



Review of Phase
Four of the National
Bowel Cancer
Screening Program

Submission to Department of Health

June 2022

ABOUT NACCHO

NACCHO is the national peak body representing 144 Aboriginal Community Controlled Health Organisations (ACCHOs). We also assist a number of other community-controlled organisations.

The first Aboriginal medical service was established at Redfern in 1971 as a response to the urgent need to provide decent, accessible health services for the largely medically uninsured Aboriginal population of Redfern. The mainstream was not working. So it was, that over fifty years ago, Aboriginal people took control and designed and delivered their own model of health care. Similar Aboriginal medical services quickly sprung up around the country. In 1974, a national representative body was formed to represent these Aboriginal medical services at the national level. This has grown into what NACCHO is today. All this predated Medibank in 1975.

NACCHO liaises with its membership, and the eight state/territory affiliates, governments, and other organisations on Aboriginal and Torres Strait Islander health and wellbeing policy and planning issues and advocacy relating to health service delivery, health information, research, public health, health financing and health programs.

ACCHOs range from large multi-functional services employing several medical practitioners and providing a wide range of services, to small services which rely on Aboriginal health practitioners and/or nurses to provide the bulk of primary health care services. Our 144 members provide services from about 550 clinics. Our sector provides over 3.1 million episodes of care per year for over 410,000 people across Australia, which includes about one million episodes of care in very remote regions.

ACCHOs contribute to improving Aboriginal and Torres Strait Islander health and wellbeing through the provision of comprehensive primary health care, and by integrating and coordinating care and services. Many provide home and site visits; medical, public health and health promotion services; allied health; nursing services; assistance with making appointments and transport; help accessing childcare or dealing with the justice system; drug and alcohol services; and help with income support. Our services build ongoing relationships to give continuity of care so that chronic conditions are managed, and preventative health care is targeted. Through local engagement and a proven service delivery model, our clients 'stick'. Clearly, the cultural safety in which we provide our services is a key factor of our success.

ACCHOs are cost-effective. In 2016, a cost-benefit analysis of the services provided by Danila Dilba to Aboriginal and Torres Strait Islander people in the Greater Darwin region was undertaken by Deloitte Access Economics. The findings demonstrated that each dollar invested in the health service provides \$4.18 of benefits to society. ACCHOs are also closing the employment gap. Collectively, we employ about 7,000 staff – 54 per cent of whom are Aboriginal or Torres Strait Islanders – which makes us the third largest employer of Aboriginal or Torres Strait people in the country.

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NACCHO Recommendations:

- Provide ongoing funding to the Aboriginal Community Controlled Health Organisation (ACCHO) sector to implement the Alternative Pathway, support the workforce and create health promotional resources that meet community needs (see focus area 1)
- NACCHO recommends the Department of Health align its consultation practices with the National Agreement on Closing the Gap to ensure meaningful and genuine consultation with the ACCHO sector and the community (see focus area 3)
- Review information technology (IT) and administrative systems to allow for accurate reporting, data collection and effective communication between primary health care staff and the National Cancer Screening Register (NCSR) (see focus area 4)
- Supply ACCHOs with bowel screening test kits to provide alternative options for Aboriginal and Torres Strait Islander people to receive and access bowel screening test kits (see focus area 5).

National Agreement on Closing the Gap

In July 2020 the Australian Government, all state and territory governments, and the Coalition of Peaks signed the National Agreement on Closing the Gap (National Agreement). The reforms and targets outlined in the National Agreement seek to overcome the inequality experienced by Aboriginal and Torres Strait Islander people and achieve life outcomes equal to all Australians. All governments have committed to the implementation of the National Agreement's four Priority Reform Areas, which seek to bring about structural change to affect ways in which governments work with Aboriginal and Torres Strait Islander organisations, communities, and individuals. The four Priority Reforms are:

Priority Reform Area 1 – Formal partnerships and shared decision-making

This Priority Reform commits to building and strengthening structures that empower Aboriginal and Torres Strait Islander people to share decision-making authority with governments to accelerate policy and place-based progress against Closing the Gap.

