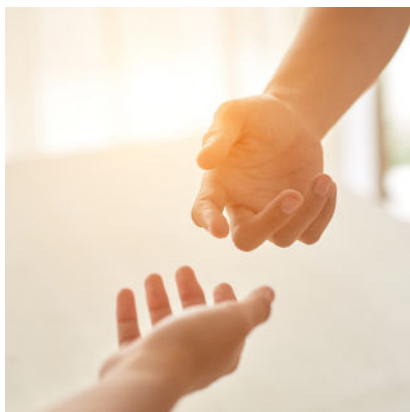


# KEY FINDINGS



## T1D impacts many areas of a person's social life:

- The ability to do things spontaneously is limited for the great majority of respondents.
- The impact on spontaneous activities was so large that it impacted people's romantic relationships (**40%**) and career choices (**33%**).
- **9 out of 10** caregivers worry when the person with T1D they care for is in the care of someone else.
- **2 out of 3** caregivers worry their child won't be invited to events (such as playdates or sleepovers) as a result of their T1D.
- **Around 30%** say no to a spur of the moment event at least once a month because of no supplies, or say no to an event because they are worried diabetes will be hard to manage.



## Poor management can have a spiralling effect:

- People with T1D who self-rate their management of T1D as poor are more likely than others to suffer from negative mental health impacts of T1D.
- People living with T1D engage in fewer social activities, their work and personal relationships are impacted and they tend to hide their condition from others.
- Respondents are also more likely to feel they have insufficient access to technology, equipment and healthcare professionals.



## Lower socio-economic groups are more negatively impacted:

- **30%** of respondents say T1D represents a very large financial burden.
- Cost has an impact when it comes to access. **45%** of people who don't have a pump say cost is the reason why, with this number rising to **71%** for CGMs.
- Those with a lower income are less likely to consider their knowledge of T1D technology to be good.



## Support outside the healthcare system is essential:

- **30%** of respondents say they receive very little to no support outside the healthcare system.
- Those who receive support manage their diabetes better and access more technology and healthcare professional support. They also look into new technologies proactively and find solutions for themselves.



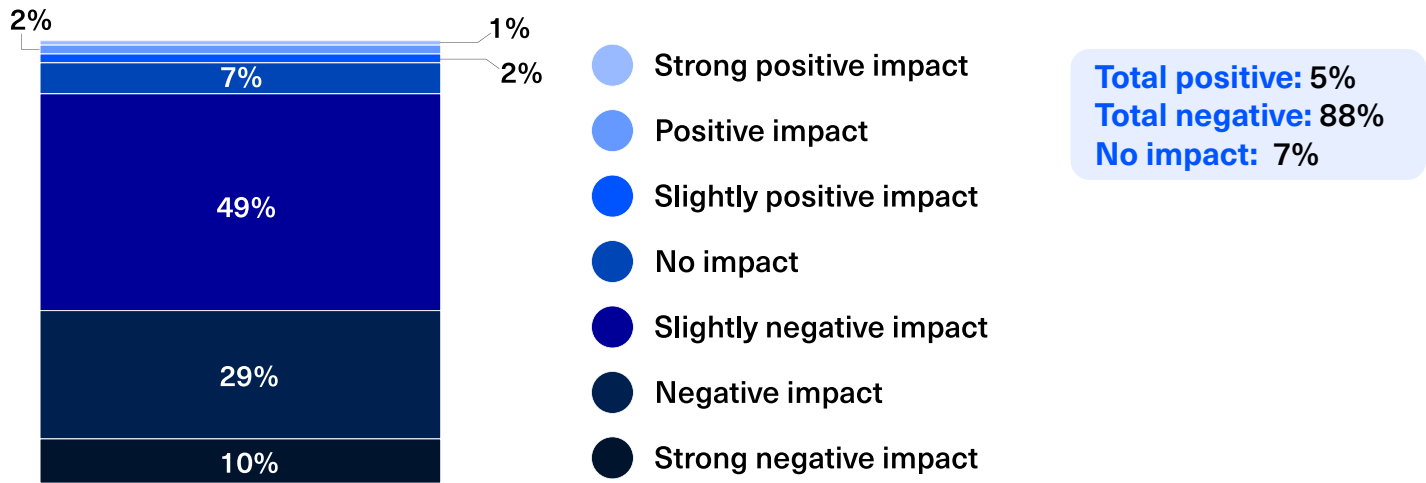
## There is a correlation between the use of Continuous Glucose Monitors (CGM) and good management of diabetes:

