Aboriginal young people's experiences of type 2 diabetes diagnosis, management and support: a qualitative study in the Kimberley region of Western Australia.

Why was this study done?

Australian Aboriginal young people and children are getting more Type 2 Diabetes (T2D), which is when your body has too much sugar/glucose in your blood that can make you very sick and cause other health problems. We wanted to understand our Kimberley Aboriginal T2D young people's stories managing their diabetes and supports, including their Carer and healthcare professional's experiences to improve models of care.

How was this study done?

Seven (7) participants aged between 12-24 from two Kimberley Aboriginal Community Controlled Health Services (ACCHS) shared their stories with a doctor researcher in September-December 2020. Two (2) case studies of a Carer, a health professional and a young person (male and female) in the East and West Kimberley was also done. Medical records were looked at for these participants to understand their whole story.

What did we find out?

The young people were aged 10,11,13,14,15,15 and 22 years old when they first got told they had diabetes (diagnosed), by being tested and were 12-24 years old at their interview. They all had different experiences and emotions when they got diagnosed with having diabetes. They find it trying (challenging) understanding and managing their diabetes, even with good family supports. Some family also had diabetes (intergenerational diabetes). They like (value) positive healthcare (clinical care) relationships.

Recommendations for action

- Improve health education for young people and families, by developing regional culturally visual resources that include Aboriginal languages and facilitate peer support, so young people can understand and manage their diabetes better.
- Dedicate staff and resource coordination of care for the young person, continuity of care from their childhood to adult: "I don't like seeing, like, people I don't know. I like seeing people that I know very well".
- Establish a register of young people with T2D, like the WA Rheumatic Heart Disease Register, which assists with ongoing patient care.
- Support the social emotional wellbeing, cultural and physical wellbeing of young people with T2D.
- Complement and assist the role of young people's Carers.
- In the Kimberley Clinical Protocol 'Type II Diabetes in Children' add, under Principles of Management: i) When a child is diagnosed, and a change of medication occurs to have an Aboriginal Health Worker/Practitioner (AHW/P) present. ii) AHW/P to strengthen coordination of young people's T2D health care and transition to adult care, continuity of care.

This Kimberley-based study forms part of a broader collaboration, of the Diabetes Across the Lifecourse: Northern Australia Partnership, whose aims including improved health outcomes for Aboriginal and Torres Strait Islander children and young people with type 2 diabetes across northern Australia. We thank all the young people and their Carers who shared their story, the health service staff in this study and the health services that agreed to participate.

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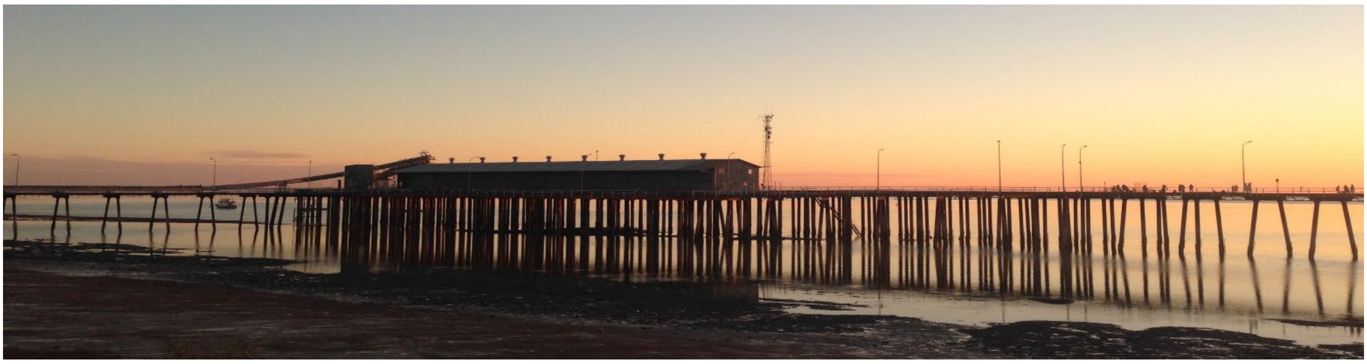
Accessible health care for Aboriginal young people in remote Australia

