




BMJ Open Prevalence and incidence of diabetes among Aboriginal people in remote communities of the Northern Territory, Australia: a retrospective, longitudinal data-linkage study

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ABSTRACT

Objectives To assess the prevalence and incidence of diabetes among Aboriginal peoples in remote communities of the Northern Territory (NT), Australia.

Design Retrospective cohort analysis of linked clinical and administrative data sets from 1 July 2012 to 30 June 2019.

Setting Remote health centres using the NT Government Primary Care Information System (51 out of a total of 84 remote health centres in the NT).

Participants All Aboriginal clients residing in remote communities serviced by these health centres (N=21 267).

Primary outcome measures Diabetes diagnoses were established using hospital and primary care coding, biochemistry and prescription data.

Results Diabetes prevalence across all ages increased from 14.4% (95% CI: 13.9% to 14.9%) to 17.0% (95% CI: 16.5% to 17.5%) over 7 years. Among adults (≥20 years), the 2018/2019 diabetes prevalence was 28.6% (95% CI: 27.8% to 29.4%), being higher in Central Australia (39.5%, 95% CI: 37.8% to 41.1%) compared with the Top End region (24.2%, 95% CI: 23.3% to 25.1%, p<0.001). Between 2016/2017 and 2018/2019, diabetes incidence across all ages was 7.9 per 1000 person-years (95% CI: 7.3 to 8.7 per 1000 person-years). The adult incidence of diabetes was 12.6 per 1000 person-years (95% CI: 11.5 to 13.8 per 1000 person-years).

Conclusions The burden of diabetes in the remote Aboriginal population of the NT is among the highest in the world. Strengthened systems of care and public health prevention strategies, developed in partnership with Aboriginal communities, are needed.

INTRODUCTION

Diabetes is a major cause of morbidity and premature mortality worldwide. Prevalence rates of type 2 diabetes and obesity have increased in recent decades due to factors such as globalisation and urbanisation, which are accompanied by sedentary behaviour and energy-dense diets.^{1 2} Accompanying these

Strengths and limitations of this study

- ⇒ This study describes the burden of diabetes among Aboriginal peoples in the Northern Territory, Australia, who represent some of the world's longest surviving cultures but experience substantial health and social inequality compared with the broader Australian population.
- ⇒ The large sample size and use of detailed, individual-level data with a robust data-linkage methodology provide reliable epidemiological estimates in a context where traditional observational studies are immensely challenging, not least due to the population being dispersed over such a vast geographical area.
- ⇒ The retrospective approach relies on existing clinical data, so the prevalence and incidence of diabetes may be underestimated due to incomplete screening.
- ⇒ Our findings are unlikely to be generalisable to Aboriginal peoples living in urban centres.

factors, there is growing interest in the role of epigenetic mechanisms and the intrauterine environment as drivers of intergenerational diabetes and obesity risk.² The increasing prevalence of diabetes is also contributed to by ageing of populations and improved survival with the condition.¹⁻³

Unlike type 1 diabetes, which is caused by insulin deficiency due to autoimmune-mediated pancreatic beta-cell failure, type 2 diabetes is characterised by insulin resistance and a degree of beta-cell dysfunction.⁴ Indigenous populations are disproportionately affected by type 2 diabetes and associated complications.⁵ Social determinants of health are likely key contributors.⁵ In Australia, diabetes was the third leading cause of death for Aboriginal and Torres Strait Islander

peoples in 2019.⁶ The 2018–2019 National Aboriginal and Torres Strait Islander Health Survey estimated a diabetes prevalence of 8% among all ages, being higher (12%) in remote areas.⁷ These self-reported data are an underestimation. There is also geographical variability, with prevalence rates up to 33% previously reported in specific communities.⁸

The Northern Territory (NT) of Australia spans a vast area of 1.35 million km² (more than twice the area of France) with a population density of just 0.2 people/km².⁹ Over 30% of the population identify as Aboriginal people, 77% of whom live in remote or very remote areas.⁹ Some areas of the NT were less impacted by colonisation until the mid-20th century and there remains great strength and diversity of culture, with more than 100 Aboriginal languages and dialects still spoken.¹⁰ The NT is commonly considered in two broad regions, the Top End and Central Australia. In 2005, the prevalence of diabetes among Aboriginal people was estimated at 16% in Central Australia and 7.7% in the Top End.¹¹ More recent accurate estimates of the diabetes burden are lacking.

In this context, we examined trends in diabetes prevalence, contemporary diabetes incidence rates and the demographic and clinical characteristics of people with diabetes among Aboriginal peoples in remote communities across the NT.

METHODS

Study population

The study included all Aboriginal clients, who were recorded as being local residents, of all remote health centres using the NT Health Primary Care Information System. This electronic medical record system is used in 51 out of 84 remote health services in the NT (approximate locations shown in figure 1). Each of these health services are in locations defined as either remote or very remote according to the Australian Statistical Geography Standard.¹² These remoteness classifications are based on relative accessibility to services in urban centres according to road distance measurements. As the clinics are sole service providers in these communities, almost all the local population are clients. To have been included, an individual must have had an interaction with a clinic since 1 July 2007. Births and deaths are updated monthly by relevant government agencies. Additionally, client lists are updated every 6 months in collaboration with local community members to account for population mobility. Aboriginal ethnicity is self-identified in NT health records. A 2011 validation study showed 98% concordance between Aboriginal identification in health records and findings from interviews.¹³

Study design

A retrospective cohort analysis of linked clinical and administrative data from 1 July 2012 to 30 June 2019 was performed.

