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## Use of a Primary Care Dataset to Describe ‘The Real Picture’ of Diabetes in Kimberley Aboriginal Communities

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# Use of a Primary Care Dataset to Describe 'The Real Picture' of Diabetes in Kimberley Aboriginal Communities

## Abstract

### Objective

Aboriginal communities are impacted by high rates of diabetes, however these are currently underestimated by national data sources used by policy and decision makers to inform allocation of health resources. We aimed to estimate diabetes prevalence and screening coverage using primary care electronic medical record data.

### Methods

A cross-sectional audit was conducted using primary care data from Aboriginal regular Aboriginal Community Controlled Health Service (ACCHS) clinic attendees aged 15 years and over (n=1763) in five remote communities in the Kimberley region. Main outcome measures were overall diabetes prevalence; age-specific diabetes prevalence; prevalence of pre-diabetes; and screening rates among patients without diabetes in the previous 12 and 24 months.

### Results

The overall diabetes prevalence was 29.2%. An additional 8.6% had pre-diabetes on screening in the last 12 months. Prevalence exceeded overall nationally reported figures even in the youngest age group (15–34 years, 9.7%) and increased with age. Over a third (42.5%) of those without diabetes had been screened with an HbA1c test in the previous 12 months. This increased to 60.4% when analysed over a 24-month period.

### Conclusions

The prevalence of diabetes in Kimberley remote communities is five times higher than that reported by the National Diabetes Services Scheme (NDSS), the most widely used national data source for diabetes prevalence. The excess prevalence begins from a young age and supports regional guidelines commencing screening from 15 years of age. Screening rates compared favourably with other available studies. ACCHS are well placed to meaningfully monitor diabetes prevalence to inform effective local prevention strategies.

### Acknowledgements

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### Keywords

diabetes, prevalence, primary care, Aboriginal and Torres Strait Islander health, screening, preventive care, life course approach, health equity

The global prevalence of diabetes is rising at a rate that far exceeds previous estimates of future disease burden (Saeedi et al., 2019). In Australia, the prevalence is known to be higher in Aboriginal and Torres Strait Islander people (Australian Institute of Health and Welfare, 2023; Keel et al., 2017; Minges et al., 2011) with diabetes attributed as the second leading cause of death (Australian Bureau of Statistics, 2019a), and as causing five times the rate of diabetes-specific hospitalisation (Ride & Burrow, 2022). Prevalence is also known to be greater in remote compared to urban settings among Aboriginal and Torres Strait Islander populations (Minges et al., 2011).

Premature mortality and morbidity is driven by high levels of both microvascular and macrovascular complications and often by early onset of disease, which confers risk to the next generation (Australian Government, 2023; West et al., 2017). The impacts of colonisation and the social determinants of health are important contributors to the intergenerational experience of diabetes in First Nations populations in Australia, and in other countries (Maple-Brown & Hampton, 2020). Ongoing barriers in accessing culturally-appropriate healthcare for diabetes prevention and management (particularly in remote areas) further perpetuates the cycle of diabetes and its life-impacting complications (Australian Government, 2023; Maple-Brown & Hampton, 2020; Ryder et al., 2023).

The Australian Bureau of Statistics (ABS) health surveys, including the National Aboriginal and Torres Strait Islander Health Survey (Australian Bureau of Statistics, 2019b), and the National Diabetes Services Scheme (NDSS) registrant database are recommended as the best available sources for monitoring diabetes prevalence in Australia (Diabetes Australia, 2019; National Diabetes Strategy Advisory Group, 2015). Strengths of these data sources include their routine collection and consistency over time, however, these sources have their limitations. The most recent ABS surveys showed that Aboriginal and Torres Strait Islander Australians were 2.8 times more likely to report having diabetes or “high sugar levels” than non-Indigenous Australians (17% vs. 6%) when differences in age structure were adjusted for (Australian Government, 2023) based on self-reported data. Previous publications have shown prevalence estimates to be higher with biomedical data compared

to self-report (Ride & Burrow, 2022), highlighting the potential for these prevalence estimates to be an underestimate.

The NDSS provides prevalence estimates at the regional level derived from the NDSS registrant database, reporting the diabetes prevalence in the Kimberley region of Western Australia (WA) at 6.0%, comparable to the national figure of 5.6% (Diabetes Australia, n.d.). This is inconsistent with local estimates from individual community audits that found prevalence rates ranging from 22% to 32% (Martin et al., 2005; Straw et al., 2019), and is explained by the requirement for individual registration to the NDSS database as an opt-in system (Australian Government, 2023). Additionally, self-reported diabetes or high sugar levels in younger Aboriginal and Torres Strait Islander age-groups were only 1% in the 18 to 24 years age group and 3% in the 25 to 34 years age group in ABS surveys (Australian Government, 2023), inconsistent with other published work demonstrating the high burden of young-onset diabetes in this population (Titmuss et al., 2022), suggesting possible under-diagnosis in young people.

