

A qualitative study of genomics in cancer control for Aboriginal and Torres Strait Islander Australians

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Abstract

Objective: To describe the perspectives of Aboriginal and Torres Strait Islander peoples and health care workers on genomics in cancer care to inform the National Framework for Genomics in Cancer Control (the Framework).

Methods: A total of 37 Aboriginal and Torres Strait Islander community members, health care workers, researchers, and Aboriginal community-controlled health sector representatives participated in five in-person workshops around Australia. Data were audio recorded, transcribed and analysed using reflexive thematic analysis.

Results: Discussions of genomics in cancer control yielded six themes. *Culture* describes the cultural considerations for genomics. *Self-determination* describes the need for informed decision making in genomic healthcare and research. *Capacity building* identifies areas for improving education and awareness. *Workforce* identifies specific roles needed to support Aboriginal access to genomics. *Access* describes the barriers and enablers for genomics in cancer control. *Suggested actions for integrating genomics into cancer care* outlines participants' call to action.

Conclusions: Equitable access to precision medicine for cancer control will be strengthened by co-design with and for Aboriginal and Torres Strait Islander peoples.

Implications for public health: The findings from this study informed the development of the Framework, which will guide Australia's cancer control sector in the use of genomics.

Key words: Cancer, Genomics, Aboriginal health, Health equity

Cancer health disparities for Aboriginal and Torres Strait Islander peoples compared to non-Indigenous Australians have persisted across decades despite improvements in cancer prevention, treatment and supportive care.¹ Aboriginal and Torres Strait Islander peoples utilise cancer screening services at lower rates, frequently experience late diagnosis, are less likely to have access to treatments and clinical trials and are less likely to survive their cancer.²⁻⁶ Previous qualitative research suggests that Aboriginal and Torres Strait Islander peoples living with cancer are faced with unacceptable logistical barriers situated within health

systems that carry a colonial legacy of institutionalised racism.⁷⁻¹⁰ Addressing these cancer health disparities is a priority of Aboriginal and Torres Strait Islander communities, the Aboriginal Community Controlled Health sector and the Australian government.^{11,12}

Australia, as with many high-income countries, is entering into an era of precision medicine, wherein the knowledge of an individual's genome alongside their clinical features and lifestyle factors can inform cancer prevention, diagnosis and treatment.¹³ This deep personalisation of cancer care holds great promise to detect cancer

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earlier using genomic biomarkers, inform risk prediction and stratification, produce a wider range of targeted treatments and ensure that each person receives the right treatment for them at the right time.¹⁴ Precision medicine also has the potential to widen existing disparities in cancer outcomes and exacerbate historical harms inflicted on Indigenous peoples in genomic research.^{13–15} Advancing policy directives and precision medicine initiatives that embed Aboriginal and Torres Strait Islander sovereignty, equitable access and pathways to benefit is important to addressing current and future health inequities.

The Australian Cancer Plan is a 10-year reform agenda for the Australian cancer care sector with a significant focus on improving cancer outcomes for Aboriginal and Torres Strait Islander peoples.¹¹ Action 1.5.4 of the Australian Cancer Plan (<https://www.australiancancerplan.gov.au/>) is to develop a policy framework for genomics in cancer control across the care continuum. The purpose of this policy is to promote a common understanding of this technology, drive its safe and equitable application in practice, foster collaboration and provide future direction for its integration and use within the cancer care system. Principles of co-design with Aboriginal and Torres Strait Islander people¹⁶ were adopted in the design of this policy framework to ensure cultural safety and ethical implications of genetic research and genomic technology are addressed. We aimed to describe, for the first time, the perspectives of Aboriginal and Torres Strait Islander peoples and health care workers on the use of genomics in cancer care to inform the development of a National Framework for Genomics in Cancer Control.

Methods

This study was Aboriginal-led and privileged the perspectives of Aboriginal and Torres Strait Islander health care workers, stakeholders, community members and researchers. The research team was composed of Aboriginal researchers (JC and AB), Aboriginal consultants to Cancer Australia (JE and KT), a non-Indigenous research assistant (LC) and non-Indigenous Cancer Australia staff members and policy makers (CDV, ARS, CH, VM ad DK).

