



Co-design for indigenous and other children and young people from priority social groups: A systematic review

Paula Toko King^{a,*}, Donna Cormack^{a,b}, Richard Edwards^c, Ricci Harris^a, Sarah-Jane Paine^b

^a Te Rōpū Rangahau Hauora a Eru Pōmare (Eru Pōmare Māori Health Research Unit), University of Otago, Wellington, New Zealand

^b Te Kupenga Hauora Māori (Department of Māori Health), The University of Auckland, Auckland, New Zealand

^c Department of Public Health, University of Otago, Wellington, New Zealand

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ABSTRACT

Background: Co-design has increasingly been posited as a useful approach for Indigenous peoples and other social groups that experience inequities. However, the relatively rapid rise in co-design rhetoric has not necessarily been accompanied by increased understanding of whether co-design works for these social groups, and how equity is addressed.

Methods: We conducted a systematic review to identify the current state of co-design as theory and praxis within the context of health and/or disability related interventions or services, with a specific focus on equity considerations for Indigenous and other children and young people from priority social groups. Six electronic databases were searched systematically to identify peer-reviewed papers and grey literature (dissertation and theses) published between January 1, 2000 to December 31, 2020, and a hand-search of reference lists for selected full texts was undertaken.

Results: Fifteen studies met the inclusion criteria. Although all studies used the term ‘co-design’, only three provided a definition of what they meant by use of the term. Nine studies described one or more theory-based frameworks and a total of 26 methods, techniques and tools were reported, with only one study describing a formal evaluation. The key mechanism by which equity was addressed appeared to be the inclusion of participants from a social group experiencing inequities within an area of interest.

Conclusion: A dearth of information limits the extent to which the literature can be definitive as to whether co-design works for Indigenous and other children and young people from priority social groups, or whether co-design reduces health inequities. It is critical for quality reporting to occur regarding co-design definitions, theory, and praxis. There is an urgent requirement for evaluation research that focuses on co-design impacts and assesses the contribution of co-design to achieving equity. We also recommend culturally safe ethical processes be implemented whenever undertaking co-design.

1. Introduction

The sustained inequities experienced by Indigenous and other children and young people from priority social groups (for instance, ‘racial’/ethnic, cultural, disability, LGBTQIA+, migrant, and religious groups) have been rigorously documented (Clark et al., 2020). Co-design has increasingly been posited as a way forward in the design of health and/or disability related interventions or services with Indigenous peoples and other social groups that experience significant inequities (Chamberlain et al., 2019; Chomat et al., 2019; Eyles et al., 2016; Fehring et al., 2019; Haynes et al., 2019; Mhurchu et al., 2019; Moll

et al., 2020; Te Morenga et al., 2018; Verbiest et al., 2019). For instance, some authors have claimed “[t]he fact that co-design principles align with frameworks for indigenous health suggests that co-designed interventions will be better used and accepted, and thus be more likely to reduce inequity” (Eyles et al., 2016, p. 166). However, the relatively rapid rise in co-design rhetoric within health and disability related settings (Palmer et al., 2018; Slattery et al., 2020) has not necessarily been accompanied by an increased understanding of what co-design is. For instance, there appears to be no one established definition of the word ‘co-design’. Rather, a multitude of varying (and somewhat circular) definitions are to be found within the literature (Akama & Prendiville,

* Corresponding author. Department of Public Health, University of Otago, 23A Mein Street, Newtown. Wellington, 6021, New Zealand.

E-mail address: paula.king@otago.ac.nz (P.T. King).

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2013; Blomkamp, 2018; Britton, 2017; Eyles et al., 2016; Kimbell, 2015; Mark & Hagen, 2020; Roper et al., 2018; Sanders & Stappers, 2008; Thabrew et al., 2018; Zamenopoulos & Alexiou, 2018).

Mark and Hagen (2020) define ‘co-design’ as “a philosophical approach and evolving set of methodologies for involving people in the design of the services, strategies, environments, policies, processes, – that impact them” (p.4). Zamenopoulos and Alexiou (2018) note the term ‘co-design’ encompasses “a wide range of different practices with different historical roots ... driven by different motivations and often also different ideological, epistemological and methodological standpoints” (p.14). Britton (2017) likewise observes the term as “widely (perhaps too widely) used to minimally indicate some form of engagement ... but whose use may conceal significant ideological and conceptual distinctions” (p.41). In alignment with Britton (2017), Sanders and Stappers (2008) assert the differential nature of co-design related discourses are often driven by the ideological standpoints of design practitioners themselves. For these reasons, Blomkamp (2018) highlights it can be challenging to identify what co-design actually is, pointing out that “[w]hen co-design is loosely defined and operationalised as any type of collaborative or participatory activity, almost everyone seems to be doing it” (p.3).

While there has been much support expressed for co-design, it has also not been without critique (Blomkamp, 2018; Mark & Hagen, 2020; Moll et al., 2020; Vink et al., 2016). It has been observed that little attention, if any, has been paid to how co-design processes and practices might impact on the wellbeing of people involved, or how this is considered or addressed in approaches to co-design (Blomkamp, 2018; Farr, 2018; Moll et al., 2020; Slattery et al., 2020; Vink et al., 2016). Blomkamp (2018), Mark and Hagen (2020) and Moll et al. (2020) emphasise the risks of co-optation of the term ‘co-design’, with Blomkamp (2018) also highlighting the potential risks of “deepening cynicism if participatory projects are poorly designed, inadequately facilitated, or outright manipulative” (p.10). Mark and Hagen (2020) state “many in the community already distrust the term co-design, are experiencing a form of ‘co-design fatigue’, and can consider the term to be devalued of meaning” (p.5).

Additionally, Vink et al. (2016) observe “while there are discussions about co-design’s transformational aims in the literature, research suggests that there is a need for a systematic evaluation of results related to this goal and the outcomes of the co-design process” (p. 395). Moll et al. (2020) emphasise the requirement for genuine critical reflection to ensure tokenism and perpetuation of inequities does not result. Consequently, when it comes to co-design with Indigenous peoples and other social groups that experience significant inequities, what may be missing is a critical overview of what co-design looks like in current practice, whether it results in better achievement of desired outcomes (and less non-desired outcomes), and the contribution of co-design to addressing issues of equity. The aim of this narrative systematic review was thus to identify the current state of co-design as theory and praxis within the context of health and/or disability related interventions or services, with a specific focus on equity considerations for Indigenous and other children and young people from priority social groups.

