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REVIEW

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Codesign is the zeitgeist of our time, but what do we mean by this? A scoping review of the concept of codesign in collaborative research with young people

Briony Lipton^{1*}, Jodie Bailie², Helen Dickinson¹, Belinda Hewitt³, Emma Cooper⁴, Anne Kavanagh⁵, Zoe Aitken⁵ and Marissa Shields⁶

Abstract

Background Codesign is increasingly valued in health research as a way to actively include stakeholders in the research process, particularly for groups that have been historically excluded, such as young people. Despite its popularity, codesign is often inconsistently defined in literature. This creates challenges for applying it consistently across research projects and for evaluating its effectiveness. To address this definitional ambiguity, we conducted a scoping review to examine and clarify the concept of codesign in research with young people in the health and social sciences.

Methods This scoping review drew on methodological guidance from JBI. Searches were conducted in Proquest, Scopus, Informit and Science Direct for relevant peer-reviewed publications for the period of January 2003–August 2023. Publications were included if they used the term codesign and/or related participatory research methods with young people aged 15–24 years. Screening, full-text review and data extraction were completed by two independent reviewers. Qualitative synthesis was used to identify definitions.

Results The search yielded 1334 publications, with 49 meeting the inclusion criteria. Publications varied with respect to the age range of included young people and focused on a variety of populations, including young people with mental ill-health or with disabilities, First Nations youth and young people involved with specific services or programs. In analysing the way codesign was described, we found considerable variation, with most studies using multiple terms to refer to their methods. Common terms included coproduction ($n=21$), coresearch ($n=15$), participatory research ($n=10$), codesign ($n=9$) and participatory action research ($n=7$).

Conclusions Many different terms were used to describe codesign research with young people. Codesign was used and operationalized in a myriad of ways and overlapped with methods taken in other participatory approaches. This overlap may reflect the so-called blending of approaches in practice, highlighting the need to tailor different collaborative approaches to specific research projects, processes and participants. Ultimately, the ambiguity and overlap of terms describing collaborative methods such as codesign may matter less than the need for researchers to be transparent about their methods, their understanding of the terms and approaches they are using in research and their justification for undertaking collaborative research.

Keywords Codesign, Coproduction, Coresearch, Participatory research, Young people

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Background

Codesign, along with other participatory approaches, have been heralded as the new zeitgeist by proponents [1]. This new spirit of participation is driven by the principles of voice and engagement – emphasizing that those with lived experience should be actively involved in development, design and improvement processes. This scoping review aims to clarify how codesign is used in research with young people in health and social sciences. Codesign emerged in the 1970s in Scandinavian participatory design traditions, primarily within product and industrial design. These early design practices focused on democratic engagement with end users and foregrounded the value of local knowledge and lived experience. Over time, codesign has migrated into health and social science research, often with less attention to its theoretical and professional origins. Acknowledging this history is important for understanding codesign not only as a method but also as a broader participatory ethos with political and philosophical foundations. The rise of codesign in research must also be understood in relation to broader societal movements that have challenged traditional hierarchies of knowledge production. Activist and advocacy-driven slogans such as “nothing about us without us” have underscored the demand for more inclusive, participatory approaches across sectors including disability, youth and mental health. These movements have catalysed a shift in how research is conducted, highlighting the ethical imperative to involve those most affected by the work.

From the early teens to mid-twenties, young people are at a pivotal life-stage characterized by significant change. During this time, they navigate unique challenges that affect various aspects of their lives, including their mental health and well-being, their engagement in education and employment and their relationships and support networks [2]. Young people’s perspectives and experiences may differ from those of adults (for example, [3]) and are critical to informing interventions, policies and research focusing on them. The right of young people and children to have their views considered and taken seriously in matters affecting them is enshrined in the United Nations Convention on the Rights of the Child [4]. This right extends to the research process, wherein a growing body of literature has emphasized the importance of including young people in research [5–8].

However, the involvement of young people in research has often historically been tokenistic [9–11]. Proxies such as parents, carers or teachers may be included to provide input about young people [12]. When included, young people may simply be consulted on their views without their input into the research design or analysis of findings. Increasingly, however, researchers have

considered how young people are engaged in research and what is truly meant by including the voices of young people in these processes. Over the past decade, codesign has emerged as a prevalent method across diverse social and health domains, engaging a range of stakeholders to ensure research and subsequent initiatives, programs or recommendations address their needs and are user-friendly [13, 14]. Codesign integrates generative and exploratory research with developmental design [15], emphasizing the collaborative involvement of end users as equal partners in the research process [1].

Previous reviews have attempted to explore the conceptualization of codesign and how it is used in health and social sciences literature. Slattery, Saeri and Bragge’s rapid review found that research codesign was widely used in health research but was inconsistently described and not evaluated in detail [16]. In a systematic review of so-called coapproaches, Grindell et al. found that coproduction, codesign and cocreation shared key aspects, such as bringing individuals together as equal partners, and reasons for employing the approach, such as valuing all knowledge and producing more relevant research. However, the review did not delineate between the approaches [17]. A qualitative systematic review of participatory research among children and young people identified a “baffling array of terminology used” in the area, including the term codesign, although it focused more on reasons for undertaking participatory research and levels of participation as opposed to conceptual clarity around terminology [18]. King et al.’s systematic review solely examined the term codesign in the context of research with young people from marginalized social groups, finding that most publications did not define what they meant by codesign [19]. Additionally, there may be increasing overlap between terminology and concepts, such as codesign and coproduction, as found in Masterson et al., highlighting the need to consider a broader range of terms [13]. Taken together, these reviews indicate a lack of conceptual clarity regarding what constitutes codesign and how these terms are used in the context of youth research. This may be further complicated by the proliferation of varied terminology employed within health disciplines and the social sciences to describe codesign methodologies [10, 15, 20–27].

