

## Type 2 Diabetes in Aboriginal and Torres Strait Islander Children and Young People – their story

### Why was this study done?

Rates of type 2 diabetes among Aboriginal and Torres Strait Islander children and young people are increasing. Youth onset diabetes can have serious complications, significantly impair quality of life and reduce life expectancy. Managing youth type 2 diabetes can be challenging and research is needed to understand the needs of young people with type 2 diabetes. In this study we wanted to talk to and learn from young peoples’ experience of living with type 2 diabetes to develop strategies to better meet their needs and promote effective diabetes management.

### Who was involved in the study?

In the Northern Territory we engaged with one urban and one remote health service in the Top End and Central Australia (4 sites), where we interviewed twenty-seven young Aboriginal and/or Torres Strait Islander people with type 2 diabetes (see Tables 1 & 2 for age and sex breakdowns).

Table 1: Participant Age

Age	Urban	Remote	Totals
11-15	4	8	12
16-20	4	-	4
21-25	7	4	11
<b>Totals</b>	<b>15</b>	<b>12</b>	<b>27</b>

Table 2: Participant Sex

Sex	Urban	Remote	Totals
Male	2	4	6
Female	13	8	21
<b>Totals</b>	<b>15</b>	<b>12</b>	<b>27</b>

We also undertook one case study in each site (n=4) to obtain a more in-depth understanding of youth type 2. This involved an interview with one young person, their carer and chosen health professional as well as examining the young person’s medical record.

### What did we find?

Major themes that emerged from interviews are included below, as well as supporting quotes from multiple participants.

#### Initial response

At time of diagnosis young people reported a variety of responses including feelings of confusion, denial, worry, shame, anger and stress.

*“I was full on crying. I just wanted to get out of there.”*

*“I didn’t want to believe it. It was horrible. Horrible [...] horrible when I found out.”*

#### Identity

Some participants felt that having diabetes affected their identity and were concerned about how others would perceive them.

*“I felt like I was [...] a burden and you don’t want [your friends] to be sad for you because you’re sick. You just want them to treat you as normal, not a sick person.”*

#### Shame and isolation

Some young people were ashamed of their diabetes which contributed to a sense of isolation.

*“Getting shame, other mob, other young people they keep it secret.”*

*“...before, I wouldn’t want to [...] tell you my story at all because I [...] was ashamed of it.”*

### Diabetes is a common story

All young people reported family members who had type 2 diabetes which often contributed to the normalisation of diabetes.

*“Everyone’s got diabetes [...] it’s not like, oh no, you need to make sure you look after yourself, and cut down on these sweets. It’s more like, yeah, everybody’s got it, so what.”*

### Understanding type 2

When asked about their understanding of type 2, young people spoke mostly about needing to limit their “sugar” but they were unable to explain how diabetes affects their body.

*“I don’t really know what diabetes is. I just need somebody to explain to me a bit more.” “They’ve explained it to me heaps of times; I still can’t get it right.”*

### Life is complex

Young people have complicated lives and many competing demands including co-morbidities, caring responsibilities and unstable home environments.

*“I have rheumatic heart disease, so I thought that was that, just keep an eye on me for that. So, then they told me that I have diabetes...I have two things.”*

*“It’s not easy – you’ve already got other stuff going through your mind and diabetes is just a thing that just tops it off, you know, takes the cake”.*

### Supports

**Family** was the main support for many young people (in living with type 2 diabetes and life in general).

*“I talk to my mum... I talk to my aunty too... I don’t talk to anyone else.”*

Although young people don’t tend to engage in conversations about diabetes with their friends, they agreed that **support from peers**, and other young people with type 2 diabetes, would be helpful.

*“It’d be good around people the same age [...] to hear their side of the story and how they got it and what they’re doing...cause it’s hard to talk to other people.”*

Despite a general lack of engagement with health services from young people, some examples were given where young people had, over time, developed a **trusting relationship with a health professional** who became one of their key supports.

*“He’s built a relationship with her [nurse], you know, whenever we’d come [to clinic]”.*

### Where to from here?

We will use these findings to inform the next phase of this research project which aims to co-design and evaluate culturally appropriate, youth-friendly models of care for Aboriginal and Torres Strait Islander young people with type 2 diabetes across Northern Australia. This involves working with young people, their families and communities, as well as health professionals. Specifically, we will:

1. Establish peer support networks for young people living with type 2 diabetes
2. Develop diabetes related educational strategies and resources that are accessible, credible, easy to understand and relevant to young people and their families
3. Develop strategies to assist families with supporting young people
4. Enhance health professional education and confidence in youth type 2 diabetes management
5. Promote clinical guidelines
6. Assist with streamlining care and referral pathways

Thank you to everyone who shared their story for this study. If you would like more information, please contact Dr Renae Kirkham (08) 8946 8693 or [renae.kirkham@menzies.edu.au](mailto:renae.kirkham@menzies.edu.au) or [youtht2diabetes@menzies.edu.au](mailto:youtht2diabetes@menzies.edu.au)