In relation to terms used within this systematic review, there are several age brackets used to define children or young people in the (predominantly Western) literature. Under the United Nations Convention on the Rights of the Child (UNCROC), a ‘child’ is defined as every human being below the age of 18 years (United Nations General Assembly, 1989). The United Nations defines ‘youth’, as those persons between 15 and 24 years of age (UNESCO, 2017). The World Health Organization (WHO) defines ‘adolescents’ to be young people aged between 10 and 19 years, and ‘youth’ to be young people aged between 10 and 24 years (World Health Organization, 2011). For the purpose of this systematic review, we use the phrase ‘children and young people’ to describe everyone up to and including 24 years of age. In the context of discussing rights, we still use ‘children and young people’ but acknowledge under the UNCROC definition this will only include

everyone up to 18 years. We use the phrase ‘priority social groups’ as means of avoiding deficit labels (such as “vulnerable” or “hard to reach” populations), whilst acknowledging that Indigenous and other social groups (for instance, ‘race’/ethnicity, culture, disability, LGBTQIA+, migrant, religion) are more likely to experience inequities due to colonisation, coloniality, racism and other societal systems of privilege, power and oppression (Collins & Bilge, 2020; Jones et al., 2021; Reid et al., 2019).

2. Methods

The systematic review methods were informed by the ‘PRISMA-Equity 2012 Extension: Reporting Guidelines for Systematic Reviews with a Focus on Health Equity’ (Welch et al., 2015). Our research questions were:

- (1) How is co-design of health and/or disability related interventions and/or services undertaken with Indigenous and other children and/or young people from priority social groups?
- (2) What are the co-design definitions, processes (theoretical frameworks), practices (methods, techniques and tools) and evaluation measures applied?
- (3) Does co-design contribute to equity for Indigenous and other children and/or young people from priority social groups?

We deliberately focused on studies that explicitly referred to the term ‘co-design’ as we wished to understand how co-design of health and/or disability related interventions and/or services is undertaken, based upon the study investigators’ use of the descriptor of ‘co-design’ (rather than our own). We thus chose to exclude related terms involving participatory approaches to research and/or design (for instance, ‘participatory action research’, ‘participatory design’, ‘user-centred design’, ‘human-centred design’ and so forth) in the search strategy. Our inclusion criteria comprised of:

- Publication timeframe: January 1, 2000 to December 31, 2020;
- Participants: children and/or young people up to and including 24 years of age; families (if children and/or young people involved); Indigenous and other priority social groups (for instance, ‘race’/ethnicity, culture, disability, LGBTQIA+, migrant, religion); and,
- Interventions and/or services: co-design with participants (see participant inclusion criteria) of health and/or disability related interventions and/or services (within the context of a broad holistic approach to health and wellbeing and based upon the study investigators’ use of the descriptor ‘co-design’).

Six electronic databases (CINAHL, Informit Health Collection, Ovid MEDLINE (1946 to present), Proquest, PsychInfo, and Te Puna) were searched systematically to identify peer-reviewed papers and grey literature, specifically dissertations and theses, published between January 1, 2000 to December 31, 2020. The databases were searched using a detailed search strategy (without language restriction). A copy of a search strategy is provided as supplementary material.

We identified a total of 2304 potential records within the publication timeframe from the databases searched, with an additional seven records identified through hand-searching from reference lists. Of the total, 177 were duplicates. Titles and abstracts identified were imported into reference management software, where they were screened by the lead author (and 80% cross-checked by the second author) to identify which to retrieve as full text (based on the inclusion criteria). It was at this screening stage that we assessed whether the interventions or services in the papers involved children and/or young people (and families of children and/or young people involved), and therefore met our inclusion criteria. It was felt that including these terms in the search terms (refer to appendix) could result in a strategy that was too narrow, thus missing potential studies where children and/or young people were

included but not the focus of the paper.

Full texts were retrieved and where inclusion was in doubt, discussed with the second author to determine inclusion. After duplicates were removed and titles and abstracts screened to assess fit with the inclusion criteria, 48 papers were identified. A hand-search of reference lists for these texts was also undertaken. Of these 48 texts, no dissertation and theses met the inclusion criteria. A further 33 out of the 48 were excluded following screening of the full texts and rationale documented for exclusion. Thus, 15 papers representing 15 separate studies were included in the systematic review (refer to the 'PRISMA 2009 Flow Diagram' included as supplementary material).

Data from the 15 papers was extracted into standardised tables by the first author, with all papers reviewed by the second author. In addition to including criteria informed by the 'PRISMA-Equity 2012 Extension: Reporting Guidelines for Systematic Reviews with a Focus on Health Equity' (Welch et al., 2015), we incorporated further criteria. These were: author(s); year of publication; country; aim of the study; study timeframe; context (intervention/service); brief intervention/service description; participant demographics; approaches to ethics; definitions of 'co-design' used; theory-based frameworks and methods, technique and tools used; approaches to evaluation; and approaches to equity. Study characteristics are presented in the findings, using a narrative approach to synthesis.

We used the 'CONSolidated crITERtia for strengthening the reporting of health research involving Indigenous Peoples (CONSIDER) statement' (Huria et al., 2019) to assess the quality of the papers included in the systematic review against a number of "... criteria for reporting of research aimed to strengthen Indigenous health research and to advance Indigenous health outcomes and development" (p.1). We applied the CONSIDER criteria (grouped under the headings of governance; prioritisation; relationships; methodologies, participation; capacity; analysis and interpretation; and, dissemination). Two criteria under participation were not included (criteria 10 and 12) as they were not relevant to the systematic review.

