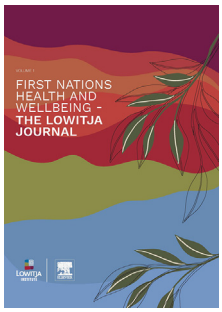

Original Research

Community acceptability of lowering the eligibility age of government funded bowel screening for Aboriginal South Australians to 40 years

Karla J. Canuto (Naghir Tribe of the Kulkalgul Clan)[a], Eugene Warrior (Wirangu, Bungala, Kokatha and Antakerinya)[b], Sharon Clarke (Wergaia, Wemba Wemba, Djadwajali and Gunditjmara)[b], Nathan Rigney (Ngarrindjeri)[b], Jie-Bin Lew[c], Eleonora Feletto[c], Katina D'Onise[d]*

[a]Wardliparingga Aboriginal Health Equity, South Australian Health and Medical Research Institute, PO Box 11060, Adelaide, South Australia 5001, Australia
[b]Prevention and Population Health, Wellbeing SA, SA Health, PO Box 287, Rundle Mall, Adelaide, South Australia 5000, Australia
[c]The Daffodil Centre, The University of Sydney and Cancer Council New South Wales, PO Box 572, Kings Cross, New South Wales 1340, Australia
[d]School of Population Health, University of Adelaide, Level 4, Rundle Mall Plaza, 50 Rundle Mall, Adelaide, South Australia 5000, Australia

Abstract

Purpose Building on a study that found that lowering the age of bowel screening for Aboriginal and Torres Strait Islander peoples to 40 years would be cost-effective, this research examined the acceptability of lowering the bowel screening age for Aboriginal and Torres Strait Islander peoples in South Australia.

Methods Aboriginal community members aged < 50 years were recruited to form Aboriginal men's (16 men) and women's (nine women) bowel cancer screening councils. The councils were presented with detailed information relating to the topic and deliberated over two days.

Main findings The men's and women's councils were unanimous in their support for reducing the age of bowel screening for Aboriginal and Torres Strait Islander peoples. The councils identified barriers to reducing the age at participation, and participation in screening in general. Both councils were highly engaged in the process of the two-day deliberation.

*Corresponding author.
E-mail address: Karla.Canuto@flinders.edu.au (K.J. Canuto).

https://doi.org/10.1016/j.fnhli.2025.100045

Current affiliation: Karla Canuto, Rural and Remote Health – NT, Flinders University.

Principal conclusions Lowering the age range for Aboriginal and Torres Strait Islander peoples participating in the bowel screening program to 40 years was acceptable to both Aboriginal bowel cancer screening councils.

Keywords: Bowel cancer; Preventive health; Aboriginal and Torres Strait Islander; Faecal occult blood test; Secondary prevention; Stakeholder participation

Highlights

- Bowel cancer is the fourth most common cancer for Aboriginal and Torres Strait Islander peoples (Australian Institute of Health and Welfare 2021).
- Aboriginal community members participated in facilitated discussions focused on the impacts of bowel cancer, the screening process and the acceptability of lowering the age of screening.
- The findings of this study suggest that lowering the age range for Aboriginal and Torres Strait Islander peoples participating in the bowel screening program is acceptable.

Introduction

Cancer is the leading cause of all deaths among Aboriginal and Torres Strait Islander peoples (Australian Institute of Health and Welfare 2018). After breast (females), prostate and lung cancer, bowel cancer is the fourth most common cancer for Aboriginal and Torres Strait Islander peoples (Australian Institute of Health and Welfare 2021).

To reduce the burden of bowel cancer, the Australian Federal Government-funded National Bowel Cancer Screening Program (NBCSP) offers free screening kits and immunochemical faecal occult blood tests (iFOBT) every two years from ages 50 to 74 years (at the time of the study). The free iFOBT is posted to eligible people at their listed postal address on Medicare, which is the Australian universal healthcare system. Recipients are invited to complete the test at home and return the sample in the reply-paid envelope. The iFOBT return rate was 40.9% nationwide in 2020–21, with 6% of the returned tests requiring follow-up, which was usually a colonoscopy (Australian Institute of Health and Welfare 2023). The iFOBT return rate was lower in Aboriginal and Torres Strait Islander peoples (31.3%) and a relatively higher proportion (9%) of the returned tests required follow-up (Australian Institute of Health and Welfare 2023).

Once diagnosed, there are significant health disparities in bowel cancer outcomes for Aboriginal and Torres Strait Islander peoples. In South Australia, Aboriginal and Torres Strait Islander peoples are up to 9 years younger at diagnosis (mean age 61 vs. 70 years), more likely to have cancer diagnosed at advanced or unknown stage (64.1 vs. 53.6%) and are significantly less likely to survive five years after their initial cancer diagnosis (57.3 vs. 67.3%) compared with non-Indigenous Australians, respectively (Banham et al. 2017). There are several barriers to care that contribute to these disparities in bowel cancer outcomes, including: lack of knowledge about bowel cancer, reduced screening and treatment, fear, lack of trust, and lack of culturally appropriate services for Aboriginal and Torres Strait Islander peoples (D'Onise et al. 2020).

