

Rethinking diabetes care for Indigenous Australians: the need for Indigenous-codedigned and led diabetes models of care

Despite concerted efforts, stark gaps in health outcomes and life expectancy between Indigenous and non-Indigenous Australians persist.¹ As illustrated by the annual Closing the Gap reports, progress is slow. Only five out of 19 targets are on track, with no improvement in life expectancy gaps, and children in out-of-home care and adult imprisonment rates.¹ The life expectancy for Indigenous men and women is nine years less than for non-Indigenous Australians (72 v 81 years and 76 v 84 years, respectively), which compares unfavourably with other nations, but has only slightly narrowed despite government initiatives on disease prevention, and primary care and health workforce expansion.² Innovative approaches involving Indigenous communities and leadership, funding, and both top-down and grassroots approaches are needed.

Positionality statement

The research team comprises both Aboriginal and non-Aboriginal researchers with diverse backgrounds, lived experiences, and professional expertise. Natalie Nanayakkara is a non-Indigenous endocrinologist with over eight years of experience providing clinical care to rural and remote Aboriginal communities in Victoria. Sharon Atkinson-Briggs is a Yorta Yorta Elder, registered nurse, and credentialled diabetes educator who holds a PhD in Indigenous diabetes, completed under the supervision of Laima Brazionis and Alicia Jenkins. She brings extensive research experience and over two decades of leadership in Aboriginal education and health across both the community-controlled and mainstream health sectors. Alicia Jenkins is a non-Indigenous endocrinologist with a long-standing commitment to Indigenous health and diabetes care and previously held a Centre of Research Excellence and a National Health and Medical Research Council Partnership grant that studied diabetic retinopathy in Indigenous Communities, and that research included Indigenous Australians, trained 19 Indigenous health workers in diabetes-related eye imaging, and had input from the local boards. Sharon Atkinson-Briggs was a member of the research teams for both of these retinopathy-related projects. Neale Cohen is a non-Indigenous endocrinologist with more than 20 years of experience in Indigenous health research and clinical service delivery in remote Aboriginal communities in Central Australia.

Factors behind the mortality gap

A complex interplay of factors contribute to the mortality gap, including infant mortality, accidents, violence, smoking, and chronic diseases.³ Diabetes, kidney and cardiovascular disease accounts for about two-thirds of the life expectancy differential.³

Medical issues are often compounded by socio-economic disadvantage, with Indigenous Australians experiencing higher rates of poverty, unemployment, inadequate housing, food insecurity, low health literacy, suboptimal health risk behaviours, and lower educational attainment, all linked to poor health outcomes.⁴⁻⁶ Lifestyle factors contribute to health outcomes. Smoking rates among Indigenous Australians are threefold higher than those for non-Indigenous Australians, and are estimated to account for 23% of the total disease burden gap.^{7,8} Smoking also increases cancer risk. As water supplies, particularly in remote areas, are often suboptimal, and bottled water is costly, there is overconsumption of soft drinks, which are less expensive and more often refrigerated.⁹ Sugar-sweetened beverage consumption helps drive obesity, which has a prevalence of 39% in Indigenous people and 22% in non-Indigenous people.¹⁰

Diabetes and its complications, particularly chronic kidney disease, retinopathy and cardiovascular disease, have a disproportionate toll on Indigenous people. Over 65 000 people (13% of Indigenous Australians) have diabetes, predominantly type 2 diabetes, which is nearly triple the national rate.³ Diabetes onset in Indigenous people is decades earlier than in non-Indigenous Australians.¹¹ Several factors drive this excess risk, including higher obesity rates, sedentary lifestyles, and, in rural or remote areas, limited access to health care services and affordable healthy foods.¹² As in other Indigenous groups globally, genetic and epigenetic factors may also modulate insulin resistance, pre-diabetes and diabetes.^{13,14}