- CGM are not known by all and the monthly cost is a lot higher than any other expense, including pump expense.
- The survey also showed using a pump and CGM together yielded even better management.

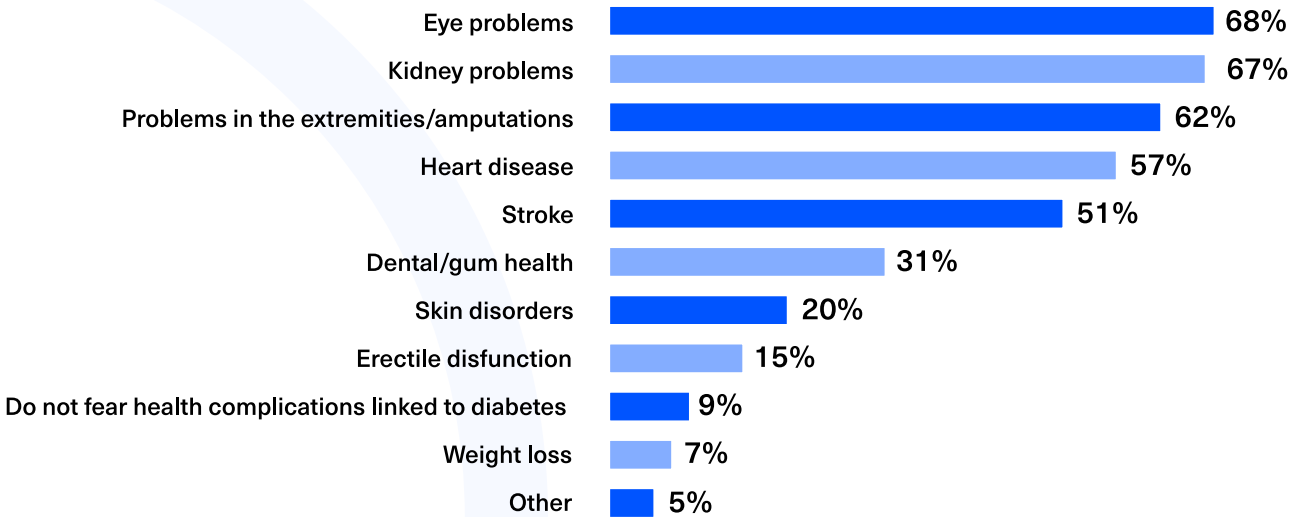
# IMPACT OF DIABETES ON QUALITY OF LIFE

87% of respondents describe the impact of T1D on their quality of life as negative. Fears of health complications also affect people with T1D, with eye problems and kidney problems the most feared complications.

Overall, what impact does diabetes currently have on the quality of life for the PWD?