Unsurprisingly, cancer was one of the health priorities identified in the 2015 Next Steps for Aboriginal Health

Research Report, which identified research priorities for South Australia (King and Brown 2015). The 'Getting to Zero' project was established through Wellbeing SA to stop the cycle of Aboriginal and Torres Strait Islander peoples dying from bowel cancer. As part of the project, a modelling evaluation was conducted and found that starting bowel screening earlier at 40 or 45 years for Aboriginal and Torres Strait Islander peoples would be cost-effective and could reduce deaths from bowel cancer by up to 32% if current return rates were maintained (Lew et al. 2022). If more kits were returned and this rate was maintained (~40%), starting bowel screening at age 40 years could potentially reduce 50% deaths from bowel cancer, and the program would be cost-effective (Lew et al. 2022). The project has also conducted a systematic literature review on the barriers, enablers and implemented strategies of faecal occult blood tests for Indigenous adults – it identified multiple strategies that could be implemented in Australia to increase bowel screening rates (D'Onise et al. 2020).

Acceptability of the population being screened is a critical element in the Australian Government 'Population based screening framework', in addition to a range of critical factors such as cost-effectiveness and that early identification of disease leads to reduced morbidity and mortality through effective treatment (Lew et al. 2018). The second phase of the 'Getting to Zero' project and the aim of this paper was to understand the acceptability of reducing the age of bowel screening to 40 years for Aboriginal and Torres Strait Islander peoples.

Methods

To appropriately engage local Aboriginal representatives from across South Australia, to make an informed recommendation, a community engagement process was established. The community engagement process was designed as a way of directly engaging with a range of community members in a culturally sensitive way to address a specific issue. The groups of representatives who were brought together were referred to as 'bowel councils' to reflect that participants could call for any additional information they needed to come to a decision, as active participants in the process.

In 2021, members of the bowel councils were recruited through the Wellbeing SA Aboriginal bowel cancer screening officer, via personal recommendations, automated flyers, promotion through Aboriginal community-based organisations, personal and business contacts, and word of mouth. It was not possible to estimate the proportion of people reached through any of the abovementioned processes to determine the participation rate. Interested people were sent a participant package that included information (written in plain English) about bowel cancer screening and the purpose of the workshop, workshop details (venue, times) and details about sitting fees, travel arrangements, reimbursement if travelling in own vehicle and a participant consent form. The eligibility criteria were: 1) Aboriginal and/or Torres Strait Islander person aged < 50 years, 2) ability to participate in a two-day process and 3) consent to research participation. Informed consent from the council members was obtained through a written consent form. Ethics for this project was obtained from the Aboriginal Human Research Ethics Committee of the Aboriginal Health Council of South Australia (#04-21-922). The project adhered to the principles of the South Australian Aboriginal Health Research Accord (Morey et al. 2017).

Participants were paid sitting fees at a rate of AU$30 per hour for their time and input into the workshops. To support the attendance of council members from outside the Adelaide metropolitan area, travel and

accommodation were organised and paid for, and a travel allowance was paid to members who travelled the day before and/or after the workshop. Transport was provided to the workshop venue and to return participants to the accommodation each day following the workshop. Catering was included for each day and a group barbecue dinner was held on day one at the venue after the workshop.

Following cultural protocol to support cultural safety, two bowel councils were established: an Aboriginal men's and an Aboriginal women's council.

It was anticipated that no intellectual property arising from the research would generate any future financial and/or intellectual benefits other than informing the acceptability of reducing the bowel cancer screening age.

Aboriginal bowel cancer screening workshops

Over a two-day workshop in June 2021, the Aboriginal men's and Aboriginal women's councils were provided with the evidence, participated in discussions on the benefits and risks of bowel cancer screening and asked to vote on whether offering free bowel cancer screening to Aboriginal and Torres Strait Islander peoples aged 40–49 years was acceptable. The councils were conducted in English only with no translators. The role of the councils was to determine whether it is acceptable to offer free bowel cancer screening to Aboriginal and Torres Strait Islander peoples from age 40 years instead of waiting to 50 years.

The workshop was deliberative. Participants had the opportunity to focus on the one issue of bowel screen over the course of two days and were provided with the resources to do so. The goal for the decision-making was to reach consensus, if possible, with discussion on all matters encouraged. Participants had the opportunity to ask any questions and to seek information from whoever they chose to contribute to the deliberations.

Day one started with a Welcome to Country and an introductory presentation to the whole group, which included both the men's and women's councils. The introductory presentation, given by a public health physician, included relevant evidence to make an informed decision, including the fact that compared with screening at the current target age range (50 years +), extending bowel cancer screening to younger ages could prevent more bowel cancer, bowel cancer deaths and potentially be cost-effective (Lew et al. 2022). Whilst lives would be saved, the risks to an individual were also presented. An outline of the content is provided in Box 1.