Diabetes and kidney disease in Indigenous people

Diabetes accounts for 7.3% of Indigenous deaths, 4.7 times that of non-Indigenous Australians² with death rates of Indigenous Australians in remote areas 8.8 times higher than that of non-Indigenous Australians.¹¹ Similarly, diabetes-related hospitalisations of Indigenous Australians are four times the rate of non-Indigenous people. Chronic kidney disease affects 20% of Indigenous Australians with diabetes and accounts for 10% of new patients with end-stage renal disease annually.¹⁵ Compared with non-Indigenous counterparts, Indigenous peoples have over six times the end-stage renal disease risk and are less likely to receive kidney transplants, necessitating dialysis, which greatly reduces patient and carer quality of life and social and emotional wellbeing.^{16,17} Other prevalent complications among Indigenous Australians include retinopathy (29.4%) and poor vision (often due to uncorrected refraction errors), neuropathy (41.2%), and cardiovascular disease (47.1%).^{2,18} These poor outcomes are driven by many

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factors, including marked hyperglycaemia and failure to reach targets for blood pressure, lipids and body weight. Prevention, early detection and care of diabetes complications through improved models of care represent an opportunity to narrow health disparities.

Several new therapeutics may improve outcomes. Sodium–glucose co-transporter 2 (SGLT-2) inhibitors and glucagon-like peptide-1 (GLP-1) receptor agonists (GLP-1 RAs) have benefits including glycaemia, weight loss, and cardiovascular and renal protection,¹⁹ which could prove valuable for Indigenous Australians given their disproportionate burden of obesity, diabetes, cardiovascular disease and chronic kidney disease. However, there are access challenges and little data on their effectiveness, safety and acceptability in Indigenous populations. Relevant research, advocacy, and translational activities are crucial to ensure that cutting-edge therapies reach all those who may benefit.

The higher diabetes risk of Indigenous Australians is compounded by over 20% of this population living in remote or very remote areas, regions that are associated with a five-year lower life expectancy than urban settings.¹ These areas often also lack access to comprehensive, responsive health care services; diabetes education for patients; Aboriginal health practitioners; and uptake of screening and monitoring tests, even though point-of-care finger prick-based tests are often available at Indigenous health services.^{20,21} Lack of healthy, affordable foods and water further hampers outcomes.²¹ Providing coordinated, multidisciplinary, best practice-aligned diabetes care is challenging in isolated settings with limited resources, workforce shortages and high staff turnover. Therefore, it is important to explore and rigorously evaluate novel care delivery models optimised for rural and remote Indigenous contexts, such as community outreach, mobile clinics, telehealth, and task-shifting responsibilities with community health care providers. Developing innovative solutions in collaboration with Indigenous communities is crucial.

Community engagement and Indigenous leadership are pivotal

Community engagement and Indigenous leadership are pivotal to inform effective health-related interventions.¹⁷ Aboriginal Community Controlled Health Services have improved access and patient engagement by prioritising self-determination and culturally safe care delivery. As an example, a model of care by author SAB, embedding eye screening in diabetes education in Indigenous health general practice services, showed the feasibility of this model for increasing eye screening rates to up to 79%, a rate shown to be associated with lower rates of diabetes-related vision loss.²² Unfortunately, ongoing funding for trained Indigenous staff was unavailable, even though many services have on-site retinal cameras. The [Box](#) provides relevant publications and examples of Indigenous Australian co-designed or led studies. Inconsistent funding and support hamper the scale-up of successful interventions. For the best chance of success, Indigenous communities must be empowered to co-design accredited diabetes programs and services

tailored to local resources, customs and priorities, and from which registered practitioners can earn continuing professional development points. This includes upskilling local health workers to provide comprehensive care with training, support and ongoing mentorship from specialist diabetes clinicians and researchers. Additional staff must be employed to undertake tasks when workloads are at capacity.