3. Results

3.1. Characteristics of the included studies

Table 1 displays the characteristics of the 15 studies included in the systematic review. The studies were published between 2012 and 2020 and were in 13 countries including a study conducted across Tanzania and Mozambique (Duveskog & Sutinen, 2013), and another study conducted across Belgium, Croatia, England, Portugal and Spain (Marent et al., 2018). The largest number of studies were in Australia (n = 5), followed by the United States (US) (n = 3). Six of the studies reported the study timeframe, ranging from eight months (Duveskog & Sutinen, 2013; Gilbert et al., 2020) to three years (Wright et al., 2019).

There was some minor variation in the health and disability related focus of the studies. For instance, sexual health (n = 7), mental health (n = 4), and disability (n = 2) were the main areas of focus. A further study (based in Canada) focused on exploring factors influencing empowerment for First Nations girls within the context of trauma experiences (Gaspar et al., 2019). Another study involved the co-design of a health promotion nutrition-based intervention grounded within local food systems for Indigenous school children living in a remote community in Alaska (Nu & Bersamin, 2017).

One of the two studies with a disability focus involved a community development project to strengthen inclusivity and connectivity within a regional community in Australia that included Indigenous children and families with lived experience of disability, amongst other groups (Robinson & Notara, 2015). The second study (based in Cambodia) involved children's aesthetic preferences regarding the design of prosthetic legs (Hussain & Sanders, 2012).

One of the four studies focusing on mental health was based in New Zealand and involved Indigenous Māori young people (amongst other

Table 1
Characteristics of the 15 studies included in the systematic review.

Characteristics	No.	References
Publication year	2012–2014	2 (Duveskog & Sutinen, 2013; Hussain & Sanders, 2012)
	2015–2017	3 (Nu & Bersamin, 2017; Payton, 2016; Robinson & Notara, 2015)
	2018–2020	10 (Christie et al., 2019; Davis et al., 2020; Gaspar et al., 2019; Gilbert et al., 2020; Lee et al., 2020; Marent et al., 2018; Ospina-Pinillos et al., 2019, 2020; Patchen et al., 2020; Wright et al., 2019)
Country	New Zealand	1 (Christie et al. (2019)
	Australia	5 (Davis et al., 2020; Gilbert et al., 2020; Ospina-Pinillos et al., 2019; Robinson & Notara, 2015; Wright et al., 2019)
	Belgium	1 (Marent et al. (2018)
	Cambodia	1 (Hussain and Sanders (2012)
	Canada	1 (Gaspar et al. (2019)
	Colombia	1 (Ospina-Pinillos et al. (2020)
	Croatia	1 (Marent et al. (2018)
	England	2 (Lee et al., 2020; Marent et al., 2018)
	Mozambique	1 (Duveskog and Sutinen (2013)
	Portugal	1 (Marent et al. (2018)
	Spain	1 (Marent et al. (2018)
	Tanzania	1 (Duveskog and Sutinen (2013)
	United States	3 (Nu & Bersamin, 2017; Patchen et al., 2020; Payton, 2016)
Study timeframe	<12 months	3 (Duveskog & Sutinen, 2013; Gilbert et al., 2020; Marent et al., 2018)
	12–24 months	1 (Payton (2016)
	>24 months	2 (Ospina-Pinillos et al., 2020; Wright et al., 2019)
	Not reported	9 (Christie et al., 2019; Davis et al., 2020; Gaspar et al., 2019; Hussain & Sanders, 2012; Lee et al., 2020; Nu & Bersamin, 2017; Ospina-Pinillos et al., 2019; Patchen et al., 2020; Robinson & Notara, 2015)
Study participant numbers	<50	7 (Davis et al., 2020; Gaspar et al., 2019; Gilbert et al., 2020; Hussain & Sanders, 2012; Ospina-Pinillos et al., 2019, 2020; Payton, 2016)
	50–99	2 (Patchen et al., 2020; Robinson & Notara, 2015)
	100–300	3 (Duveskog & Sutinen, 2013; Lee et al., 2020; Marent et al., 2018)
	Not reported	3 (Christie et al., 2019; Nu & Bersamin, 2017; Wright et al., 2019)
Ethnicity/ "Race"	Aboriginal/Torres Strait Islander	3 (Gilbert et al., 2020; Robinson & Notara, 2015; Wright et al., 2019)
	African	1 (Duveskog and Sutinen (2013)
	African American	2 (Patchen et al., 2020; Payton, 2016)
	Alaska Native	1 (Nu and Bersamin (2017)
	Black African	1 (Lee et al. (2020)
	Black Caribbean	1 (Lee et al. (2020)
	European	1 (Ospina-Pinillos et al. (2019)
	First Nations	1 (Gaspar et al. (2019)
	Latin American	3 (Lee et al., 2020; Ospina-Pinillos et al., 2019, 2020)
	Māori	1 (Christie et al. (2019)
	New Zealand European	1 (Christie et al. (2019)
	"non-Indigenous"	1 (Gilbert et al. (2020)
	"Other non-white"	1 (Lee et al. (2020)
Pacific peoples	1 (Christie et al. (2019)	
White	1 (Marent et al. (2018)	
Not reported	1 (Davis et al. (2020)	
Age	3	

(continued on next page)

Table 1 (continued)

Characteristics	No.	References
Children (<12 years)		(Gaspar et al., 2019; Hussain & Sanders, 2012; Robinson & Notara, 2015)
Adolescents (12–18 years)	8	(Christie et al., 2019; Davis et al., 2020; Duveskog & Sutinen, 2013; Gaspar et al., 2019; Gilbert et al., 2020; Hussain & Sanders, 2012; Ospina-Pinillos et al., 2019; Patchen et al., 2020)
Young adults (19–24 years)	10	(Davis et al., 2020; Duveskog & Sutinen, 2013; Gilbert et al., 2020; Hussain & Sanders, 2012; Lee et al., 2020; Marent et al., 2018; Ospina-Pinillos et al., 2019, 2020; Patchen et al., 2020; Payton, 2016)
Adults (>24 years)	7	(Hussain & Sanders, 2012; Lee et al., 2020; Marent et al., 2018; Nu & Bersamin, 2017; Ospina-Pinillos et al., 2019, 2020; Robinson & Notara, 2015; Wright et al., 2019)

ethnic groups). The study involved the development of a mobile app mental health intervention using gamifying features supporting cognitive behavioural therapy skill development (Christie et al., 2019). A further study based in Australia focused on increasing Aboriginal and Torres Strait Islander young people's engagement with mental health services (Wright et al., 2019). Two separate studies (undertaken by the same lead researchers) involved the cultural adaptation of a youth-orientated web-based mental health clinic with Spanish speaking international students living in Australia (Ospina-Pinillos et al., 2019), and, with young people living in Colombia (Ospina-Pinillos et al., 2020).