The group was then asked to consider whether the benefits of bowel screening outweigh the harms or do

Box 1. Introductory presentation content summary

- Incidence and mortality from bowel cancer for Aboriginal and Torres Strait Islander peoples and the whole of Australia, including trends over time.
- Evidence about earlier age of onset for Aboriginal and Torres Strait Islander peoples.
- Cost-effectiveness of lowering the age of screening to 40 and 45 years, including the need for more colonoscopies to be conducted to diagnose a single case by reducing the age of screening.
- Benefits and risks of bowel screening (immuno-chemical faecal occult blood tests [iFOBT] and colonoscopy), including the risks of bowel perforation, need for further surgery, anxiety/distress while awaiting results.
- How an iFOBT is completed.
- What a positive iFOBT indicates.
- Follow-up assessments after a positive iFOBT.
- Common bowel cancer treatments.

the harms outweigh the benefits and is it acceptable to lower the age of screening from 50 to 40 years. A process for anonymous polls was agreed upon to determine the number of council members who were supportive of lowering the bowel cancer screening age. Each council member was asked to cast their vote on paper, which included the question: How do you feel about lowering the age of bowel cancer screening offered to Aboriginal people from 50 to 40 years of age? There were five possible answers to select from: I love it, I like it, I can live with it, I can't live with it and I loathe it. There was also a small space provided for a written answer to the question: Please tell us why you feel that way. This 'check-in' was asked and recorded three times over the two days.

Council discussions were documented by the facilitators during the discussion on a computer with the screen projected such that everyone could see what was recorded, verify and/or request amendments in real-time; this included direct quotes. All documentation was checked and agreed to by participants before being shared beyond the group and included in the results.

The men's and women's councils moved to separate spaces to ensure that all members were comfortable to discuss body-related issues with others of their own gender as is culturally appropriate. Each council began with introductions, encouraging members to share their personal journeys of family members who have either been diagnosed with bowel cancer or who have succumbed to the disease. Each council then discussed the various issues raised in the introductory presentation, guided by an experienced facilitator. Each council heard one additional presentation outlining, in more detail, what the differences in lives saved and costs saved could be if bowel screening was offered to Aboriginal and Torres Strait Islander peoples from the age of 40 or 45 years. The information was based on a modelling study previously conducted by Lew et al. and highlighted that, compared with screening at the current target age range (50 to 74 years), extending bowel cancer screening to younger ages for Aboriginal and Torres Strait Islander peoples could prevent more bowel cancer cases and deaths and be cost-effective, but it could result in more risks (Lew et al. 2022).

The women's council was facilitated by an Aboriginal woman trained in facilitation. She has 50+ years' experience working as a nurse in mainstream and Aboriginal community-controlled health services, including working collaboratively with cancer screening services at a national, state and local level to address the high incidence of cancer in the Aboriginal population in health and Aboriginal women's cancer in South Australia. She was known to some of the participants and some of the participants knew each other, which seemed to contribute to a happy and relaxed atmosphere, where people were engaged and wanted to learn more from each other. The two-day workshop began with informal social discussions, which were important to create a relaxed atmosphere to carry on over the two days.

The women's council continued by establishing group norms to ensure that it was a culturally safe and inclusive environment for everyone during the workshop. The facilitator summarised the workshop schedule and then led a group discussion about group dynamics and 'ground rules' for the workshop, to ensure that everybody felt welcomed and safe to contribute to the discussion. Ground rules included 'no judgement' and 'respect each other'.

The Aboriginal men's council discussions were facilitated by three Aboriginal men trained in facilitation, with detailed knowledge of bowel cancer and bowel cancer screening. The facilitators were known to some

of the Aboriginal men's council members and some (but not all) of the members to each other; however, the two-day format allowed for connections to be made between the participants and with the facilitators, allowing for open and trusting discussion.

The facilitators of both groups emphasised the key questions for the workshop: Is it acceptable to lower the age of bowel screening from 50 to 40 years of age?, What are the benefits and harms of screening at a younger age? and What stops people and encourages people from participating in bowel screening?.

Theoretical framework and analysis

This project was driven entirely by Wellbeing SA, which does not have a formal Aboriginal governance structure. The team facilitating the workshop comprised all health professionals who are supportive of and promote bowel cancer screening in their professional practice. This perspective may have created a bias in the research. The team attempted to manage their bias by providing factual information, including the benefits and risks of screening. The facilitators and presenters always avoided emotive language or persuasion. The team members for 'Getting to Zero', including the researchers and health service staff who facilitated the workshop, have broad perspectives and experiences including Indigenous and non-Indigenous members, clinicians, researchers and service providers, as described in the Author biographies. Findings were extracted from the facilitators' notes and thematically analysed. Themes were checked by the facilitators for accuracy and appropriateness. The findings and representation of the project has been confirmed and supported by the entire team.