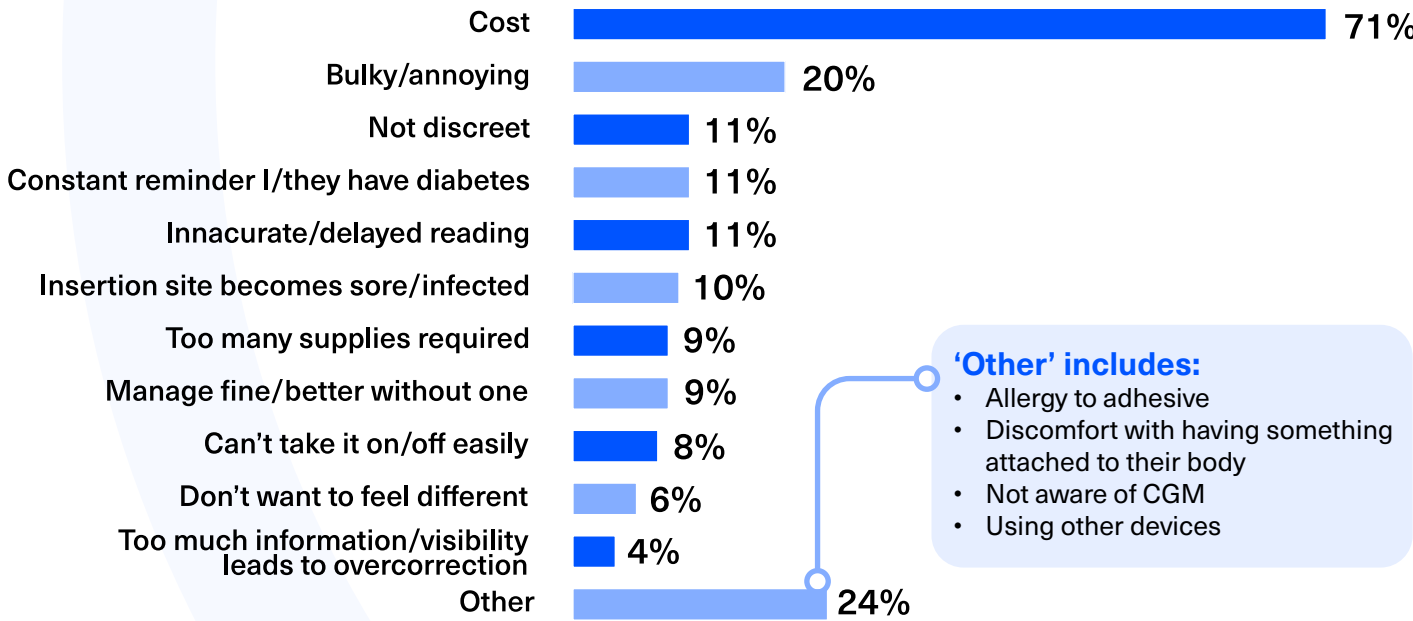
Which of the following health complications linked to diabetes do you have fear of getting?



