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Diabetes in the community for Aboriginal people (DiCAP) project

Statewide report – phase one

September 2024

NSW GOVERNMENT

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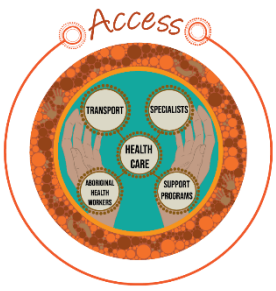
Title	Diabetes in the community for Aboriginal people (DiCAP) project: Statewide report – phase one		
Published	September 2024		
Produced by	Aboriginal Chronic Conditions and Diabetes and Endocrine Networks		
Preferred citation	NSW Agency for Clinical Innovation. Diabetes in the community for Aboriginal people (DiCAP) project: Statewide report – phase one. Sydney: ACI; 2024.		
TRIM AC1/D23/3975	SHPN (ACI) 240294	ISBN 978-1-76023-842-1	ACI_ 9235

Contents

Summary

- The DiCAP project has sought to answer the question: How can we improve care for Aboriginal peoples living with type 2 diabetes within the community?
- Phase one of this Aboriginal-led project sought to gather experiences from Aboriginal community members living with type 2 diabetes and staff who provide care. The purpose was to identify what is working, existing gaps and how services can do things differently to improve care and outcomes for Aboriginal people across seven regions in NSW.
- The regions are Central Coast, Illawarra Shoalhaven, Mid North Coast, Northern NSW, South Western Sydney, Western NSW and Western Sydney.
- Each region formed a local working group which consisted of relevant local health district (LHD) staff and key local partners, such as members of the Aboriginal Community Controlled Health Services (ACCHSs).
- Using a mixed method approach, the regions gathered experiences and stories from Aboriginal community members living with type 2 diabetes and staff who provide care, totalling 370 people.
- Thirty themes identified by community members and healthcare staff reinforce focus areas that can improve care and outcomes for Aboriginal people living with type 2 diabetes within the community.
- A workshop was held with region working groups to validate findings and prioritise themes for phase two – solution design. The following 11 themes were prioritised to move into phase two of the project.



Access

Cultural responsiveness

Diabetes knowledge and management

Diet and nutrition

Education

Racism

Services

Social and emotional wellbeing

Social determinants of health

Support

Workforce

Limitations

We cannot generalise about these finding and claim this is a statewide account for all Aboriginal communities. Health staff participants were self-selected, and Aboriginal community members were invited to complete surveys or join community yarn ups.

There may be bias among the healthcare staff on reporting practices. In addition, Aboriginal community member responses were broad in range and responses may not represent a full range of healthcare experiences for the diverse Aboriginal communities across the seven regions.

However, the results provide insights into the care for Aboriginal peoples and communities in these seven regions of NSW.

Unavoidable delays

It is important to acknowledge the COVID-19 pandemic impact on the healthcare system, including across the Agency for Clinical Innovation (ACI) and its region partners during the diagnostic phase one of the project.

The ACI hibernated the DiCAP project in March 2020, impacting the initial engagement on the project from LHDs and partners.

The project was paused again between July and October 2021, due to the outbreak of the COVID-19 Delta variant, and later slowed down again due to the Omicron variant. This impacted ACI project team's ability to complete the thematic analysis of responses gathered.

Bush fires and flooding across NSW at different points in time also caused further delays to phase one of the project.

Many regions were severely affected for prolonged periods. This led to increased pressures on resources, the workforce and infrastructure.

Some regions were not able to commit resources to the project until the situation eased. It also meant the ACI project team could not travel to support community data collection.

However, the resilience of the regions showed through. The way regions devised strategies to best meet local needs in response to the fires, floods and COVID-19, while engaging the community and staff for this project, is commendable.

Background

Diabetes mellitus among Aboriginal peoples

This report is focused on Aboriginal people living with type 2 diabetes mellitus. Where the word 'diabetes' is written, this is referring to people living with type 2 diabetes.

The number of people diagnosed with diabetes increases with age and socioeconomic disadvantage. It was the second leading cause of death for Aboriginal and Torres Strait Islander people in 2018.[1,2] The Australian Institute of Health and Welfare reports that:

> "In 2017-18, there were around 70,000 hospitalisations for type 2 diabetes (as the principal and/or additional diagnosis) among Aboriginal and Torres Strait Islander people, a rate of 8,500 hospitalisations per 100,000 population."

After adjusting for differences in the age structure of the populations:

- the rate of type 2 diabetes hospitalisations among Indigenous Australians was 4.3 times the rate for non-Indigenous Australians
- the difference in rates between Indigenous Australians and non-Indigenous Australians was greater for females than males – 5.6 times as high for females and 3.2 times as high for males."[3]

Governance

Aboriginal self-determination and governance for the project occurred across three levels:

- The ACI Aboriginal Chronic Conditions Network Executive identified this as a priority project, refined project scope and provided Aboriginal executive sponsorship.
- A statewide Aboriginal Advisory Group, inclusive of the diverse Aboriginal health sector, provided overarching advice, guidance and support.
- Region-based working groups provided community leadership and led the project at a local level.

Terminology

Within NSW Health, the term 'Aboriginal' is generally used in preference to 'Aboriginal and Torres Strait Islander', in recognition that Aboriginal people are the original inhabitants of NSW.[4]

Method

Aim

This project sought to answer the question: How can we improve care for Aboriginal peoples living with type 2 diabetes within the community?

Project teams

The project is across seven regions in NSW: Northern NSW, Mid North Coast, Western NSW, Central Coast, Illawarra Shoalhaven, Western Sydney and South Western Sydney.

Each region formed a local working group which consisted of relevant LHD staff and staff from key local partners, including ACCHSs.

Design

A mixed-method approach was developed to gather experiences and stories from Aboriginal people living with type 2 diabetes and from health professionals who provide care. The approach included yarning (or yarn ups) with community and a survey for health professionals and community.