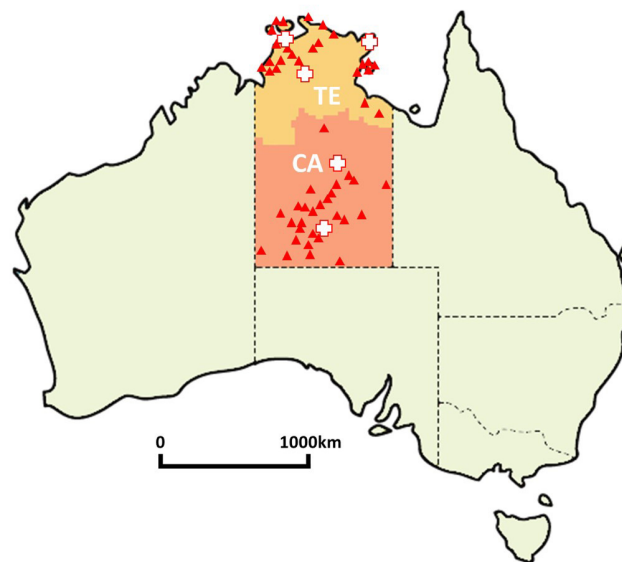


Figure 1 Map of the Top End (TE) and Central Australia (CA) regions of the Northern Territory, Australia, showing the 51 remote clinics (triangles) and 6 hospitals (crosses) contributing data to this study. There are two hospitals in the location at the top left (North West) of the Top End. Distances and locations are approximate.

Data sources

De-identified data were from the NT Health Primary Care Information System (PCIS) and the Hospital Inpatient Activity data set. Individual level records were deterministically linked using a unique identifier, the Hospital Reference Number (HRN), which is used across all NT Health services. The HRN and other personal identifiers are routinely stored in a centralised Client Master Index, which connects to and synchronises across various NT Health information systems, including both PCIS and the Hospital Inpatient Activity data set. The Client Master Index is subject to continual audit and review and is deemed reliable for deterministic linkage in research.^{13 14} Implementation of PCIS commenced in 2004 and was completed by 2010. Data for this study included demographics, community ‘resident’ or ‘visitor’ status, International Classification of Primary Care (ICPC) coded diagnoses, medication prescriptions, biochemistry results and date of death. The Hospital Inpatient Activity data set provided International Classification of Diseases, 10th revision, Australian Modification (ICD-10-AM) codes for principal and secondary diagnoses for inpatient admissions to the NT’s six public hospitals during the study period and date of death from discharge coding.

Outcome definitions

Individuals meeting any of the following criteria were considered to have diabetes: (i) coding for diabetes in primary care (ICPC) or hospital (ICD-10-AM) data, (ii) prescription of a diabetes medication according to

Anatomical Therapeutic Chemical classification code A10 other than metformin, and/or (iii) biochemical evidence of diabetes on at least two occasions. Details of ICPC and ICD-10-AM inclusions are in online supplemental table 1. Metformin was excluded from the diabetes definition as it is commonly used for other indications, including polycystic ovarian syndrome and 'pre-diabetes'. Our case ascertainment was informed by a manual validation study of individual patient records (details in online supplemental appendix). Biochemical criteria included haemoglobin A1c (HbA1c) $\geq 6.5\%$ (≥ 48 mmol/mol), fasting plasma glucose ≥ 7.0 mmol/L, 2-hour plasma glucose ≥ 11.1 mmol/L and/or random capillary or plasma glucose ≥ 11.1 mmol/L.¹⁵ In order to avoid inclusion of gestational diabetes mellitus (GDM), data were excluded for 9 months prior and 3 months following a diagnosis code for GDM in either the primary care or hospital data sets. Type 1 and 'other' diabetes were identified using ICD-10-AM and ICPC coding. People with diabetes, not identified as type 1 or 'other', were presumed to have type 2. If a person was assigned conflicting codes relating to diabetes type (n=39), their clinical records were manually reviewed and diabetes type adjudicated based on documentation by their treating clinicians and relevant investigations.

Statistical analysis

Descriptive statistics were calculated for the total study population, people with prevalent diabetes and people with incident diabetes. Annual diabetes prevalence (%) was calculated for the total population for each financial year (1 July to 30 June) between 2012/2013 and 2018/2019, with 95% CIs calculated using: $\hat{p} \pm 1.96 \sqrt{\frac{\hat{p}(1-\hat{p})}{n}}$. Current prevalence (2018/2019) was stratified by sex and decade of age and also calculated for adults, defined as ≥ 20 years old for consistency with the International Diabetes Federation Diabetes Atlas.¹⁶ Trends in prevalence over time were assessed using negative binomial regression. Subgroup analyses of the Top End and Central Australia regions were performed for 2018/2019 due to known demographic and epidemiological differences between these populations.^{11 17} Comparisons between regions were performed using the Pearson χ^2 test, non-parametric equality-of-medians test and unpaired t-test as appropriate.

