Commentary

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"Shame job": the exclusion of Aboriginal and Torres Strait Islander peoples in genomics and precision medicine

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Abstract

The underrepresentation of Aboriginal and Torres Strait Islander peoples in genomics and precision medicine research is a critical oversight with profound implications for health equity. This commentary examines the neglect of prospective recruitment of Indigenous participants in genomics research and its impact on the health disparity gap. It argues that this exclusion perpetuates Eurocentric biases in health care, limiting the potential of precision medicine to benefit all populations equitably. Addressing these gaps requires systemic changes that prioritise Indigenous leadership, culturally safe methodologies, and meaningful community engagement. By embedding Indigenous governance and perspectives into genomics research, we can ensure that precision medicine serves as a tool for reducing health disparities, rather than perpetuating them.

Keywords

Aboriginal and Torres Strait Islander peoples, culturally safe research, genomics, health equity, Indigenous health, precision medicine

Introduction

The rapid advancement of genomics and precision medicine has revolutionised health care globally, offering tailored therapeutic interventions based on genetic, environmental, and lifestyle factors. However, the benefits of these advancements remain inequitably distributed, particularly for Aboriginal and Torres Strait Islander peoples in Australia. However, the benefits of precision medicine have not been equitably distributed, particularly among Aboriginal and Torres Strait Islander peoples, who continue to experience profound health disparities compared with non-Indigenous Australians (Australian Institute of Health and Welfare [AIHW], 2023). Despite the potential of genomics to address these inequities, Aboriginal and Torres Strait Islander peoples remain significantly underrepresented in research, reflecting systemic inequities that marginalise Indigenous participation in scientific advancements and fail to value Indigenous knowledge systems (Bobba, 2019; Smith, 2012). This lack of representation exacerbates the Eurocentric bias in genomic research, limiting its applicability to diverse populations and hindering its ability to deliver equitable health care outcomes (Atutornu et al., 2022; Corpas et al., 2025; Popejoy & Fullerton, 2016).

The lack of prospective recruitment of Aboriginal and Torres Strait Islander peoples in genomics research is particularly concerning given the disproportionate burden of chronic diseases within our population (AIHW, 2023). Precision medicine's promise of personalised health care is compromised by the absence of genetic data that reflects the diversity of Indigenous communities, leading to diagnostic gaps and the development of interventions that may not be effective in these populations (Kowal et al., 2015). Furthermore, the marginalisation of Indigenous perspectives in research perpetuates a health care system that fails to address the broader social determinants of health impacting Aboriginal and Torres Strait Islander peoples (NHMRC, 2018).

This commentary explores the critical implications of this neglect, examining the systemic barriers to the inclusion of Aboriginal and Torres Strait Islander peoples in genomics research and the potential consequences for health equity. It argues for a transformative shift towards inclusive practices that prioritise Aboriginal and Torres Strait Islander leadership, culturally safe methodologies, and meaningful community engagement. Embedding Indigenous governance and perspectives into genomics research is essential not only for fulfilling the scientific promise of precision medicine but also

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for achieving social justice and recognising the inherent rights of Aboriginal and Torres Strait Islander communities to participate in and benefit from scientific progress. Addressing these challenges requires urgent action to build trust, foster community-driven research, and ensure that precision medicine contributes to closing the health disparity gap rather than widening it (Bessarab & Ng'andu, 2010).

The legacy of exclusion

Research involving Indigenous peoples has long been characterised by extractive and exploitative practices, creating a legacy of mistrust that persists to this day. From the early 20th century, when eugenics-influenced scientific research targeted Indigenous populations, to more recent biomedical studies that failed to obtain informed consent, Aboriginal and Torres Strait Islander peoples have been subjected to unethical research practices (Bobba, 2019; Smith, 2012). This history of exploitation has fostered deep scepticism towards research institutions and created significant barriers to engagement. The systemic inequities entrenched in health care and research practices continue to marginalise Indigenous participation in genomics research, perpetuating patterns of exclusion.

In recent years, initiatives such as those led by the National Centre for Indigenous Genomics (NCIG) have sought to address these historical injustices by promoting Indigenous governance and control over genomic data. The NCIG's (2023) work emphasises data sovereignty, the right of Indigenous peoples to govern the collection, ownership, and application of data about their communities as a critical framework for rebuilding trust and ensuring ethical research practices. Similarly, Aboriginal scholars including Professor Alex Brown have highlighted the necessity of embedding Aboriginal and Torres Strait Islander perspectives and leadership in genomics research to address these systemic inequities. This body of work advocates for a strengths-based approach that prioritises the health and wellbeing of Indigenous communities while acknowledging the legacies of colonialism in research practices (Hudson et al., 2020; Waanders et al., 2023).