Thank you to the reference group, participants in the study and board and management of Derby Aboriginal Health Service



This study was a joint project between Derby Aboriginal Health Service (DAHS) and Rural Clinical School of Western Australia (RCSWA) and was funded through a RCSWA Early Career Grant. Please direct any questions or comments to Dr Susannah Warwick by email (susannah.warwick@rcswa.edu.au) or phone (08) 91616600.

Young Aboriginal people's perspective on access to health care in remote Australia: hearing their voices

What is the issue?

- Young Australian Aboriginal people experience poor health outcomes but have low utilisation of health care.

Why was this study done?

- To find out what helps and hinders adolescent and young adult Aboriginal people in seeking health care at a remote Western Australian Aboriginal Community Controlled Health Service.
- To improve access to health care in this group of young people.

What did we do?

- We interviewed 16-25 year old Aboriginal people from Derby and surrounding communities to find out what they thought about accessing health care.

What did we find?

- The young people interviewed valued good communication and relationships with health care staff, and identified that local, long term , gender matched Aboriginal staff were best placed to provide this.
- Confidentiality was very important to the participants.
- Shame was a barrier to seeking health care.
- The participants identified that health education and promotion for young people was important.

Who should care most?

- Community members and primary health care managers who establish primary health facilities for people who are under-utilising health care services, particularly young people.
- Primary health care stake-holders involved in staff recruitment, retention and training.
- Young people who need to access health services.

Recommendations for action

- Primary health care providers should be involved in health promotion and education targeted to young people.
- Primary health care facilities should be intentional in recruiting, training and retaining appropriate staff to work with young people.
- Good communication and strong relationships should be emphasised in provision of health care services.