Yarning (or yarn ups) is a process that involves sharing stories and developing knowledge in a culturally respectful way.[5] Two regions identified this approach as culturally safe and respectful. The mixed-method approach provided an opportunity for the participation of Aboriginal peoples geographically spread across NSW.

The community and health staff surveys were developed by the ACI project team, then refined by the Aboriginal Project Advisory Group. The surveys were later refined by local region groups who collected the information. These surveys were seen as the most simple and effective means of measuring the behaviours, attitudes and opinions of both community members living with type 2 diabetes and the health staff who provide care.

The seven working parties agreed to participate and identified this approach as culturally safe and respectful for the local communities.

Participants and recruitment

Aboriginal people in the community

Staff across the LHD and partner organisations invited Aboriginal community members attending services to either complete the survey with the support of a staff member or attend a planned yarn up. All community members who completed a survey or attended the yarn ups received a $20 Coles voucher or a food hamper to the value of $20.

Healthcare providers

Invitations to complete the online health professional survey were distributed through the LHDs Aboriginal health and diabetes workforces. In some regions they were distributed to partner workforces, such as the local Aboriginal medical service and other stakeholders across primary care.

Data collection

Yarn ups

Five yarn ups were facilitated with community in Dubbo (2), Brewarrina (1), Lightning Ridge (1) and Western Sydney (1) between 10 February and 5 May 2021. The yarn ups were held in a locally nominated culturally safe environment and co-facilitated by local Aboriginal health practitioners. The facilitators used a semi-structured interview guide for between 90 minutes and three hours for each session.

Surveys

Data was collected from healthcare staff using a survey administered through SurveyMonkey from March to July 2021. This survey included 12 open and closed questions (see Appendix 1).

Community data was collected with the support of a health staff member assisting the community member to complete the survey in person, via phone at a health service or at home. iPads were loaned from ACI to the Northern NSW LHD staff, to assist staff to conduct surveys with community members while attending home visits.

The community surveys were collected between the same period as the staff survey, March to July 2021. The survey included 23 open and closed questions (see Appendix 2).

Analysis

Inductive thematic analysis followed Braun and Clarke's six phases of qualitative analysis: familiarisation, coding, generating themes, reviewing themes, defining and naming themes and writing up.[6] The approach was used to identify, report and interpret patterns or themes within the data.[7]

Double-coding and iterative discussion were used to achieve consistency, explore relationships between codes and agree upon the main themes. Mind maps depicted relationships between the identified codes and themes. Illustrative quotes were selected to demonstrate key points and the prevalence of the themes.

Community partnerships

Region working groups were established in each of the seven regions to provide a local governance structure to oversee the project. Examples of members included:

- Local Health District: Credentialled diabetes educator, Aboriginal health worker or practitioner, registered nurse, chronic care program manager
- Aboriginal Community Controlled Health Organisation: Aboriginal health worker or practitioner, diabetes educator, nursing staff and senior executive leaders
- Primary Health Network and non-government organisations: Credentialled diabetes educator and Aboriginal health workers.

Some regions chose specific sites across the district to be targeted for inclusion in the information gathering, such as Lismore, Tweed, Grafton and Casino, in the Northern NSW area. Other regions, such as South Western Sydney, chose to spread across their whole footprint.

Ethical considerations

A retrospective ethics application was considered by the AH&MRC Ethics Committee. The application included description of the strong structures of Aboriginal governance, engagement of ACCHS and potential impact to improve health outcomes for Aboriginal peoples.

The application was approved on the 30 May 2023.

The ACI project team will continue to provide updates to the AH&MRC Ethics Committee until project completion.

Community and staff survey summaries

A total of 370 people has participated in community and staff surveys. This includes a breakdown of:

- 182 Aboriginal people living with type 2 diabetes completed a survey via telephone or paper copy survey, or via a healthcare staff with an iPad.
- 46 Aboriginal people living with type 2 diabetes participated in a yarn up.
- 142 responses to the health staff online survey.

Health staff have provided an honest insight, regarding professional experiences of providing care to Aboriginal peoples living with type 2 diabetes.

A summary of the approach and findings from each region is included below.

Central Coast

Participation

A local working group was established in the Central Coast region to provide a local governance structure to oversee the project. Membership included people from Central Coast Local Health District and Eleanor Duncan Aboriginal Health Services

Staff were nominated by the LHD to participate in the working group. These staff members facilitated the inclusion of the ACCHS sector.

Themes

Across all Central Coast region community and staff responses 10 themes were identified.

This includes two shared themes: education and diet and nutrition.

Across community responses a further two unique themes were identified: cost and social and emotional wellbeing.

Across all staff responses, six additional themes were identified: access, cultural responsiveness, services, social determinants of health, support and workforce.

Discussion

Some of these themes were highlighted more than others, including education, workforce, diet and nutrition and cultural responsiveness.

Both groups have identified a series of key enablers and barriers to improving the standard of care across the region. Community and staff have identified the opportunity to strengthen service design and delivery, that listens to community needs. Here services can increase community engagement through community-based tailored education and healthy lifestyle programs. These programs can embed Aboriginal culture and connection to country through the cultural determinants of health.

Additionally, there was a reported need to increase culturally responsive education that improves community members knowledge of what is diabetes, its impacts on the body and how best to have success for self-management over time. It was identified that this education should be flexible so can be delivered through a patient centred, family and/or a community approach.

Half of the staff who completed the survey advised they didn't feel, or were unsure if, they had the cultural capability to engage respectfully with Aboriginal peoples. This is an example of staff being honest in each person's response and identifying the need to upskill cultural knowledge and confidence to engage respectfully with diverse Aboriginal peoples and communities.

Aboriginal workforce was a critical element in delivering culturally responsive services. Both community and staff reported the need to employ more Aboriginal health staff and upskill existing Aboriginal workforce to play a central role in diabetes care. This includes exploring pathways for Aboriginal diabetes educators, the role Aboriginal staff can play in delivering education and providing ongoing support to a person, family and/or community as part of a multidisciplinary team.