The association of Type 2 diabetes (T2D) with end-organ damage even in asymptomatic stages, and the opportunity to provide diabetes management at an earlier stage in disease progression to improve outcomes provides a rationale for screening populations at increased risk of T2D (Colagiuri et al., 2009; Ke et al., 2023; Klein Woolthuis et al., 2013; National Aboriginal Community Controlled Health Organisation and The Royal Australian College of General Practitioners, 2018). Screening can also detect pre-diabetes which confers an increased risk of gestational diabetes, progression to T2D and cardiovascular disease (Bell et al., 2020). Within Australia, screening intervals and eligibility varies by region and by population group (Paul et al., 2017). Kimberley regional guidelines recommend annual screening with HbA1c from 15 years old in keeping with the starting age of the annual adult Aboriginal and Torres Strait Islander Peoples Health Assessment (Kimberley Aboriginal Health Planning Forum, 2020). Previous research has suggested that annual screening might be difficult to achieve, especially in younger patients (Paul et al., 2017).

Reliably monitoring diabetes prevalence maintains diabetes awareness and promotes prevention, encourages improvements in diagnosis and management, identifies population groups at increased risk, and provides essential data for health service planning and resource allocation (Australian Institute of Health and Welfare, 2009; Saeedi et al., 2019; P. Zimmet et al., 2016; P. Z. Zimmet, 1999). To achieve useful estimates of T2D prevalence, screening programs must achieve sufficient coverage and cases must be able to be accurately recorded and reported. Using the electronic medical record system utilised by the Kimberley Aboriginal Community Controlled Health Service (ACCHS) sector, this research aims to reliably provide the real picture of diabetes in five remote Aboriginal communities in the Kimberley region of WA, including estimates of screening coverage according to Kimberley guidelines. The findings of this research will assist to better inform service planning and delivery for the prevention and management of diabetes in the Kimberley.

## **Methods**

### **Setting and population**

The Kimberley region in WA spans more than 400,000 square kilometres and has a population of approximately 34,000 people with 42% of the population identifying as Aboriginal (Australian Bureau of Statistics, 2017). Data from five remote Kimberley communities are included in this study. All receive primary health services through the ACCHS Sector, use the same electronic medical record system (MMEx, ISA Technologies) and are classified as Modified Monash 7 (very remote) (Australian Government Department of Health and Aged Care, 2019). Three communities were analysed together (as “Community 1”) due to clinic proximity, shared clinic management and regular patient movement between communities. Point-of-care HbA1c testing is available in all included communities through the Australian Government’s Quality Assurance for Aboriginal Medical Services (QAAMS) Program.

## Design

Data collected included demographic information (patient identification number, date of birth, sex); diabetes care plan information (assigned or not assigned); and HbA1c results for all regular clinic attenders aged 15 years and over to 1 January 2021. Name and Medicare number were temporarily retained to identify duplicate patient files before de-identification and analysis. Both venous and point-of-care HbA1c results were included (Marley et al., 2015).

Community population denominators were calculated from the number of regular clinic attendees, defined as persons attending the clinic at least three times in the 24 months preceding the study's census date (1 January 2021).

A diagnosis of diabetes was defined as assignment of a diabetes care plan within the electronic medical record or a recorded HbA1c  $\geq$  6.5% (48 mmol/mol) in keeping with Kimberley T2D guidelines for diagnosis (Kimberley Aboriginal Health Planning Forum, 2020). To estimate the number of non-type 2 diabetes diagnoses, a medical record keyword search was run ("type 1", "T1", "insulin", "latent", "LADA") and identified only two confirmed cases. Most cases included in these prevalence estimates are therefore likely to represent T2D; however, prevalence estimates are quoted as undifferentiated "diabetes" estimates in the interests of accuracy.

Persons not meeting criteria for a diabetes diagnosis were considered to have pre-diabetes if their most recent screening HbA1c was between 5.7% to 6.4% (39-46 mmol/mol) and further categorised into low-range (HbA1c 5.7-5.9%) or high-range (HbA1c 6.0-6.4%) pre-diabetes (Bell et al., 2020). Recency of screening was analysed over the 12 months prior to the census date, as per Kimberley T2D guidelines (Kimberley Aboriginal Health Planning Forum, 2020) and also over an extended 24 month period, allowing a pragmatic margin for identification, recall and completion of screening.