One of the seven studies focusing on sexual health concerned the development of a pre-conception health resource and involved Aboriginal and Torres Strait Islander young people (Gilbert et al., 2020). A further study based in Australia involved the development of a digital resource that addressed pornography literacy needs of "vulnerable" young people (Davis et al., 2020). Another study based in the US involved the development of a mobile-based sexual health intervention (video game) for African American young people (Patchen et al., 2020). Two further studies (one in the US, the other in Tanzania and Mozambique) focused on the development of multimedia digital platforms for HIV and AIDS related health literacy (Duveskog & Sutinen, 2013; Payton, 2016). Another two studies involved HIV related health service delivery and included young adults but were adult-focused (Lee et al., 2020; Marent et al., 2018). The first study focused on the use of digital vending machines for delivery of HIV self-testing (Lee et al., 2020). The other study, conducted across five European Union countries, involved the development of a mobile health platform to be incorporated into clinical models of HIV care (Marent et al., 2018).

Although there were a range of ages, only three of the 15 studies involved children under 12 years of age (Gaspar et al., 2019; Hussain & Sanders, 2012; Robinson & Notara, 2015) with the youngest participants being four years of age (Robinson & Notara, 2015). Six of the 15 studies involved Indigenous peoples, either as the focus (Gaspar et al., 2019; Gilbert et al., 2020; Nu & Bersamin, 2017; Wright et al., 2019) or as one social group included alongside other groups (Christie et al., 2019; Robinson & Notara, 2015). Other participants included secondary school students (Christie et al., 2019; Duveskog & Sutinen, 2013; Nu & Bersamin, 2017; Patchen et al., 2020), university students (Duveskog & Sutinen, 2013; Nu & Bersamin, 2017; Patchen et al., 2020; Payton, 2016), international students (Ospina-Pinillos et al., 2019), young people from an orphanage (Duveskog & Sutinen, 2013), young people who were out of school or in alternative education (Davis et al., 2020; Duveskog & Sutinen, 2013), children and young people with lived experience of disability (Davis et al., 2020; Hussain & Sanders, 2012; Robinson & Notara, 2015), young people and adults identifying as

LGBTQIA+ (Lee et al., 2020; Marent et al., 2018; Patchen et al., 2020), and people living with HIV (Marent et al., 2018). Adults included in the child and/or youth focused studies were parents (Hussain & Sanders, 2012; Nu & Bersamin, 2017; Robinson & Notara, 2015), grandparents (Robinson & Notara, 2015), and Indigenous elders (Gaspar et al., 2019; Nu & Bersamin, 2017; Wright et al., 2019). The rest of the adults were participants in the two adult-focused studies (also involving young adults) (Lee et al., 2020; Marent et al., 2018).

3.2. Approach to ethics

Eight of the 15 studies reported that ethical approval was obtained from a research ethics committee (Davis et al., 2020; Gaspar et al., 2019; Gilbert et al., 2020; Marent et al., 2018; Nu & Bersamin, 2017; Ospina-Pinillos et al., 2019, 2020; Wright et al., 2019). Another five studies described obtaining either verbal or written consent from participants or parents/caregivers of participants (Hussain & Sanders, 2012; Lee et al., 2020; Patchen et al., 2020; Payton, 2016; Robinson & Notara, 2015). Other ethical considerations, however, were not discussed. Only one study explicitly acknowledged the rights of children and young people under the UNCROC and the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD) (Robinson & Notara, 2015).

3.3. Co-design definitions, processes and practices

Although all 15 studies used the word 'co-design' (or variations of the term) in their description of the studies, only one provided a referenced definition for the word 'co-design'. Robinson and Notara (2015) defined 'co-design' as "one part of co-production, which also includes co-commissioning, co-delivery, and co-assessment of services" (p.727) citing Needham (2008). Gilbert et al., (2020) defined 'co-design' as a "participatory approach to the development of interventions that brings together technical expertise and lived experience from users" (p.2). Davis et al. (2020) defined co-design as "a tool of human-centred design and design thinking ... methods involve bringing together key users, designers, and subject matter experts who participate in iterative workshops to understand and empathize with users" (p.3). Rather than defining the term co-design, two studies provided a cited definition of 'participatory design' (that included the word 'co-design' as part of the definition). 'Participatory design' was defined by Hussain and Sanders (2012) as "a design practice that involves non-designers in various co-design activities throughout the design process" (p.44) citing Sanders and Stappers (2008). Payton (2016) defined 'participatory design' as the "direct involvement of people in the co-design of artifacts, processes and environments that shape (and influence) their lives" (p.322), citing Robertson and Simonsen (2013). The remainder of studies (n = 10) provided no description of what was meant by their use of the term 'co-design'.

Nine studies reported one or more theory-based frameworks broadly incorporating either some form of participatory design or participatory research (refer to Table 2). In addition, seven studies described a series of stepwise phases. Two of these related to the development of multimedia digital platforms for HIV and AIDS health literacy (Duveskog & Sutinen, 2013; Payton, 2016). For both studies, the phases broadly incorporated: 1) an analysis of existing digital/non-digital interventions for HIV and AIDS education; 2) developing the digital platform with participants; 3) testing the prototype of the platform; and 4) implementing the platform. Payton (2016) also evaluated the implementation of the platform. Gilbert et al. (2020) used a series of phases previously developed by Bowen et al. (2013). These were: 1) understanding and sharing experiences; 2) exploring 'blue sky' ideas; 3) selecting and developing 'blue sky' concepts; 4) developing practical proposals; and 5) prototyping and evaluating (Bowen et al., 2013; Gilbert et al., 2020). Nu and Bersamin (2017) described a two-phase process that involved formative research that looked at Indigenous participants' views of wellbeing in connection with salmon as an Indigenous food source.