Participants and recruitment

Participants were eligible to participate if they were (1) Aboriginal and Torres Strait Islander community members (2) Aboriginal and Torres Strait Islander people with lived experience of cancer, (3) health care workers in the mainstream or community-controlled sectors, (4) health researchers focusing on Aboriginal cancer or Indigenous genomics, or (5) representatives of organisations that provide care or services to Aboriginal and Torres Strait Islander cancer patients. The study team conducted a targeted recruitment process to privilege and prioritise participation of Aboriginal and Torres Strait Islander stakeholders across relevant organisations and geographic areas. After identifying potential attendees through contacts of Cancer Australia and Indigenous advisors to the consultation, a member of the study team contacted these individuals to confirm interest and eligibility, followed by a formal letter of invitation.

Data collection

Workshops were facilitated by Aboriginal study team members (JE, KT and JC). Participants received an overview of workshop content

and provided written informed consent prior to commencing the workshop. Facilitators provided an introduction to genomics in cancer care and a conceptual outline of the National Framework for Genomics in Cancer Control. A three-hour guided discussion was conducted by facilitators on genomics across cancer prevention and early detection; diagnosis, treatment and clinical trials; awareness and education; and supportive care. Workshops were audio recorded and transcribed verbatim. Participants were offered reimbursement for their time and travel expenses.

Data analysis

Transcripts were imported into NVivo (QSR International Pty Ltd, Version 1.7.2). Reflexive thematic analysis was conducted by two authors (JC and LC). JC, a post-doctoral researcher and Aboriginal woman, was immersed in the data from the outset having assisted in data collection. LC, a non-Indigenous research assistant and post-graduate student participated in the data analysis phase only. JC and LC independently read, systematically coded and iteratively reviewed all transcripts. Application and consistency of coding were compared over multiple discussions and discrepancies were resolved where necessary. A high level of coding agreement was achieved, and it was decided to utilise a single codebook to develop themes. Themes were developed and then refined with feedback from all co-authors. There was no difference in the approach taken to analyse Aboriginal and Torres Strait Islander compared to non-Indigenous data. Participants had the opportunity to attend a final workshop to provide feedback on findings, as well as an updated draft of the National Framework for Genomics in Cancer Control. Thirty participants attended this workshop; a combination of previous attendees and others who were invited but unable to attend previously.

Results

Workshops were conducted in Sydney, Darwin, Perth, Adelaide and Melbourne with 37 participants, the majority of whom were Aboriginal and Torres Strait Islander (n=26) and represented Aboriginal community members (n=4), the Aboriginal community-controlled organisation (ACCHO) sector (n=13), mainstream health care (n=15), Aboriginal health researchers (n=3) and other Aboriginal organisations (n=2; [Table 1](#)). Reflexive thematic analysis of the data identified six key themes regarding participant's perspectives of genomics in cancer control: Culture, Self-determination, Capacity building, Workforce, Access, and Suggested actions for integrating genomics into cancer care.

Culture

Family and community structures are central to Aboriginal and Torres Strait Islander culture and identity: *Because so much of life is family and community focused too. That's a lot of how it differs from westernised, individualised life...* (Aboriginal community member) Participants frequently identified the link between family, community and genetic inheritance: *And a genetic situation will not affect just the patient. It will affect the family and the community inherently.* (Aboriginal health researcher).

Participants discussed the intersection of culture with the collection of biospecimens and DNA. They emphasised that individuals should have the option for return or repatriation of biospecimens including

Table 1: Participant characteristics.

Participants (total n=37)	
State/Territory	
New South Wales	9
Northern Territory	8
Western Australia	8
South Australia	3
Victoria	9
Indigenous status	
Aboriginal and Torres Strait Islander	26
Non-Indigenous	7
Unknown	4
Position	
Aboriginal community member	4
ACCHO representative	13
Mainstream health care representative	15
Aboriginal health researcher	3
Other Aboriginal organisation representative	2

DNA samples: ...a few people wanted their DNA back, a lot of people did say no but some people did say yes. Because if I'm dying that's coming back with me. From a cultural perspective they wanted all their bits with them on their last day. (ACCHO representative).