Due to smaller numbers, diabetes incidence was assessed in aggregate over a 3-year period (2016/2017–2018/2019). Trends in incidence over time were not assessed. A diagnosis was considered incident when a person was first recorded as meeting the study criteria for diabetes and that person had records available within the preceding 5 years with no evidence of diabetes.

All analyses were performed in Stata (v16.1, StataCorp, Texas).

Patient and public involvement

Interpretation and reporting of the study findings involved Aboriginal people living in the NT, including

two of the authorship group and a third contributor, who requested to remain anonymous. Wider dissemination and communication of the research findings back to Aboriginal communities in the NT and the development of future translational work to address the public health concerns raised in this study will be guided by the Aboriginal and Torres Strait Islander Advisory Group of the Diabetes across the Lifecourse: Northern Australia Partnership.

Ethics

The study was approved by the Human Research Ethics Committee of Northern Territory Department of Health and Menzies School of Health Research (Ref: 2016–2675).

RESULTS

Over 7 years, 21 267 Aboriginal people from 51 remote communities across the NT were included. Median age at baseline was 22 (IQR 9–39) years, 10 902 (51.3%) were women, 15 035 (70.7%) were from the Top End and 1059 (5.0%) died during the study period. In the 2012/2013 financial year, 14.4% (95% CI: 13.9% to 14.9%, n/N=2749/19 042) of people had diabetes. By 2018/2019 this prevalence had increased to 17.0% (95% CI: 16.5% to 17.5%, n/N=3477/20 429), with 98.6% (n/N=3429/3477) of diagnoses classified as type 2 diabetes. **Figure 2** depicts the 18% increase in prevalence over the study period (annual increase 2.5%, 95% CI: 1.9% to 3.1%, $p < 0.001$). In 2018/2019, the prevalence among adults was 28.6% (95% CI: 27.8% to 29.4%, n/N=3414/11 939). **Figure 3** shows that diabetes prevalence was higher with increasing age, except in the oldest age-group (≥ 70 years), and that there were more women than men with diabetes in all age-groups.

In 2018/2019, diabetes was more prevalent across all ages in Central Australia (23.0%, 95% CI: 22.0% to 24.1%) than the Top End (14.5%, 95% CI: 13.9% to 15.1%, $p < 0.001$). When restricted to adults, the prevalence was 39.5% (95% CI: 37.9% to 41.1%) in Central Australia compared with 24.2% (95% CI: 23.3% to 25.1%) in the Top End ($p < 0.001$). Characteristics of all people with diabetes in 2018/2019 are presented in **table 1**. Among these, 2115 (60.8%) were women, 669 (19.2%) were prescribed insulin and 567 (16.3%) had HbA1c $\geq 10\%$ (≥ 86 mmol/mol). In Central Australia, a greater proportion of people had an HbA1c $\geq 10\%$ (≥ 86 mmol/mol) and rates of insulin prescribing were higher than in the Top End (both $p < 0.001$).

Between July 2016 and June 2019, there were 483 new cases of diabetes. The incidence rate in the total population was 7.9 (95% CI: 7.3 to 8.7) per 1000 person-years. Age-specific incidence rates are presented in **figure 4**. Median age at diabetes diagnosis was 38 (IQR 29–49) years. The peak incidence was among 50–59-year-olds (16.4 (95% CI: 15.9 to 16.9) per 1000 person-years), with similarly high rates among 30–39 and 40–49-year-olds. Among adults, the incidence rate was 12.6 (95% CI: 11.5

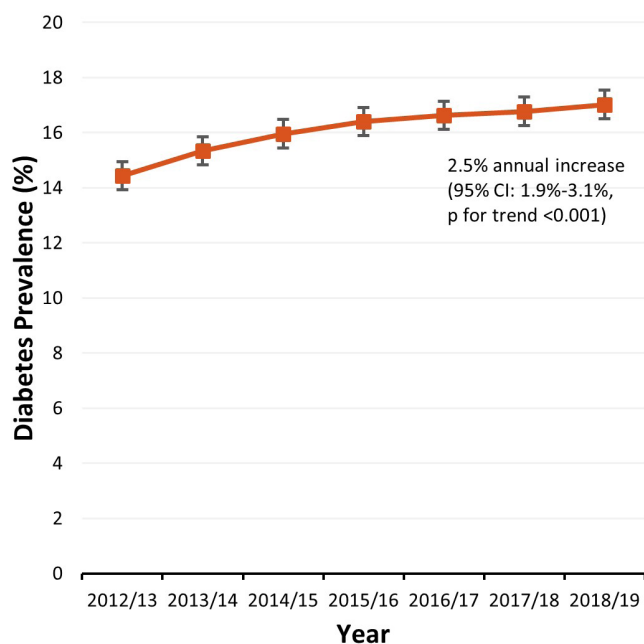


Figure 2 Trend in crude diabetes prevalence among Aboriginal people (all ages) in remote Northern Territory communities over 7 years. Error bars are 95% CIs. Note the vast majority of prevalent diagnoses were classified as type 2 diabetes (98.6% type 2, 0.17% type 1 and 0.07% other diabetes in 2018/2019).

to 13.8) per 1000 person-years. Of all people with incident diabetes, 287 (59.4%) were women, 328 (67.9%) lived in the Top End and 481 (99.6%) had type 2 diabetes.