Community members were able to advise in detail the diabetes appointments and the frequency of appointments each person attended. However, when asked in the following question to outline the routine diabetes check-ups, there seemed to be a disconnect with half of community members advising they couldn't name these routine check-ups. Based on this response, it could be that there is a need to provide further education on what the diabetes cycle of care is, why it's important and how not engaging in routine check-ups can have a negative impact on each person's health.

A high number of community participants shared only using the National Diabetes Services Scheme (NDSS) service once or less a year. There is an opportunity to follow up with community members to ensure people are aware of the NDSS and can make informed decisions about accessing the service. Several community members shared the struggles of living with type 2 diabetes, and the social and emotional impact this continues to have. As with other regions, information provided by staff and community recognises the need to look at strengthening not only the social and emotional supports for patients, but also other forms of ongoing support.

Staff provided some good feedback about existing partnerships. However, staff identified the need and opportunity to strengthen existing partnerships across the region. These focus areas include how:

- resourcing (funding, staffing and equipment) can be increased across these services
- a specialised diabetes clinic can be co-designed and delivered
- staff relationships across services can be developed and strengthened
- case coordination and care planning can be improved.

There is a willingness from staff to do things different and scale up success that is based on community need. The information captured provides the opportunity to continue the efforts across the Central Coast region, to strive for services design and delivery that is culturally responsive, improves the standard of care and leads to better health outcomes for Aboriginal peoples.

Illawarra Shoalhaven

Participation

A local working group was established in the Illawarra Shoalhaven region to provide a local governance structure to oversee the project. Membership included people from Illawarra Shoalhaven Local Health District, Grand Pacific Health and Waminda - South Coast Women and Wellbeing Aboriginal Corporation

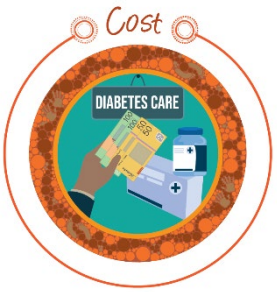
Themes

Across all Illawarra Shoalhaven region community and staff responses 15 themes were identified.

While aspects of each of these 15 themes were identified in responses, only education stood out as common between both groups.

Community responses identified seven themes, including cultural responsiveness, diabetes knowledge and management, diet and nutrition, education, expectation of diabetes, physical activity, and social and emotional wellbeing.

Staff responses identified nine themes including, cost, education, empowerment, health literacy, racism, services, support, social determinants of health and workforce.



Discussion

The findings within the community responses highlighted a preconceived notion of expecting to get diabetes due to a strong family history of diabetes. Responses highlighted that most community members had a good understanding of diabetes, how it works and how it affects different parts of the body.

Community reported how diabetes had a range of impacts on people's lives, while some were managing okay, others described it as a balancing act and managing it was often difficult and stressful.

Across community responses, a majority of community members were active, walking most days and were attending weekly programs such as the Aunty Jeans Program for ongoing support of diabetes management.

Community members reported having clear goals and were achieving them slowly. Most of the goal setting targets were dietary-related, but included increasing physical activity, losing weight, quitting smoking, reducing alcohol consumption and maintaining a healthy life balance.

Some barriers for not achieving goals included financial stressors, lack of social supports, inability to access services and affordability of healthy foods.

The findings across staff responses highlighted that the social determinants of health are key factors in preventing behavioural change to manage diabetes.

In addition, staff across services identified several key enablers to self-management of diabetes, including:

- the need to improve education and health literacy
- increasing the Aboriginal workforce to support and develop exercise and nutritional programs
- having the multidisciplinary team on board to support lifestyle choices
- strengthening partnerships including having better coordination between primary health care, general practitioners, LHDs, ACCHSs and other agencies and services
- improving referral pathways and general practice management and treatment plans to reduce risk factors and complications
- follow-up services for prevention, awareness and support
- more outreach services to develop trust and respect in the community
- encouraging self-determination, empowerment and improving shared decision making to improve clinician-person relationship to break down any racism or language barriers experienced by Aboriginal people.

Mid North Coast

Participation

A local working group was established in the Mid North Coast region to provide a local governance structure to oversee the project. Membership included people from Mid North Coast Local Health District, Galambila Aboriginal Health Service and Durri Aboriginal Corporation Medical Service.

Staff were nominated by the LHD to participate in the working group. These staff members facilitated the inclusion of the ACCHS and non-government health sector members.

Sites

Specific sites across the region were targeted for inclusion in the information gathering. These were from across the Hastings Macleay and Coffs Clinical Networks.

Themes

Across all Mid North Coast region community and staff responses 13 themes were identified.

This includes seven shared themes: access, culturally responsiveness, diet and nutrition, education, services, social and emotional wellbeing and workforce.

Community responses identified a further two themes: physical activity and time.

Staff responses identified a further four themes: partnerships, racism, social determinants of health and support.

Discussion

Community shared how services delivered are culturally responsive, with local ACCHSs playing a large part in this. However, community have advised that services could be strengthened by further engagement and connection to community, by embedding culture across diabetes services and creating more diabetes community support groups.

Workforce was a stand-out theme, with a focus needed to increase access to diabetes educators, Aboriginal health practitioners, Aboriginal health workers and dietitians across services. Additionally, it was recognised that there is a need to upskill the existing Aboriginal workforce and increase the overall number of staff in diabetes care.

Community reported barriers to making and maintaining healthy lifestyle changes. These focused on aspects of diet and nutrition, including healthy eating, portion size and food preparation. Community reported they would benefit from additional education and practical support around diet and nutrition.

Additional education that focuses on what diabetes is, how it impacts the body and ongoing successful self-management were also identified as priority education areas for both community and staff groups. Education that is tailored to different community groups, that can have a stronger focus on family and community-based education were all stand out responses.