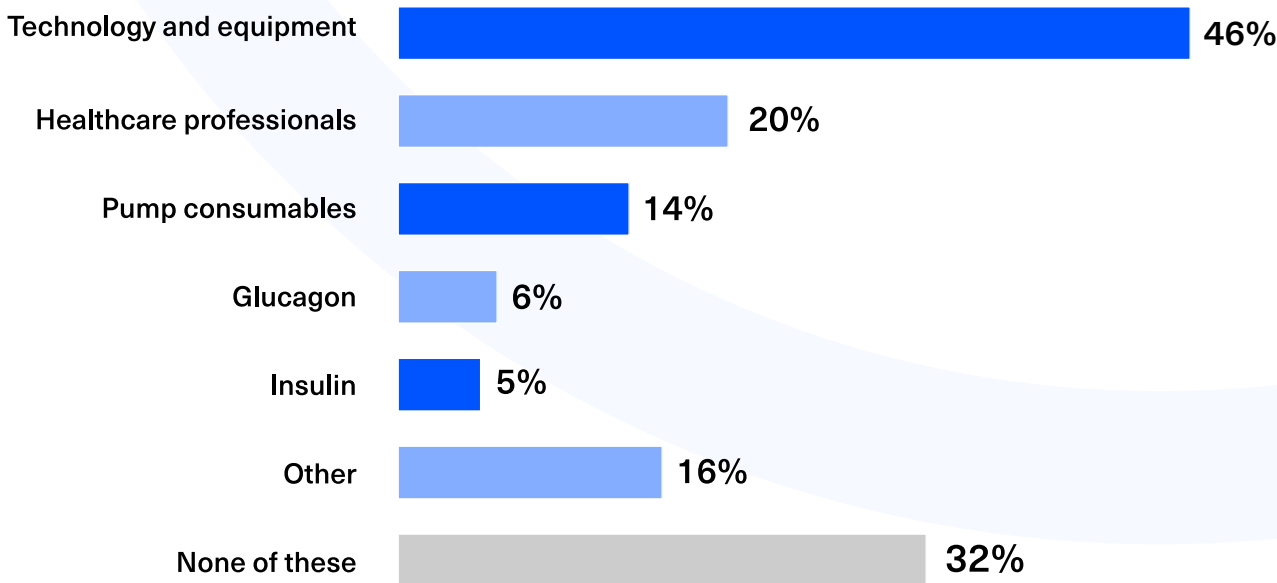
# TECHNOLOGY

When it comes to technology such as CGM, cost is by far the biggest barrier to access, with 7 in 10 saying they don't have one for this reason. This is a particular concern, as when it comes to access, technology and equipment is what people with T1D consider they are lacking the most.

Why don't you use a CGM?



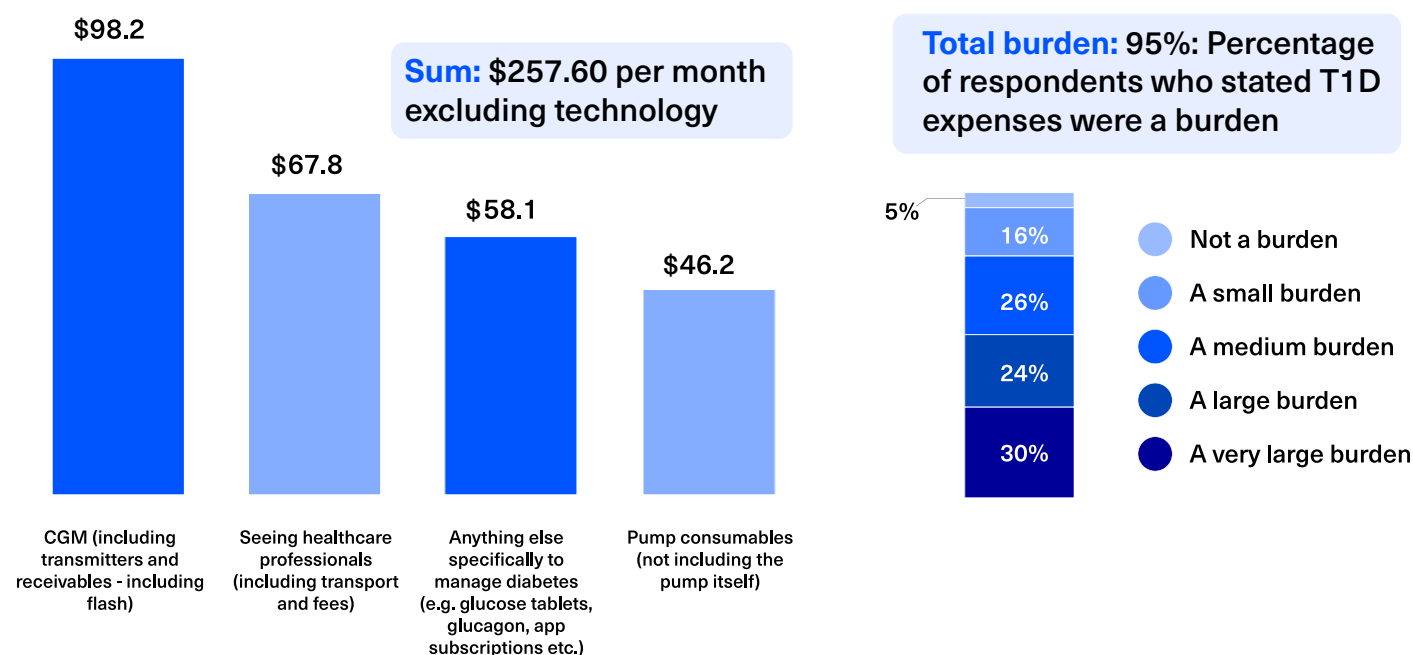
What do you feel you have insufficient access to for the management of T1D?