Priority Reform Area 2 - Building the community-controlled sector

This Priority Reform commits to building Aboriginal and Torres Strait Islander community-controlled sectors to deliver services to support Closing the Gap. In recognition that Aboriginal and Torres Strait Islander community-controlled services are better for Aboriginal and Torres Strait Islander people, achieve better results, employ more Aboriginal and Torres Strait Islander people and are often preferred over mainstream services.

Priority Reform Area 3 - Transformation of mainstream institutions

This Priority Reform commits to systemic and structural transformation of mainstream government organisations to improve to identify and eliminate racism, embed and practice cultural safety, deliver services in partnership with Aboriginal and Torres Strait Islander people, support truth telling about agencies' history with Aboriginal and Torres Strait Islander people, and engage fully and transparently with Aboriginal and Torres Strait Islander people when programs are being changed.

Priority Reform 4 – Sharing data and information to support decision making

This Priority Reform commits to shared access to location-specific data and information (data sovereignty) to inform local-decision making and support Aboriginal and Torres Strait Islander communities and organisations to support the achievement of the first three Priority Reforms.

Introduction

NACCHO welcomes the opportunity to provide a submission to the Department of Health on the Review of Phase Four of the National Bowel Cancer Screening Program.

Amongst Aboriginal and Torres Strait Islander people, bowel cancer is the third most prevalent cancer, and this is a significant health burden to individuals and the community. Bowel cancer is a preventable cancer, and if detected early, it can be successfully treated in up to 90% of cases. Data shows Aboriginal and Torres Strait Islanders aged 50-74 participated in the National Bowel Cancer Screening Program (NBCSP) at much lower rates than other Australians (23% versus 42%)¹. Indigenous Australians who are diagnosed with bowel cancer experience a much lower five-year survival rate, 58% compared to 67% for non-Indigenous Australians and are more likely to die from bowel cancer at a younger age². Indigenous males are diagnosed at higher rates compared with females and have a lower five-year survival rate.

As acknowledged throughout the Deloitte Access Economic Evaluation Report, the implementation of the National Indigenous Bowel Screening Pilot program was proven to be successful in increasing bowel cancer participation rates for Aboriginal and Torres Strait Islander people (39.8% compared with 23.3%). A broad roll out of the program is likely to result in improving bowel cancer burden of disease rates for Indigenous Australians.

Recognising the importance of the National Agreement on Closing the Gap (please refer to page 4)³ and aligning this with the NBCSP will be essential to reducing bowel cancer rates amongst Indigenous Australians.

Future work

NACCHO is currently working on an Aboriginal and Torres Strait Islander Cancer Plan. The Plan will emphasise Aboriginal and Torres Strait Islander leadership, evidence-based models of care, cultural safety, and data sovereignty. Additionally, the plan will recognise that improved cancer outcomes can be achieved through community-controlled primary health care and community led prevention and screening.

General comments on the Deloitte Review

The Deloitte Access Economics Evaluation Report on the Review of Phase Four of the National Bowel Cancer Screening Program (published September 2021) had a specific focus on phase four of the program. Phase four refers to the period from 2014 to July 2020, during which biennial screening was expanded to people in the 50 to 74 age range (expanded from the original 55 to 65-year range that applied since the start of the program in 2006). The review sought to evaluate the: appropriateness; fidelity; awareness and adoption; effectiveness; and efficiency of Phase Four.

NACCHO and the 2020 consultation

In November 2020, NACCHO was consulted via a Teleconference focus group on the NBCSP. This consultation focused on the administration and delivery of the program and opportunities where the program can be improved. NACCHO was supportive of rolling out the Alternative Pathway pilot, however, recognised there were several issues that needed to be addressed prior to expanding the program. These include ensuring:

¹ Australian Institute of Health and Welfare 2021. National Bowel Cancer Screening Program: monitoring report 2021. Cancer series no.132. Cat. no. CAN 139. Canberra: AIHW

² Australian Institute of Health and Welfare. Cancer in Aboriginal and Torres Strait Islander people of Australia Cat. No. CAN109. Canberra: AIHW; 2018.

