Gerrard *et al.*
International Journal for Equity in Health (2025) 24:2
https://doi.org/10.1186/s12939-024-02358-2

International Journal for Equity in Health

REVIEW

Open Access

Co-design in healthcare with and for First Nations Peoples of the land now known as Australia: a narrative review

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Abstract

Increasing use of co-design concepts and buzzwords create risk of generating 'co-design branded' healthcare research and healthcare system design involving insincere, contrived, coercive engagement with First Nations Peoples. There are concerns that inauthenticity in co-design will further perpetuate and ingrain harms inbuilt to colonial systems.

Co-design is a tool that inherently must truly reposition power to First Nations Peoples, engendering both respect and ownership. Co-design is a tool for facilitating cultural responsiveness, and therefore a tool for creating healthcare systems that First Nations People may judge as safe to approach and use. True co-design centres First Nations cultures, perspectives of health, and lived experiences, and uses decolonising methodologies in addressing health determinants of dispossession, assimilation, intergenerational trauma, racism, and genocide.

Authentic co-design of health services can reduce racism and improve access through its decolonising methods and approaches which are strategically anti-racist. Non-Indigenous people involved in co-design need to be committed to continuously developing cultural responsiveness. Education and reflection must then lead to actions, developing skill sets, and challenging 'norms' of systemic inequity. Non-Indigenous people working and supporting within co-design need to acknowledge their white or non-Indigenous privileges, need ongoing cultural self-awareness and self-reflection, need to minimise implicit bias and stereotypes, and need to know Australian history and recognise the ongoing impacts thereof.

This review provides narrative on colonial load, informed consent, language and knowledge sharing, partnering in co-design, and monitoring and evaluation in co-design so readers can better understand where power imbalance, racism, and historical exclusion undermine co-design, and can easily identify skills and ways of working in co-design to rebut systemic racism. If the process of co-design in healthcare across the First Nations of the land now known as Australia is to meaningfully contribute to change from decades of historical and ongoing systemic racism perpetuating power imbalance and resultant health inequities and inequality, co-designed outcomes cannot be a pre-determined result of tokenistic, managed, or coercive consultation. Outcomes must be a true, correct, and beneficial result of a participatory process of First Nations empowered and led co-design and must be judged as such by First Nations Peoples.

Keywords First Nations (Australia), Health, Co-design, Equity, Racism, Self-determination

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Note

The authors would like to acknowledge the Traditional Custodians and Sovereign Owners of the lands and waters upon which we live and work, the airways beneath which we exist, and the connection to Country of the Wergaia, Wadawurrung, Wiradjuri, Jagera, Turrbal, Yugambeh, Kombumerri and Darkinyung Peoples. Authors SG (Badimaya Yamatji), JC (Kaurna), and KW (Wiradjuri) are proud First Nations people who bring First Nations personal and professional lived experience and ways of being to this narrative review. Author VC is of First Nations (Māori) and European ancestries, and respectfully acknowledges her Eurocentric-dominant lived experience and her position as a learner in this space. Authors of European ancestry (SS and JG) acknowledge Western knowledge systems, colonial lens, and the biases that accompany their worldview. All authors would like to acknowledge the incommensurate value treaty, truth-telling, shared ontology, and shared epistemology would give to past, present, and future generations, collectively across Country. This work includes the nomenclature; Aboriginal and Torres Strait Islander Peoples, First Nations Peoples, and Indigenous Peoples. Neither singularly, nor collectively do they adequately represent the immense diversity of language groups and cultural values across this continent's Traditional Custodians and Sovereign Owners [1, 2]. Authors privilege ways of using terminology that are self-determined, that communicate diversity and sovereignty, and that minimise use of terms that are imposed. Proper nouns are used as a part of respectfully writing about specific names for persons, places, or things. For example, First Nations and Elders are capitalised no matter where they fall in a sentence, as are Country and Community. The latter capitalisations are used to acknowledge sovereign lands First Nations Peoples belong to and the groups First Nations Peoples form and exist within. This delineates these terms from generic interpretation of non-specific country and broader mainstream community contexts. Non-Indigenous people is the language used to represent and be inclusive of Australians who are not First Nations people [3]. The terms decolonise, decolonisation, and decolonising methodology throughout this work describe being inclusive of Aboriginal and Torres Strait Islander worldviews and holistic conceptualisations of health and well-being [4], whilst challenging and decentring dominant colonial views, and divesting colonial power [5]. Authors use standalone quotes in this work to amplify First Nations voices relating to topics and to celebrate their bringing and giving of strength. First Nations voices have a history of being silenced and this work advocates for platforms from which they can be heard. Authors' referencing follows the Indigenous Archives Collective Indigenous Referencing Guidance for Indigenous Knowledges [6] in acknowledging knowledge creation to address and dismantle oppressive systems denying people creation of their own culture [6]. This work privileges Nation, Country, or Language group in the reference list, if that information is provided within the source being cited or is clearly provided [6]. This work does not assume a person's affiliation if it is not stated clearly [6].

Introduction

The aim of this work is to provide narrative review on co-design in healthcare with and for First Nations Peoples of the land now known as Australia. Recent systematic reviews relevant to place and topic define co-design as the meaningful involvement of end-users [7] in finding and developing solutions to complicated issues [8]. The focus of the work is on discussing the fundamental elements of co-design that support a self-determined and authentic process that is undertaken with and for First Nations people across the First Nations of Australia. This authorship group consists of First Nations and non-Indigenous people with developed skills, expertise, and vast collective lived experiences in receiving, providing, teaching, researching, and driving healthcare reform within colonial systems across these lands. In this review we define co-design, consider it more broadly, and provide review of authentic co-design method and practice in healthcare with and for First Nations Peoples. The work centres on the need to address healthcare system inequity in delivery and inequality in outcome for First Nations Peoples and the urgency of bringing changes to systems that continue to actively exclude and discriminate against First Nations Peoples. In developing this work we have adopted a translational approach [9] so readers can better understand where power imbalance, racism, and historical exclusion undermine co-design, and can easily identify skills and ways of working in co-design to rebut systemic racism. It is intended to be easily understood by not just by First Nations individuals, families, and Communities, but by public and private health sector workers and organisations, by academic readers, and by non-Indigenous peoples who are systemically and systematically given umbrella terms for concepts without due explanations of real meanings.