Results

The eligible participants who were recruited were Aboriginal, with no Torres Strait Islander peoples, reflecting the majority Aboriginal population in South Australia, where 95.5% of the Indigenous population identify as of Aboriginal origin, 2.7% identify as Torres Strait Islander in origin and 1.8% identify as being of both Aboriginal and Torres Strait Islander origin (Australian Bureau of Statistics 2022).

Aboriginal men's and Aboriginal women's bowel cancer screening council members were aged < 50 years and represented a vast number of language groups, indicating both a diversity in geographical location and in group identification across South Australia. The men's council comprised 16 Aboriginal men from across South Australia. The women's council comprised nine women (see Table 1), although an additional three had participated in the opening session but withdrew from the workshop prior to providing consent. The women were not questioned as to why they chose to leave; this was intentional so as not to make them feel pressured or coerced to stay. It is possible that these women left because of language barriers, as there was no translator present and English was not their primary language. All participants were interested community members who knew of someone who had an experience of bowel cancer. One participant had a personal experience of bowel cancer. No healthcare professionals were recruited. A summary of the votes for both councils is provided in Table 2.

Aboriginal men's council discussions

Discussions that were raised, amid frustration from many participants regarding family members who had lost their lives to cancer, included the importance and encouragement of all Aboriginal men who are eligible to perform the test. Other comments included Aboriginal men's need to abandon their selfish act, 'shame' and/or embarrassment cemented in the syndrome that 'it won't happen to me' attitude. Some participants blamed sections of the Aboriginal health

Characteristic	Aboriginal men's council	Aboriginal women's council
Number of council members	16	9
South Australian local health networks		
Barossa Hills Fleurieu	2	4
Central Adelaide	4	2
Eyre and Far North	1	0
Flinders and Upper North	0	0
Limestone Coast	0	0
Northern Adelaide	3	1
Riverland Mallee Coorong	0	0
Southern Adelaide	3	1
Yorke and Northern	3	1
Age range – years		
35–39	3	1
40–44	5	2
45–49	8	6

Table 1: Characteristics of the Aboriginal men's and Aboriginal women's bowel cancer screening councils

	Vote 1	Vote 2	Vote 3
Men's council			
I love it	14	10	14
I like it	1	3	0
I can live with it	0	0	0
I can't live with it	0	0	0
I loathe it	0	0	0
No vote	1	1*	0
Women's council			
I love it	8	9	9
I like it	0	0	0
I can live with it	1	0	0
I can't live with it	0	0	0
I loathe it	0	0	0
No vote	0	0	0

*two people left before the vote.

Table 2: Voting for acceptability of lowering the age of commencement of bowel cancer screening for Aboriginal and Torres Strait Islander peoples to 40 years

services, suggesting that more work, education and promotion of cancer-related illness could be achieved by increasing the workforce of Aboriginal male health workers in local areas, stating that there are not enough men out there to help the vulnerable men. It was suggested the many men do not want to perform the test because they fear the diagnosis and they would rather not know. This is where the Aboriginal male health workers could help alleviate those fears in private conversations and spaces outside of the health service.

One member of the men's council, and cancer council ambassador, had been diagnosed with bowel cancer and survived. His personal story to the male participants reverberated through the room and with participants who had experienced this in their immediate families.

The initial responses to the first poll, as shown in Table 2, were very positive, with 14 of 16 selecting the option I love it, one vote for I like it and another who chose not to pick one of the five multichoice options but added a comment stating, 'I think it's a good idea…'. Other initial comments were centred around early detection, treatment and reducing cancer-related deaths:

'Great to be able to get early diagnosis so it can be treated quickly, and we can stop it in its tracks' and 'The more Aboriginal men do the bowel screening information, the less death.'

There was also a question from a council member about the possibility of lowering the screening age even further: 'Why don't we go to 30 years old? Get it before another 10 years'.

Following the initial votes, discussion arose around personal experiences of cancer, bowel cancer and health, lived experience and traditional knowledge. The council members also asked questions of the facilitators around bowel cancer symptoms, genetics, treatment and the bowel cancer screening process. Subsequent discussion arose about shame and stigma: 'Still a lot of stigma. I have a family member

dying from bowel cancer at the moment, he won't call it 'bowel cancer' because of the shame'. Although the shame of doing the test was acknowledged, the language also turned around: 'it would be more shame telling your family you've got cancer, when you've got the screening kit sitting in the top drawer.'

At the next poll, two of the participants had exited the workshops, precipitated by other commitments. The results of the poll were 10 I love it, three I like it and one no multiple-choice option selected but with the comment 'Need to encourage family and motivate and make sure you become priority first too'.

On the morning of day 2, the men's council discussed the need to provide more education and promotion to encourage men to participate in bowel screening. The council suggested that bowel cancer screening should be promoted through respected (Aboriginal) people: 'because when they talk, people listen'. There was a consensus that the more people know, the better, with one member saying, 'Now that I know more, it's a no-brainer to get tested.'