Staff reported strong partnerships across the region, while also identifying the opportunity to strengthen these and new relationships. This included partnerships between the LHD, ACCHSs and general practitioners, with a focus to explore sharing access to resources, funding, equipment, clinics and workforce.

Staff reported opportunities to strengthen cultural capability with a focus on building trust and rapport with community, being accepted within the community, developing an understanding of Aboriginal culture and having yarning time in clinic work.

Staff reported how education may not meet community need and lacks Aboriginal designed and focused information. They highlighted how the social determinants of health play a critical role as barriers to successful health outcomes. This includes how transport, geographic locations, living conditions, access and costs all impact one's ability to self-manage within the community and access care.

Racism was reported by staff as a critical theme that has and does impact on service delivery. Staff reported how these experiences of racism can prevent community members' behaviour change. Responses highlighted how services and staff need to recognise history, racism, mistrust of services and past trauma. This is critical as these experiences need to be taken into consideration and shape how services can be strengthened to ensure culturally safe and responsive care.

Themes identified across both community and staff responses align strongly. This alignment has supported agreement across themes and presents an opportunity to drive positive change across the Mid North Coast region for diabetes services and the management of type 2 diabetes within the community. Both community and staff are calling for the same improvements, which centre around:

- workforce and culturally responsive services that increase access to care
- support with social and emotional wellbeing, via a stronger focus on education and connection to community.

Northern NSW

Participation

A working group was established in Northern NSW to provide a local governance structure to oversee the project. Membership included people from Northern NSW Local Health District, Bulgarr Ngaru Medical Aboriginal Corporation, Bullinah Aboriginal Health Service and Rekindling the Spirit.

Sites

Specific sites across the region, which were targeted for inclusion in the information gathering, were in Lismore, Tweed, Grafton and Casino.

Themes

Across all Northern NSW region community and staff responses 11 themes were identified.

This includes five shared themes: culturally responsiveness, education, social determinants of health, support and workforce.

Across community responses a further three unique themes were identified: access, diet and nutrition and social and emotional wellbeing.

Across all staff responses, three additional themes were identified: community, holistic care and services.

Discussion

These responses outline the barriers that impact positive health outcomes. Furthermore, both community and staff identified several areas that are working and can be scaled up or done differently to strengthen healthcare services.

Both groups identified the importance of services to embed culture, listen, respond to community needs, have a stronger focus on social and emotional wellbeing and take a holistic and social determinants of health approach. These will go a long way to improve Aboriginal health outcomes across the region.

Support for both the person and broader family was identified as a need to create success for Aboriginal peoples managing diabetes within the community. This includes practical support to

navigate the journey of diabetes within the healthcare setting and ongoing support regarding emotional wellbeing and other person and family priorities that may exist.

Aboriginal workforce has been identified as critical in this journey. This includes employing more Aboriginal staff across the region, while providing the opportunity for existing Aboriginal staff to be upskilled with a focus on diabetes care.

More broadly, it was identified that non-Aboriginal staff need to be provided with access to education and yarning that will strengthen cultural capability. Key focus areas included:

- how to engage respectfully with diverse Aboriginal peoples and communities
- how to build rapport and trust
- how diabetes impacts Aboriginal culture
- how services can be designed in partnership with community.

Strong partnerships across the region between the LHD and ACCHS were recognised. Staff have advised how services with a diabetes focus can be further strengthened and build upon this success. This includes how staff can come together for program planning, sharing of resources and working through multidisciplinary teams to deliver community-based diabetes clinics and follow up.

It was widely recognised that more education is needed across the region with a focus on what diabetes is, the annual cycle of care, self-management and the complications of diabetes.

Both community and staff have shared the importance of education and the need to take a family-centred approach. This includes tailoring education to different groups and providing education within a community and or home-based setting.

The Northern NSW region was able to engage one of the highest response levels across both community and staff throughout this whole project. In addition, the strong Aboriginal-led governance and partnerships across the LHD and ACCHS sector demonstrate that the region is in a great position to collaborate, build on success to date and innovate in how diabetes services can be either scaled up or done differently, based on community needs.

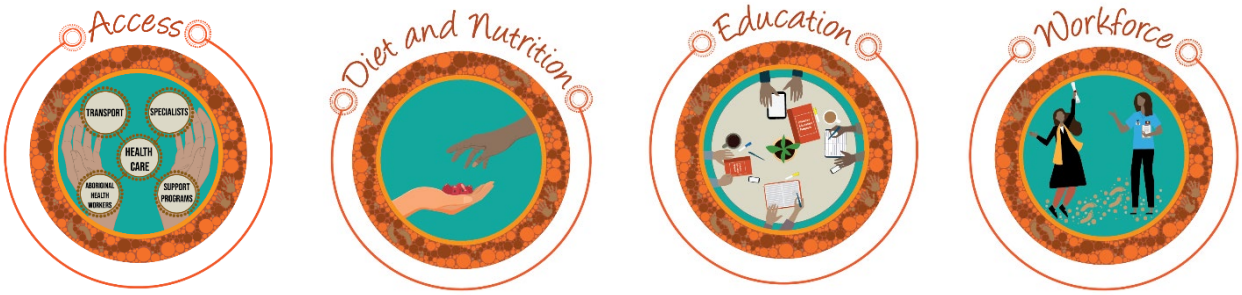
South Western Sydney

Participation

A working group was established in South Western Sydney to provide a local governance structure to oversee the project. Membership included staff across the South Western Sydney Local Health District from the Aboriginal Chronic Care Program.

Themes

Across all South Western Sydney responses, there were four core themes of access, diet and nutrition, education and workforce identified. These themes were shared between both community and staff.



Discussion

Community responses shared how it's hard to accept a diagnosis of diabetes. Community highlighted how diabetes affects a person's daily life, how it's hard to change diet and not have high sugary foods and drinks.

When rating how well community members manage their diabetes, most people indicated managing their diabetes well.

However, community responses identified that diet and nutrition is one of the most challenging aspects of living with diabetes.