New therapeutics are positively transforming diabetes outcomes. However, delivering these therapies in many communities is challenging and under-resourced. Overcoming inequities will require reconsidering and restructuring some traditional care models. It is important to rethink and appropriately resource models of care and provide robust evidence of their feasibility and efficacy. Potential innovations include improved community outreach such as mobile clinics to expand geographic reach, increased telehealth, and upskilling well trained community health workers and multidisciplinary teams. Care pathways should be redesigned through community-led quantifiable quality improvement initiatives. However, deviating from long-established practices requires robust evidence evaluating the effectiveness, feasibility, acceptability and sustainability of alternative models. This will require adequately powered clinical trials with long term real-world follow-up to definitively assess clinical outcomes, cost-effectiveness and patient and health care provider experiences. For example, a pilot program testing the Flinders Model of self-management, which comprised a patient-centred, self-management assessment and care planning conducted by Indigenous health workers, found improved glycated haemoglobin (HbA_{1c}) levels and diabetes self-management scores.²⁸ The Lower SUGAR study³⁶ in two remote communities, comprising 32 Indigenous Australians with type 2 diabetes, found a significant HbA_{1c} level improvement of 3.1% over 20 weeks using weekly nurse-administered exenatide and review, compared with standard care. There is a lack of long term randomised controlled trials evaluating interventions to improve obesity and diabetes care in Indigenous people,³⁷ and a follow-up IMPROVE SUGAR trial will soon commence.

The prospective IMPROVE SUGAR trial (Australian New Zealand Clinical Trials Registry, ACTRN12624001231538) will evaluate an intensive versus standard care model in Australian rural and remote Indigenous communities using tirzepatide (a combined GLP-1 and glucose-dependent insulinotropic polypeptide [GIP] agonist) over 12 months. A cost analysis of this model of care is part of this large national trial. This study was developed in collaboration with Indigenous people with diabetes, Indigenous health care workers and community representatives, and includes health worker employment, training, an Indigenous Advisory Board and Indigenous investigators.

Conclusion

The scale and complexity of diabetes in rural and remote Indigenous communities is a nationally important urgent health issue. The current paradigm,

Relevant publications and examples of Indigenous Australian co-designed or led studies