Table 2

Theory-based frameworks reported in the 15 studies included in the systematic review.

Theory-based frameworks	References
A “research and development cycle” approach based on the guide, ‘Participatory Design of Evidence-Based Online Youth Mental Health Promotion, Intervention and Treatment’ (Ospina-Pinillos et al., 2018).	(Ospina-Pinillos et al., 2019, 2020)
A “mixed-method, co-design approach” based on a participatory design framework previously developed within the context of health service design.	Gilbert et al. (2020)
A “co-creation theory” informed participatory design approach.	Payton (2016)
A “philosophical hermeneutics as an interpretivistic research” approach using participatory design related “generative design tools” as research method.	Hussain and Sanders (2012)
A “design science” approach using participatory design as a research method.	Duveskog and Sutinen (2013)
A “co-design principles” informed participatory research approach.	Robinson and Notara (2015)
A “community-based participatory research principles and practices” approach incorporating user-centred design and “agile methodology”.	Patchen et al. (2020)
A human-centred design and design thinking approach.	Davis et al. (2020)

Findings were then used to inform the health promotion nutrition-based intervention in collaboration with participants (Nu & Bersamin, 2017). Davis et al. (2020) utilised a four-phase approach adapted from human-centred design and design thinking methodologies that involved: 1) understanding; 2) defining; 3) ideating; and 4) designing, in the development of a digital resource addressing pornography literacy. Two further studies (involving the same lead researchers) relating to the cultural adaptation of a youth-orientated web-based mental health clinic described a six-phase process involving: 1) co-design workshops; 2) knowledge translation; 3) language translation and cultural adaptation; 4) rapid prototyping and user-testing of alpha prototype; 5) rapid prototyping and user-testing of beta prototype; and 6) real-world testing of final prototype (Ospina-Pinillos et al., 2019, 2020).

Table 3 (attached as supplementary material) provides an overview of the 26 methods, techniques and tools reported in the co-design process for the 15 studies. The most common were ethnographic observation (n = 7). This was followed by user-testing (n = 6), usability analysis (n = 6), focus groups (n = 6), workshops (n = 6), prototyping (n = 6) and sketching (n = 6). Ethnographic observation, user-testing and usability analysis tended to be employed as methods in the development of digital platforms (such as mobile health apps or websites). The studies that included children under 12 years of age involved focus groups or story sharing, or methods that involved sketching or making things (for instance, paper dolls). The studies including Indigenous peoples tended to involve focus groups, story sharing and community advisory and/or working groups that included Indigenous young people and adults. One study described spending time “On Country” as a method whereby Elders, youth and adult participants visited locations of cultural significance and “spent time walking, sitting and being on boodja (country) ... These ‘On Country’ activities place Nyoongar culture and country at the centre of the engagement and honours the wisdom and leadership of the Elders” (Wright et al., 2019, p. 1508).

3.3.1. Evaluation of co-design impacts

Only one study described a formal evaluation (Payton, 2016). This involved a social media evaluation of the digital platform developed. Data from Twitter was evaluated over an eight-month timeframe (following the intervention) with the age and gender distribution of Twitter followers reported as 60 percent females and 40 percent males, and between the ages of 18 and 24 years – this aligned with the intended social group of interest. Thus, the measure related to engagement with the intervention (rather than impact on desired outcomes). No other evaluation measures were described. Duveskog and Sutinen (2013) did

not report a formal evaluation of the developed digital platform, but the researchers reflected on their overall learnings from the study. As part of this reflection, they identified three factors optimising web-based learning environments for the delivery of health literacy materials on HIV and AIDS within developing contexts (Duveskog & Sutinen, 2013). Likewise, Hussain and Sanders (2012) did not report a formal evaluation but three of the participants (young children with lived experience of disability) were asked about their experiences of the research. The researchers also reflected on their learnings around co-designing with the children (Hussain & Sanders, 2012). Marent et al. (2018) noted that an evaluation was occurring at the time of writing, and a further three studies indicated they were either undertaking (Patchen et al., 2020) or planning (Christie et al., 2019) a randomised controlled trial (RCT), or evaluation (Davis et al., 2020). We specifically searched for evidence of potential publications mentioned by the researchers; however, we could not find any to date.

3.3.2. Approach to equity

Although none of the studies explicitly stated the purpose of the study was to address equity, almost all the studies demonstrated an acknowledgement of the presence of inequities for the participants involved in the studies (to varying degrees). For most of the studies, the means by which equity was addressed appeared to be related to the inclusion of participants from an intended social group experiencing inequities in an area of interest, in the design of an intervention or service. For instance, two studies focusing on the development of a digital platform for HIV and AIDS health literacy used an evidence-based approach to establish the intended target social group, then recruited participants who were representative of this group (Duveskog & Sutinen, 2013; Payton, 2016). Duveskog and Sutinen (2013), highlighting HIV and AIDS among Tanzanian youth to be of considerable concern (and particularly so in the Iringa region where prevalence rates are higher than in other areas of Tanzania) specifically recruited young people from Iringa as participants. Payton (2016), highlighting inequities in the estimated rates of new HIV infections for young Black women compared with white and Latinx in the US, purposely recruited young Black women attending a college campus as participants. Davis et al. (2020) noted the possibility that some young people may be at greater risk of harms from pornography “as a result of the sociocultural and environmental contexts in which they view it” (p.2), (for instance, limited access to relevant education including pornography literacy), and thus specifically recruited participants from youth services programmes and alternative education.

Robinson and Notara (2015) described a community development project that targeted children with disability and their families within a regional Australian community. The researchers reported on experience of racism and impacts of this on Aboriginal families of children with lived experience of disability. Within this community, the researchers used specific recruitment and participatory methods with Aboriginal children and their families, stating, “[t]he involvement of a trusted Aboriginal support worker was key in recruiting Aboriginal families ... The group method had stronger cultural resonance for Aboriginal families, many of whom preferred not to be involved on an individual basis” (Robinson & Notara, 2015, p. 729).