Attempts to measure Indigeneity have occurred in Australia, with the caste system justifying the forced removal of Aboriginal children. In the US, blood-quantum requirements, a calculation of Native American ancestry, often determine eligibility for tribal membership. Measuring Aboriginality has proven deeply harmful in Australia, and Aboriginal and Torres Strait Islander participants raised concerns about the potential for ancestry estimation following DNA sequencing, and the impacts this may have on cultural identity: *Or that fear of community checking their DNA. Like the cultural police. So, for those mob who don't have it come up in their DNA, but they've identified for a long time for whatever reason, they may not be Aboriginal? ...There's that minefield of identity.* (ACCHO representative).

Participants identified that family and community obligations were priorities for Aboriginal cancer patients, and they often had to choose between fulfilling these obligations and accessing cancer care: ...its younger people providing care for older people, they're not engaging outside services to do that, it's the informal care arrangements – so they've got so many family obligations, they can't leave. (Mainstream health care representative).

However, proper integration and consideration of the family in cancer care could be an enabler for Aboriginal and Torres Strait Islander patients to seek treatment: ...sometimes it can be the family... demands that's stopped them going. But when they're all there and they listen, the family are on board and they understand that they need to go, it's very important. (ACCHO representative).

Participants suggested that culture should be better integrated into the cancer journey for Aboriginal and Torres Strait Islander patients by offering cancer support groups that are not based on disease type: *I would say more of a collective of your own family to navigate how you support your journey.* (ACCHO representative) Additionally increasing the recognition of traditional medicines: *I think there needs to be more advocacy for us to actually do our own healing as well.* (Aboriginal community member).

Self-determination

Aboriginal and Torres Strait Islander self-determination across cancer care, genomic testing, genomic data and research was important to participants and often came in the form of informed consent and informed choice. Participants specified that informed consent must meet a number of minimum requirements: *That the environment that happens in is safe. We hear all about that white coat that's saying it. But then more than that, you know, do they have a supporting family member? Is it in a language they can understand? Are the resources reflective of what's been – can they take it away and think about it and not have to make a split decision right there? Where is this taking place? Is it on Country? Is it in a metro hospital? That kind of thing.* (Aboriginal health researcher).

Informed consent models for multiple points of testing and secondary research were discussed, and data governance or data sovereignty were identified as additional mechanisms of self-determination: ...*Either individually, to say I would choose where my genetic information can be made available, or whether particularly for our mob, whether we've got to have some sort of data governance around.* (ACCHO representative).

Participants described awareness and information for Aboriginal and Torres Strait Islander cancer patients about genomics in cancer control as something that could empower their choices: *Basic self-determination is like, well, here are all the treatment options available to me: traditional healing methods, drug, drug A, B, C, precision medicines. Will I do it? You know, so you understand what, what the risks are, side effects.* (Aboriginal community member).

Capacity building

A number of participants stated that they had not heard of genomics until the day of the workshop. Participants discussed the need for community engagement to raise awareness among Aboriginal and Torres Strait Islander community members face-to-face and in appropriate languages and settings: *Just getting back to the, the crux of the conversation with the genomics and getting people interested in being tested and having that. So, it's visiting, it's having people with that language that can also make it clear to come into our communities and talk about it.* (ACCHO representative).