Imperative to underpinning co-design, in this work we acknowledge, respect, and actively promote the United Nations Declaration on the Rights of Indigenous Peoples (UNDRIP). The UNDRIP principles have been adhered to as a means of exemplifying ways of working in the pursuit of health equity. This is to found First Nations empowered self-determination in work and to privilege the rights of First Nations Peoples. Articles 2, 3, 4, and 24 of the Declaration state that Indigenous Peoples have;

'the right to be free from any kind of discrimination'; 'the right to self-determination'; 'the right to autonomy'; and 'the right to their traditional medicines and to maintain their health practices' [10]. Articles also state that Indigenous Peoples have 'the right to access, without any discrimination, to all social and health services'; 'an equal right to the enjoyment of the highest attainable standard of physical and mental health'; and the right to free, prior, and informed consent [10].

In providing current narrative review on co-design, we do not regurgitate victim-blaming statistics that support deficit discourse and the misrepresentations that First Nations Peoples are in some way inferior to a 'non-Indigenous normal' [11]. 'The statistical story of Indigenous health and death, despite how stark, fails to do justice to the violence of racialised health inequities that Aboriginal and Torres Strait Islander peoples continue to experience' [12]. As authors of this narrative review we recognise the root cause of inequalities in health outcomes, ongoing colonisation and systemic racism [13–19], and do not perpetuate systemic racism by reporting or ascribing First Nations Peoples as an inherently vulnerable population [13]. Our ways of working recognise and centre around the fundamental role and power of culture in health and well-being and the need for this to be foremost in co-design. First Nations Peoples bring collective responses to experiences of intergenerational trauma which are supportive and shared, and bring transformative resources maintained through cultural practices [20]. First Nations Peoples are strong, and colonisation is bad for your health [21].

> *"If you have come to help me, you are wasting your time. But if you have come because your liberation is bound up with mine, then let us work together"*[1] *[22].*

What co-design is, what co-design is not, and what co-design needs to be

The term 'co-design' originated in co-produced services in economics, political science and business [23], and in participatory research in Scandinavia in the later twentieth century [8]. More recently however, co-design, co-production, experience-based co-design, co-creation, and other synonyms for methods describing professionals and end users co-creating solutions [8, 9, 24] to identified gaps in the evidence-to-practice cycle [25] have become catchphrases [26, 27]. After becoming a National Health Service Quality Improvement tool in the United Kingdom in the early twenty-first century, initiatives boasting synonyms of co-design method have proliferated [28]. In the land now known as Australia, increasingly popular use of co-design concepts and buzzwords [17] create real risk of generating rapidly 'co-design branded' healthcare research and healthcare system design involving insincere, contrived, coercive engagement with First Nations Peoples. This raises concerns firstly in relation to co-design without First Nations leadership failing to deliver self-determined, empowered design that will result in benefits for the people seeking change to systems that discriminate against them [29]. Secondly, there are concerns that inauthenticity in co-design will actually further perpetuate and ingrain harms, discrimination, and disadvantage inbuilt to colonial systems [8, 30]. This sees colonial systems manifest a social control, by covert systemic means rather than overt coercion, negatively stereotyping First Nations Peoples as responsible for their poorer health outcomes which can only be seen to be fixed by a non-Indigenous discoverer [31], non-Indigenous saviour, or non-Indigenous expert [32].

Authentic co-design within healthcare has a developing evidence base in Aotearoa New Zealand and Australia for reducing health inequities and improving health outcomes in communities marginalised by ongoing colonial racial violence and oppression [24, 27, 33–38]. There is emerging, but lagging, literature on the topic of the great need for tailored, authentic co-design with populations who have been pervasively disempowered [28]. Ongoing work seeks to address continual issues in co-design centred on power sharing, equitable participation, decision making, and sustaining improvements and benefits [28, 39]. This is more progressive in Aotearoa than in the land now known as Australia as the Treaty of Waitangi [40] protects the right of Māori self-determination (Tino rangatiratanga) [41]. Lessons learned from Aotearoa include research highlighting such Māori philosophy as a key measure against which co-design is assessed [41]. Within healthcare systems, Western biomedical research perpetuates ongoing colonisation, often reinforcing power differentials [32]. It is therefore critical that self-determination be centred in work with and for First Nations Peoples, and this needs to be surrounded by healing and psychological, social, and political decolonisation [5, 9]. When engaging in co-design in healthcare and research across the First Nations of the land now known as Australia, we need to consider the situated character of the work, research, and design processes themselves [9, 42]. Many considerations need to be addressed in foregrounding work intending equitable outcomes. A non-exhaustive list of pre-emptive questions to ask of co-design

[1] Authorship recognises Aunty Lilla Watson, visual artist, activist, and academic is credited with this quote, most likely from the 1985 United Nations Decade for Women Conference in Nairobi. Authorship considers that Aunty Lilla is reported as not being comfortable with being credited for something which emerged from a collective process; preferring it be attributed to Aboriginal Activists Group, Queensland, 1970s.

should include: On whose terms is co-design? Who holds the power in design and the control of systems in which work is absorbed? Who holds the funding for process? Whose cultures are centred? Whose methods are used? Who's being remunerated for input? Whose knowledges and ways of doing are privileged? For whose benefit is it? Who loses out if the work is unfinished or unsuccessful? Who judges and evaluates outcome success? When engaging in co-design with and for Aboriginal and Torres Strait Islander Peoples, mere good intentions do not translate into positive outcomes. Co-design is not just about saying sorry for inequity in health research and healthcare delivery, or being sorry for inequality in healthcare outcomes, it is about 'doing' sorry. Co-design is about action, beginning with actions of learning, relearning, and indeed unlearning. It is about listening and about using a developing and actively learned skillset to support and facilitate authentic approaches and processes. These have evidence of effectiveness in addressing health inequities for Indigenous Communities [24].