The exception to this were two studies authored by Marent et al. (2018) and Hussain and Sanders (2012). Marent et al. (2018) recruited participants living with HIV and involved (but did not specifically target) priority social groups within this target population. As a result of this approach, they noted white gay men were overrepresented compared with all other social groups. Hussain and Sanders (2012) on the other hand, acknowledged the existence of inequities for children and their families in Cambodia, stating, “[m]ost parents of young children in present-day Cambodia are survivors of the Khmer Rouge regime ... A lot of people are still struggling with symptoms of post-traumatic stress disorder because of the atrocities experienced during this time” (pp.54–55). They argued however, their study did not:

focus on children living in developing countries as an oppressed group, and research methods and data analysis [were] not based on an ideology ... The empowerment of child participants is seen as a positive and important extended result of a design project but not the primary reason for organising and conducting the project. (Hussain & Sanders, 2012, p.49, p.49)

Hence the participants (children and families with lived experience of disability), and the context within which they were situated, appeared almost a secondary consideration to the study's underpinning theoretical and methodological approach to co-design.

Thus, other than describing processes to address equity (via the degree of participation from priority social groups), there was no actual evaluation of desired outcomes in relation to equity. It was also unclear as to whether the studies explicitly considered power in the processes and practices of co-design (including the researchers' undertaking self-critique around issues of power). Three studies included young people on advisory and/or working groups (Gilbert et al., 2020; Nu & Bersamin, 2017; Patchen et al., 2020). Nu and Bersamin (2017) observed that collaboration with Indigenous communities had ensured the intervention was "relevant to local people's lived realities by inviting community members to participate in promoting the long-term well-being of their community" (p.79). Gilbert et al. (2020) established a youth working group (involving Aboriginal and Torres Strait Islander young people) as a means of addressing the "gap in culturally responsive preconception health resources" (p.6). They described the benefit of this approach as "provid[ing] the opportunity for youth to have significant involvement and decision-making rights in the resource design. Consultation meetings captured youth perspectives, insights and lived experiences ..." (Gilbert et al., 2020, p. 6). However, issues around power and addressing power imbalances were not explicitly critiqued.

4. Discussion

The findings of this systematic review emphasise the dearth of published research on co-design with Indigenous and other children and young people from priority social groups. Only 15 studies met the inclusion criteria. In almost half of the studies, reporting of ethics procedures (such as ethics review board approval and consent) was inadequate and only one study referred to the rights of children and young people (under the UNCROC and UNCRPD).

All the studies used the word 'co-design', but only three provided an actual definition of the term, or what they meant by their use of the term. Lack of definitional clarity around the term 'co-design' has been previously highlighted in the literature as especially unhelpful to the field (Blomkamp, 2018; Britton, 2017). Studies drew on a variety of theory-based frameworks and included a range of different approaches and methods. Similar to our findings, a systematic review by Eyles et al. (2016) also found inadequate reporting of co-design interventions. However, we also observed that although the studies reported the theoretical frameworks and methods, techniques and tools used, lack of sufficient detail was provided regarding approaches to engaging participants across all the studies, acknowledgement of participant's contributions, and a wide range in the level of detail reported regarding co-design activities.

Only one study described a formal evaluation process but this only measured degree of engagement (rather than outcomes or other relevant process measures). Although this may have been due to some of the included papers only reporting on a particular stage of co-design, this was not always the case. Blomkamp's (2018) research has likewise found "while co-design may have transformative effects, many of the claims about its benefits have not been rigorously evaluated" (p.6). A recent rapid overview of reviews conducted by Slattery et al. (2020) concurs, noting that "co-design appears to be widely used but seldom described consistently or evaluated in detail" (p.12).

Although none of the studies explicitly discussed whether the

purpose of the study was to address equity, all demonstrated an acknowledgement of the presence of inequities for the participants involved. The key mechanism around addressing equity appeared to relate to the inclusion of participants from an intended social group that experience inequities within a specific area. However, the only analysis of impact on equity was the degree to which priority groups were recruited into the study, rather than assessment of impacts on outcomes and whether inequities were reduced, or whether co-design was more acceptable to priority groups (rather than other approaches). Hence, there was little evidence as to whether co-design is more effective at achieving desired outcomes and equity than other approaches.

A strength of this systematic review is that, to our knowledge, it is the first to overview the evidence on approaches to co-design with Indigenous and other children and young people from priority social groups, critiquing issues of equity. Another strength involves the systematic approach undertaken in accordance with relevant guidelines (Welch et al., 2015). Limitations include that the 15 studies were only located in peer reviewed journals, as the databases we searched did not identify any grey literature that met the inclusion criteria, thus, selection bias cannot be excluded. There is also a small possibility that some applicable studies were excluded due to publication timeframe restriction (last 20 years), however, as the 15 studies meeting the inclusion criteria were published in the last decade (between the years 2012–2020), it is unlikely that the restricted timeframe resulted in many applicable studies being missed.

Our systematic review highlights several important implications for the field. Co-design (alongside other participatory approaches) has been coined the "new Zeitgeist" by proponents (Palmer et al., 2018).

The rationale for this new spirit of participation relates to voice and engagement (those with lived experience should be engaged in processes of development, redesign and improvements), empowerment ... and advancement (quality of life and other health outcomes and experiences of services for everyone involved should improve as a result). (Palmer et al., 2018, p.247, p.247)

Yet, we found insufficient detail in the studies regarding what co-design with Indigenous and other children and/or young people from priority social groups looks like in practice, in addition to there being a lack of formal evaluation and hence a lack of evidence as to whether co-design works. Thus, there is an urgent need for research that evaluates the co-design impacts in addition to assessing the contribution of co-design to achieving equity. There also appeared to be less engagement with ethics across the studies than would be expected for research with children and young people. Based on the findings of this systematic review, it is thus difficult to ascertain whether co-design works, whether co-design has a role to play in achieving equity, or whether there is, in fact, potential for harm.