One critical issue is the overwhelming Eurocentric bias of genomic databases, which are predominantly composed of data from populations of European ancestry (Atutornu et al., 2022; Corpas et al., 2025; Popejoy & Fullerton, 2016). This imbalance not only skews research findings but also limits the applicability of precision medicine to non-European populations, including Aboriginal and Torres Strait Islander peoples. Without adequate representation in genomic studies, Aboriginal and Torres Strait Islander communities are excluded from advancements in personalised health care that could address their unique health needs.

Another significant barrier is the lack of culturally safe research practices. Many existing frameworks fail to align with Indigenous worldviews, protocols, and priorities, deterring participation and contributing to the marginalisation of Indigenous voices in research (NHMRC, 2018). For example, the standardised approaches to ethics approval and participant recruitment often prioritise institutional requirements over community-centred processes, overlooking the importance of building trust and respecting Indigenous governance.

This exclusion is further compounded by structural barriers that limit access to research opportunities. Aboriginal and Torres Strait Islander communities frequently face geographic isolation, resource limitations, and inadequate funding for community-led initiatives. These challenges are exacerbated by the underrepresentation of Indigenous researchers and leaders within the field of genomics, perpetuating a disconnect between research priorities and community needs (Kowal et al., 2015). The absence of Indigenous leadership in genomics research also undermines efforts to integrate Indigenous knowledge systems, which could offer valuable insights into health and wellbeing.

Health implications of exclusion

The exclusion of Aboriginal and Torres Strait Islander peoples from genomics research has far-reaching consequences that deepen existing health inequities. A significant issue is the limited relevance of genomic findings derived predominantly from non-Indigenous populations. Most large-scale genomic studies have been conducted with samples of European ancestry, failing to capture the genetic diversity of Indigenous peoples. This imbalance restricts the applicability of research findings to Aboriginal and Torres Strait Islander populations, creating diagnostic gaps and ineffective treatments for diseases that disproportionately affect these communities (Popejoy & Fullerton, 2016). A critical manifestation of this imbalance is evident in global reference databases used for variant interpretation, such as gnomAD. These repositories are disproportionately populated with samples of European ancestry—individuals of European descent comprise approximately 75% of samples in gnomAD v4, while Aboriginal and Torres Strait Islander peoples have 0% representation (gnomAD, 2025). In bioinformatics workflows, allelic frequency is a key metric used to assess pathogenicity (Ciesielski et al., 2024); variants that are rare in reference populations are more likely to be flagged as potentially pathogenic. When Indigenous populations are absent from these data sets, variants that are common in Aboriginal and Torres Strait Islander peoples may be misclassified as pathogenic or remain as variants of uncertain significance (VUS), simply because they are rare or absent in European data sets (Chen et al., 2023). Such misclassification can lead to inappropriate clinical interventions or missed opportunities for accurate diagnosis and treatment.

The absence of genomic data tailored to Aboriginal and Torres Strait Islander populations means that precision medicine remains inaccessible, undermining its potential to address the conditions that impact on our morbidity and mortality most (AIHW, 2023). By contrast, populations well represented in reference genomes benefit from greater certainty in variant interpretation and, consequently, more precise health care.

The missed opportunities for precision interventions further exacerbate health inequities. Diseases that disproportionately affect Aboriginal and Torres Strait Islander peoples require tailored approaches informed by comprehensive and inclusive genomic data. Without such data, interventions often fail to account for the unique genetic, environmental, and cultural factors influencing health outcomes in Indigenous communities. This exclusion not only undermines the effectiveness of treatments but also contributes to a broader cycle of health care disparity and mistrust in research institutions (Kowal et al., 2015).

In addition, the lack of Aboriginal and Torres Strait Islander inclusion perpetuates systemic inequities within health care. Precision medicine promises to personalise health care delivery, offering solutions grounded in individual genetic profiles. However, when entire populations are excluded from the foundational research driving these advancements, the promise of precision medicine remains unfulfilled for those most in need. Aboriginal and Torres Strait Islander peoples are thus systematically denied access to innovations that could significantly improve health outcomes. This exclusion reflects a broader failure to prioritise equity in health care and research, reinforcing structural disadvantages that disproportionately burden Indigenous populations (Sherwood, 2013).

Efforts to address these implications must centre on creating genomic research frameworks that are inclusive, equitable, and respectful of Indigenous data sovereignty. Institutions such as the NCIG are leading the way by advocating for Indigenous governance and control over genomic data, recognising the need for culturally appropriate methodologies that empower communities to engage in research on their terms (NCIG, 2023). These initiatives highlight the importance of embedding Indigenous leadership in genomic research to ensure that its benefits are shared equitably and that health care innovation contributes meaningfully to reducing health disparities.