Most community members reported attending routine check-ups. When a person was unable to attend a medical appointment, it was reported that barriers included: feeling unwell at the time, mobility issues, including pain and a lack of transport.

Some community members reported needing to be taken to hospital for diabetes related issues including unstable blood glucose levels, diabetic ulcers, amputations and heart problems.

Community responses identified the need for more targeted diabetes education, as the average response was reported as 'having little knowledge'.

Community reported opportunities for further education regarding information about blood glucose levels, signs and symptoms of hypoglycaemia and medication use and insulin.

Almost all community members indicated that the information they had received to help manage their diabetes was culturally appropriate and most said they had routine diabetes check-ups.

Community themes highlighted improvement areas for diabetes management focusing on how to eat well, exercising, checking blood sugar levels and regularly taking medication.

Staff responses at the time highlighted the need for a full-time diabetes educator, with other staffing resources not meeting community population ratio. Staff shared how resources are needed to meet an increase in referrals across the region.

Staff identified that out-of-pocket community expenses for medication and equipment costs are barriers to good care.

Staff reported how community members with multiple health conditions created additional barriers and made it difficult for a person to manage their diabetes.

Responses highlighted how the social determinants of health impact on a person's ability to successful manage living with diabetes.

Staff reported how core principles of trust and respect between health service providers and the community is essential.

Potential barriers to diabetes self-management in the local community included poor health literacy, a person being overwhelmed with diabetes and other life stressors, difficulties in navigating complex health systems and access to resources.

Possible ways to improve care included listening to the community, peer group support, better general practitioner relationships and expanded multidisciplinary team approaches to care.

Staff identified opportunities to expand and develop upon existing successful healthy lifestyle programs, peer group support and ensuring regular health checks can improve health for the community.

Western NSW

Participation

A working group was established in the WNSW to provide a local governance structure to oversee the project. Membership included staff from the Western NSW Local Health District and Marathon Health.

Staff were nominated by the LHD to participate in the working group, and these staff members facilitated the inclusion of partner organisations.

Themes

Across all Western NSW region community and staff responses 13 themes were identified.

This included three common themes of diet and nutrition, education and workforce.

Across community responses a further five unique themes were identified: cultural responsiveness, living with diabetes, racism, social and emotional wellbeing, and yarning and connecting.

Across all staff responses five additional themes were identified: change behaviour, community, other conditions, services and social determinants of health.

Discussion

All core themes across the two groups have close similarities. This includes core themes of, community, cultural responsiveness, diet and nutrition, education, social and emotional wellbeing and workforce.

Within this, there were some standout findings that have been identified at the time across all responses.

Both community members and staff agree that there is a need and opportunity to:

- increase overall access to diabetes educators across Western NSW
- upskill existing Aboriginal workforce with a focus on diabetes management
- increase credentialled Aboriginal diabetes educators
- strengthen workforce's cultural capability to engage respectfully with community and provide culturally responsive services
- engage Aboriginal community members to co-design diabetes services and education across the region
- increase Aboriginal-designed education resources
- increase the design and delivery of tailored community-based education programs, which have a focus on healthy lifestyle programs, food education and education on what is diabetes and living with diabetes

- create services that are holistic, community and family-centred
- improve pathways and services that include social and emotional wellbeing support for both the client and family members
- strengthen partnerships between health services across western NSW, that include a focus on sharing of funding, staffing resources and equipment
- explore how services can take a social and cultural determinants approach to delivery care.

Western Sydney

Participation

Endorsement for the project was provided locally by the Western Sydney diabetes and Aboriginal health steering committee. This committee consists of key partners, such as the Western Sydney Local Health District, Greater Western Aboriginal Health Service, Western Sydney Primary Health Network (WentWest), Kildare Road Medical Centre and Diabetes NSW/ ACT.

This committee nominated an Aboriginal health practitioner as the project lead who reported back all project activities.

Aboriginal community members and staff across the Western Sydney region participated in the project through the yarn up and community and staff surveys.

Themes

Across all Western Sydney region community and staff responses 18 themes were identified.

This included four common themes: cultural responsiveness, diet and nutrition, education and support.

Across community responses a further five unique themes were identified: diabetes knowledge and management, expectations of diabetes, family, social and emotional wellbeing and workforce.

Across staff responses nine additional themes were identified: access, cost, health literacy, healthy lifestyle, resources, respect, services, social determinants of health and transport.

Discussion

Several key themes have been identified which enabled a discussion on what may be needed at a local level to improve care provided to Aboriginal people living with type 2 diabetes in the community.

Common themes emerged across the yarn up and community surveys.

Many community members reported expecting to get diabetes, as a result of family history or noted prevalence in the community.

A high proportion of community were unable to adequately describe what diabetes is and how it effects the body.

Low levels of awareness on what the NDSS is, as well as lower than average registration, was also observed across community responses.

Many community responses highlighted barriers regarding diet and nutrition, what the challenges were relating to dietary changes, what was needed to support a healthy diet in diabetes (such as cooking groups), as well as the cost and access of healthy food.

Many community members reported wanting more education and provided examples of how and where it should be delivered, and what the gaps were. It must be noted that community support groups were requested on numerous occasions.

The delivery of care by Aboriginal staff was preferred, and it was emphasised that more Aboriginal staff, including those trained in diabetes, were needed.

Yarn up participants placed emphasis on the role of family when a member of the family has diabetes, and the importance to start prevention education early on with the younger generation.

The community survey participants identified the need for more culturally appropriate and inclusive services, as well as recognising the impact of social and emotional wellbeing on the community when living with diabetes.

It can be seen that a number of key findings and themes identified through the healthcare staff survey are aligned to findings through the yarn up and community survey.

These themes include access, cost, cultural responsiveness, diet and nutrition, education, support and transport.

The findings within the staff survey are valuable to highlight additional areas as staff had the opportunity to report from a service perspective what they believed were key barriers and enablers.