# COST

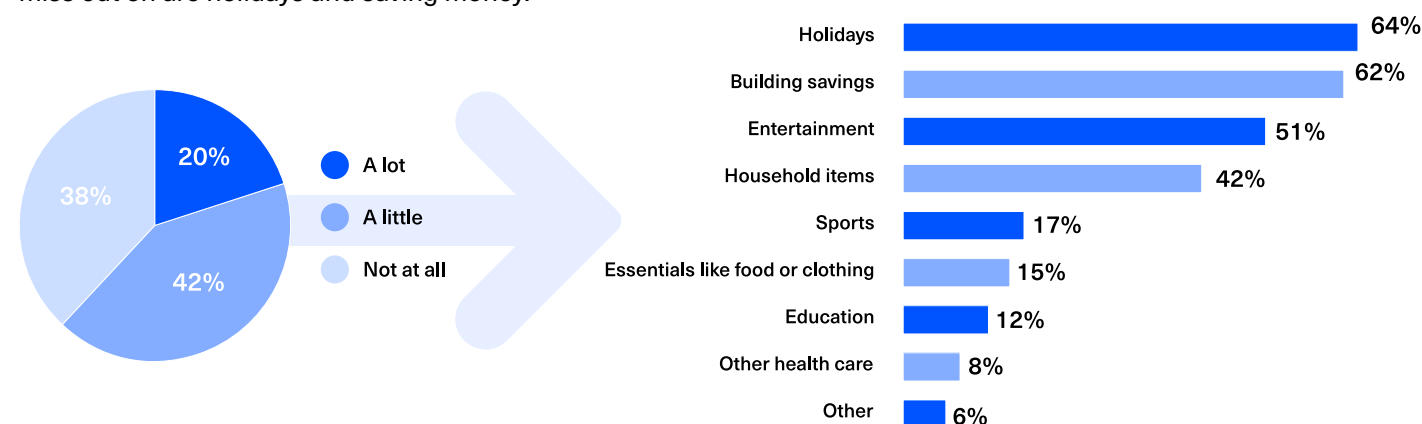
After reimbursements, people with T1D and their carers report an average of \$257.60 per month (which excludes the substantial cost of the technology itself) for those using every item listed, CGM being the most expensive of all. T1D expenses represent a burden to 95% of PWD and carers, including 30% who say it is a very large burden.

*After reimbursements from the government, health insurance, NDSS or anyone else, how much do you spend per month (out of your own pocket) on each of the following?*



*To what extent do you feel like you / your family misses out on other things because of the costs associated with T1D?*

This cost has a flow on effect, with 62% of respondents feel they miss out on other things because of the cost associated with diabetes. The most common things they miss out on are holidays and saving money.



# CHALLENGE OF CURRENT ACCESS PATHWAYS



## CONTINUOUS GLUCOSE MONITORS

Currently, there is a government program that ensures access to CGMs to anyone under 21 with T1D. To qualify for government support for CGM if a person with T1D is over 21, they need to either have a healthcare concession card or be a female who is pregnant or contemplating pregnancy.

Otherwise, everyone must pay full price for CGM and associated consumables such as sensors and transmitters. There is no way, currently, for this vital technology to be supported through Private Health Insurance.

**One of the ways we can begin to turn the tide of this inequity is for the expansion of existing program to those turning 21 who have been using CGM.**

We believe people who have accessed the technology through the program should continue to do so.



## FLASH GLUCOSE MANAGEMENT

This is currently available through the same access pathways as CGM.



## THE FUTURE

This is just a snapshot of the technology widely used in Australia. There is a technology revolution, led by options such as the already available patch, pump and hybrid closed-loop systems – that have the potential to revolutionise T1D technology in Australia. The challenge, and the reason we are calling for smarter access, is ensuring those who would benefit the most from these technologies will have the opportunity to access them.