Talamaivao et al. (2021) highlight that enduring change in health and disability systems "can only occur when power imbalances are examined and addressed – for example, by reorienting funding structures, services, access and representation for and partnerships with Indigenous peoples" (pp.54–55). Co-design has been touted as a means by which power imbalances can be addressed (Chauhan et al., 2021; Mark & Hagen, 2020; Moll et al., 2020), however Mark and Hagen (2020) caution that the term 'co-design' has been used on occasion to "infer a degree of power sharing, participation and partnership that never really existed" (p.5). We observed that a critique of power base, power relations and power dynamics in the study settings and co-design processes and practices was lacking by the authors of the studies included in this systematic review. Farr (2018), in their research around the multiple dimensions of power in co-design, advise "constant critical reflective practice and dialogue is essential to facilitate more equal relational processes ..." (p.623) whilst Moll et al. (2020) emphasise how a lack of reflection around power has the potential for "perpetuating marginalisation and tokenism, since unexamined power imbalances

may delegitimise forms of knowledge that depart from the status quo" (p.2). Moll et al. (2020) have since developed a tool supporting reflexivity in co-design with "vulnerable populations" to address issues of power (the authors specify their description of the term "vulnerability" does not reflect "an individual characteristic, but as the result of social and systemic barriers" (p.1). Based upon their co-design with diverse ethnic social groups, Chauhan et al. (2021) outline important mechanisms around addressing power imbalances. These include, amongst others, the building of strong relationships with communities and specifically, addressing the socio-cultural needs of participants involved in the co-design to support their equitable participation. However, crucially, they note that success is "contingent upon health system environment, culture and organisational commitment that prioritises and sufficiently resources high-quality co-design" (p.5). This necessitates commitment from those in positions of power in ensuring that high-quality co-design is prioritised and that appropriate resources are allocated from the outset (Chauhan et al., 2021).

In response to the lack of adequate reporting within the field of co-design, Eyles et al. (2016) have recommended the development of a standardised checklist, suggesting the work of Hoffman et al. (2014) as a starting point. Moll et al. (2020) also propose the use of the 'Guidance for Reporting Involvement of Patients and the Public (GRIPP2)' (Staniszewska et al., 2017) in health and social care research. We concur but note that it is critical for quality reporting to occur regarding the contribution of co-design to impacting on desired outcomes and to achieving equity. This includes reporting co-design definitions, theory, and praxis, measuring desired outcomes, in addition to applying an equity lens to the evaluation of the effectiveness of co-design. We suggest the CONSIDER statement' (Huria et al., 2019) could be used as the basis for this in addition to other tools mentioned. We also recommend culturally safe ethical processes responsive to Indigenous and other children and young people from priority social groups be implemented when undertaking co-design (Curtis et al., 2019; Graham et al., 2013; Pallawi, 2017; Committee on the Rights of the Child, 2009), noting that cultural safety necessitates the power shift from organisations and practitioners to Indigenous and other children and young people from priority social groups (Curtis et al., 2019).

5. Conclusion

Limited studies report whether co-design of health and/or disability

Appendix 1. Ovid Medline/PsychInfo search strategy

The search strategy was amended as required for the other databases searched.

1.	(co-design*).mp. [mp = title, abstract, original title, name of substance word, subject heading word, keyword heading word, protocol supplementary concept word, rare disease supplementary concept word, unique identifier, synonyms]
2.	(codesign*).mp.
3.	1 or 2
4.	exp Ethnic Groups/
5.	exp Minority Groups/
6.	4 or 5
7.	(indigen* or aborigin* or "first nation" or native or maori or torres or indian or hawai* or inuit or metis or sami or rac* or ethnic* or cultur* or religio* or migra* or immigra* or refugee* or disab* or gender* or sexua* or queer or rainbow or LGBT*).mp.
8.	6 or 7
9.	3 and 8
10.	limit 9 to (humans and yr = "2000-2020")

related interventions or services with Indigenous and other children and young people from priority social groups contribute to positive outcomes and to achieving equity. To ensure that co-design leads to equitable outcomes, co-design must be grounded within a robust evidence-base. It is thus critical for quality reporting to take place regarding co-design definitions, theory, and praxis. Additionally, there is an urgent need for research that evaluates the impacts of co-design with a focus on the contribution of co-design to achieving equity. We also recommend culturally safe ethical processes responsive to Indigenous and other children and young people from priority social groups be implemented whenever co-design is undertaken.

Ethical statement

Our article is a systematic review of the literature. As data has not been collected from human subjects, ethical approval has not been sought.

Statement of author contributions

Paula Toko King led the overall manuscript design and development, reviewed and analysed the literature, and led the drafting of the manuscript. Donna Cormack provided supervision of the manuscript design and development, contributed to the review and analysis of the literature, and contributed to draft manuscripts. Richard Edwards reviewed the manuscript design and development, contributed to the review and analysis of the literature, and contributed to draft manuscripts. Ricci Harris reviewed the manuscript design and development, and contributed to draft manuscripts. Sarah-Jane Paine reviewed the manuscript design and development, and contributed to draft manuscripts. All authors read and approved the final manuscript.

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Appendix 2. PRISMA flow diagram