In addition to diet and nutrition, staff identified more broadly the importance of support for healthy lifestyle interventions to improve diabetes management.

Staff highlighted the importance of respect as a foundation of culturally appropriate service delivery to the community and the important role that the social determinants of health play in one's ability to manage chronic illnesses.

Statewide themes

A combined total of thirty themes were identified across the seven regions.

This result highlights the complexity that Aboriginal people face when living with and managing type 2 diabetes.

Following an in-depth thematic analysis, these themes were grouped into higher, middle and lower frequency categories and can be viewed in Appendix 3.

An Aboriginal artist, Belinda Coe, designed icons to visually represent each theme.

Statewide workshop

On 20 June 2022, a workshop at 1 Reserve Road Sydney was held to validate and prioritise themes identified during the information gathering phase. 30 people were in attendance, with each of the seven regions represented, and advisory group members and two community members.

The workshop was supported by the ACI consumer and co-design manager, and the patient experience and consumer engagement officer. The DiCAP project team scribed throughout the workshop, in addition to transcribing notes from butchers' paper which participants used during activities.

Activity one focused on theme validation. As part of this activity, participants looked at the list of themes, with a focus on medium and lowest frequency themes. Participants discussed whether any of these themes needed to be shifted into the higher frequency list. Groups scribed their responses and feedback to the wider group.

Activity two focused on prioritisation of these themes. As individuals, each participant was asked to read and reflect on the modified list of themes, following on from activity one. They were then asked to vote on which themes they wanted to prioritise, by placing a dot sticker next to the theme. Each participant had three dots to vote across all 30 themes.

The themes were written up on butchers' paper and placed on a workshop wall. Participants used dot stickers to prioritise themes. While reflecting and voting, participants were encouraged to think about the following key points:

- Impact on community and health outcomes
- Impact on staff who provide care
- Ease of implementation
- What we have influence over.

Using this vote process, workshop participants categorised themes into highest, medium and lowest frequency by how many doted votes each theme received. Lowest frequency included 0-2 votes, medium frequency included 3-5 votes and highest frequency included 6 or more votes.

It is important to note that all themes identified are considered critical to the success of improving service delivery and health outcomes for Aboriginal peoples living with type 2 diabetes in the community.

Tables 1 and 2 summarise the outcomes following the prioritisation activity. The higher frequency themes have been voted by workshop participants as the most critical, with recognition that all other themes are core elements that underpin each other.

Table 1: Initial statewide themes (based on all seven region responses)

Frequency	Themes
Highest frequency	• Education • Workforce • Cultural responsiveness • Services • Social and determinants of health • Social and emotional wellbeing • access • Support • Diet and nutrition
Medium frequency	• Diabetes knowledge and management • Racism • Cost
Lowest frequency	• Community • Health literacy • Holistic care • Physical activity • Partnerships

	• Empowerment • Family • Living with diabetes • Time • Expectations of diabetes • Healthy lifestyle • Change behaviour • Housing • Other conditions • Resources • Respect • Transport • Yarning and connecting

Table 2: Statewide themes frequency updated after workshop

Frequency	Themes (no. of votes)
Highest frequency	• Education (20) • Workforce (16) • Cultural responsiveness (13) • Diabetes knowledge and management (13) • Racism (11) • Services (11) • Social and determinants of health (10) • Social and emotional wellbeing (10) • Access (9) • Support (7) • Diet and nutrition (6)
Medium frequency	• Community (4) • Health literacy (4) • Holistic care (4) • Partnerships (4) • Physical activity (3)
Lowest frequency	• Cost (2) • Empowerment (2) • Family (2)

	• Living with diabetes (2) • Time (2) • Expectations of diabetes (1) • Healthy lifestyle (1) • Change behaviour (0) • Housing (0) • Other conditions (0) • Resources (0) • Respect (0) • Transport (0) • Yarning and connecting (0)

Conclusion

Using an Aboriginal-led collaborative partnership, seven regions were engaged to ask how can we improve care for Aboriginal peoples living with type 2 diabetes in the community?

The DiCAP project has established and maintained strong Aboriginal governance at a state and local level that has resulted in a significant partnership approach across the ACI, LHDs, ACCHSs and non-government organisations across primary care.

This approach has been based on the core principle of Aboriginal leadership and decision-making working in partnership with diabetes expertise across health services.

Across the seven regions of Central Coast, Illawarra Shoalhaven, Mid North Coast, Northern NSW, South Western Sydney, Western NSW and Western Sydney, 370 people have shared experiences of living with, or providing care for, Aboriginal peoples living with type 2 diabetes.

These experiences and insights shared by community members and staff were based around being diagnosed with type 2 diabetes, education provided across the journey of living with diabetes, a person's current understanding of diabetes and the annual cycle of care.

This has also included a focus on cultural safety of services, cultural capability of staff, key enablers and barriers that lead to positive health outcomes and what health services could do differently to meet the needs of community members.

A thematic analysis and validation process identified thirty themes. Eleven of these themes were prioritised with a recognition that the other nineteen themes are core elements and foundational across all themes.

The eleven prioritised themes are: access, cultural responsiveness, diabetes knowledge and management, diet and nutrition, education, racism, services, social and emotional wellbeing, social determinants of health, support and workforce.

Across the eleven themes, people's shared lived experiences and professional expertise have identified what community and staff are calling for to improve health services across their region.

People have shared lived experiences of racism from health staff, hospitals and the health system. This included how racism and experiences of trauma impacts on a person's wellbeing and ability to access care and leads to poorer health outcomes.

People outlined how they want services to be designed and delivered based on community needs, which embeds an Aboriginal lens. Services need to be culturally safe and respectful with a focus on staff strengthening cultural capability.

For workforce, community and staff have identified the need for more Aboriginal health workers to be involved in the annual cycle of diabetes care. This includes upskilling existing workforce and access to more Aboriginal diabetes educators.