Health service outcomes are always co-produced; between the deliverer (health systems/health services/health practitioners) and recipient of healthcare (service user) [23]. It seems obvious then, that for authentic, beneficial health service outcomes, both parties involved in production must be involved in design – a process of co-design. The Lowitja Institute, Australia's only Aboriginal and Torres Strait Islander Community controlled health research institute, is forthright in advocacy when calling for more transparent detail of co-design method and process to clearly differentiate it from less inclusive disempowering methods of consultation informing system design, re-design, and policy [27, 43].

Tools guiding co-design capability exist in healthcare locally [44, 45]. These toolkits, which are easily accessible and are designed as guides for those inexperienced and seeking education in the co-design space, describe co-design as a collaborative change process bringing stakeholders together, creating equal relationships between stakeholders, with equal partnerships, equal voice, shared ownership, and shared control, with a core capability for co-design described as balancing power [44, 45]. On paper these principles infer good things, however exclusion of First Nations' perspectives and without contextualising historical and ongoing inequities [44, 45], such guides and toolkits do not move beyond 'equality' and 'sameness' rhetoric. They do not progress to descriptions of meaningful actions and method to bring benefits to Communities. Co-design with First Nations Peoples is not about morphing terminology to branded catchphrases, ignoring history, espousing equality within method, and balanced power. Co-design in healthcare with and for First Nations Peoples of the land now known as Australia is a tool for social justice [25, 46]. It is a tool for decolonisation [8, 38]. It is a tool for equity, making it a tool for dismantling oppressive sameness. Co-design is a tool for rebutting systemic racism and discrimination that is ongoing [12, 17]. Co-design is a tool that can hand leadership and power to First Nations Peoples to make changes to healthcare systems designed by non-Indigenous people, for non-Indigenous people, that favour non-Indigenous people.

> *"The system ain't broken, it's the way that it works"*[2] *[47].*

> *"... in contemporary Australia, Aboriginal Community members experience acts of racism and discrimination as health professionals and as consumers of health and support services" [37].*

Co-design done proppa [48] ways

Co-design is a tool that inherently must truly reposition power to First Nations Peoples [8, 17], engendering both respect and ownership [9, 34]. First Nations Peoples have been designing, establishing, and operating successful health paradigms across more than 260 First Nations language groups [36, 49] since time immemorial. Yet First Nations Peoples have been, and still are, treated as less than, 'othered' [38, 50], and negatively stereotyped within health systems. First Nations Peoples have been conducting science and research to improve the health and wellbeing of their Communities for thousands of years [37]. Despite this, First Nations Peoples are excluded from design of healthcare, were historically barred from accessing healthcare, and are still subjected to institutional racism through such systems as healthcare [21, 38]. Healthcare exemplifies systems used as mechanisms of oppression which still actively sustain ongoing colonisation [21, 38]. Co-design of healthcare systems with inherent and true power repositioning sees black lives as deserving of care, not in need of saving [12], increases access to healthcare for First Nations Peoples, dismantles barriers to service, and delivers equity in healthcare service, without perpetuating inequality in healthcare outcomes. Co-design is a tool for facilitating cultural responsiveness [51], and therefore a tool for creating healthcare systems that Aboriginal and Torres Strait Islander people may judge as safe to approach and use [51]. It is a tool for bringing sustained benefits of skill development geared at sustaining change, improved

[2] This phrase is quoted from song, demonstrating its ongoing widespread relatable use by First Nations Peoples. Authorship intends to attribute the quote in this manner, rather than by unknown original source.

Aboriginal Community Controlled Health Organisation capabilities within co-design (as identified by Community), and increased leadership capacities of empowered First Nations individuals, families, and Communities [8, 17, 36]. It is a tool that enables First Nations Peoples to set agendas for solving issues that are important to them [17]. Co-design is throughout, not just upfront [9].

Calls for research efforts to highlight the potential of co-design to reconfigure power relations exist [46]. Co-design without inclusive First Nations governance is not co-design [38], and without true repositioning of power it changes little, if anything at all. Non-Indigenous health researchers, health professionals, people working in health governance, people involved in health system design, and non-Indigenous people given responsibility and power to make decisions on health policy all need to categorically understand this. With co-design literature largely failing to critically engage with issues of historical and ongoing power relations [46, 52] this requires learning and unlearning to challenge what is considered 'the norm'. In-depth understanding of power distribution in co-design processes is urgently needed to reset entrenched system provider and health service recipient roles that obscure equity and mutual respect required in co-design, and to avoid simplistic deployment of empowerment which may actually maintain oppression and exclusion [46]. An Australian Commonwealth, State, and Territory government agreement, more recently including First Nations peak organisation partnering in 2019, is the Indigenous health policy 'Closing the Gap' [53]. If any sustained, meaningful, and beneficial change is to be made to the ongoing cycle of failure of 'Closing the Gap' [12, 18, 54] and to the ongoing 'racial violence within the Australian health system' [12], co-design must be led by First Nations Peoples supported by 'the genuine allies of Indigenous peoples, the change-makers' [31].