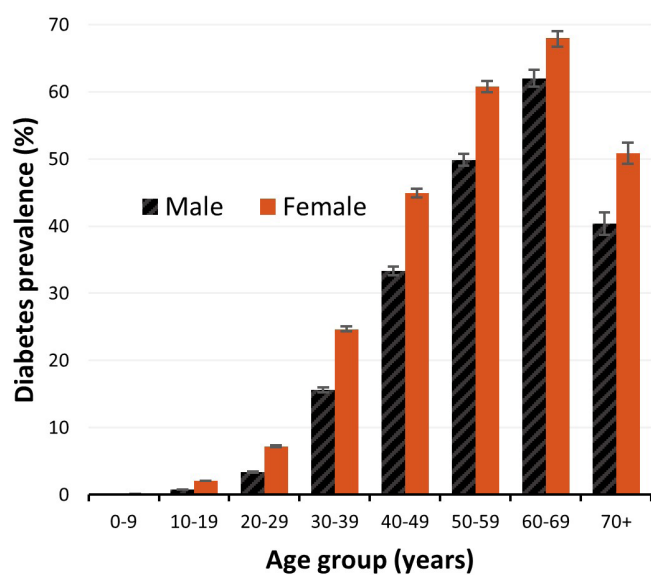


Figure 3 Age and sex-specific diabetes prevalence in 2018/2019 among Aboriginal people in remote Northern Territory communities. Error bars are 95% CIs.

DISCUSSION

The burden of type 2 diabetes among Aboriginal people in remote communities of the NT, Australia, is immense and growing. Despite the relatively young age of this population, which includes children, we report a current diabetes prevalence of 17%, of which 99% is classified as type 2 diabetes. The findings are particularly concerning when restricted to adults (29% affected). The prevalence was greatest in Central Australia, where 40% of adults now have diabetes. Age of onset was relatively young with high incidence rates observed between 30 and 59 years of age. Of people with diabetes who had an HbA1c level checked in 2018/2019, more than one in five had an HbA1c $\geq 10\%$ (≥ 86 mmol/mol). This combination of young age of onset and severe chronic hyperglycaemia is likely to be accompanied by a high burden of diabetes complications and premature mortality.^{18 19} Of additional concern is the high proportion of people meeting criteria for diabetes who were not prescribed glucose-lowering therapy (47%) despite the mean HbA1c being 7.9% (63 mmol/mol). This suggests a significant gap between established treatment recommendations and real-world implementation into practice.

The epidemic of type 2 diabetes among Aboriginal people in the remote NT has occurred in recent history and has continued to grow in the last few decades. In 1997, the prevalence of diabetes in Aboriginal adults from 15 remote communities was estimated at 15%.²⁰ Using similar data sources to our study (also including children), the prevalence of diabetes in 2005 was estimated at 16% in Central Australia and 7.7% in the Top End.¹¹ We report rates of 23% in Central Australia and 15% in the Top End. Thus, in less than 15 years, there has been substantial growth in the diabetes burden. The adult prevalence among Aboriginal people in Central Australia is among the highest ever reported, being similar to what was famously reported among the Pima Indian population of Arizona in the 1970s (42% among those aged ≥ 25 years) and higher than the current top country-wide prevalence, which is in the Marshall Islands (31% among those aged ≥ 20 years).^{16 21} These comparisons are made for illustrative purposes only given the differences in study methodologies and lack of age standardisation to a common reference population.

There are limited published data examining temporal trends in diabetes epidemiology among Aboriginal people in Australia. An early study conducted in a single community in Central Australia, showed that the prevalence of diabetes increased from 11.6% in 1987 to 20.7% in 1995.²² More recent studies from Western Australia and the NT have examined diabetes prevalence trends during pregnancy, showing substantial growth in the number of Aboriginal women with type 2 diabetes diagnosed prior to pregnancy.^{23 24} In addition, the incidence of diabetes among Aboriginal and Torres Strait Islander children (aged under 16 years) in Western Australia increased considerably between 2000 and 2019.²⁵ Our findings add to this existing literature, showing an 18% increase

Table 1 Characteristics of Aboriginal people with prevalent diabetes in 2018/2019 in the NT, with comparison by region