At the final poll, the men's council members unanimously decided as a group in discussion that it is acceptable to offer bowel cancer screening from age 40 years for Aboriginal and Torres Strait Islander peoples.

Aboriginal women's council discussions

In the first poll at the beginning of the workshop, eight of nine participants liked or loved the proposal to lower the bowel screening age, and in polls two and three, all nine participants liked or loved the proposal. One member changed her vote from I can't live with it to I like it. She explained her reason for changing her mind: 'After seeing the demonstration of the kit, that's what swayed me' (see Table 2).

One of the participants shared a personal story about her family member's experience with bowel cancer and his survival. The other participants admired her bravery in telling a story and they reported that it helped them to realise the severity of bowel cancer and the importance of screening.

The facilitator conducted a health promotion and education session on bowel screening and follow up if the test was positive for cancer, utilising the bowel screening flip chart and 'How to do a bowel screening test' (Menzies School of Health Research 2017). The kit was unpacked and the process was walked through.

As a group, there was then reflection on the session and what they heard. The discussion included comments that the information was eye-opening, and information had not been available to them before. They learned that bowel cancer does not discriminate (all races affected), how to do the test (iFOBT) and the age range of bowel cancer. Although the information was overwhelming, they thought that it was good that they had a 'better understanding of the process of what you have to do', they learnt how to do the test and thought it useful to 'learn from a person with a personal journey with cancer'. A women's council member explained:

> *You get this thing [bowel cancer screening kit] posted to you and it makes you feel intimidated. I pushed it away. Then another one came. Now I know about it [after viewing the kit in the workshop,] I'd do it. At least we know what we're doing now when we do get it…seeing the kit made us all at ease… when she (facilitator demonstrating kit) actually took it out rather than seeing a picture.*

The next session was a presentation on how bowel cancer screening could save lives and money. During

the afternoon session the women's council had further discussions and explored the potential benefits and harms of earlier bowel cancer screening. The Aboriginal women's council spoke about the 'need to have screening done' and the importance of 'screening at a younger age' because 'earlier detection means earlier treatment' and that if it is 'picked up early, easy to treat' and that it will 'save lives'. One participant stated:

> *If you don't get to the doctors there will be a risk of getting very ill, and won't be able to treat it before it (bowel cancer) gets to a big risk and they won't be able to help.*

They also talked about the prevention of bowel cancer through healthy eating, exercise and avoiding alcohol. There was ongoing acknowledgement that the test may make people feel embarrassed or 'shame': 'five minutes shame job is worth it'. They also agreed that there were low risks of potential harm from bowel screening: 'Yes, definitely benefits outweigh the harm. Only harm is if anything goes wrong during [colonoscopy] procedure'.

The women's council members unanimously decided as a group in discussion that it is acceptable to offer bowel cancer screening from age 40 years for Aboriginal and Torres Strait Islander peoples.

On day two, the women's council had some queries around bowel screening and colonoscopies. A female public health physician (KDO) was invited to come back to the women's workshop to answer their questions. Further discussion included conversations about the potential harms, including the waiting time (approximately 3 months) for a colonoscopy following a positive bowel cancer screening test result: 'Waiting could cause more stress and harm'. There were further questions about the existence of Aboriginal support groups and financial support for people and their family members if people need to travel to Adelaide from rural/remote South Australia for the follow-up.

Overall council consensus

During the conclusion of the workshop the Aboriginal men's and women's councils were brought back together, where the facilitators of each council presented the council's decision about supporting the reduction in age for bowel screening from 50 to 40 years. There was further discussion as a group, including further questions to the facilitators in addition to feedback on how the two days had gone. Both councils agreed that they were supportive of offering bowel screening to Aboriginal and Torres Strait islander peoples from the age of 40 years. While there was no formal evaluation of participants' satisfaction with the workshop, anecdotal, informal comments as the day concluded suggested that they found it to be useful, informative and a positive experience.

Discussion

The NBCSP was established in 2006 and offered to people aged 50 to 74 years based on available evidence at the time. The program has since undergone a series of evaluations and changes to the 50 to 74 years target age range in place at the time of the study (Lew et al. 2018). Recent calls for re-evaluation have been revived by changing bowel cancer trends (Feletto et al. 2019), updated international guidelines (United States Preventive Services Task Force 2021) and moves towards risk-stratified screening approaches (Lansdorp-Vogelaar et al. 2022). Recent evidence of the acceptability of reducing the age of bowel screening in the general population has centred around the shift to risk-stratified screening regimes (Dunlop et al. 2021; Young et al. 2019). Although the focus of their study was on cancer screening based on genetic risk, Dunlop et al.

illustrated that the Australian population are supportive of risk-stratified screening, with increased frequency for those at increased risk (Dunlop et al. 2021). These findings are broadly aligned with the current study, where bowel cancer-related health disparities for Aboriginal and Torres Strait Islander peoples contributed to the acceptability of lowering the screening age for the study participants.