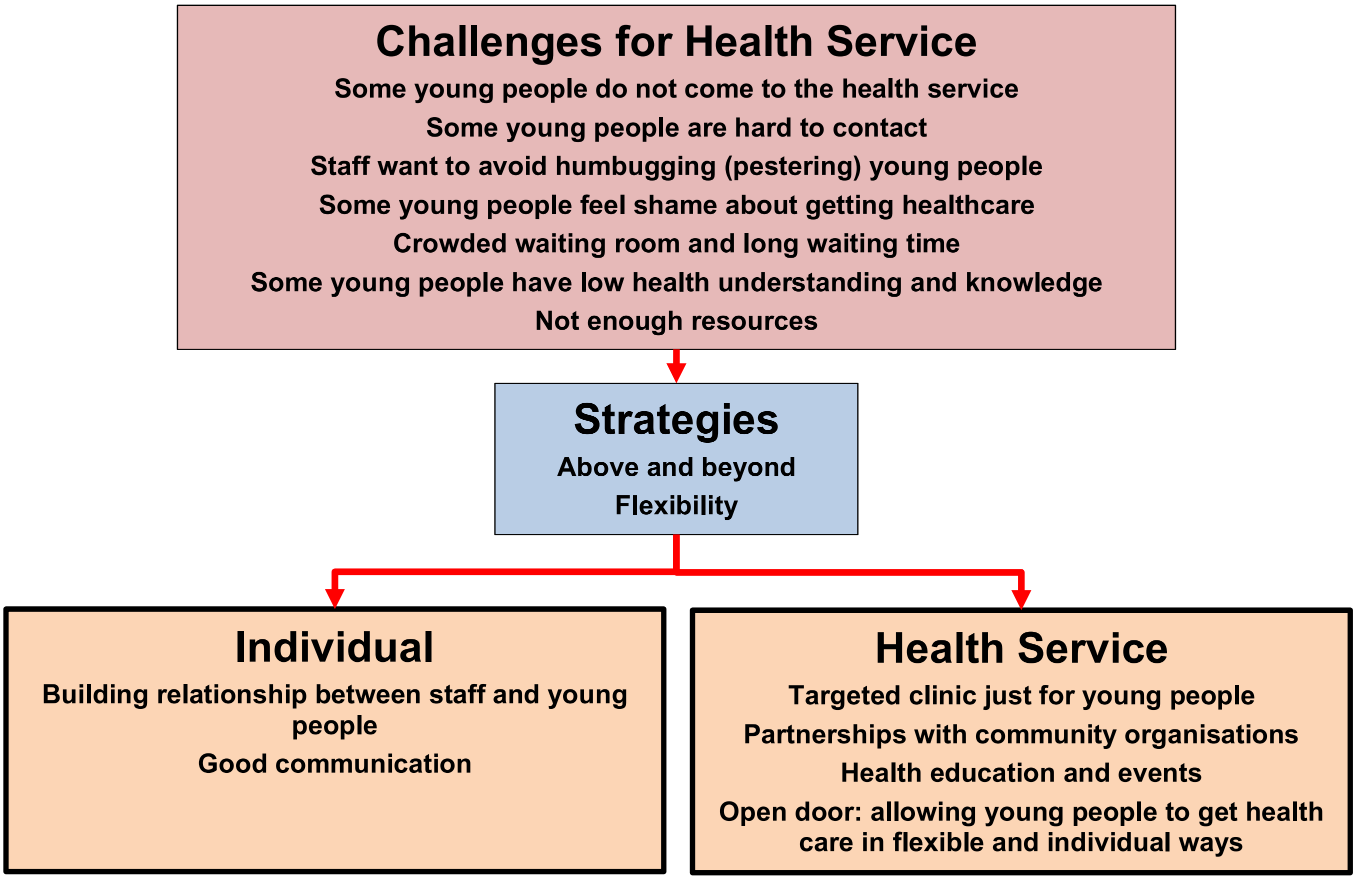
Above and Beyond: Fashioning an accessible health service for Aboriginal youth in remote Western Australia

Why was DAHS Access Study #2 done?

- The young people told us that health staff were very important, so we decided to ask the health staff what they thought.

What does this research show?

- Staff at the health service said that there were challenges in working with the young people and they said there were a number of strategies they used in overcoming them.



Challenges for Health Service

Some young people do not come to the health service
Some young people are hard to contact
Staff want to avoid humbugging (pestering) young people
Some young people feel shame about getting healthcare
Crowded waiting room and long waiting time
Some young people have low health understanding and knowledge
Not enough resources

Strategies

Above and beyond
Flexibility

Individual

Building relationship between staff and young people
Good communication

Health Service

Targeted clinic just for young people
Partnerships with community organisations
Health education and events
Open door: allowing young people to get health care in flexible and individual ways

What does this mean for health services and staff who work with young Aboriginal people?

- Employ staff who communicate well with young people and who can build relationships with them.
- Develop a health service which:
  - Has a young people's clinic
  - Works with other youth focussed organisations
  - Emphasises health education and events
  - Allows young people to get their health care in a number of different ways, by a number of different routes.

Publications

Warwick S, Atkinson D, Kitaura T, LeLievre M, Marley JV. Young Aboriginal People's Perspective on Access to Health Care in Remote Australia: Hearing Their Voices. Prog Community Health Partnership 2019; https://doi.org/10.1353/cpr.2019.0017

Warwick S, LeLievre M, Seear K, Atkinson D, Marley JV. Above and Beyond: Fashioning an Accessible Health Service for Aboriginal Youth in Remote Western Australia. Prog Community Health Partnership 2021; 15:e7. https://doi.org/10.1353/cpr.2021.0049

Susannah Warwick. Accessible health care for Aboriginal young people in remote Australia: The University of Western Australia; 2021. https://doi.org/10.26182/ax1g-s033

Checking for diabetes in high-risk young people is important but challenging

Why was this study done?