The year 2020 saw the instatement of The National Scheme's Aboriginal and Torres Strait Islander Health and Cultural Safety Strategy 2020–2025 [55]. Published in The Medical Journal of Australia of the same year, Bond and colleagues called for a health justice framework that included 'foregrounding of Indigenous sovereignty rendering visible the strength, capability, and humanity of Aboriginal and Torres Strait Islander Peoples, services and communities in all processes of health policy formation and implementation, not as partners but as architects' [12]. Since 2020, Butler et al. conducted systematic review of optimal approaches to co-design in health with First Nations Peoples [8], which supported Bond et al., concluding that in order to be safe and effective, any application of co-design in health with First Nations Peoples must be led by First Nations individuals, families and Communities, and must demonstrate true power redistribution [8]. In Australia, the Productivity Commission provides 'independent research and advice to Government on economic, social and environmental issues affecting the welfare of Australians' [53]. Moving forward to July 2023, the key findings from the Productivity Commission's Closing the Gap report were: 'There is some evidence that governments demonstrate ability and willingness to partner in shared decision-making but change is not occurring; Accountability is limited; Progress is falling short of envisaged expectations' [56]. Memo; 'You cannot apologise for treating someone badly, without then changing your behaviour towards them in the future' [57, 58].

> *"...the failure to respect the right to self-determination and the right to full and effective participation... is alarming. [The compounded effect of these policies has contributed to the] failure to deliver on the targets in the areas of health... in the Closing the Gap strategy... I urge the Government to use this momentum to reset the relationship with the First Nations of Australia and in a collaborative manner construct a new joint pathway to the future." [18, 59]*

The recent co-design work reported by Milroy et al. 2022 adds to a growing body of literature focusing on how decolonising work is undertaken with and for First Nations Peoples is as important as the outcomes [36]. Privileging Indigenous research methods, the 2022 Butler et al. systematic review analysis distinguished a set of six overarching themes that highlight a range of factors considered important in conducting co-design with First Nations Peoples in health in the land know known as Australia: First Nations leadership; Culturally grounded approach; Respect; Benefit to First Nations Communities; Inclusive partnerships; and Evidence-based decision making [8]. The authors describe First Nations leadership as the 'central theme' to co-design [8] for all levels of process to truly support First Nations empowered self-determination, to effect real change, and to bring benefits to Aboriginal and Torres Strait Islander Peoples. First Nations Peoples must be 'leading, controlling and owning all aspects of the co-design process' [8] through a 'bottom-up approach' [8, 9] for co-design to achieve results judged as successful by Aboriginal and Torres Strait Islander Peoples themselves [17]. Importantly this may not be outcomes associated with equality to a non-Indigenous standard, but outcomes that are self-determined, achieved, and sustained, and that are different to and are improvements upon, non-Indigenous standards, measures, and concepts.

When considering co-design in First Nations contexts it is critically important to recognise the historical and ongoing relationship between research and Aboriginal and Torres Strait Islander Communities; a one-way relationship favouring the colonist and colonial control resulting in fear, negative impacts, scepticism, mistrust, and reluctance of First Nations Peoples to participate in work privileging positivist methodologies [5, 9, 36, 37, 60]. Such relation sees continuous silencing in and exclusion from health service planning and reform [37, 61]. In future, leadership of co-design in healthcare with and for First Nations Peoples of the land now known as Australia must privilege First Nations worldviews, knowledges, voices, and ways of being and doing, and synchronously rebut impacts of ongoing colonisation [8]. Leadership must also be relational, consensus driven, and culturally bound in privileging First Nations ways [17, 35]. True co-design centres First Nations cultures, perspectives of health, and lived experiences, and uses decolonising methodologies [5, 8] in addressing health determinants of dispossession, assimilation, intergenerational trauma, racism, and genocide [8, 21, 36, 62].

Cultural determinants of health are imperative to First Nations wellbeing [43, 63]. Culturally centred approaches to health and wellbeing are advocated for by First Nations Peoples and need implementation in current and future health policy and systems [43, 63]. In 2022, Urquhart et al. published a co-design practice model in the context of First Nations wellbeing citing power sharing, equitable partnerships, and collaborative knowledges as leading real change in healthcare. Results from collaborative yarning described culturally safe, relational, shared, respectful, communicative, flexible, and strengths-based ways of being as required in authentic co-design work [27]. High level policy frameworks, such as the National Aboriginal and Torres Strait Islander Health Plan 2013–2023 (NATSIHP) and The National Scheme's Aboriginal and Torres Strait Islander Health and Cultural Safety Strategy 2020–2025 exemplify the privileging of First Nations voices required to re-shape the culture of historical and ongoing overwhelming non-Indigenous led policy making [43, 63]. To implement the key cultural health determinants of connection to Country; family, kinship and Community; Indigenous beliefs and knowledge; cultural expression and continuity; Indigenous language, and self-determination and leadership [43, 63–65], co-design leadership strategies must strengthen cultural authority, implement strength-based approaches to First Nations health, empower Community driven policy and decision making, envisage a health system free of racism, commit to historical truth-telling, invest in cultural capability, and develop evidence-based co-design standards [43, 63]. Leadership must see co-design recognise difference and not homogenise approaches, developing discrete nuanced instances of co-design specific to diverse populations [49], cultures, and places [3, 9, 17]. Co-design leadership needs to promote two-way learning, build trust, alleviate the traumas inflicted by scientific racism and its dehumanising and oppressive ongoing impacts [36], and fight the pandemic of ongoing racism across all First Nations since 1788 [1, 8, 12, 66]. Authentic co-design of health services can reduce racism and improve access through its decolonising methods and approaches which are strategically anti-racist [5, 18]. Non-Indigenous people involved in co-design need to be committed to continuously developing cultural responsiveness [9, 51], self-reflexivity, and cultural humility [67] to oppose the power inherent in Western design favouring 'top-down' [8, 9, 38] research and governance approaches that have actively excluded, and continue to exclude, Aboriginal and Torres Strait Islander Peoples [8]. Non-Indigenous peoples' continual development of cultural responsiveness at all levels of First Nations self-determined led co-design can change behaviours, programs, and systems [51]. Non-Indigenous individuals require education and critical reflection on power and privilege [38] influencing historical and ongoing inequities, and organisations require education and reflection on 'non-Indigenous institutional control over Aboriginal and Torres Strait Islander peoples' lives and contemporary consequences' [51]. Education and reflection must then lead to actions [51], developing skillsets and challenging 'norms' of systemic inequity.