Systemic barriers to inclusion

The neglect of Aboriginal and Torres Strait Islander peoples in genomics research is intrinsically linked to systemic inequities that have shaped research practices over decades. Ethical challenges play a significant role in this exclusion. Research guidelines often prioritise institutional compliance and scientific rigour over meaningful community engagement, resulting in frameworks that overlook Indigenous governance and fail to align with culturally safe methodologies (NHMRC, 2018). Such approaches disregard the need for co-designed research processes that respect and empower Aboriginal and Torres Strait Islander voices.

Historical mistrust further compounds these barriers. Aboriginal and Torres Strait Islander communities have long been subjected to exploitative and unethical research practices, including instances where informed consent was neglected, or data were misused (Smith, 2012). These experiences have left many communities sceptical of scientific endeavours, particularly when they do not prioritise their health needs or cultural values. This mistrust has created a significant gap between researchers and Indigenous communities, limiting opportunities for collaboration and mutual benefit.

Another critical barrier is the lack of representation in research leadership. Aboriginal and Torres Strait Islander researchers remain underrepresented in genomics, perpetuating a disconnect between research priorities and the needs of Indigenous communities (Kowal et al., 2015). The absence of Indigenous leadership in this field restricts efforts to integrate Indigenous knowledge systems and values, which are essential for addressing health disparities. Without adequate representation, research continues to prioritise non-Indigenous perspectives, reinforcing systemic inequities in health care and scientific inquiry.

Pathways to inclusion

Overcoming the systemic barriers to Aboriginal and Torres Strait Islander inclusion in genomics research requires transformative and culturally grounded approaches that centre Indigenous governance and leadership. At the core of this transformation is the prioritisation of Aboriginal and Torres Strait Islander voices and knowledge systems, which have long been excluded from research frameworks. Community-controlled health organisations are uniquely positioned to lead these efforts, ensuring alignment with the principles of self-determination and Indigenous data sovereignty (NCIG, 2023). These organisations provide culturally secure environments where Indigenous priorities and methodologies can be embedded into research design, fostering trust and collaboration.

Equally critical is the adoption of culturally safe and strengths-based research methodologies that respect Aboriginal and Torres Strait Islander ways of knowing and being. Traditional Western research paradigms often fail to accommodate these perspectives, alienating communities and reinforcing distrust. Approaches such as yarning, a relational and conversational method grounded in Indigenous cultures, facilitate meaningful dialogue and co-design of research initiatives (Bessarab & Ng'andu, 2010). Participatory action research, another inclusive methodology, enables researchers to work collaboratively with communities to address shared priorities and develop locally relevant solutions. By incorporating these methods, genomics research can become more inclusive and responsive to the specific needs of Aboriginal and Torres Strait Islander peoples.

Diversification of genomic databases is another essential strategy. Genomic research has predominantly relied on data from populations of European ancestry, limiting its relevance to diverse groups, including Indigenous Australians. Addressing this imbalance requires targeted efforts to include genomic data from Aboriginal and Torres Strait Islander peoples, ensuring that research findings are broadly applicable, clinically relevant and that precision medicine delivers equitable health care outcomes. The work of NCIG (2023) highlights the importance of Aboriginal and Torres Strait Islander governance in the ethical collection and use of genomic data, demonstrating how community-led initiatives can strengthen the integrity and inclusivity of genomics research.

Capacity building is crucial for fostering Indigenous leadership in genomics. Investment in education, training programmes, and mentorship opportunities for Aboriginal and

Torres Strait Islander researchers can help create a sustainable pipeline of Indigenous expertise. Initiatives such as scholarships for genomics education and partnerships with universities and research institutes are vital for empowering Aboriginal and Torres Strait Islander researchers and ensuring their representation across all stages of the research process. This representation enhances the cultural competence of genomics research and reduces the disconnect between scientific inquiry and community health priorities.

Finally, robust partnerships with funding bodies are necessary to drive systemic change. Funding agencies must prioritise Aboriginal and Torres Strait Islander-led research initiatives and allocate long-term resources to support community-driven projects. By mandating Indigenous representation in genomics research and directing resources towards culturally safe methodologies, funding bodies can play a pivotal role in addressing the inequities that currently define the field. These structural changes are essential to ensure that genomics research contributes to reducing health disparities rather than perpetuating them.

The role of funding bodies

Funding bodies hold a crucial responsibility in driving systemic change within genomics and precision medicine research. By prioritising Indigenous-led research initiatives and ensuring sustained, long-term support for community-driven projects, funding agencies can address the entrenched inequities that have long marginalised Aboriginal and Torres Strait Islander peoples in this field. Indigenous-led initiatives not only provide opportunities for communities to shape research agendas but also ensure that the outcomes are directly relevant to the health needs and priorities of these populations. The National Health and Medical Research Council (NHMRC, 2018) has taken steps in this direction by establishing grant schemes dedicated to Indigenous health research, highlighting the importance of embedding culturally safe and community-driven approaches in funded projects.