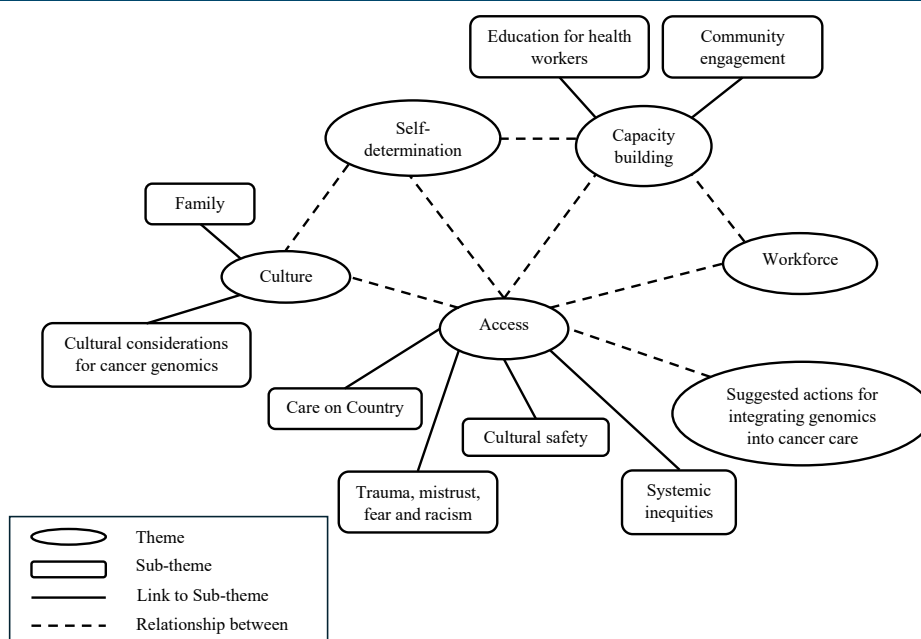
Participants identified that the health care workforce, particularly in primary care, required sound knowledge in three areas to ensure effect delivery of genomic medicine for Aboriginal and Torres Strait Islander cancer control: genomics, cancer and health equity: *You're almost relying on your primary health provider whether that be a GP¹ or an ACCO² staff member or whatever, to direct you to this potentially being a genetic related condition. So it's really empowering the capability and capacity of whoever that person is...* (ACCHO representative).

Some participants expressed a desire to upskill the primary health sector, particularly in the ACCHO setting, for cancer diagnosis and early detection: ...*there needs to be a lot more capacity building and support for the ACCHOs... That there are regional labs set up to support ACCHOs regionally and rurally for some of these more specialised tests, so you're not sort of pushing people into cities or waiting for weeks. And*

¹General Practitioner

²Aboriginal Community Controlled Organisation

Figure 1: Connections between identified themes and subthemes.



then upskilling staff and providing the resources and the staff for the more specialised parts of cancer care. (Aboriginal health researcher).

Conversations came back to cultural safety and building knowledge of health equity issues for Aboriginal and Torres Strait Islander peoples: *But it's also about making sure that the workforce who aren't Aboriginal or Torres Strait Islander have learnt about cultural awareness and safety to be able to deliver that care.* (Mainstream health care representative).

Workforce

Participants discussed the workforce needs for genomics in cancer control, identifying the importance of an Aboriginal and Torres Strait Islander workforce, ideally with local connections: *Either our RN³ practice manager down there, she's local, then we've got the ALO⁴ who's local... But they are really on top of it and have that continuity of care. They know the people in that area and I think that's really important.* (Mainstream health care representative).

Participants identified specific roles that are needed for genomic services, cancer care and clinical trials for Aboriginal and Torres Strait Islander peoples. Genetic counselling was specified: *Like that genetic counselling is vital because you don't know what result you're going to get... And I don't think there's probably much Aboriginal support in genetic counselling is there, I don't think I've heard of anything really.* (Mainstream health care representative).

Care coordinator roles with expert knowledge in cancer genomics were frequently highlighted as important: *[The care coordinators] need some specialist training in genomics though... because I guess that's what we're actually aiming for is that - you know, it's part of the whole journey rather than just a one off or lucky.* (Aboriginal health researcher).

Access

Access, that is Aboriginal and Torres Strait Islander access to genomics in cancer control, was a central theme of all workshop discussions. Adequate cultural considerations, provisions for enhanced Aboriginal and Torres Strait Islander self-determination, genomics capacity building for health workers and community, and growth of the Aboriginal and Torres Strait Islander workforce are all potential facilitators of access (Figure 1).

Participants highlighted fundamental barriers to access by describing experiences of trauma, mistrust, fear and racism: *at the moment, there is no possibility to be getting any genomic services or health care within an ACCO or within a culturally safe space. There is a barrier to actually accessing and presenting at a tertiary centre, for example, that has a lot of trauma embedded within it.* (ACCHO representative).