The results of the program of work relating to evidence for reducing age for bowel screen eligibility formed part of the Australian Government review of the bowel screen program. While the policy position for reducing the age to 40 years for Aboriginal and Torres Strait Islander peoples was evidence-based, the decision was made to lower eligibility for all Australians to 45 years. Between the ages of 45 to 49 years, people must ring or submit a webform to access a test kit rather than the usual process of being delivered a test kit.

This study used innovative methods to understand the acceptability of a younger age at bowel screening for Aboriginal and Torres Strait Islander peoples. It went beyond the common focus group approach by utilising deliberative democracy (McWhirter et al. 2014) to engage participants. This approach was taken as it was considered important that the participants be provided with access to information or experts to fully understand the benefits and risks of screening, alongside sufficient time to deliberate and decide on the outcome. Participants had discussions among themselves but also with the facilitators, at times seeking answers to specific questions to enable ongoing participant discussions. Given the sensitivity of the topic, the two days enabled supported discussion about cancer and its impact on individuals, families and communities, allowing for shared experiences to inform discussions.

Over the two days, the groups were provided with the evidence, discussed the benefits and risks, and voted on whether offering bowel screening to Aboriginal and Torres Strait Islander peoples aged 40 to 49 years was acceptable. The discussions of the Aboriginal men's and women's councils occurred independently, the discussions were similar, and both councils were unanimous in their decision that it is acceptable to offer bowel cancer screening from age 40 years for Aboriginal peoples within South Australia.

There were some limitations in the process undertaken in this research. Participants gave the feedback that they would have preferred at least another day to discuss the issues presented, and so it would be recommended to allow for more time to deliberate in future. There were no interpreters present, which limited the ability for some participants to fully participate and may have played a part in three participants opting to leave early. Additionally, the fact that all of the participants knew someone who had had bowel cancer or had a personal experience with bowel cancer likely positively influenced their participation in the workshop and their willingness to support a lowered age for bowel screening to commence. The proportion of the Aboriginal and Torres Strait Islander population who would similarly know someone impacted by bowel cancer or how unique these groups of participants were is currently unclear. More time for recruitment would have been preferred to enable maximum participation from Aboriginal and Torres Strait Islander communities across South Australia. The discussions were recorded via note taking by the facilitators. The notes did not attribute any remarks to individuals, hence why the quotes do not include a participant identifier.

Implications for public health

This research found that Aboriginal South Australians who participated in a two-day workshop came to

consensus that lowering the age range for Aboriginal and Torres Strait Islander peoples participating in the bowel screening program is acceptable. This finding builds on previous work that also found lowering the age to be cost-effective (Lew et al. 2022). The next step is to understand the feasibility of lowering the age at screening for Aboriginal and Torres Strait Islander peoples and the health information/education required to increase uptake of screening. Aspects of implementation feasibility have been considered, including a trial that examined the benefits of primary healthcare distribution of test kits for Aboriginal and Torres Strait Islander peoples, with good signs of effectiveness in increasing participation in the screening program (Menzies School of Health Research 2020). Engaging with the Aboriginal community using the council methods described here was successful in soliciting useful perspectives to guide culturally appropriate healthcare.

The implementation of modified screening regimes by risk or population groups requires tailored, clear messages specific to the target audience, an understanding of the audience's perceptions, trust in the program and must be convenient (Dunlop et al. 2022; Dunlop et al. 2021). This study also highlighted issues around the need for cultural safety, especially to manage the shame associated with cancer. The councils suggested that information about bowel screening be provided more clearly but in a clear, culturally sensitive way and by the appropriate people. For example, it is more culturally appropriate to receive information and advice from a healthcare professional of the same gender and this will require building the capacity of health workers. Access to the test is also an ongoing issue in the community, given the lack of fixed housing or lodging without a street postal address, as the current NBCSP kits are not sent to postal boxes or other non-traditional addresses.

Logistically completing the two-sample test can also be challenging, as the samples need to be refrigerated before they are returned to pathology. This additional step is a barrier for those in shared housing or with no fixed address. Addressing these barriers is key to encouraging more Aboriginal and Torres Strait Islander peoples to participate in screening and reduce the burden of bowel cancer.

Author contributions

K. D'Onise: study conception and design, workshop facilitation and delivery, interpretation of results, draft manuscript preparation. S. Clarke: workshop facilitation and delivery, data collection, analysis. E. Warrior: workshop facilitation and delivery, data collection, analysis. N. Rigney: workshop facilitation and delivery, data collection, analysis. J. Lew: workshop facilitation and delivery, interpretation of results, draft manuscript preparation. E. Feletto: workshop facilitation and delivery, interpretation of results, draft manuscript preparation. K. Canuto: analysis, interpretation of results, draft manuscript preparation.

All authors reviewed the results and approved the final version of the manuscript.