³ Coalition of Peaks: National Agreement on Closing the Gap. Canberra; Coalition of Peaks; July 2020

- Information can be easily accessed from and uploaded to the NCSR
- Adequate funding through Medicare Benefits Scheme (MBS) to ensure ACCHO staff are adequately compensated for time
- Referral pathways for Aboriginal and Torres Strait Islander people are culturally appropriate
- Investment in a funding program to ensure adequate access to colonoscopy in the public system
- All decisions on engaging with non-ACCHOs are made by engaging and consulting with large Aboriginal and Torres Strait Islander patient groups
- The Alternative Pathway is nationally co-ordinated.

NACCHO also specified there were no indications that the screening age needed to be brought forward for Aboriginal and Torres Strait Islander people. NACCHO recommended focusing on the importance of early detection, improving participation rates in screening, access to early colonoscopy in the public system and ensuring there are culturally appropriate pathways and communication materials to raise awareness about bowel cancer for Aboriginal and Torres Strait Islander people.

Specific responses aligned with the five focus areas outlined in the Consultation Paper are provided below.

Focus Area 1: Appropriateness of the Program

Lowering the bowel screening participation age

NACCHO is aware of research which suggests lowering the screening age to 45 ⁴, however NACCHO identifies more urgent priorities for immediate focus. These include rolling out the Alternative Pathway more broadly and funding the ACCHO sector to strengthen locally led health promotion and screening initiatives. Expanding a program that has not proven effective for Aboriginal and Torres Strait Islander peoples in its current form may not be a cost-effective solution, and at a minimum would require a large investment into wrap around supports and services.

Resources

Resources created through the mainstream NBCSP are not culturally appropriate for Indigenous Australians when compared to the resources developed for and implemented in the National Indigenous Bowel Screening Pilot program. Although these resources were favourably evaluated, Aboriginal and Torres Strait Islander communities are diverse; therefore, the ability for resources to be tailored at a local level is essential to meet community needs, this aligns with Priority Reform 2 (refer to page 4).

Medicare

Health professionals in the ACCHO sector invest time to ensure patients receive holistic comprehensive primary health care and in the case of bowel cancer screening, spend time to ensure clients fully understand the bowel screening process. Expansion of the Alternative Pathway program is important, and yet may pose a risk to the ACCHO sector as their time is generally not appropriately compensated through Medicare. The true cost of delivering holistic comprehensive primary health care goes beyond the immediate bowel cancer screening test, hence adequate funding is needed to support the ACCHO sector. This supports Priority Reform 2 and 3 to build a strong community-

⁴ Lew, J., Feletto, E., Worthington, J., Roder, D., Canuto, K., Miller, C., D'Onise, K. and Canfell, K., 2022. The potential for tailored screening to reduce bowel cancer mortality for Aboriginal and Torres Strait Islander peoples in Australia: Modelling study. *Journal of Cancer Policy*, 32, p.100325.

controlled sector and transform mainstream organisations to advocate for Aboriginal and Torres Strait Islander people.

ACCHO workforce and considerations when following up a positive iFOBT

Approximately 51% of Aboriginal and Torres Strait Islander people access primary health care through ACCHOs and approximately 49% utilise mainstream services⁵. Aboriginal and Torres Strait Islander people are more likely to participate in screening when discussed with a trusted health professional from their local ACCHO, as opposed to receiving a test kit in the mail. Time-poor health professionals, working in under-resourced environments are less likely to have these discussions. Increasing the number of Aboriginal Health Practitioners (AHPs) / Aboriginal Health Workers (AHWs) in the community-controlled sector and mainstream health services is crucial to creating environments for discussions with patients to encourage screening.

NACCHO recommendation: Provide ongoing funding to the ACCHO sector to implement the Alternative Pathway more broadly, support the workforce and create health promotional resources that meet community needs. This would align with:

- Priority 3 in the National Aboriginal and Torres Strait Islander Health Plan ⁶ which acknowledges the importance of the Aboriginal and Torres Strait Islander workforce and the unique skills they bring to providing culturally safe care to communities ⁷
- Priority Reform 2 of the National Agreement 8 (refer to page 4)
- Priority 2 in the National Aboriginal and Torres Strait Islander Health Plan ⁹, delivering Aboriginal and Torres Strait Islander community controlled comprehensive primary health care.