Systemic inequities included the often-insurmountable logistical challenges of receiving cancer care such as the burden of travel to major treatment centres: *the Aboriginal hostels are always full. [Not-for-profit accommodation] doesn't have enough beds. There's nowhere else to go except hotels and PATS⁵ don't cover that, so people end up on the street. It's just a reality, it creates homelessness.* (Mainstream health care representative).

Some participants identified the systemic inequities arising from a lack of Aboriginal and Torres Strait Islander representation in reference genome resources: *first of all, we don't know if those treatments work the same in mob... it's too narrow-minded to even just call Aboriginal and Torres Strait Islander people one. It's so diverse. It's way more diverse than the Caucasian genome... so you're excluding them - you don't even know if that medication's going to work.* (Aboriginal health researcher).

³Registered Nurse

⁴Aboriginal Liaison Officer

⁵Patient Assistance Transport Scheme

Participants highlighted systemic barriers to receiving genetic testing including the cost and the highly specific requirements for subsidisation: *It also comes down to what is subsidised and what is accessible... you can't just get a Medicare subsidised genetic test for the sake of getting a genetic test. There needs to be that familial link first...* (ACCHO representative) Participants questioned whether genetic testing should be triggered by family history, suggesting that Aboriginal people who were in foster care or whose family were part of the Stolen Generations may not know their family history: *I don't think it should be reactive to this family history thing.* (Aboriginal health researcher) Participants were concerned about the potential impacts of genetic results on life insurance coverage: *For patients without a diagnosis of cancer, screening them... that has lots of dangers as well, starting from insurance, if you have a predisposition...* (Mainstream health care representative).

Conversely, participants provided solutions for embedding genomics for prevention and early detection, once evidence-based, into routine care for Aboriginal and Torres Strait Islander people: *If we're screening and doing genomics screening, around and part of that 715⁶ process, that health check process, that'd be the way I'd be trying to get it into the communities.* (Mainstream health care representative).

Cultural safety was considered critical to ensuring safe access to genomics in cancer control, and it was discussed in the context of capacity building and both staff and patient experiences: *Well, for me it means you can build the solution anywhere in the mainstream, but if people don't access it, it's useless. So ensuring the cultural safety of Aboriginal people is maintained from primary healthcare or community through to the diagnosis, treatment, aftercare, and then in community again, which can be multiple times in the journey.* (Aboriginal community member).

Participants identified alternative models of care that could address some of the major barriers to access to cancer care for Aboriginal and Torres Strait Islander peoples. Utilising ACCHOs for the delivery of cancer care and genomic services was often discussed: *...It may take us a while to get mainstream services culturally safe and so in the interim, why are we not looking at Aboriginal Community Controlled models of cancer treatment? For example, does it all need to be run through the hospital systems?* (ACCHO representative).

Increasing cancer care, clinical trials and genomic services closer to home or on Country was another possible solution identified by participants: *And then looking at the trial itself, say it's just what a medication, a new medication, can they receive this at home through their local health clinic you know cause that's always going to be 100% the way to get people involved in something.* (Mainstream health care representative).

Suggested actions for integrating genomics into cancer care

Many participants worked in Aboriginal and Torres Strait Islander health or research, and many were Aboriginal and Torres Strait Islander peoples themselves, conferring a depth of experience that they applied to the subject matter. Participants provided the study

team with suggested actions for integrating genomics into Aboriginal and Torres Strait Islander cancer care, which are dispersed throughout the five aforementioned themes.

Participants provided detailed suggestions about capacity building, stating that when designing training for health care workers, we should *design it to the minimum of an AHP⁷...skillset* (ACCHO representative), *offer CPD⁸ hours for nursing, most clinicians* (Mainstream health care representative), *offer training with the staff through virtual reality* (ACCHO representative) and *consider telehealth training to professionals in rural and remote areas.* (ACCHO representative) A participant suggested that *one of the tools that we could use is the optimal care pathways... we could also help invest in that for genomics.* (Aboriginal community member).

Participants provided advice on how community engagement could be delivered and who should deliver it: *I also would like an ad on tele, but I'd also like to speak to someone with a lived experience.* (ACCHO representative) To reach more people, participants suggested the use of social media: *number one, social media. That always seems to work for us with a very, very, very simple video.* (Mainstream health care representative).