People have shared how being diagnosed and living with diabetes impacts a person's social and emotional wellbeing. This includes creating feelings of depression, anxiety and low mood or further compounding existing mental health conditions. People have shared how this makes it hard to manage diabetes and impacts a person's motivation to make healthy lifestyle choices.

The theme of social determinants of health outlined how this impacts a person's ability to successfully manage diabetes care. This includes housing, transport, employment, education and

income. Community members advised a need for more support from staff navigating the health system.

The theme of education identified a gap in community members diabetes knowledge, while at the same time recognising that community want to learn more. People want more culturally responsive education that is centred on both the individual and family.

This education needs to be held within the community, tailored to all age groups and have a stronger community-based education focus, including healthy life-style programs.

Diet and nutrition was another stand out theme. People advised this was one of the hardest things to manage. This included a focus on access to and costs of healthy food along with community asking for more community-based education programs.

People want improved access to diabetes specialists and diabetes programs within the community. These services need to be designed based on community need, delivered face-to-face and virtually.

Services need to be family-focused, supported by multidisciplinary teams and include a strong Aboriginal workforce. Services can focus on strengthening follow-up services, general practice management plans and improved referral pathways.

These eleven themes will now inform the future phases of the DiCAP project through a suite of solution design activities, implementation of local solutions and building sustainability of solutions to continue beyond the DiCAP project.

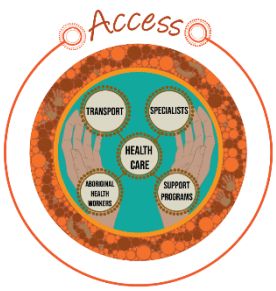
The next phase of DiCAP will include solution design activities that focus on brainstorming, idea generation and designing local solutions.

The DiCAP project team will then support regions to implement local solutions and build sustainability of solutions across the region in partnership with local service partners.

At all times, the DiCAP project will uphold the core principle of Aboriginal leadership and decision-making working in partnership with diabetes expertise across health services.

A health service that embeds Aboriginal voices, community connections and the broader social and cultural determinants of health will pave the way for improving care for Aboriginal peoples living with type 2 diabetes within the community.

Themes



Access

Cultural responsiveness

Diabetes knowledge and management

Diet and nutrition

Education

Racism

Services

Social and emotional wellbeing

Social determinants of health

Support

Workforce

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Appendix 1: Community survey

Q1	When were you diagnosed with diabetes?
Q2	How did this diagnosis make you feel? And how do you feel about your diabetes now?
Q3	Which health professionals did you see after your diagnosis? (select all that apply)
Q4	How often do you see these health professionals now? (Please specify for each subject, e.g. endocrinologist - once a fortnight; podiatrist - once every 2 months, etc.)
Q5	Can you name the routine diabetes check-ups you are supposed to attend throughout the year? Have you been going to them? What are the main reasons as to why you might miss them? (Please leave a space between your response to each of the 3 questions)
Q6	Please describe what diabetes is and how it affects your health and daily life.
Q7	When were you first educated on diabetes management?
Q8	Has diabetes education been delivered to you in a culturally sensitive manner?
Q9	Please provide details of instances where diabetes education has been delivered to you in a culturally insensitive manner.
Q10	What resources do you prefer to use when seeking information and support?
Q11	Are you registered with the NDSS?
Q12	How often do you use the NDSS resources?
Q13	Do you feel you are able to make the changes that health professionals recommend to help you with your diabetes? Are you lacking any resources that might help you implement these changes? (Please leave a line between your responses to the 2 questions)
Q14	Have any health professionals advised you to make any changes that you do not want to adopt?
Q15	What were the suggested changes?
Q16	Do you have any nutrition or health lifestyle goals?
Q17	Are you achieving these goals?
Q18	What are the main reasons as to why you have/have not been able to achieve these goals?
Q19	What forms of physical activity do you engage in?
Q20	How often do you engage in these forms of physical activity? (Please specify for each form and indicate if you are a member of a club, e.g. walking group - twice a week; club netball - once a week, etc.)
Q21	Do you think diabetes services could be improved?
Q22	How could diabetes services be improved?
Q23	Is there anything else you would like to see done differently to help you with your diabetes?

Appendix 2: Staff survey

Q1 What title most accurately captures your current role?

Q2 Where do you work (service and location)?

Q3 At what stage of a typical diabetes journey do you see Aboriginal people with diabetes?

Q4 Please list what you consider to be the key enablers of diabetes self-management for Aboriginal people/communities.

Q5 From your experience, what are some of the key factors preventing Aboriginal people from making necessary behavioural changes to better manage their diabetes?

Q6 Are there any other significant barriers Aboriginal people face in managing their diabetes? If so, please list them.

Q7 How can we improve the standard of care for Aboriginal people living with diabetes in the community?

Q8 Do you feel you have the cultural capability to provide adequate care for Aboriginal people with diabetes?

Q9 Please describe the cultural capabilities you think you might be lacking.

Q10 As a health professional, are you lacking any resources that are essential to delivering quality care? If so, please list them.

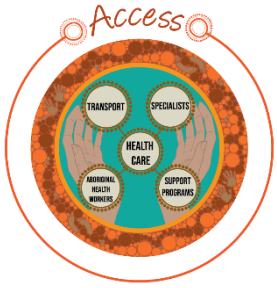
Q11 Are there any opportunities for partnerships between services to be strengthened across your region? If so, please provide details.

Q12 Is there anything else that can be done to improve the overall healthcare experience for Aboriginal people living with diabetes in the community? If so, please provide details.