Data were extracted via Microsoft Excel for cleaning and duplicate removal ( $n = 23$ ) before being imported into Stata 16 (StataCorp 2019) for analysis. Implausible results were removed (HbA1c  $<2\%$  or  $>30\%$ ) as suspected data entry errors. The hypothesis of no

difference in median age between communities and between genders was tested using the K-sample equality-of-medians test. Diabetes prevalence rates and screening rates for the three communities and for gender were compared using Pearson's chi-square test, with a p-value of <0.05 considered statistically significant. The date of the most recently recorded HbA1c for each patient without diabetes was used to determine if diabetes screening was up to date.

### **Research Priorities and Ethics**

This research was undertaken at the request of the Kimberley Aboriginal Health Planning Forum (KAHPF). The KAHPF was formed in 1998 and is now the peak regional health forum for improving health outcomes for Aboriginal people in the Kimberley. The KAHPF is co-chaired by Kimberley Aboriginal Medical Services (KAMS), which is the peak Aboriginal Community Controlled Health Organisation in the Kimberley region. The KAHPF's membership includes all Kimberley ACCHS and other health service providers with long-standing relationships with Aboriginal people in the region (Kimberley Aboriginal Health Planning Forum, 2023). This research was conceptualised and supported by KAMS after KAHPF members identified that the number of people requiring care for diabetes far exceeded available regional health resources and was not reflected in regional prevalence data in nationally available data sets. KAMS executive staff endorsed the manuscript prior to submission for publication.

This study received ethics approval from the Western Australian Aboriginal Health Ethics Committee (Project 1010) and received support from the KAHPF Research Subcommittee. Both of these committees include Aboriginal leadership and exist to support and promote research that reflects and is responsive to the needs of Aboriginal people (Aboriginal Health Council of WA, n.d.; *Kimberley Aboriginal Health Planning Forum Research Subcommittee*, n.d.).

### **Results**

There were 1763 Aboriginal and/or Torres Strait Islander regular clinic attendees aged 15 years and over in the study population during the period of analysis. Demographics

are presented in Table 1. There was no significant difference in median age between communities or between male and female attendees. Over half (55.7%) of participants were female and most (52.3%) were aged between 15 and 34 years. There was no significant difference between age distribution in females with diabetes (median age 33 years, IQR 23-47) and males with diabetes (median age 34 years, IQR 24-27).

The overall prevalence of diabetes in the study population was 29.2% (515/1763) and ranged from 25.2% in Community 2 to 34.8% in Community 3 (Table 1). Diabetes prevalence increased with age, up to 66.7% in those aged 65 years or older (Table 2). In those without known diabetes, 42.5% (530/1248) had been screened with venous or point-of-care HbA1c in the 12-month period before census date. Males were less likely to have been screened in the past 12 months than females (0.38% vs 0.45%,  $p=0.01$ ). Of these, 10.8% (57/530) had high-range pre-diabetes, 17.7% (94/530) had low-range pre-diabetes, and the remainder 71.5% (379/530) had no diabetes detected. Screening coverage increased to 60.4% (754/1248) when a 24-month period was used for analysis, the remaining 39.6% (494/1248) had no screening test within the preceding 24 months. This included 39 individuals who had a HbA1c in the pre-diabetes range (5.7-6.4%) at last test and 307 individuals who had no screening test on record. Screening coverage was lowest in the 15-24-year age group and increased with age.

There was a statistically significant difference between communities in the proportion of patients with diagnosed diabetes ( $p=0.001$ ). Post-hoc tests showed Community 3 had a higher prevalence of diabetes than Community 1 (34.8% v 26.7%  $p=0.001$ ) and Community 2 (34.8% v 25.2%  $p=0.003$ ). This difference was associated with higher 12-month screening rates when Community 3 was compared to Community 1 (proportion unscreened – 36.5% v 44.1%  $p=0.004$ ) but not when compared to Community 2 (proportion unscreened – 36.5% v 39.6%  $p=0.4$ ).