Participants suggested that a conversation about genomics could start in the context of family history: *Who in your family was sick and do you know how they were sick? And you can have those ice-breaking conversations to start why genomics is being done. Why it's important.* (ACCHO representative) This could be followed by addressing any myths: *As soon as you know the myths, you've got to jump onto them and address them.* (Mainstream health care representative) A full list of suggestions provided by participants are summarised within [Table 2](#).

Discussion

This study explored the perspectives of Aboriginal and Torres Strait Islander peoples and health care workers on the use of genomics in cancer control for Aboriginal and Torres Strait Islander patients, families and communities. The findings highlight concerns, potential challenges and solutions for integrating genomics into the Australian cancer control sector. Our study included 70% Aboriginal and Torres Strait Islander individuals, most of whom were either health care workers, researchers or community members. Nineteen percent of our sample were non-Indigenous Australians, most of whom were health care workers delivering cancer care to Aboriginal and Torres Strait Islander patients. A further 10% of our sample did not disclose their Indigenous status. This sample was purposefully chosen as a representative sample of stakeholders with critical roles in the future delivery of genomics in cancer control to Aboriginal and Torres Strait Islander communities.

The concept of accessible precision oncology for Aboriginal and Torres Strait Islander peoples is central to our findings. Study participants outlined the components of this: it is culturally safe, coordinated, affordable, close to home, with well-informed providers at every level of care and self-determination for patients over their cancer journey as well as their data. Many previous studies report on issues of accessibility of cancer services, citing the burdens of travel

⁶Medicare Benefits Schedule item number 715, the Aboriginal and Torres Strait Islander health assessment

⁷Aboriginal Health Practitioner

⁸Continuing professional development.

Table 2: Participant suggestions for integrating genomics into cancer care.

Topic	Suggestions
Data and sample use	<ul style="list-style-type: none"> • Provide repatriation of biospecimens as an option • Create a protocol of how data and biospecimens will be used, stored and disposed of that is adaptable to individual preferences • Uphold Indigenous data sovereignty and governance for databases that are created for genomics in cancer control
Screening	<ul style="list-style-type: none"> • Perform genomic screening proactively, rather than reactive to family history • Perform genomic screening as part of the 715 Aboriginal health check • Reduce the out-of-pocket costs associated with genetic testing • Ban the use of adverse genetic testing results in life insurance • Promote cancer screening by performing it as part of community events
New models of care	<ul style="list-style-type: none"> • Provide Aboriginal cancer care navigators who have knowledge of genomics in cancer care • Actively involve Aboriginal health practitioners in cancer care • Create new models for cancer care such as oncology clinics within Aboriginal medical services • Improve access to clinical trials by offering more trials on Country through local Aboriginal health clinics and incorporating telehealth consults • Increase cancer treatment services available on Country such as through outreach services • Provide more cancer support groups, offering different models according to patient needs e.g. centring family and community rather than other cancer patients • Recognise traditional healing as a valuable part of the cancer journey
Improving services	<ul style="list-style-type: none"> • Provide more translation services • Improve cultural safety in tertiary services • Improve the continuity of care across sites and jurisdictions, especially to support patients travelling across multiple services for care
Education for health care workers	<ul style="list-style-type: none"> • Design education that is accessible from an Aboriginal health practitioner skillset • Use telehealth to deliver health worker training • Use VR headsets to deliver health worker training • Offer training that contributes to health care worker's CPD hours • Improve the incorporation of genomics into the optimal care pathways for cancer
Community engagement	<ul style="list-style-type: none"> • Engage with community members face-to-face about genomics • Produce genomics education in multiple formats such as online resources, printed resources and videos, delivered via multiple routes including social media and television, and provide translation into local languages as needed • Provide genomics information in a safe space for community members such as community events, art days and yarning circles • Conduct a conversation about genomics by (1) relating genomics to family history to explain it, then (2) communicating the potential benefits and (3) addressing myths

away from home, the financial costs of care and the lack of cultural safety in health services as major barriers experienced by Aboriginal and Torres Strait Islander cancer patients.^{10,17–19} Our study is supportive of previous evidence that Aboriginal care coordination, as well as care closer to home, are solutions for many of the challenges experienced by Aboriginal and Torres Strait Islander patients facing a cancer diagnosis.^{10,17,19}