To be effective and to generate culturally valid outcomes, co-design governance needs to include both broad participation and broad stakeholder engagement in place of dominant individualised Western leadership models [17] to hear from the most marginalised groups and silenced voices [8, 9]. This can be achieved through a framework such as Indigenous Allied Health Australia's Cultural Responsiveness Framework inclusive of respect for centrality of culture, inclusive engagement, self-awareness, leadership, proactivity and responsibility, and accountability [51]. Engaging First Nations Peoples in meaningful and longstanding trusted dialogue to lead co-design is a major requirement identified for systems to action renewal of First Nations health and wellbeing [51]. Co-design governance must rebut politically defined visions of the future [52] born from a government that excluded First Nations Peoples from full federal voting rights in democratic political process up until 1984 [68]. Such exclusion disempowered First Nations Peoples from influencing historical, cultural, and social determinants of health, as well as policy decisions impacting their health, compounding inequities [18]. First Nations leadership also allows for design to be both place- and

strengths-based [9, 69, 70], and to recognise the connection to Country and cultural protocols of Aboriginal and Torres Strait Islander Peoples across all First Nations which are fundamental to co-design [8, 38]. In short, co-design leadership must be in the hands of First Nations Peoples and allow self-determination through genuine power redistribution.

Embedding cultural safety in co-design

Beyond 2024, respectful co-design in healthcare must include provision of a culturally safe space for First Nations Peoples to approach and work in, as judged by Aboriginal and Torres Strait Islander Peoples themselves. Non-Indigenous people working in co-design must understand that lack of cultural safety in mainstream healthcare is a significant barrier to access [36], perpetuating ongoing harms to individuals' cultural identities, health, and wellbeing [36]. The National Scheme's Aboriginal and Torres Strait Islander Health and Cultural Safety Strategy 2020–2025 released under The Australian Health Practitioner Regulation Agency (Ahpra) describes four key elements to ensure culturally safe and respectful healthcare. These elements need to be actively embedded, demonstrated, and practised in the co-design of healthcare systems foregrounding their development:

1. Acknowledge colonisation, systemic racism, and social, cultural, behavioural, and economic factors which impact individual and Community health;
2. Acknowledge and address individual racism, our own biases, assumptions, stereotypes and prejudices, and provide care that is holistic, free of bias and racism;
3. Recognise the importance of self-determined decision-making, partnership, and collaboration in healthcare which is driven by the individual, family and Community;
4. Foster a safe working environment through leadership to support the rights and dignity of Aboriginal and Torres Strait Islander Peoples and colleagues [55].

The strategy clearly demands health reform from individuals, institutions, and their regulatory systems [12, 55], to whom all, co-design is a mechanism for action and change. Co-design work needs to apply these principles of cultural safety with non-Indigenous team members learning ongoing cultural capabilities to be able to work safely with First Nations Peoples [36]. This takes the use of an ever-developing skillset and the requirement for non-Indigenous people supporting work in the space to position themselves as learners (and to undertake unlearning). In doing so, non-Indigenous people working and supporting within co-design need to acknowledge their white or non-Indigenous privileges, need ongoing cultural self-awareness and self-reflection, need to minimise implicit bias and stereotypes, and need to know Australian history and recognise the ongoing impacts thereof [3, 17, 71]. A culturally safe co-design space is one which truly understands racism and its impact upon the health and well-being of First Nations Peoples [72], changes conversations away from deficit discourse, truly and deeply listens to Aboriginal and Torres Strait Islander voices, and abides by the United Nations Declaration on the Rights of Indigenous Peoples [3, 17, 71]. Now and into the future, safe and respectful co-design must be flexible, adaptable to cultural protocols of diverse First Nations populations and places [3, 49], and must privilege Indigenous knowledges. An example of leadership in this space is the Aremella Arratyenye-ileme: Doing It Right work guided by The National Health and Medical Research Council's (NHMRC) Keeping Research on Track which contextualises First Nations priorities to the places and peoples of Mparntwe (Alice Springs) and the surrounding Communities. First Nations determined core values to working with individuals, families, and Communities in this area are Justice and Fairness, Commitment, Responsibility, Upholding culture, Respect and relationships, and Sharing [73].

Embedding participatory action research principles in co-design

To change systemic injustices producing healthcare inequity, research underpinning co-design must meet high thresholds as measured against the Aboriginal and Torres Strait Islander Quality Appraisal Tool [74] and use Indigenous decolonising methodologies to create new knowledges at cultural interfaces as well as in third spaces combining with mainstream worldviews [32]. 'De-centring Western epistemologies' and emphasising 'the productive potential of difference' sees true collaboration [32]. Participatory Action Research is a method used to deliver safer spaces for co-design partnerships and work. In culturally safe spaces First Nations Peoples are welcomed, believed, supported, and do not experience racism in any form [3, 43, 63]. Participatory design brings humans' rights and lived experiences to shaping the world in which they live and is implicit in changing power relations and centring culture [32, 34, 46, 75]. This is both 'critical and urgent in order to interrogate and reveal associations between colonisation, racism, poverty, and poor health' [32]. Emulating Māori, Kaupapa Māori methodology challenges the dominance of Western worldview by centring matauranga Māori (Māori knowledge) and tikanga (cultural protocols) in research process. This emphasises action that provides self-determined beneficial outcomes to Community [5, 24], facilitating Participatory Action