**Table 1***Demographic Characteristics and Diabetes Status of the Study Sample by Community*

Characteristic	Community 1	Community 2	Community 3	Total
<b>Demographic characteristics</b>				
Sex (female) (n (%))	473 (54.7)	169 (56.7)	340 (56.7)	982 (55.7)
Median age in years (IQR)	33.0 (23-46)	35.0 (24-50)	33.0 (24-48)	33.0 (24-47)
Age group (years) (n (%))				
15-24	249 (28.8)	76 (25.5)	157 (26.2)	482 (27.3)
25-34	205 (23.7)	70 (23.5)	165 (27.5)	440 (25.0)
35-44	167 (19.3)	64 (21.5)	95 (15.8)	326 (18.5)
45-54	142 (16.4)	34 (11.4)	93 (15.5)	269 (15.3)
55-64	61 (7.1)	33 (11.1)	62 (10.3)	156 (8.8)
≥65	41 (4.7)	21 (7.0)	28 (4.7)	90 (5.1)
Total	865 (100)	298 (100)	600 (100)	1763 (100)
<b>Diabetes status</b>				
Diabetes	231 (26.1)	75 (25.2)	209 (34.8)	515 (29.2)
No diabetes, by screening status <sup>a</sup> :				
Pre-diabetes	68 (7.9)	26 (8.7)	57 (9.5)	151 (8.6)
Normal HbA1c	185 (21.4)	79 (26.5)	115 (19.2)	379 (21.5)
Unscreened	381 (44.4)	118 (39.6)	219 (36.5)	718 (40.7)
Total	865 (100)	298 (100)	600 (100)	1763 (100)

*Note.* Pre-diabetes defined as those with most recent screening HbA1c between 5.7 and 6.4% (39 and 46 mmol/mol). Normal HbA1c defined as those with most recent screening HbA1c <5.7% (<39 mmol/mol).

<sup>a</sup>Using HbA1c performed in the last 12 months, disaggregated by HbA1c result.

**Table 2**

*Diabetes Status by Age Group (including age-specific prevalence rates) and by Screening Status in Last 12 Months and 24 Months, All Communities*

Age group (years)	Total study population (n (%))	Diabetes diagnosis <sup>a</sup> (n (%))	No diabet es diagno sis <sup>b</sup> (n)	Most recent HbA1c screening result in patients with no diabetes diagnosis					
				Within previous 12 months n (% of total study population)			Within previous 24 months n (% of total study population)		
				Pre- diabetes <sup>c</sup> (%)	Normal <sup>d</sup>	No result	Pre- diabetes <sup>c</sup> (%)	Normal <sup>d</sup>	No result
				15-24	482	26 (5.4)	456	29 (6.0)	136 (28.2)
25-34	440	63 (14.3)	377	36 (8.2)	130 (29.6)	211 (48.0)	54 (12.3)	198 (45.0)	125 (28.4)
35-44	326	128 (39.3)	198	37 (11.4)	56 (17.2)	105 (32.2)	50 (15.3)	81 (24.9)	67 (20.6)
45-54	269	152 (56.5)	117	27 (10.0)	33 (12.3)	57 (21.2)	33 (12.3)	46 (17.1)	38 (14.1)
55-64	156	86 (55.1)	70	16 (10.3)	16 (10.3)	38 (24.4)	22 (14.1)	20 (12.8)	28 (18.0)
≥ 65	90	60 (66.7)	30	6 (6.7)	8 (8.9)	16 (17.8)	6 (6.7)	13 (14.4)	11 (12.2)
Total	1763	515 (29.2)	1248	151 (8.6)	379 (21.5)	718 (40.7)	205 (11.6)	549 (31.1)	494 (28.0)

<sup>a</sup>Diabetes defined as those with a diabetes care plan assigned to their electronic medical record or those with an HbA1c  $\geq 6.5\%$  ( $\geq 48$  mmol/mol) at any time before 1 January 2021.

<sup>b</sup>Eligible for routine screening.

<sup>c</sup>Pre-diabetes defined as those with most recent screening HbA1c between 5.7 and 6.4% (39 and 46 mmol/mol).

<sup>d</sup>Normal HbA1c defined as those with most recent screening HbA1c  $<5.7\%$  ( $<39$  mmol/mol).

## Discussion

This study has provided reliable diabetes prevalence estimates for a remote Kimberley Aboriginal population. As expected, the diagnosed diabetes prevalence in this population group was high (Martin et al., 2005; Straw et al., 2019), five times the prevalence currently reported for the region by the NDSS (Diabetes Australia, n.d.).

Encouragingly, over 40% of the population without known diabetes had been screened within the last 12 months, and over 60% in the last 24 months. This compared favourably to a large national practice database (32.3 – 61.3% screened over three years, stratified by identified risk factors) (Zheng et al., 2022), despite the narrower definition of screening used in our study (where fasting or random BSL alone was not counted as “screened”). Thirty-nine individuals had pre-diabetes at last HbA1c but had not been re-screened within two years, a high-risk group requiring enhanced follow-up given a high rate of annual conversion to overt diabetes (Bansal, 2015).