Declaration of interests

The authors declare no competing interests.

Funding

This research did not receive any specific grants from funding agencies in the public, commercial or not-for-profit sectors and was funded by Wellbeing SA.

Acknowledgments

The authors wish to acknowledge the wonderful contribution and cooperation of the Aboriginal men and women who provided invaluable feedback, for

which we are extremely grateful. Our Aboriginal facilitators, Nathan Rigney (Associate Director, Aboriginal Health Promotion, Wellbeing SA) and Sharon Clarke (Senior Project Officer, Aboriginal Well Women's Screening Program, Secondary Prevention, Prevention and Population Health) and Alex Herewane (Aboriginal Men's Screening Project Officer, Secondary Prevention, Prevention and Population Health), who engaged with local Aboriginal representatives from across South Australia to make informed recommendations and form the council. The professionalism of facilitators' demeanour and understanding of the current health issues that Aboriginal people face in daily life ensured that the day proceeded with great fun, laughter and valuable information. We acknowledge that this work took place in Tarndanya (Adelaide), on the traditional lands of the Kaurna people. We pay our respects to Kaurna Elders past and present and acknowledge the traditional lands of the Aboriginal participants who contributed generously to this work.

Author biographies

Karla Canuto is a Torres Strait Islander, descendent of the Naghir Tribe of the Kulkalgul Clan and Associate Professor of Aboriginal and Torres Strait Islander Health Research at Rural and Remote Health, Flinders University. Karla has over 20 years' experience in Aboriginal and Torres Strait Islander health and health research. With a background in sports science and health promotion, Karla is passionate about evaluation and supporting Aboriginal and Torres Strait Islander communities to achieve their health-related goals. Karla is also committed to building the capacity and capabilities of the next generation of Aboriginal and Torres Strait Islander health researchers.

Eugene Warrior is a descendant of the Wirangu, Bungala, Kokatha and Antakerinya clan groups in South Australia. Eugene is the Director, Aboriginal Health, Flinders and Upper North Local Health Network, having conducted research into otitis media in Aboriginal communities and Aboriginal leadership in national universities. Eugene has an extensive background in sports, recreation and health promotion. He is enthusiastic in his support of Aboriginal people gaining access to health institutions for their health needs. Eugene is passionate about building the capacity of Aboriginal people who in turn focus on creating new opportunities for other Aboriginal people.

Sharon Clarke is Wergaia, Wemba Wemba and Djadwajali on her mother's side, which is in the northwestern region of Victoria, and, on her father's side, Gunditjmara (Dhauwurd Wurrung) in the western district of Victoria. Her current role is Wellbeing SA, Prevention and Population Health Directorate in Aboriginal Women's Health. Sharon has a nursing background and has previously worked for an Aboriginal community-controlled health service and the Department of Health. Sharon is passionate about Aboriginal women's health and supporting the recruitment and retention of Aboriginal and Torres Strait Islander nurses, midwives and students across health and education organisations.

Nathan Rigney is a Ngarrindjeri man and public health professional, currently leading the Aboriginal Health Promotion team at Wellbeing SA. Nathan has a counselling background and is currently in the public health graduate program at the University of Adelaide. With more than 12 years' experience in the health sector, Nathan has led and supported the development of key strategies to support the South Australian Aboriginal community, addressing issues related to cancer, tobacco control, racism and strengthening culture as a protective factor for better health and wellbeing.

Jie-Bin Lew is a Research Fellow of the Gastrointestinal Cancers and Policy Evaluation Stream of Daffodil Centre, a joint venture between Cancer Council NSW and the University of Sydney. She has more than 15 years of experience in evaluating cancer screening interventions using predictive modelling approaches. Her current research focuses on identifying effective, safe and affordable 'best buy' bowel cancer screening approaches for the general population and Aboriginal and Torres Strait Islander peoples in Australia. She is passionate about optimising the National Bowel Cancer Screening Program's screening approach and improving access to bowel cancer screening across Australia.

Eleonora Feletto is an associate professor and cancer epidemiologist. She has worked in research for over 15 years and now works at the Daffodil Centre, a joint venture between Cancer Council NSW and the University of Sydney. She researches bowel and liver cancer and works closely with stakeholders to help translate research into practice change that can help Australians improve their health outcomes. She is passionate about improving access to bowel cancer screening and increasing participation the National Bowel Cancer Screening Program.

Katina D'Onise is a public health physician and epidemiologist. She currently works as Adjunct Professor Public Health at the University of Adelaide. Katina has worked in a range of roles, including communicable disease control, Aboriginal health, cancer screening programs, health promotion, epidemiology and academia. She has overseen the development of several data systems, including leading the development of legislative frameworks for data, and aligning the data system with the strategy. She is an active user of data for policy planning, research, evaluation and research translation, and supports other stakeholders to use data for decision-making.