- Type 2 diabetes is too much sugar/glucose in the blood and is responsible for a lot of sickness in the Kimberley. If you have diabetes you may get very sick. You may need to go onto a machine (kidney problems), you may get eye problems, you may get feet problems, you may get heart problems.
- Most people do not know they have diabetes, and therefore it is important to check for it.
- Diabetes in young people (under 25) is a bad type of diabetes and leads to problems much faster than if you get diabetes when you are older.
- From 2015, HbA_{1c} tests have been used instead of lab blood sugar tests to check for diabetes in Kimberley adults. HbA_{1c} tests are quicker and easier than lab blood sugar tests as you only have to do one test and it doesn't matter if you have eaten anything, so it can be done straight away.
- To check for diabetes in Kimberley young people aged 10-14, the more complicated blood sugar/glucose tests were still being used. We wanted to know if using HbA_{1c} tests would improve checking for diabetes in young people.

How was this study done?

- Two sites took part in this study (an Aboriginal Community Controlled Health Service (ACCHS), and a Regional Hospital), as well as remote clinics covered by these sites.
- We developed a better way to check for diabetes for 10-14 year olds – we added HbA_{1c} tests, and asked staff at the two sites to try this out for 6-months. While all adults should be checked for diabetes each year, we asked staff to only check for diabetes in 10-14 year olds who had a high risk of having diabetes.
- To find out whether this change resulted in more 10-14 year olds being checked for diabetes, we looked at the number of people that had tests done during the 6 month period after the new test and compared this to an earlier 6-month period. We also asked staff what they thought of the new way of checking for diabetes.

What did we find?

- Checking for diabetes increased a lot at the ACCHS, where nurses and Aboriginal Health Workers do an initial assessment of people before they see a doctor.
- Lots of people (staff and patients) were worried about checking for diabetes in 10-14 year olds, as they did not want to hurt them.

What does this mean?

- Checking for diabetes in 10-14 year olds that have a high risk of having diabetes is important.
- This study has given us ideas on what we need to do to improve checking for diabetes in 10-14 year olds. We will take these into account when we update the current advice on checking for diabetes in this age group.

Many thanks to patients, staff and Council of participating services. Without your help this research would not have been possible.
This study was a joint project between Kimberley Aboriginal Community Controlled Health Organisations, WA Country Health Service and the Rural Clinical School of Western Australia.

If you have any questions or comments please direct them to Julia Marley by email julia.marley@rcswa.edu.au or phone (08) 9194 3235.

Kimberley Investigation and Description of type 2 Diabetes of Young-onset (KIDDY) – Manuscript #1 – plain language report for patients: Complex screening algorithms

Complex diabetes screening guidelines for high-risk adolescent Aboriginal Australians: a barrier to implementation in primary health care

Why was this study done?

- Type 2 diabetes (T2D) is a major health issue in the Kimberley. Patients usually do not know they have diabetes and therefore it is important to screen for it.
- Young-onset diabetes (diabetes that develops under age 25) is particularly aggressive and leads to kidney, feet, eye and heart complications much quicker than adult-onset diabetes.
- The T2D guideline for adults in the Kimberley was changed in 2015 to recommend use of HbA_{1c} capillary point of care (POC) and venous tests to screen for diabetes instead of venous blood glucose tests. This was done after a local study found it was a better way of diagnosing T2D in remote areas.
- The current T2D guideline for adolescents (aged 10-14) still recommends using laboratory blood glucose samples. This makes testing for diabetes difficult as patients have to be fasted for the test.
- We wanted to find out if using HbA_{1c} tests in 10-14 year olds, using either POC or venous tests, would increase diabetes screening in that age group. We also wanted to find out what sorts of things encouraged or prevented staff from screening.

How was this study done?