	Total NT (n=3477)	Central Australia (n=1382)	Top End (n=2095)	P value (CA vs TE)
Age, years	49 (39–58)	48 (37–58)	49 (40–58)	0.003
Female	2115 (61)	834 (60)	1281 (61)	0.637
Diabetes type				0.269
Type 2	3429 (98.6)	1368 (98.9)	2061 (98.4)	
Type 1	34 (1.0)	9 (0.7)	25 (1.2)	
Other	14 (0.4)	5 (0.5)	9 (0.4)	
Treatment				
No GLT	1627 (47)	542 (39)	1085 (52)	<0.001
Non-insulin GLT	1181 (34)	508 (37)	673 (32)	0.005
Combined GLT (with insulin)	610 (18)	307 (22)	303 (15)	<0.001
Insulin alone	59 (1.7)	25 (1.8)	34 (1.6)	0.678
Mean HbA1c*				
(NGSP %)	7.9 (±0.04)	8.4 (±0.07)	7.7 (±0.05)	<0.001
(mmol/mol)	63 (±0.4)	68 (±0.8)	61 (±0.5)	
Median HbA1c*				
(NGSP %)	7.2 (6.1–9.4)	7.8 (6.3–10.1)	7.0 (6.0–8.9)	<0.001
(mmol/mol)	55 (43–79)	62 (45–87)	53 (42–74)	
HbA1c category*				<0.001
<7.0% (<53 mmol/mol)	1216 (35)	375 (27)	641 (40)	
7.0%–7.9% (53–63 mmol/mol)	415 (12)	159 (12)	256 (12)	
8.0%–9.9% (64–85 mmol/mol)	540 (16)	228 (17)	312 (15)	
≥10% (≥86 mmol/mol)	567 (16)	281 (20)	286 (14)	
No result	739 (21)	339 (25)	400 (19)	

Data are n (%), median (IQR) or mean (±SE).
 *The single most recent HbA1c result for each individual within the 2018/2019 year was included. Individuals with no HbA1c in that 12-month period were excluded from calculation of means/medians and reported in the 'no result' category.
 CA, Central Australia; GLT, glucose lowering therapy; HbA1c, haemoglobinA1c; NT, Northern Territory ; TE, Top End.

in diabetes prevalence over 7 years. Numerous factors, not assessed in our study, may have contributed to the observed change, such as increasing incidence, improved survival and greater uptake of screening.

We found that diabetes was more common with increasing age, except over 70 years, where prevalence dropped considerably. In Western populations, diabetes prevalence consistently increases with age.²⁶ However, studies in the NT Aboriginal population from the 1990s and early 2000s found that diabetes prevalence peaked in middle age (45–54 years) and then decreased among older age-groups.²⁷ This was likely due to a combination of a 'healthy survivor' effect and the timing of lifestyle changes relating to colonisation. Another contributing factor could be that, despite the importance of connection to country, as a last resort, older people with chronic conditions are more likely to move to urban centres with better access to services, leaving a relatively healthier older

population in remote communities. Now, two decades later, the age at which this phenomenon is observed is proportionately higher. This likely reflects improvements in life expectancy for people with chronic conditions and a greater length of time since these communities underwent rapid social and environmental transitions.

The higher prevalence of diabetes observed among women compared with men in all age groups is noteworthy. This difference has been observed in Aboriginal Australians previously and also in other Indigenous populations in North America.^{8 21 28 29} It contrasts with the national Australian population and most populations internationally, in which the prevalence of known diabetes is greater among men.^{1 16 26} The disparity observed among Aboriginal women in Australia has been shown to relate to obesity.^{8 22} However, further research is needed to understand the mechanisms underlying this disparity in metabolic health between Aboriginal women and men.

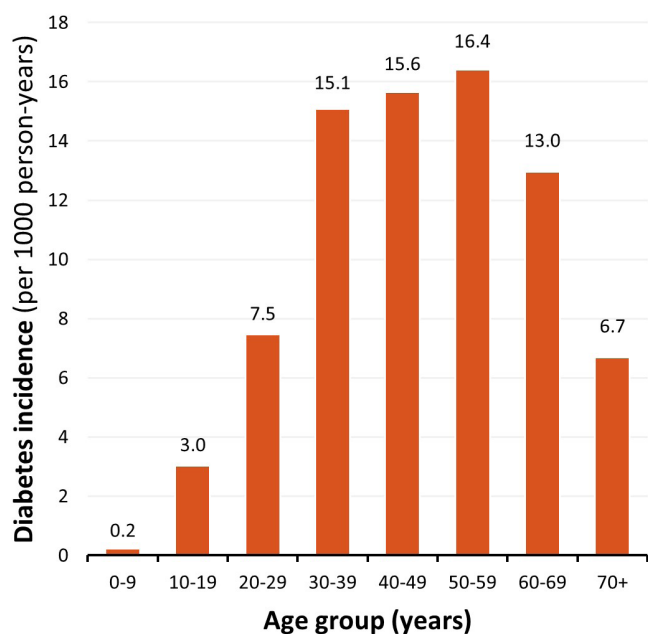


Figure 4 Age-specific diabetes incidence rates between 2016/2017 and 2018/2019 among Aboriginal people in remote Northern Territory communities. Error bars are 95% CIs. Out of 483 incident diabetes diagnoses, 481 (99.6%) were recorded as type 2 diabetes.

One postulated mechanism is a sex-specific difference in the impact of maternal glycaemia on the developing fetus and thus diabetes risk in that next generation. The effect of fetal hyperinsulinism on both birth weight and post-natal growth appears to differ between girls and boys.^{30 31} It has been hypothesised that fetal hyperinsulinism may lead to a degree of persistent insulin resistance that is more pronounced in girls.³¹ Nevertheless, it is likely that numerous biological and sociocultural factors are contributing to the higher prevalence of diabetes among women than men. Differences in physical activity may be partly responsible, especially among younger age groups.²² Additionally, uptake of screening may contribute to some of the observed difference, with national data showing that women are more likely than men to undertake a routine health check specifically funded for Aboriginal and Torres Strait Islander people.³² Routine screening for diabetes during pregnancy and following a pregnancy complicated by gestational diabetes may also have an impact.