Research method engaging First Nations Peoples in all levels of work and processes [9, 18, 35, 76] and 'culturally valid and meaningful knowledge development' [76]. Such method seeks to give First Nations Peoples control of forces that adversely impact their lives [9, 18, 35, 76]. In an Aboriginal and Torres Strait Islander context, participatory action in co-design opposes the colonial approach to research [34]. The researched become the researchers [9]. Such methods are planned to inevitably translate findings into sustainable changes in policy and practice [34, 74] and ensure that they are meaningful and align with First Nations priorities [33]. Dreise and Mazurski, (2018) discuss ideal co-design and participatory research in Aboriginal contexts weaving a convergence of both lived and studied experiences. Work should be carried out *with*, not *on* First Nations Peoples, things should be done *with* not be done *to* First Nations Communities [9, 34, 36]. Kendall et al., in 2011 advocated for Aboriginal research moving beyond Western premised knowledge and epistemology, and more recent work continues to do so [9, 77]. Increasing self-determined empowerment, Aboriginal Participatory Action Research integrates Indigenous epistemology, ontology, axiology (the equivalent language for Indigenous ways of knowing, being and doing) in Western knowledge systems and the dominant culture in Australia [3, 36, 78]. This is complimented by Indigenous research methodology [60, 78, 79] 'designed to centre and increase Indigenous voice and 'epistemic self-determination" [79, 80] or a dominance of First Nations families' and Communities' worldviews [33]. Indigenous methods may include yarning (talking together) in consultation, 'Dadirri' (Ngangikurungkurr language word for deep listening) in establishing trust, and 'Ganma' (Yolgnu language word for two-way knowledge sharing) in cross-cultural interactions [37]; many First Nations share these concepts which are but a few examples of Indigenous ways of working. Aboriginal Participatory Action Research is led and governed by First Nations self-determination and Aboriginal Advisory Groups, is flexible and iterative, facilitates power shift from dominant Western style [36], and recognises the sovereignty of Aboriginal and Torres Strait Islander knowledges [18].

Colonial load

Cultural load burdens First Nations peoples, positioning them as responsible for explaining, authenticating, and justifying First Nations ways in colonised processes. Load is compounded with expectations to be accepting of the damaging aspects of ignorance. First Nations-led Weenthunga[3] Health Network 'advances wellbeing, healing and health justice for First Nations people' [81] and leads 'transformational change in health and health education systems by advocating for First Nations-led spaces, anti-racism work, and embedding and valuing First Nations' knowledge and practice' [81]. Weenthunga Health Network works to position culture with responsibility and the resultant load where it belongs – exemplifying how colonial load is reduced when it is carried by non-Indigenous people [82]. Non-Indigenous people need to identify harmful behaviours and inequities adding to 'colonial load' of First Nations colleagues and demonstrate action to take responsibility for colonial load [82]. This should include for example, planning more time for work. Culturally safe and respectful co-design process must not burden First Nations People with excessive workloads but must be respectful of First Nations Peoples' time and competing priorities [8, 17]. With First Nations leadership and direction, process can be better designed to fit within peoples' lives rather than become burdensome [33]. Respectful co-design process must also understand the positioning of First Nations Peoples regarding not automatically being able to provide comment, lens, or cultural authority to all First Nations matters [17]. Safe and respectful co-design must meet the pace of Community working, whilst providing adequate staffing positions and remuneration, critically demonstrating the true positioning and value of expertise [8, 17]. The experts in First Nations health are First Nations Peoples themselves [83]. Importantly, the future of co-design in healthcare requires underpinning by investment of significant time building mutually beneficial relationships based on trust and respect for First Nations Peoples [38]. Process should never be rushed, irrespective of familiarity with the Communities and organisations involved [3]. Truly responsive projects evolve over time [33]. All non-Indigenous co-design support needs to recognise this requirement in this way of working and to understand the need to consult and respect timelines of Communities involved in process [17]. Before co-design process actually 'starts' by Western linear timeline definition, lengthy periods of dedicated time demonstrating such trust and respect must precede supportively working in co-design spaces [38]. This includes non-Indigenous stakeholders being transparent in divulging what financial, reputational, academic, career, and/or political gains they obtain from co-design process work [17]. Cultural expectations will be that trusting relationships are developed well before 'co-design business' commences [17, 38]. Non-Indigenous support is not to provide watered down consultation, often one-way, [27] that re-colonises Communities, and co-design needs to be adequately funded. 'There's a difference between 'we have no budget for this' and 'we didn't allocate any budget for this'…' [84] and that difference is a feature of systemic racism [84].

[3] 'Weenthunga [ween-tunga] means 'hear / understand' in Woiwurrung, language of the Wurundjeri People of the Kulin Nation' [78].

Informed consent

Respect in co-design extends to First Nations Peoples having the sovereign rights to make informed decisions to approve or reject any proposed co-design project [8, 43, 63]. Co-design governance must also respect all First Nations Community and ethical protocols and approvals [8]. Respectful co-design follows Community consent [9]. The United Nations Declaration on the Rights of Indigenous Peoples Articles 10, 11, 19, 28, 29 and 32 explicitly describe First Nations Peoples' free, prior, and informed consent centred in their human rights [10].