Title	Findings
Integrating diabetic retinopathy screening within diabetes education services in Australia's diabetes and indigenous primary care clinics ²³	Explores a model of care integrating retinopathy screening into the routine clinical workflows of diabetes education services to improve screening uptake and facilitate early detection of retinopathy
A model of culturally-informed integrated diabetes education and eye screening in indigenous primary care services and specialist diabetes clinics: study protocol ²⁴	Outlines a protocol for integrating diabetes education and eye screening in Indigenous health care settings, with three components (retinal photography, lifestyle and behaviour surveys, personalised diabetes education) to facilitate timelier diabetic retinopathy screening, referral pathways and treatment of sight-threatening retinopathy
Prevalence of diabetic retinopathy and reduced vision among Indigenous Australians in the nurse-led integrated Diabetes Education and Eye Screening study ¹⁸	A nurse-led model of care integrating diabetes eye screening and education at a single visit was successful at recruiting Indigenous Australian adults with diabetes and reported a 34% prevalence of retinopathy and subnormal presenting vision in 33%
Mixed diabetic retinopathy screening coverage results in Indigenous Australian primary care settings ²²	A credentialed nurse-educator implemented a model of retinal image-based diabetes education, and met the "acceptable 75% eye screening coverage" benchmark and improved patient eye screening guideline adherence at the one site where the nurse-educator had access to patient recruitment and scheduling
Health-risk behaviours among Indigenous Australians with diabetes: A study in the integrated Diabetes Education and Eye Screening (iDEES) project ⁶	Indigenous Australian adults with diabetes exhibit notable modifiable health risk behaviours, including a 36% smoking rate, a suboptimal diet, and 34% experiencing moderate to severe depressive symptoms, highlighting the importance of tailored health promotion interventions
Nurse-led vascular risk assessment in a regional Victorian Indigenous primary care diabetes clinic: An integrated Diabetes Education and Eye disease Screening [iDEES] study ²⁵	A nurse-led model of integrated clinical risk assessment and diabetes education in an Indigenous-led primary care clinic found that most patients did not meet the recommended targets for risk factors such as body mass index, smoking, blood pressure, glycated haemoglobin (HbA _{1c}) level, kidney function, and blood lipids, with only three or four of the nine risk factor targets being met
Co-creation of a student-implemented allied health service in a First Nations remote community of East Arnhem Land, Australia ²⁶	A co-created, student-implemented allied health service with embedded culturally responsive practice in East Arnhem, a remote First Nations community, was feasible and acceptable
Ten principles relevant to health research among Indigenous Australian populations ²⁷	Outlines ten principles, such as partnership with the community, open and transparent relationships, capacity building flexibility in study implementation, and cultural respect for research involving Indigenous Australians
Research implementing the Flinders Model of self-management support with aboriginal people who have diabetes: findings from a pilot study ²⁸	Evaluates the Flinders Model for diabetes self-management support, showing improved self-management and HbA _{1c}
Community health workers improve diabetes care in remote Australian Indigenous communities: results of a pragmatic cluster randomized controlled trial ²⁹	A community health worker-led case management model reduced HbA _{1c} by 1.0% v 0.2% over 18 months ($P = 0.02$) and improved nutrition and dental service uptake
Effect of a Birthing on Country service redesign on maternal and neonatal health outcomes for First Nations Australians: a prospective, non-randomised, interventional trial ³⁰	Compares the Birthing in Our Community (BiOC) service, which was co-designed by stakeholders and based on Birthing on Country principles, to standard care, revealing doubled odds of five or more antenatal visits, a 38% reduction in preterm birth, and a 34% increase in breastfeeding at discharge
Supporting healthy lifestyles for First Nations women and communities through co-design: lessons and early findings from remote Northern Australia ³¹	Using experience-based co-design (EBCD) and incorporating First Nations participatory research principles across two Northern Territory regions facilitated collaboration between Aboriginal women, communities, and health services to identify shared priorities and solutions to reduce diabetes-related health risks
Aboriginal community-controlled aged care: principles, practices and actions to integrate with primary health care ³²	In-depth case studies in two metropolitan Aboriginal Community Controlled Health Services identified principles (identity support, connections with elders and community, self-determination) to guide culturally safe aged care services tailored to Aboriginal and Torres Strait Islander peoples
Enablers and barriers to the implementation of primary health care interventions for Indigenous people with chronic diseases: a systematic review ³³	Evidence from 23 studies revealed five themes (planning/design, workforce, partnerships, care pathways, and patient access) with enablers/barriers being modifiable, source-dependent and interrelated. These factors enable or inhibit the implementation of interventions aimed at improving chronic disease care for Indigenous people
Characteristics of Indigenous primary health care service delivery models: a systematic scoping review ³⁴	Identifies eight interdependent primary health care service characteristics: culture, accessibility, community participation, continuous quality improvement, culturally appropriate skilled workforce, flexible care, holistic health, and self-determination and empowerment
Exploring self-determined solutions to service and system challenges to promote social and emotional wellbeing in Aboriginal and Torres Strait Islander people: a qualitative study ³⁵	This study examined self-determined solutions proposed by Aboriginal and Torres Strait Islander people and service providers to address local challenges, enhance the service system, and promote social and emotional wellbeing