- A screening algorithm for 10-14 year olds incorporating HbA_{1c} tests was developed based on Australian and international best practice and in consultation with local and regional health practitioners. The algorithm allowed for screening via an HbA_{1c} or a blood glucose pathway, and stipulated that only high risk adolescents should receive venous testing.
- The algorithm was piloted for 6 months (27 June 2016 – 26 December 2016) at two participating primary health care (PHC) services: an Aboriginal Community Controlled Health Service (ACCHS); and the General Practice (GP) and Emergency Department (ED) at a hospital in the same town. Remote clinics covered by these sites were also included.
- Using electronic medical record data from the PHC services, we compared the number of people screened during the pilot with an earlier 6 month period (1 October 2015 – 31 March 2016).
- Interviews were held from October to December 2016 with staff from the participating PHC services, to assess their knowledge and satisfaction with the algorithm, and to identify barriers and enablers to implementing it.

What did we find?

Screening increased significantly at the ACCHS

- Screening via capillary and venous blood tests increased significantly at the ACCHS (36% during the pilot v 22% before the pilot).
- Seven patients received initial or follow-up venous blood tests during the pilot, compared to none before the pilot. All venous tests conducted were HbA_{1c} tests.
- Screening was most commonly initiated by a nurse, child health nurse or Aboriginal Health Worker (AHW) for routine observations. Other reasons included for Aboriginal health checks (eg Medicare Benefits Schedule item 715), or because the patient had particular risk factors for diabetes.

Screening did not change at the hospital

- There was no difference in screening during the pilot compared to before the pilot (0.02% v 0.02%). More patients were screened in the General Practice compared to ED presentations (6 of 29 GP patients screened v 5 of 435 ED patients screened).
- Doctors initiated all screening tests.
- It is likely more screening occurred at the hospital than we identified from the electronic health records, as uncomplicated presentations to ED were commonly only recorded in paper files.

Barriers to using the algorithm

- Apprehension about T2D screening in young adolescents was a significant barrier to screening, with health practitioners often reluctant to follow recommendations outlined in the algorithm. This was evident in a number of staff reporting that they did not want to perform POC or venous tests due to their concern that they may cause unnecessary pain to patients. Similarly, only a small proportion of patients received follow-up venous testing despite being identified as high risk.
- Certain characteristics of the hospital's General Practice may have contributed to the hospital's comparatively lower rates of screening. These included: patients not having routine observations taken by a nurse or AHW prior to their consult with a doctor; shorter appointment times; the General Practice being staffed by a rotating roster; and a high reliance on locum staff.

What does this mean?

The results from this study gives us ideas on what sorts of things could improve diabetes screening in 10-14 year olds. These include:

- Clear guidelines that include HbA_{1c} testing;
- Targeted screening programs which focus on patients that have a high risk of having diabetes;
- Educating staff, patients and their families about the importance of diabetes screening in 10-14 year olds, and about the evidence supporting our approach to screening;
- Organisational practices which support screening, including AHWs performing an initial assessment of a patient before they see a doctor; and
- Use of POC HbA_{1c} tests, which could prevent the need to take a venous HbA_{1c} test. We know from a previous study that this improves diabetes screening in adults.

Where to from here?

We will take the findings from this study into account as we update the guideline for diabetes screening in 10-14 year olds.

Many thanks to patients, staff and Council of participating services. Without your help this research would not have been possible.

This study was a joint project between Kimberley Aboriginal Community Controlled Health Organisations, WA Country Health Service and the Rural Clinical School of Western Australia.

Publication:

Andreana Manifold, David Atkinson, Julia V. Marley, Lydia Scott, Gavin Cleland, Paula Edgill and Sally Singleton. Complex diabetes screening guidelines for high-risk adolescent Aboriginal Australians: a barrier to implementation in primary health care. *Aust J Prim Health* 2019; 25:501-508. Available from: https://doi.org/10.1071/PY19030

To receive a full copy of the paper or if you have any questions or comments please direct them to Julia Marley by email julia.marley@rcswa.edu.au or phone (08) 9194 3235.