Few studies have examined diabetes incidence in Aboriginal communities in Australia. The first available estimate is from two remote Central Australia communities, published in 1999. Diabetes incidence among people aged ≥ 15 years was 20.3 per 1000 person-years.³³ Our current observed adult incidence rate across remote NT communities was lower (12.6 per 1000 person-years). This incidence rate is also lower than that observed in an Aboriginal cohort in Queensland between 1999 and 2007.³⁴ Each of these studies involved geographically and culturally distinct populations and employed different

methodologies. Furthermore, the estimates are not age and sex-standardised.

While there may have been some improvement in diabetes incidence in the last two decades, the observed rates remain high. Australian data from the National Diabetes Services Scheme (NDSS) show that the national type 2 diabetes incidence rate in 2014 was 2.4 per 1000 person-years.³⁵ These NDSS data may underestimate the true incidence due to unregistered cases. Nevertheless, it has been estimated that 87% of people with diabetes are NDSS-registered.³⁶ Compared with these data from the multiethnic national population of Australia, the age-specific incidence rate in our study cohort was 26-times greater at 20–29 years, 12-times greater at 30–39 years and 5-times greater at 40–49 years (DJ Magliano, personal communication). Establishing the contemporary diabetes incidence rate in our study context is important for the future evaluation of public health strategies aimed at preventing diabetes.

Our study again confirms the high rates of metabolic disease that accompany rapid transitions in lifestyle among previously lean and physically active populations. Such epidemiological transitions have particularly impacted Indigenous peoples with similar histories of European colonisation.^{5 37} The underlying determinants are not well delineated but are likely multifactorial and compound each other. A degree of heightened genetic susceptibility is hypothesised but not well proven.³⁸ Growing evidence suggests epigenetic mechanisms also have a role, with factors such as intrauterine exposure to hyperglycaemia or maternal undernutrition impacting long-term phenotypic expression in the offspring.³⁹ Such alterations in gene expression may also be passed on to subsequent generations.⁴⁰ The NT Aboriginal population continues to experience elevated rates of low birth weight and preterm birth.²⁴ At the same time, rates of diabetes in pregnancy and high birth weight are increasing.²⁴ These early-life risk factors may be contributing to the ongoing diabetes epidemic.

The higher burden of diabetes observed in Central Australia compared with the Top End is consistent with previous studies.¹¹ There are numerous distinct Aboriginal people groups across the NT, with great diversity in culture, environment and socioeconomic factors. An early study from the 1980s found that Aboriginal people from desert communities had greater hyperinsulinaemia than coastal communities.⁴¹ The authors predicted that this could indicate a future greater burden of diabetes in these people groups as the duration of urbanisation increased.⁴¹

Underlying these biological hypotheses, the most important contributors to this epidemic are likely to be social and environmental factors. Aboriginal people in the NT experience socioeconomic disadvantage across numerous domains, including income, employment, education and housing.⁴² These factors explain a large portion of the inequity in health outcomes relative to non-Aboriginal people.⁴² These challenges are more

pronounced in remote areas, where overcrowded, inadequate housing and food insecurity are major issues.⁴³ Healthy food items are expensive in remote stores, with survey data suggesting more than a third of daily energy intake is from discretionary food and drinks.⁴³ Previous evidence suggests that some of the health disparities between Central Australia and Top End communities relate to differences in social and environmental factors.¹⁷

Strengths of our study include the use of detailed, individual-level data and the large sample size. The use of a client population raises the question of whether the study cohort represents the true population of these remote communities. As discussed in the methods, the client databases of these sole-provider remote health services include almost all the local Aboriginal population. The study is inherently limited by the retrospective design. Our diabetes estimates are reliant on known diagnoses and it is likely the population is incompletely screened, which would contribute to an underestimation of both prevalence and incidence. There may also be some bias regarding the demographics of people who are more likely to participate in screening. Significant heterogeneity exists between Aboriginal communities across the NT. The inclusion of data in our study from most, but not all, remote communities in the region could have introduced some bias and limit the generalisability. Furthermore, our findings may not be generalisable to Aboriginal peoples living in urban centres due to the unique environments and population characteristics of remote Aboriginal communities. Unfortunately, we were unable to assess time trends in diabetes incidence due to limited numbers and the potential unreliability of differentiating incident and prevalent cases in the early years of the PCIS electronic medical record system.

CONCLUSION

The burden of type 2 diabetes among Aboriginal people in remote communities of the NT is among the highest reported of any population globally despite the population being relatively young. Many factors associated with increasing prevalence of diabetes are beyond individual control, and thus strengthened systems of care and public health prevention strategies, developed and implemented in partnership with Aboriginal communities, are needed. These strategies should be holistic, considering emotional, spiritual and mental well-being, as well as physical health. The enormity of the diabetes burden necessitates population-wide prevention strategies, including cross-sectoral collaboration to address the social determinants of health.