Appendix 3: Statewide themes

Higher frequency

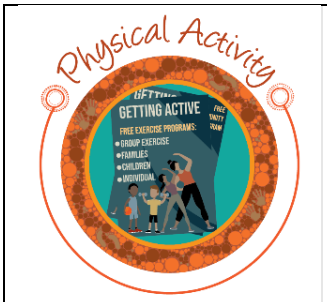
	**Education**	There is a gap in diabetes knowledge and people want to learn more. People want more culturally responsive education that is centred on both the individual and family. This education needs to be held within the community, tailored to all age groups and have a stronger community-based education focus (healthy lifestyle programs).
	**Workforce**	People want more Aboriginal Health workers to be involved in diabetes care. This includes upskilling existing workforce and access to more Aboriginal diabetes educators.
	**Cultural responsiveness**	People want services to be designed and delivered based on community needs, which embeds an Aboriginal lens. Services need to be culturally safe and respectful. Focus on staff strengthening cultural capability.
	**Diabetes knowledge and management**	People reported limited knowledge of diabetes and difficulties managing care within the community.
	**Racism**	People have shared lived experiences of racism from health staff, hospitals and across the health system. Racism and experiences of trauma impacts on a person's SEWB, ability to access care and leads to poorer health outcomes.

	**Services**	People want access to culturally safe services. These services need to be designed based on community need, delivered face to face and virtually. Services need to be family-focused, supported by multidisciplinary teams, and include a strong Aboriginal workforce. Services can focus on strengthening follow up services, general practice management plans and improved referral pathways.
	**Social determinants of health**	The social determinants of health impacts a person's ability to successfully manage diabetes care. This includes housing, transport, employment, education and income.
	**Social and emotional wellbeing**	Being diagnosed and living with diabetes impacts a person's social and emotional wellbeing ("feelings of depression, anxiety and low mood"). This makes it hard to manage diabetes and have positive health outcomes.
	**Access**	People want improved access to diabetes specialists and access to diabetes programs within the community.
	**Support**	People living with diabetes require more support from staff, regarding SEWB, family support and navigating the health system.

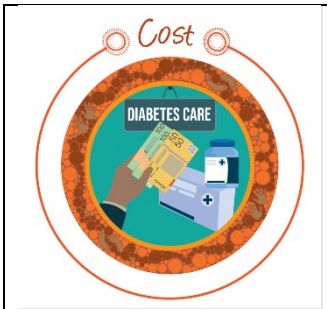
	**Diet and nutrition**	This is one of the hardest things to manage, including access to and costs of healthy food. People want community-based education programs.

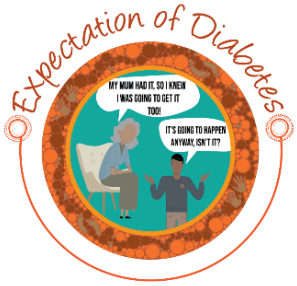
Middle frequency

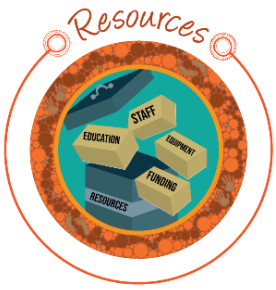
	**Community**	Services and staff need to listen and connect with community. This includes engaging with community to co-design services, that embed culture and enable community to co-deliver care.
	**Health literacy**	People would like to see more education and a focus on improving health literacy within the community.
	**Holistic care**	Services need to consider the person, family and community as a whole. This includes holistic care that includes a focus on the social, emotional, spiritual and physical aspects of Aboriginal health.
	**Partnerships**	People want to see improved partnerships between government and Aboriginal Community Control Health Services. This includes partnering to share funds, staffing and improved access to culturally safe care.

	**Physical activity**	People want more physical activity programs delivered in community with a family focus.

Lower frequency

	**Cost**	A person's income impacts the ability to make healthy lifestyle choices and successfully manage diabetes care. This includes being able to afford the high costs associated with accessing diabetes care, medications and healthy food.
	**Empowerment**	Empowerment and self-determination have been identified as crucial in improving health outcomes.
	**Family**	Services need to focus more on taking a family approach in delivering care. This includes education and community-based programs.
	**Living with diabetes**	People shared that it is hard living with diabetes. The social determinants of health, access to care, managing medication, treatment and other co-morbidities mean that there are many challenges to successfully manage diabetes care.

	**Time**	People want more time to yarn, to build trust and connect with community.
	**Expectation of diabetes**	People reported high rates of diabetes within families and the feeling that being Aboriginal means you get diabetes.
	**Healthy lifestyle**	People requested more healthy lifestyle programs (cooking, physical activity) to help manage diabetes.
	**Change behaviour**	There are many factors that impact a person's ability to change behaviour, including established habits, poor SEWB, family responsibilities and the expectation that if you are Aboriginal, you get diabetes.
	**Housing**	Housing issues, including overcrowding and homelessness, impacts a person's ability to manage diabetes care.

	**Other conditions**	People shared how hard it is to manage diabetes with other co-mobilities.
	**Resources**	People shared that they need more diabetes equipment for managing care in the community, more testing materials, funding and staff across services.
	**Respect**	People reported there is a gap in respect from staff to community. This includes the identified need to focus more on building staff cultural capability.
	**Transport**	Access to transport, living in rural and remote areas impacts a person's ability to access healthcare and manage diabetes.
	**Yarning and connecting**	People want to increase a focus on services connecting to community, have time to yarn and develop trusting relationships.

Acknowledgements

The Agency for Clinical Innovation recognises and appreciates the efforts of the Aboriginal Chronic Conditions Network, Diabetes Endocrine Network, project sponsors, NSW DiCAP Aboriginal Advisory Group and the seven local region working groups. Each of these key stakeholders have provided cultural and diabetes expertise across the project, which has ensured that Aboriginal leadership has been elevated in a true working partnership with diabetes services across NSW.

The success and findings of this report are possible because of the time, commitment and willingness of all to work in partnerships based on respect, Aboriginal leadership and shared purpose to improve care for Aboriginal peoples living with type 2 diabetes.

We would also like to recognise and say thank you to the 370 Aboriginal community members living with type 2 diabetes and the staff who provide care for their honest and thoughtful contributions that identified success, gaps and ideas about how the NSW Health system can respond to design culturally responsive services that meet the needs of diverse Aboriginal communities and staff who provide care across NSW.

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