Language and knowledge sharing

Article 13 of The United Nations Declaration on the Rights of Indigenous Peoples states 'Indigenous peoples have the right to revitalize, use, develop and transmit to future generations their histories, languages, oral traditions, philosophies, writing systems, and literatures, and to designate and retain their own names for Communities, places and persons' [10]. Having input to process in First Languages is strength-based, demonstrates respect, and fosters engagement in co-design but is under emphasised in the literature [33]. Language used in co-design needs to be seen for what it is; colonising language as a negative, a tool of oppression, and First Nations languages as a positive, a protective factor for health and social and emotional wellbeing. Communication of all kinds must be culturally safe within co-designing healthcare led by First Nations Peoples. Communication must respect data sovereignty [27, 60] and true knowledge holders [85], and dissemination of information, policy, and/or product must be meaningful and accessible for Aboriginal and Torres Strait Islander Peoples. First Nations Communities own data in culturally safe evaluation process and it must be communicated that there is no assumption that non-Indigenous individuals and organisations supporting co-design work claim ownership [3]. Communication with Communities involved needs to be safe and clear to convey messages of what the principle and involvement of co-design work is, in order to avoid reluctance to participate for fear of shame of being seen as not understanding [9]. Such communication may include use of First languages and concepts such as Pitjantjatjara terms Malparara (friendships producing strong outcomes working together) and Ngapartji Ngapartji (reciprocity for those engaging in a shared work) [38, 86], and Gumbaynggirr terms Duguula Gayirray (yarning together to make power dynamics transparent), Yandaarray (walking together to navigate complexity), and Duguula Nguraljili (sharing together to employ diverse knowledges) [27]. Communication may also include pictures, art, illustrations, and examples [9]. This would do well if aligned to the NHMRC Indigenous Research Excellence Criteria best-practice research principles including engagement, benefit, sustainability, transferability, and capacity-building [87]. An essential sign of meaning and respect is First Nations branding of co-design that signifies it is grounded in First Nations leadership, empowerment, and self-determination [8]. This may include for example, painting, First Languages, songs, stories, truths, dance, artefacts, poetry, and use of metaphors [27, 32], and signifies strength-based discourse and power redistribution in co-design establishment and processes. It may additionally increase broader, more far-reaching awareness of work [8], and signify a safer space for approach.

Partnering in co-design

Partnering within co-design needs to be multiple, collaborative, inclusive, and supportive of self-determined First Nations leadership [8]. Partnering requires embracing differences in culture rather than resisting them, which facilitates sharing knowledges of transforming systems [32]. Co-design relationships require trust, privileging of First Nations voices, and must pursue equity for Communities. When they do, the expertise of lived experiences and local knowledges improves efficiencies of resources including costs and time [17]. Pre-arranged meetings are more likely at times suiting First Nations availability, considering seasonal and cultural periods, and spontaneous meetings arise from social and cultural activities like fishing, or from incidental daily conversations [33]. Partnerships within co-design must be real, developed over sustained periods, and be 'working together' [8] spaces for two-way learning and for deep listening to Aboriginal and Torres Strait Islander Peoples' lived experiences. Meaningful co-design partnerships occur when health professionals place equal or greater value on First Nations' ways of working [38]. 'Indigenous clients and clinicians have stories to tell of the violence of racism in the health system, of being cast in the category of less capable, less compliant, less deserving of care, and less worthy of the category of human' [12]. Listening to truths needs to be followed with periods of self-reflexivity for non-Indigenous stakeholders [8, 35, 36]. Co-design partnerships involving trust-based invitations from Communities for travelling to Country, sharing food, talking, and listening [36] are a gift and should be treated as such. Stakeholders must be open and transparent for partnering and processes to be sustained and must demonstrate reciprocity for relationships to last well after Western conceptualised linear timelines fade [8]. Evidence-based decisions in co-design need to be made with participants and end-users, and with benefits to Community heavily weighted in considerations [3, 8, 9].

Monitoring and evaluation in co-design

Co-design monitoring and evaluation needs a decolonising approach that is inclusive of First Nations methods, responsive to First Nations voices, consultation, and judgement, and needs to allow for feedback and direction from Community in a manner that is preferred by Community [8, 9]. Culturally responsive funding stipulations narrow gaps between ways of working and eliminate non-Indigenous short cuts which erode authentic co-design. Process must also include culturally safe evaluators, and evaluation practices and roles [3]. First Nations led and empowered, and non-Indigenous supported, culturally safe evaluations within true co-design reset the benchmark evaluation process defined by the dominant culture which 'overshadows, invisibilises, and dictates to any cultural values that fall outside of its own' [3]. Goal and desired outcome identification with involvement of Community leaders from the outset should inform evaluation and measurement approaches [9] to ensure 'the accountability of the project on delivering culturally grounded and meaningful outcomes' [8] and not impose outcomes often lacking cultural context [9]. Co-designed health care and health system evaluations empower Communities [9] against the imposition of dominant culture through systemic racism and accumulative intergenerational trauma resulting from historical and ongoing colonisation [3].

> *"If we don't get Indigenous evaluation right, we contribute to the inappropriate funding of projects and programs that don't work at the expense of those that do. We fuel racism and at worst, retrigger families and Communities…" [3]*

Co-design with and for First Nations Peoples in Australia should consult works such as the Australian Evaluation Society First Nations Cultural Safety Framework [3] and the Evaluation Framework to Improve Aboriginal and Torres Strait Islander Health [88] in aiming to bring systemic change required to bring benefit, and strengthen existing benefits, for First Nations Peoples in evaluation processes [88]. In this pursuit, the evaluation framework describes both what to evaluate and how to evaluate, promoting accountability to First Nations principles and ethical capabilities in work with Communities [88]. The Evaluation Framework to Improve Aboriginal and Torres Strait Islander Health recommends improved transparency in reporting and documenting evaluations that include principles of working with First Nations Peoples be reflected in evaluations [88]. First Nations leadership should be throughout planning and evaluation and roles within evaluation should be ethically allocated to maximise health outcomes [88]. Supporting these evaluation framework recommendations are the directives that training opportunities and long-term partnerships be provided to support First Nations leadership in evaluation and active engagement in co-design [88].