References

Australian Bureau of Statistics, 2022. South Australia: Aboriginal and Torres Strait Islander population summary. Accessed on 14 November 2022 at: https://www.abs.gov.au/articles/south-australia-aboriginal-and-torres-strait-islander-population-summary.

Australian Institute of Health and Welfare, 2018. Cancer in Aboriginal and Torres Strait Islander people of Australia. Australian Government, Canberra. Accessed on 14 November 2022 at: https://www.aihw.gov.au/reports/cancer/cancer-in-indigenous-australians.

Australian Institute of Health and Welfare, 2021. Cancer in Australia 2021. Australian Government, Canberra. Accessed on 14 November 2022 at: https://www.aihw.gov.au/reports/cancer/cancer-in-australia-2021/summary.

Australian Institute of Health and Welfare, 2023. National Bowel Cancer Screening Program: monitoring report 2023. Australian Government, Canberra. Accessed on 7 August 2023 at: https://www.aihw.gov.au/reports/cancer-screening/nbcsp-monitoring-2023/summary.

Banham, D., Roder, D., Keefe, D., Farshid, G., Eckert, M., Cargo, M., Brown, A., 2017. Disparities in cancer stage at diagnosis and survival of Aboriginal and non-Aboriginal South Australians. Cancer Epidemiol 48, 131–139.

D'Onise, K., Iacobini, E.T., Canuto, K.J., 2020. Colorectal cancer screening using faecal occult blood tests for Indigenous adults: a systematic literature review of barriers, enablers and implemented strategies. Preventive Med 134, 106018.

Dunlop, K., Rankin, N., Smit, A., Newson, A., Keogh, L., Cust, A., 2022. Views of the Australian public on the delivery of risk-stratified cancer screening in the population: a qualitative study. Public Health Res Pract. https://doi.org/10.17061/phrp32232213.

Dunlop, K., Rankin, N., Smit, A., Salgado, Z., Newson, A., Keogh, L., Cust, A., 2021. Acceptability of risk-stratified population screening across cancer types: qualitative interviews with the Australian public. Health Expectations 24 (4), 1326–1336.

Feletto, E., Yu, X., Lew, J., St John, D., Jenkins, M., Macrae, F., Mahady, S.E., Canfell, K., 2019. Trends in colon and rectal cancer incidence in Australia from 1982 to 2014: Analysis of data on over 375,000 cases, colorectal cancer trends in Australia from 1982 to 2014. Cancer Epidemiol Biomarkers Prev 28 (1), 83–90.

King, R., Brown, A., 2015. Next Steps for Aboriginal Health: Research exploring how research can improve the health and wellbeing of Aboriginal people in South Australia: Final Report February 2015. Accessed on 14 November 2022 at: https://ahcsa.org.au/resources/Next-Steps-for-Aboriginal-Health-Research.pdf.

Lansdorp-Vogelaar, I.M., Reiner, de Jonge, L., Buron, A., Haug, U., Senore, C., 2022. Risk-stratified strategies in population screening for colorectal cancer. Int J Cancer 150 (3), 397–405.

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

Lew, J., St John, D., Macrae, F., Emery, J., Ee, H., Jenkins, M.A., He, E., Grogan, P., Caruana, M., Greuter, M.J., Coupé, V., 2018. Benefits, harms, and cost-effectiveness of potential age extensions to the National Bowel Cancer Screening Program in Australia: The optimal bowel cancer screening age range in Australia. Cancer Epidemiol Biomarkers Prev 27 (12), 1450–1461.

McWhirter, R.E., Critchley, C.R., Nicol, D., Chalmers, D., Whitton, T., Otlowski, M., Burgess, M.M., Dickinson, J.L., 2014. Community engagement for big epidemiology: deliberative democracy as a tool. J Pers Med 4 (4), 459–474.

Menzies School of Health Research, 2017. National Indigenous Bowel Screening test instruction brochure. Accessed on 14 November 2022 at: https://www.menzies.edu.au/page/Resources/National_Indigenous_Bowel_Screening_test_instruction_brochure/.

Menzies School of Health Research, 2020. National Indigenous Bowel Screening Pilot. Final Report. Accessed on 14 November 2022 at: https://www.health.gov.au/resources/publications/final-report-on-the-national-indigenous-bowel-screening-pilot?language=en.

Morey, K., (On behalf of the Wardliparingga Aboriginal Health Equity Research Theme), 2017. South Australian Aboriginal Health Research Accord: Companion Document. Accessed on 14 November 2022 at: https://sahmri.blob.core.windows.net/communications/ACCORD%20Companion%20Doc-Final-Updated-2021.pdf.

United States Preventive Services Task Force, 2021. Colorectal Cancer: Screening. Accessed on 14 November 2022 at: https://www.uspreventiveservicestaskforce.org/uspstf/recommendation/colorectal-cancer-screening.

Young, G., Rabeneck, L., Winawer, S., 2019. The global paradigm shift in screening for colorectal cancer. Gastroenterology 156 (4), 843–851.