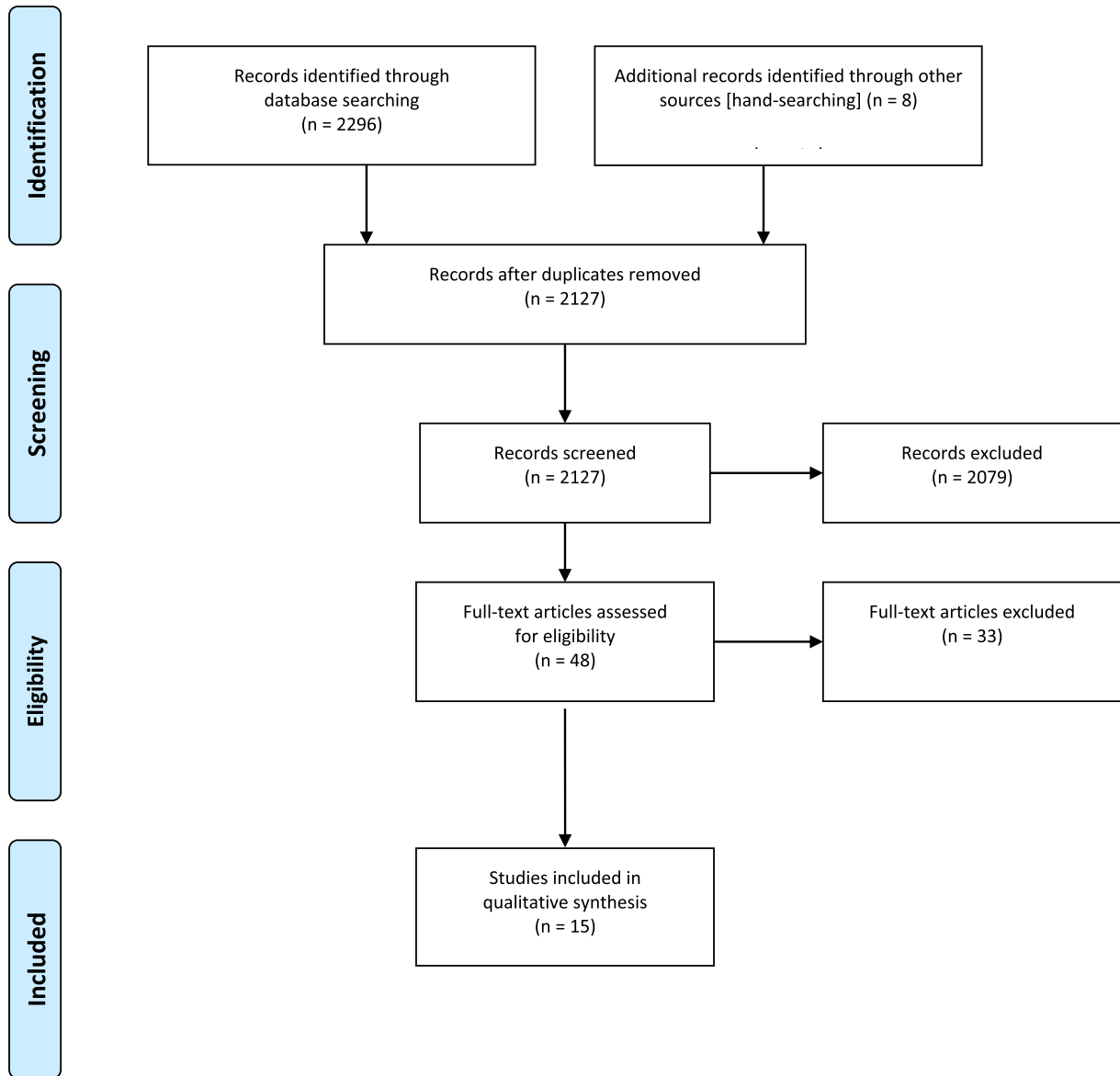


Fig. 1. Adapted from (Moher et al., 2009).

Appendix 3. Co-design methods, techniques and tools

Table 3 Methods, techniques and tools reported in the 15 studies included in the systematic review

Methods/Techniques/Tools	No. of studies	References
Ethnographic observation (researchers and/or participants)	7	(Christie et al., 2019; Davis et al., 2020; Duveskog & Sutinen, 2013; Hussain & Sanders, 2012; Ospina-Pinillos et al., 2019, 2020; Payton, 2016)
User-testing	6	(Christie et al., 2019; Duveskog & Sutinen, 2013; Hussain & Sanders, 2012; Ospina-Pinillos et al., 2019, 2020; Patchen et al., 2020)
Usability Analysis	6	(Christie et al., 2019; Duveskog & Sutinen, 2013; Ospina-Pinillos et al., 2019, 2020; Patchen et al., 2020; Payton, 2016)
Focus groups	6	(Christie et al., 2019; Hussain & Sanders, 2012; Nu & Bersamin, 2017; Patchen et al., 2020; Payton, 2016; Robinson & Notara, 2015)
Workshops	6	(Davis et al., 2020; Gilbert et al., 2020; Marent et al., 2018; Ospina-Pinillos et al., 2019, 2020; Robinson & Notara, 2015)
Prototyping	6	(Christie et al., 2019; Davis et al., 2020; Ospina-Pinillos et al., 2019, 2020; Patchen et al., 2020; Payton, 2016)
Sketching	6	(Davis et al., 2020; Duveskog & Sutinen, 2013; Hussain & Sanders, 2012; Ospina-Pinillos et al., 2019; Ospina-Pinillos et al., 2020; Robinson & Notara, 2015)

(continued on next page)

Table 3 (continued)

Methods/Techniques/Tools	No. of studies	References
Interviews	4	(Duveskog & Sutinen, 2013; Hussain & Sanders, 2012; Marent et al., 2018; Robinson & Notara, 2015)
Literature review	4	(Duveskog & Sutinen, 2013; Ospina-Pinillos et al., 2019, 2020; Patchen et al., 2020)
Story sharing (oral/written/story-board/digital)	4	(Davis et al., 2020; Duveskog & Sutinen, 2013; Gaspar et al., 2019; Wright et al., 2019)
Youth or Community Advisory/Working Group	3	(Gilbert et al., 2020; Nu & Bersamin, 2017; Patchen et al., 2020)
Survey	2	(Gilbert et al., 2020; Lee et al., 2020)
Peer researchers	2	(Marent et al., 2018; Payton, 2016)
Community/place-mapping	2	(Davis et al., 2020; Robinson & Notara, 2015)
“Blue-sky” ideation	2	(Davis et al., 2020; Gilbert et al., 2020)
Music/singing	2	(Davis et al., 2020; Duveskog & Sutinen, 2013)
Digital drawings/animations	1	Duveskog and Sutinen (2013)
Role-play	1	Hussain and Sanders (2012)
Photos	1	Hussain and Sanders (2012)
Paper dolls	1	Hussain and Sanders (2012)
Daily activity description	1	Hussain and Sanders (2012)
Pictorial Maps	1	Robinson and Notara (2015)
Personas	1	Davis et al. (2020)
Lego	1	Davis et al. (2020)
Videos	1	Davis et al. (2020)
Spending time “On Country”	1	Wright et al. (2019)

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