We confirm the concerning finding of a high prevalence of diabetes in young people. In those aged 15 to 34 years, 9.7% had diabetes and an additional 10.2% had pre-diabetes when last screened. This is in keeping with the known high rates of T2D observed in First Nations youth globally, including in Australia (Magliano et al., 2020), however is not well represented by national self-report data (Australian Bureau of Statistics, 2019b). Young-onset T2D is associated with a greater risk of complications, a faster decline in beta-cell function than older-onset T2D (Magliano et al., 2020), increased rates of morbidity and mortality and intergenerational impact (Harris et al., 2017; Magliano et al., 2020; Mendelson et al., 2011; Nguyen et al., 2016). The younger the onset of T2D the more likely it is to affect young women during pregnancy, a key risk factor for young-onset T2D in the next generation (Harris et al., 2017; Magliano et al., 2020; Mendelson et al., 2011). Unfortunately, more than half (54%) of 15- to 34-year-olds had not been screened in the last 12 months. Given the important implications of pre-diabetes and undiagnosed T2D in this age group (Jamieson et al., 2021; Magliano et al., 2020), and the benefits of screening (Colagiuri et al., 2009; Ekoe et al., 2018; Gilmer & O’Connor, 2010; National Aboriginal Community

Controlled Health Organisation and The Royal Australian College of General Practitioners, 2018; Nguyen et al., 2016), prioritising age-appropriate screening strategies is a priority.

Although achieving high screening rates can be challenging (Paul et al., 2017), uptake can be maximised by integrating screening into existing preventive health activities. This includes routine health checks, alongside opportunistic screening for and management of sexually transmitted infections, during preconception care (Griffiths et al., 2020), and in early pregnancy (Jamieson et al., 2021). Identifying women with previously undiagnosed diabetes, pre-diabetes, or who are at risk of gestational diabetes in early pregnancy is a key opportunity to manage hyperglycaemia during pregnancy, reduce pregnancy-related maternal and neonatal risks, and reduce the long term risk of developing T2D in both mother and child (Harris et al., 2017; Jamieson et al., 2021; Magliano et al., 2020). Screening must link in with effective and culturally-appropriate longitudinal care to address T2D prevention and glycaemic management (Harris et al., 2017). Engaging young people in prevention and management of T2D can be challenging, but has proven feasible in the primary health setting in the Kimberley (Seear et al., 2019; Warwick et al., 2019). Potential strategies to improve engagement with young people with a Kimberley ACCHS have been explored elsewhere and include gender-matched staff, clear confidentiality policies and specific young people's clinics (Warwick et al., 2019).

This study highlights the benefit of using primary care data sets to generate regionally accurate prevalence data to inform service delivery for diabetes prevention and management, and policy planning. This is likely to be particularly important for rural and remote areas, and for areas where population demographics and characteristics are not well represented by national data sources such as the NDSS. In the remote Kimberley, there are limited direct benefits associated with NDSS registration, as provision of products and support services are most often obtained through the local clinic rather than through the scheme (Australian Government, 2023).

A strength of our study was the analysis of diabetes prevalence in conjunction with screening rates. The screening rate of 60% over 24 months is relatively high, contributing to the accuracy of our estimates. The ACCHS was the only primary care provider in the area, enabling high levels of case ascertainment.

We did not distinguish between type 1 diabetes mellitus (T1D) and T2D in our data collection and analysis; however, rates of T1D have been shown to be similar in Aboriginal and Torres Strait Islander populations to the national population (Australian Government, 2023), with the excess burden attributable to T2D. It is likely that only a small minority of patients in our study population have T1D, as supported by medical record keyword searches performed on the electronic medical record system. We did not attempt to quantify the impact of gestational diabetes.

An additional limitation is the impact of COVID-19 on chronic disease service delivery during the audit period. Although clinics continued to provide care, opportunistic care provided to unwell patients may have been reduced due to infection control concerns and staffing pressures. This would have a greater impact on 12-month than 24-month screening rates. The overall impact of COVID-19 on diabetes screening could be more formally assessed in additional studies.

### **Conclusion**

The prevalence of diabetes in Kimberley remote communities is five times higher than that reported by the NDSS. Young people and people with a previously abnormal HbA1c are groups that may benefit from enhanced screening programs. Diabetes screening in young people is an important strategy in the life course approach to the prevention and management of diabetes in Aboriginal people. Annual screening for age-eligible patients may be difficult to achieve; however, the recommendation is supported by the prevalence rates demonstrated in this study. Screening can be integrated into preventive clinic activities and monitored through continuous quality improvement activities within primary health care services. The ACCHS sector is well placed to meaningfully monitor diabetes prevalence to inform effective local prevention strategies.

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