Conclusion

Justification of co-design work or method is not met by bolting First Nations knowledge practices onto mainstream approaches [32], nor by disempowering extractive colonisation [89] of First Nations knowledges by mainstream healthcare systems and researchers. 'Co-design is a process, not just a workshop' [9] to which '*long time*' (sustained engagement over years) is central [9]. Co-design with Aboriginal and Torres Strait Islander Peoples cannot be rushed [36]. While the understanding of co-design principles and process is imperative, authentic First Nations led, equitably empowered co-design is not possible without the demonstrated commitment of non-Indigenous support engaging in two-way learning and ongoing skillset development to work in the space. To impact the narrative of failure that is a mark of the Australian health system [12] co-design must repeatedly deliver more than just mere recommendations or words on a page as if they are some sort of outcomes in themselves.

'First Nations people never ceded sovereignty over their lands and now live in two worlds' [3]. If the process of co-design in healthcare across the First Nations of the land now known as Australia is to meaningfully contribute to change from decades of historical and ongoing systemic racism perpetuating power imbalance and resultant health inequities and inequality, co-designed outcomes cannot be a pre-determined result of tokenistic, managed, or coercive consultation. Outcomes must be a true, correct, and beneficial result of a participatory process of First Nations empowered and led co-design and must be judged as such by First Nations Peoples.

Abbreviations

Ahpra	Australian Health Practitioner Regulation Agency
NATSIHP	National Aboriginal and Torres Strait Islander Health Plan (2013–2023)
NHMRC	National Health and Medical Research Council
UNDRIP	United Nations Declaration on the Rights of Indigenous Peoples

Acknowledgements

Following cultural protocols of the lands now known as Australia, paying respect to Country and First Nations Elders needs to precede content.

Authors' contributions

All listed authors made substantial contributions to this work. Authors JG, SG, and VC contributed to conceptualisation, methodology, and writing—original draft of the study and the search and retrieval of resources. Authors JC, SS, and KW contributed to writing—review and editing, revising work critically for important intellectual content. As First Nations people, SG, JC, and KW contributed to methodology, supervision, and project administration delivering Aboriginal Participatory Action Research ways of working. All authors gave final approval of the version to be submitted. This is a true statement that all authors meet the criteria for authorship and that all people entitled to authorship are listed as authors.

Data availability
No datasets were generated or analysed during the current study.

Declarations

Ethics approval and consent to participate
Not applicable.

Consent for publication
Not applicable.

Competing interests
The authors declare no competing interests.

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Received: 21 August 2024 Accepted: 9 December 2024
Published online: 06 January 2025

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Publisher's Note

James Gerrard (*he/him*) is non-Indigenous with over 45 years of accumulated privilege drawn from a lifetime of social, economic, and political systems which benefit him. He lives on Wadawurrung Country, works on Arrernte Country, and studies on Wiradjuri Country. James has an 18-year history of working and studying in a Western tertiary academic and research space but has learned (and un-learned) more working with and for the original human healers, scientists, and researchers of the land now known as Australia. James is learning to centre culture in health and healing, that racism makes you sick, and that colonisation is bad for your health.

Shirley Godwin (Badimaya Yamatji) is a Badimaya Yamatji woman and Senior Lecturer at La Trobe University Rural Health School. Shirley's early career was spent in health research, firstly in a biomedical laboratory and then in Community-based Aboriginal health research. Since completing a MBBS in 2010, Shirley has been working in First Nations health and Cultural Safety education across health disciplines. Embedded in Shirley's work are First Nations ways of working that listen to, learn from and privilege Community voices, and a focus on decolonising health curriculum development and delivery to create culturally safer spaces in higher education.

Kim Whiteley (Wiradjuri) a distinguished Indigenous healthcare leader and educator, is a proud descendant of the Warramunga clan from the Bogan River in Central West NSW, Wiradjuri nation. With over 35 years of experience in corporate First Nations policy, strategy, and leadership in Aboriginal and Torres Strait Islander program delivery, she specializes in rural, remote, and regional health. As the leader of the former Remote Area Health Corps, Kim champions Community-centred solutions to enhance health workforce outcomes. Her commitment to aligning workforce needs with Community and health service requirements, and her focus on strengthening clinic support and Community impact and Aboriginal and Torres Strait Islander self-determination principles, reflect her deep dedication to enhancing Aboriginal Community control and empowering others.

James Charles (Kaurna) is a proud Kaurna man from Adelaide Plains, South Australia, currently serving as Director of the First Peoples Health Unit at Griffith University. He is one of the first Aboriginal podiatrists in Australia, and first to achieve a Master of Podiatry and a PhD in Aboriginal foot health. Professor Charles has contributed extensively to Aboriginal health, delivering clinical podiatry services across urban, rural, and remote communities nationwide alongside numerous peer-reviewed publications and book chapters. He chaired Indigenous Allied Health Australia (2009–2010) and represented on the national "Close the Gap" committee (2008–2009). He has received multiple national and international awards in recognition of his academic achievements and contributions to Aboriginal health and education.

Sean Sadler is a lecturer at Western Sydney University, Dharawal Country (Campbelltown). He is a non-Indigenous person of European ancestry. Sean continues to learn and work with and for Aboriginal and Torres Strait Islander Peoples in research and clinical areas related to foot health and wellbeing, co-design, Indigenous research methodologies, and culturally responsive and safe health care (as determined by Aboriginal and Torres Strait Islander Peoples).

Vivienne Chuter is of Māori and European ancestries. She respectfully acknowledges her Eurocentric-dominant lived experience and her position as a learner in this space. She is a clinician researcher working with and for First Nations Peoples to support development and delivery of Community-led co-designed health care services in regional and rural New South Wales and a Professor in the School of Health Sciences at Western Sydney University. Her research work supports Community driven research priorities for improving foot health outcomes and reducing impacts of diabetes related foot disease.