One notable example of funding agencies driving innovation in this space is the ZERO Childhood Cancer Programme. This initiative, a national collaboration supported by government funding and philanthropic contributions, aims to deliver precision medicine for children with high-risk cancers. While its primary focus is childhood cancer, the programme's approach to integrating genomic data into personalised care provides a model that could be extended to include Aboriginal and Torres Strait Islander children. Ensuring Indigenous governance and participation in similar large-scale initiatives would enable culturally secure adaptations of such models, addressing the unique health challenges faced by Aboriginal and Torres Strait Islander children and contributing to broader equity in genomic research (ZERO Childhood Cancer Program, 2023).

Promoting Aboriginal and Torres Strait Islander representation in all genomics research projects is another essential step for funding bodies. This approach would encourage accountability and inclusion, fostering environments where Indigenous voices can shape research design, implementation, and dissemination, while recognising that participation must remain voluntary and aligned with community priorities. Such mandates should be accompanied by funding provisions to build the capacity of Indigenous researchers and support their participation in leadership roles. Capacity-building programmes, such as those run by the Lowitja Institute, have demonstrated the potential for investment in Aboriginal and Torres Strait Islander researchers to transform the health research landscape, creating pathways for sustainable Indigenous leadership (Lowitja Institute, 2023).

Moreover, funding bodies must prioritise projects that adopt strengths-based and culturally safe methodologies. Research initiatives that employ approaches like yarning or participatory action research have been shown to build trust and promote meaningful engagement with Aboriginal and Torres Strait Islander communities (Bessarab & Ng'andu, 2010). Funding guidelines should explicitly incentivise the use of such methodologies, ensuring that research is conducted ethically and with the full participation of Aboriginal and Torres Strait Islander peoples.

Finally, funding agencies must advocate for the establishment of Indigenous-controlled genomic databases to support ethical data collection and governance. Such databases, exemplified by the NCIG, provide a foundation for inclusive genomic research that respects Indigenous data sovereignty. Funding bodies should allocate resources to develop and maintain these databases, ensuring that they are accessible, culturally secure, and governed by Aboriginal and Torres Strait Islander communities.

By adopting these strategies, funding bodies can play a transformative role in genomics research, ensuring that it serves as a tool for reducing health disparities and promoting equity for Aboriginal and Torres Strait Islander peoples.

Conclusion

The exclusion of Aboriginal and Torres Strait Islander peoples from genomics and precision medicine research is a glaring oversight with profound implications for health equity in Australia. This neglect not only reflects systemic inequities in health care but also undermines the ethical principles of inclusion and equity that should underpin scientific research. Precision medicine, with its promise of tailoring treatments to individual genetic, environmental, and cultural contexts, cannot achieve its full potential while Indigenous communities remain underrepresented.

Addressing this oversight requires a paradigm shift towards systemic changes that prioritise Aboriginal and Torres Strait Islander leadership, culturally safe practices, and meaningful community engagement. This leadership is critical in ensuring that research agendas are aligned with community priorities and that the benefits of genomics are shared equitably. The adoption of culturally safe practices, including methodologies such as yarning and participatory action research, is equally essential. These approaches build trust, foster collaboration, and ensure that research processes are respectful and inclusive of Indigenous perspectives (Bessarab & Ng'andu, 2010).

Embedding Aboriginal and Torres Strait Islander perspectives into genomics research also involves recognising the importance of Indigenous governance and data sovereignty. Institutions like the NCIG have demonstrated the value of community-led frameworks that empower Indigenous peoples to control and govern their genomic data, ensuring ethical use and equitable outcomes (NCIG, 2023). Such initiatives are vital in rebuilding trust and addressing the historical exclusion of Indigenous peoples from research.

By embedding these changes into the fabric of genomics research, we can move closer to realising the potential of precision medicine to reduce health disparities. This approach not only benefits Aboriginal and Torres Strait Islander Australians but also strengthens the integrity and applicability of genomics research, ensuring equitable health care outcomes for all Australians.

Authors' note

Genomics research has historically excluded Aboriginal and Torres Strait Islander peoples and often failed to deliver equitable benefit. This manuscript draws on Indigenous scholarship and advocates for Aboriginal and Torres Strait Islander leadership, governance, and strengths-based approaches in genomics research.

The first author is an Aboriginal Australian clinician and academic grounded in Aboriginal ways of knowing, being and doing. The second author is a non-Indigenous Canadian scientist and academic committed to Indigenous-led and ethically governed research. Both authors acknowledge power asymmetries in genomics research and write in support of Indigenous self-determination and equity.

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Glossary

Yarning	A conversational method used in Indigenous research to build relationships and gather qualitative data

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