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Contributors MJLH led the analysis planning, interpretation of findings and drafting of the manuscript. HF and LM-B contributed equally as senior authors, supervising all aspects of the study, including conception of the study, ethics application, study design, study conduct, analysis planning, interpretation of findings and manuscript preparation. YZ, SG, PB and ELMB contributed to study conception, study design, analysis planning, interpretation of findings and critically revised the manuscript. YZ additionally provided statistical expertise and undertook the data analysis. DB (a Jawoyn woman and health policymaker), AR (a Gubbi Gubbi woman and Senior Remote Medical Practitioner in Central Australia) and EE (Endocrinologist in Central Australia) contributed to interpretation of data and critically revised the work for important intellectual content. All authors approved the final version and agreed to be accountable for the work. YZ is the guarantor for the analyses.

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Competing interests MJLH has received honoraria for lectures and consultancies from AstraZeneca, Eli Lilly and Novo Nordisk.

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.

Provenance and peer review Not commissioned; externally peer reviewed.

Data availability statement Data may be obtained from a third party and are not publicly available. The Northern Territory Department of Health is the owner of the data used for this study. Reasonable requests for access to the de-identified study data set would be considered after required approvals from the data custodians are in place.

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REFERENCES

- NCD Risk Factor Collaboration (NCD-RisC). Worldwide trends in diabetes since 1980: a pooled analysis of 751 population-based studies with 4.4 million participants. *Lancet* 2016;387:1513–30.
- Zimmet PZ, Magliano DJ, Herman WH, et al. Diabetes: a 21st century challenge. *Lancet Diabetes Endocrinol* 2014;2:56–64.
- Harding JL, Pavkov ME, Magliano DJ, et al. Global trends in diabetes complications: a review of current evidence. *Diabetologia* 2019;62:3–16.
- Hare MJL, Topliss DJ. Classification and Laboratory Diagnosis of Diabetes Mellitus. In: Bandeira F, Gharib H, Griz L, et al, eds. *Endocrinology and diabetes*. Springer, Cham, 2022: 303–13.
- Harris SB, Tompkins JW, TeHiwi B. Call to action: a new path for improving diabetes care for Indigenous peoples, a global review. *Diabetes Res Clin Pract* 2017;123:120–33.
- Australian Bureau of Statistics. Causes of death, Australia. Canberra: ABS, 2020. Available: <https://www.abs.gov.au/statistics/health/causes-death/causes-death-australia/2019> [Accessed 30 Dec 2020].
- Australian Bureau of Statistics. National Aboriginal and Torres Strait Islander health survey, 2018–19. Ref: 4715.0. Canberra: ABS, 2019. Available: <https://www.abs.gov.au/statistics/people/aboriginal-and-torres-strait-islander-peoples/national-aboriginal-and-torres-strait-islander-health-survey/2018-19> [Accessed 19 May 2020].
- Minges KE, Zimmet P, Magliano DJ, et al. Diabetes prevalence and determinants in Indigenous Australian populations: a systematic review. *Diabetes Res Clin Pract* 2011;93:139–49.
- Northern Territory Government Department of Treasury and Finance. Northern Territory Economy - Population. Darwin: Northern Territory Government, 2020. Available: <https://nteconomy.nt.gov.au/population> [Accessed 28 Oct 2020].
- Northern Territory Government. Aboriginal languages in nt, 2018. Available: <https://nt.gov.au/community/interpreting-and-translating-services/aboriginal-interpreter-service/aboriginal-languages-in-nt> [Accessed 18 Aug 2021].
- Zhao Y, Connors C, Wright J, et al. Estimating chronic disease prevalence among the remote Aboriginal population of the Northern Territory using multiple data sources. *Aust N Z J Public Health* 2008;32:307–13.
- Australian Bureau of Statistics. 1270.0.55.005 Australian Statistical Geography Standard (ASGS): Volume 5 - Remoteness Structure. Canberra: Commonwealth of Australia, 2018.
- Foley M, Zhao Y, Condon J. *Demographic data quality assessment for Northern Territory public hospitals 2011*. Darwin: Northern Territory Government Department of Health, 2012.
- Li L, Guthridge S, Li SQ, et al. Estimating the total prevalence and incidence of end-stage kidney disease among Aboriginal and non-Aboriginal populations in the Northern Territory of Australia, using multiple data sources. *BMC Nephrol* 2018;19:15.
- The Royal Australian College of General Practitioners. *Management of type 2 diabetes: a Handbook for general practice*. East Melbourne, Vic: RACGP, 2020.
- Saeedi P, Petersohn I, Salpea P, et al. Global and regional diabetes prevalence estimates for 2019 and projections for 2030 and 2045: Results from the International Diabetes Federation Diabetes Atlas, 9th edition. *Diabetes Res Clin Pract* 2019;157:107843.