Focus Area 2: Appropriateness of colonoscopy

For Aboriginal and Torres Strait Islander people at a high risk of bowel cancer, routine colonoscopies should be considered a key component of routine screening ¹⁰. Aboriginal and Torres Strait Islander people living in rural and remote areas may find it difficult to access colonoscopies or face barriers of leaving community to undertake a colonoscopy ¹¹, therefore it is important referral pathways are culturally appropriate and affordably available to all. An increase in screening participation rates will likely result in increased referrals to public hospitals for colonoscopy.

NACCHO recommendation: As NACCHO mentioned in the 2020 consultation, additional funding to ensure adequate access to colonoscopy services in the public system is needed (aligns with Priority Reform 3).

Focus Area 3: Governance

The review of Phase Four of the National Bowel Cancer Screening Program contains minimal representation of ACCHO voices and their valuable insights on the NBCSP and working with their

⁵ Australian Institute of Health and Welfare 2020. Aboriginal and Torres Strait Islander Health Performance Framework 2020 summary report Cat. no. IHPF 2. Canberra: AIHW.

⁶ National Aboriginal and Torres Strait Islander Health Plan 2021-2031

⁷ National Aboriginal and Torres Strait Islander Health Plan 2021-2031, pp 29-31

⁸ Coalition of Peaks: National Agreement on Closing the Gap. Canberra; Coalition of Peaks; July 2020

⁹ National Aboriginal and Torres Strait Islander Health Plan 2021-2031, pp 26-28

¹⁰ Ramsey, S.D., Grady, W.M. and Lamont, J.T., 2015. Screening for colorectal cancer in patients with a family history of colorectal cancer or advanced polyp

¹¹ Christou A, Katzenellenbogen JM, Thompson SC. Australia's national bowel cancer screening program: does it work for indigenous Australians?

communities. Input from stakeholders and listening to the sector provides the best opportunity for informing change which will ultimately lead to positive health outcomes.

NACCHO recommendation: NACCHO recommends the Department of Health align its consultation practices with the National Agreement on Closing the Gap. In particular:

- Priority Reform 1 (refer to page 4)
- Priority Reform 3 (refer to page 4).

Focus Area 4: Data Collection

Outcomes from the National Indigenous Bowel Screening Pilot final report ¹² highlighted that more user-friendly IT arrangements are needed for health professionals to report to the NCSR. Successful design of the administrative procedures requires input from the users and prior testing to ensure compatibility and practicality measures are met. These suggestions have been considered and are currently under development by the Commonwealth Department of Health.

NACCHO recommendation: Review IT and administrative systems to allow for accurate reporting, data collection and effective communication between primary health care staff and the NCSR. This aligns with Priority Reform 4 of the National Agreement on Closing the Gap (refer to page 4).

Focus Area 5: Participation

Accessibility to kits

Low Medicare enrolment rates and outdated Medicare details means that some Aboriginal and Torres Strait Islander people do not receive their kits in the mail. Limited access to reliable, affordable internet or a phone presents a barrier to people registering for Medicare or updating their contact details.

Overcrowded housing is a concern for many Aboriginal and Torres Strait communities. Some individuals may have access to bowel screening kits but are prevented from using the kit at home due to privacy concerns.

The storage and return of test samples may pose a barrier for Aboriginal and Torres Strait Islander people as they may not have a functioning refrigerator or there may be reluctancy to store a sample in the family refrigerator along with food items. Accessibility to a post box may be limited or the post collected infrequently, particularly in rural and remote communities. In these situations, samples returned for testing are likely to yield an inconclusive result due to prolonged exposure to high temperatures.

NACCHO recommendations:

Codesign of achievable solutions with community is most likely to yield effective results (aligns with Priority Reform 1 and 2). For example, supply ACCHOs with funding to purchase polystyrene storage containers and icepacks for home storage of samples until they can be posted may encourage athome screening.

Supplying ACCHOs with bowel screening test kits and resources to promote alternative options for Aboriginal and Torres Strait Islander people to receive and access bowel screening test kits (aligns with Priority Reform 2).

¹² Menzies School of Health Research. National Indigenous Bowel Screening Pilot. 2020