- Australian primary care settings: a nurse-led model of integrated diabetes care. *J Adv Nurs* 2022; 78: 3187-3196.
- 23 Atkinson-Briggs S, Jenkins A, Keech A, et al; Centre of Research Excellence in Diabetic Retinopathy. Integrating diabetic retinopathy screening within diabetes education services in Australia's diabetes and indigenous primary care clinics. *Intern Med* 2019; 49: 797-800.
- 24 Atkinson-Briggs S, Jenkins A, Keech A, et al; Centre of Research Excellence in Diabetic Retinopathy Study Group. A model of culturally-informed integrated diabetes education and eye screening in indigenous primary care services and specialist diabetes clinics: study protocol. *J Adv Nurs* 2021; 77: 1578-1590.
- 25 Atkinson-Briggs S, Ryan C, Keech A, et al; Centre of Research Excellence in Diabetic Retinopathy Study Group. Nurse-led vascular risk assessment in a regional Victorian Indigenous primary care diabetes clinic: an integrated Diabetes Education and Eye disease Screening [iDEES] study. *J Adv Nurs* 2022; 78: 3652-3661.
- 26 Barker R, Witt S, Bird K, et al. Co-creation of a student-implemented allied health service in a First Nations remote community of East Arnhem Land, Australia. *Aust J Rural Health* 2022; 30: 782-794.
- 27 Jamieson LM, Paradies YC, Eades S, et al. Ten principles relevant to health research among Indigenous Australian populations. *Med J Aust* 2012; 197: 16-18. <https://www.mja.com.au/journal/2012/197/1/ten-principles-relevant-health-research-among-indigenous-australian-populations>
- 28 Battersby MW, Kit JA, Prideaux C, et al. Research implementing the Flinders model of self-management support with aboriginal people who have diabetes: findings from a pilot study. *Aust J Prim Health* 2008; 14: 66-74.
- 29 McDermott RA, Schmidt B, Preece C, et al. Community health workers improve diabetes care in remote Australian Indigenous communities: results of a pragmatic cluster randomized controlled trial. *BMC Health Serv Res* 2015; 15: 68.
- 30 Kildea S, Gao Y, Hickey S, et al. Effect of a Birthing on Country service redesign on maternal and neonatal health outcomes for First Nations Australians: a prospective, non-randomised, interventional trial. *Lancet Glob Health* 2021; 9: e651-e659.
- 31 Dias T, MacKay D, Canuto K, et al. Supporting healthy lifestyles for First Nations women and communities through co-design: lessons and early findings from remote Northern Australia. *Front Clin Diabetes Healthc* 2024; 5: 1356060.
- 32 Dawson A, Harfield S, Davy C, et al. Aboriginal community-controlled aged care: principles, practices and actions to integrate with primary health care. *Prim Health Care Res Dev* 2021; 22: e50.
- 33 Gibson O, Lisy K, Davy C, et al. Enablers and barriers to the implementation of primary health care interventions for Indigenous people with chronic diseases: a systematic review. *Implementation Sci* 2015; 10: 71.
- 34 Harfield SG, Davy C, McArthur A, et al. Characteristics of Indigenous primary health care service delivery models: a systematic scoping review. *Global Health* 2018; 14: 12.
- 35 Dawson AP, Warrior E, Pearson O, et al. Exploring self-determined solutions to service and system challenges to promote social and emotional wellbeing in Aboriginal and Torres Strait Islander people: a qualitative study. *Front Public Health* 2023; 11: 1206371.
- 36 Ekinci EI, Pyrlis F, Hachem M, et al. Feasibility of once weekly exenatide-LAR and enhanced diabetes care in Indigenous Australians with type 2 diabetes (Long-acting-Once-Weekly-Exenatide laR-SUGAR, "Lower SUGAR" study). *Intern Med* 2021; 51: 1463-1472.
- 37 Tan C, Williams Z, Islam MA, et al. Interventions for Aboriginal and Torres Strait Islander people with type 2 diabetes that modify its management and cardiometabolic risk factors: a systematic review. *Med J Aust* 2024; 221: 623-630. <https://www.mja.com.au/journal/2024/221/11/interventions-aboriginal-and-torres-strait-islander-people-type-2-diabetes> ■