Self-determination and agency over the cancer journey were identified as important to participants in the present study and previous studies.^{9,18} In our study, self-determination extended to informed consent, particularly relating to complex clinical trials and genetic testing, as well as self-determination over genomic data and samples. The right of Indigenous peoples to govern and control their own data and samples is known as Indigenous data sovereignty.²⁰ It is a growing movement worldwide characterised by the recognition that Indigenous data is a resource that can empower the health of our communities and conversely has been used historically to disempower us. In fact, without addressing community concerns over data use, these concerns can deter individuals from obtaining genetic testing for either clinical or research purposes.²¹ Our data confirms that Indigenous data sovereignty principles outlined within national and international guidelines should be a key consideration for

genomics in cancer control involving Aboriginal and Torres Strait Islander peoples.^{20,22}

Workforce capability and capacity have been identified in previous literature as major challenges to the implementation of precision medicine as part of routine care.¹³ Participants within the present study frequently highlighted this same issue with a particular focus on the ability of health workers to support their patients to understand and access genomics in cancer care. Participants suggested that capacity building should focus on the primary health sector and should include Aboriginal staff such as Aboriginal liaison officers, Aboriginal health practitioners, and staff within ACCHOs. The emphasis participants placed on strengthening the community-controlled sector in Aboriginal and Torres Strait Islander cancer control supports the aims of the NACCHO Aboriginal and Torres Strait Islander Cancer Plan.¹²

This study was designed to inform the design of Cancer Australia's National Framework for Genomics in Cancer Control. The findings from this study and a conceptual outline of the Framework were presented to n=30 Aboriginal and Torres Strait Islander stakeholders for review and feedback, prior to the release of the draft Framework for further public consultation. Decision makers both internal and external to our research team were responsible

for the content of the final Framework. Our findings were integrated into the broader Framework document, with 15 of 29 Framework Actions directly reflecting our findings.²³ Participants within our study made numerous suggestions for improvements and potential solutions to the issues raised, and we emphasised these suggestions in a similar fashion to some previous studies.^{9,17} These suggestions are invaluable beyond the National Framework for Genomics in Cancer Control, providing critical insights into what Australian precision medicine initiatives should prioritise if they are to meet the needs of Aboriginal and Torres Strait Islander peoples affected by cancer.

Strengths and limitations

The strengths of this study include Aboriginal leadership throughout project planning, workshop facilitation and data analysis. Cancer Australia formed a dedicated Indigenous Governance Group for the Framework project, which oversaw project planning and provided feedback on the data analysis process. We were able to recruit participants from both mainstream health care and community-controlled health care sectors, providing valuable perspectives important to the future state of Aboriginal and Torres Strait Islander cancer control. One of the greatest strengths of the study was buy-in from policymakers from the project outset, meaning that our findings were able to be rapidly translated into national policy.

Genomics is a topic that is often completely unfamiliar to non-experts, and a limitation of the study was that participants were expected to absorb information about this new concept directly before being asked to have a critical discussion on the topic. Although participants responded honestly from their professional and personal experience, they may have been better equipped for the discussion if the study team had dedicated more time and resources to ensuring participants were better informed about genomics in cancer control prior to discussions taking place.

Conclusions

Our study identifies that, like any cancer control measure, genomics in cancer control requires purposeful design to facilitate access and uphold the rights of Aboriginal and Torres Strait Islander peoples. This study has made valuable contributions to the National Framework for Genomics in Cancer Control. The suggestions made by participants are valuable beyond the Framework, and should be used to inform future policy, research, education and health systems strategic planning for the use of genomics in Australian cancer care.

Conflicts of interest

The authors have no conflicts of interest to declare.

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Ethical statement

Ethical approval was provided by the Australian Institute of Aboriginal and Torres Strait Islander Studies (AIATSIS; REC-0309) and Australian National University (ANU; H/2024/0798).

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