- Munoz E, Powers JR, Nienhuys TG, et al. Social and environmental factors in 10 aboriginal communities in the Northern Territory: relationship to hospital admissions of children. *Med J Aust* 1992;156:529–33.
- Magliano DJ, Sacre JW, Harding JL, et al. Young-onset type 2 diabetes mellitus - implications for morbidity and mortality. *Nat Rev Endocrinol* 2020;16:321–31.
- Stratton IM, Adler AI, Neil HA, et al. Association of glycaemia with macrovascular and microvascular complications of type 2 diabetes (UKPDS 35): prospective observational study. *BMJ* 2000;321:405–12.
- Daniel M, Rowley KG, McDermott R, et al. Diabetes and impaired glucose tolerance in Aboriginal Australians: prevalence and risk. *Diabetes Res Clin Pract* 2002;57:23–33.
- Bennett PH, Burch TA, Miller M. Diabetes mellitus in American (Pima) Indians. *Lancet* 1971;2:125–8.
- McDermott R, Rowley KG, Lee AJ, et al. Increase in prevalence of obesity and diabetes and decrease in plasma cholesterol in a central Australian Aboriginal community. *Med J Aust* 2000;172:480–4.
- Ahmed MA, Bailey HD, Pereira G, et al. Trends and burden of diabetes in pregnancy among Aboriginal and non-Aboriginal mothers in Western Australia, 1998–2015. *BMC Public Health* 2022;22:263.
- Hare MJL, Barzi F, Boyle JA, et al. Diabetes during pregnancy and birthweight trends among Aboriginal and non-Aboriginal people in the Northern Territory of Australia over 30 years. *Lancet Reg Health West Pac* 2020;1:100005.
- Haynes A, Curran JA, Davis EA. Two decades of increasing incidence of childhood-onset type 2 diabetes in Western Australia (2000–2019). *Med J Aust* 2021;214:285–6.
- Dunstan DW, Zimmet PZ, Welborn TA, et al. The rising prevalence of diabetes and impaired glucose tolerance: the Australian diabetes, obesity and lifestyle study. *Diabetes Care* 2002;25:829–34.
- Brimblecombe J, Mackerras D, Garnggulkpuy J, et al. Leanness and type 2 diabetes in a population of Indigenous Australians. *Diabetes Res Clin Pract* 2006;72:93–9.
- Dyck R, Osgood N, Lin TH, et al. Epidemiology of diabetes mellitus among first nations and non-First nations adults. *CMAJ* 2010;182:249–56.
- Scavini M, Stidley CA, Shah VO, et al. Prevalence of diabetes is higher among female than male Zuni Indians. *Diabetes Care* 2003;26:55–60.
- Shields BM, Knight B, Hopper H, et al. Measurement of cord insulin and insulin-related peptides suggests that girls are more insulin resistant than boys at birth. *Diabetes Care* 2007;30:2661–6.
- Regnault N, Botton J, Heude B, et al. Higher cord C-peptide concentrations are associated with slower growth rate in the 1st year of life in girls but not in boys. *Diabetes* 2011;60:2152–9.
- Australian Institute of Health and Welfare. Indigenous health checks and follow-ups. cat. No. IHW 209. Canberra: AIHW, 2021. Available: <https://www.aihw.gov.au/reports/indigenous-australians/indigenous-health-checks-follow-ups/> [Accessed 27 Sep 2021].
- Daniel M, Rowley KG, McDermott R, et al. Diabetes incidence in an Australian Aboriginal population. An 8-year follow-up study. *Diabetes Care* 1999;22:1993–8.
- McDermott RA, Li M, Campbell SK. Incidence of type 2 diabetes in two Indigenous Australian populations: a 6-year follow-up study. *Med J Aust* 2010;192:562–5.
- Magliano DJ, Chen L, Islam RM, et al. Trends in the incidence of diagnosed diabetes: a multicountry analysis of aggregate data from 22 million diagnoses in high-income and middle-income settings. *Lancet Diabetes Endocrinol* 2021;9:203–11.
- Davis WA, Peters KE, Makepeace A, et al. Prevalence of diabetes in Australia: insights from the Fremantle diabetes study phase II. *Intern Med J* 2018;48:803–9.
- Maple-Brown LJ, Hampton D. Indigenous cultures in countries with similar colonisation histories share the challenge of intergenerational diabetes. *Lancet Glob Health* 2020;8:e619–20.
- Pearson ER. Dissecting the etiology of type 2 diabetes in the Pima Indian population. *Diabetes* 2015;64:3993–5.
- Hjort L, Novakovic B, Grunnet LG, et al. Diabetes in pregnancy and epigenetic mechanisms-how the first 9 months from conception might affect the child's epigenome and later risk of disease. *Lancet Diabetes Endocrinol* 2019;7:796–806.
- Gluckman PD, Hanson MA, Cooper C, et al. Effect of in utero and early-life conditions on adult health and disease. *N Engl J Med* 2008;359:61–73.
- O'Dea K, Traianedes K, Hopper JL, et al. Impaired glucose tolerance, hyperinsulinemia, and hypertriglyceridemia in Australian aborigines from the desert. *Diabetes Care* 1988;11:23–9.
- Zhao Y, You J, Wright J, et al. Health inequity in the Northern Territory, Australia. *Int J Equity Health* 2013;12:79.
- Australian Indigenous HealthInfoNet. Summary of nutrition among Aboriginal and Torres Strait Islander people. Available: <https://healthinfonet.ecu.edu.au/nutrition2020> [Accessed 2 Nov 2020].