## INSULIN PUMPS

The majority of people who can access a pump do so through Private Health Insurance. This means in almost all cases, people with T1D have to pay high premiums as pumps are only available on the most expensive insurance products.

The JDRF-administered Insulin Pump Program (IPP) provides 220 pumps (paid for by the Federal Government) to people under 18 who meet certain financial and medical criteria. In addition, the National Diabetes Service Scheme (NDSS) provides subsidised access to pump consumables.

However, product choice and interoperability with CGM products are an issue. Research shows the best clinical outcomes are delivered through the use of pumps and CGM in unison, hence why interoperability is so important and a safety net for those who cannot afford technology is paramount to easing the impact of T1D.



# TACKLING THESE CHALLENGES

## OUR APPROACH

Everyone living with T1D should have access to a basic standard of care, which today involves access to technology used to manage T1D. The scope of that technology will mean different things for different audiences. Our task in today's landscape is to ensure that Australians with T1D can access technology, meaning that:

- those who have access to technology don't lose it
- individuals who need it can get it
- people can choose what is best for them from the broadest range of technology on offer.

To do this we need to make access Fairer, Better and Smarter.

### Fairer access:

- Technology works, so we need to find ways to keep it in patients' hands for longer.
- It makes no sense to take access away from patients who already have it.

For younger Australians with T1D this means:

- Continued eligibility for subsidised CGM access once they turn 21.
- Extend access to Insulin Pump Program from 18 to 21. This aligns access to the two key technologies that work best in tandem to produce health outcomes.

### Better access:

- There is an acute access gap and need for the creation of a safety net for those who can't afford access to technology.
- Private Health Insurance (PHI) and Government subsidy programs provide access for many people with T1D to these technologies.
- However, not everyone fits the subsidy criteria and not everyone can afford to buy the technology, or the Private Health Insurance that will give them access to technology.
- There is no safety net for the people who don't fit the subsidy criteria and don't have the financial means to access the technology.


### Smarter access:

- Getting access to technology in Australia is difficult and complicated.
- Those who fall between government support, private health insurance and being able to pay get left behind.
- Additionally, leading edge technology is often slow to come to Australia.
- The pathways by which Australians access technology must be a better fit for purpose, so available technology is swiftly available to the Australians who will benefit from using it.


**We look forward to working with Government and stakeholders to create a system that delivers access that is Fairer, Better and Smarter.**

# GETTING INVOLVED


## YOU CAN ASSIST US AND THE T1D COMMUNITY IN MAKING THIS CHANGE:




**Sign up to be a Game Changer:**  
Learn about the latest advances in T1D research, find clinical trials relevant to you and be part of our communication campaigns. Sign up here: [jdrf.org.au/get-involved/become-a-game-changer/](https://jdrf.org.au/get-involved/become-a-game-changer/)



**Become an advocate:**  
JDRF is a community powered organisation, driven by grassroots advocacy, with the aim of having an advocate in every Federal electorate in Australia. To see if there is an advocate in your electorate and how you could get involved, [jdrf.org.au/advocacy/become-an-advocate/](https://jdrf.org.au/advocacy/become-an-advocate/)



**Sign up to the Blue Army:**  
Where you can take part in a huge range of fundraising activities to help us turn type one into type none. Visit [bluearmy.jdrf.org.au/](https://bluearmy.jdrf.org.au/)







**Share the survey findings:**  
Alongside this report, we have developed a number of social tiles – share them on your social networks, talk to friends and help us #MoveTheNeedle for T1D



**Note on research:** The research was commissioned by JDRF and conducted by Lonergan Research in accordance with the ISO 20252 standard. Lonergan Research surveyed 1,299 Australians who have or care for a person with Type 1 diabetes. Surveys were distributed mostly via a JDRF email or social post but also via other T1D organisations or word of mouth. The survey was conducted online between 27 August and 16 September 2020. Due to rounding, percentages may not precisely reflect the absolute figures.



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