While past reviews have noted the growing use of codesign and other participatory approaches with young people, few have focused specifically on how these methods are defined, theorized and operationalized in literature. Given current trends towards codesigned research and a relative lack of guidance on best-practice approaches with young people, this review aims to clarify the concept of codesign in research with young people in the health

and social sciences. In doing so, we wish to inform our own future coworking and benefit young people, with the hope that this will also be of value more broadly.

Research aims

The aim of this scoping review is to clarify the concept of codesign as a method across the health and social sciences disciplines, including public health, public policy and disability studies and to identify methodological considerations for collaborating with young people. The research for this paper is part of a broader project that explores:

1. What definitions of research codesign (concept) have been used in health and social sciences research (context) that involve young people (population)?
2. What are the barriers and facilitators to engaging with young people in codesigned research?

This paper focuses on the first of these questions, with barrier and facilitators addressed in a separate paper [28]. In addressing this question, we developed further questions related to clarifying the concept of codesign, in particular:

3. What specific methodological approaches are employed in research codesign with young people in health and social sciences?
4. How do these definitions and theories of research codesign differ?

These additional questions, addressed in this paper, aim to explore various dimensions of research codesign, providing a comprehensive understanding of its application, challenges and impact in health and social sciences involving young people.

Methods

A scoping review methodology was selected because our purpose was to identify and clarify key concepts and definitions in the literature related to codesign and young people [29]. This scoping review was conducted in accordance with the JBI (formerly known as Johanna Briggs Institute) methodology for scoping reviews [30] and reported in accordance with the Preferred Reporting Items for Systematic Reviews and Meta-analyses Extension for Scoping Review (PRISMA-ScR) [31]. An unpublished protocol is available from the authors upon request. Critical appraisal and risk-of-bias assessment were not conducted, consistent with JBI methodology for scoping reviews.

Search strategy

For this scoping review, we searched ProQuest, Scopus, Informit and Science Direct from January 2003 to August 2023 using a basic search strategy to identify studies using codesign and related terminology and focused on young people. We purposefully included the terms codesign, coproduction, and participatory research in our search strategy. These terms were selected on the basis of preliminary scoping, which showed their frequent use in youth-engaged research and their conceptual proximity. While other related terms such as cocreation or integrated knowledge translation (iKT) are also relevant, they were excluded from the search strategy to maintain a focused and feasible review scope. However, instances where these terms appeared in included literature were captured in our synthesis and are discussed in the results. The search strategy was developed in consultation with a research librarian. See Appendix 1 for the search terms used. The search was restricted to peer-reviewed literature published in English.

Eligibility criteria

Participants: we considered publications that included young people aged 15–24 years in a codesign process. Publications were excluded if they did not undertake codesign processes with young people. We included publications that used different age ranges that overlapped with our target age group, as there is not one singular definition of young people (for example, the United Nations defines youth as 15–24 years [17], WHO considers young people to be 10–24 years old [32] and International Labour Organizations considers young people to be 15–29 years old [33]).

Concept: we included studies that used codesign and related methods. As noted in the introduction, codesign is often used interchangeably with terms such as participatory research, coproduction, cocreation and coresearch. To account for this conceptual ambiguity, we adopted broad inclusion criteria to capture studies that may have referred to codesign using alternative terminology. Publications that employed participatory research, coproduction, community-based participatory research, action research or community development methodologies were only included if they also explicitly used the term codesign. Studies referring to participatory research without referencing codesign were excluded to maintain focus on our central concept. While cocreation was not used as a search term, we considered it during data extraction and synthesis when it appeared as an overlapping or interchangeable concept with codesign. Articles were excluded if they did not explicitly state the use of codesign or collaborative methods or if the codesign process undertaken was limited to user

engagement in a testing or implementation phase of a project (that is, a nonresearch process or project). Studies that asked participants for their opinions and perspectives (for example, focus groups, interviews and surveys) without any formal involvement in the research process were also excluded.

Context: journal articles published within the context of codesign in settings relevant to health and social sciences research, including public health and disability studies (for example, mental health research) and public policy (for example, education and employment transitions processes), were included. Publications in English and from any country were considered.

Types of sources: we considered peer-reviewed studies that used a variety of designs, including systematic and scoping reviews, qualitative and quantitative studies and evaluations and descriptions of codesign methodologies. Unpublished material, grey literature and laws and regulations were not included as we were interested in the use of codesign methods in peer-reviewed literature.

Screening and selection of studies

Two reviewers (B.L. and M.S.) independently reviewed titles and abstracts using Covidence, a web-based review platform [34]. Disagreement was resolved by including the article. Articles identified as potentially relevant were screened in full and assessed for inclusion independently by two reviewers (B.L. and M.S.). Conflicts were resolved through discussion with a third reviewer (H.D.).

Data extraction

Data for each included study were independently extracted by two reviewers using a data extraction tool in Covidence, with seven reviewers (B.L., M.S., H.D., B.H., Z.A., J.B. and E.C.) contributing to the data extraction process. The data extraction tool was piloted by two reviewers (B.L. and M.S.). Additional team members undertook pilot data extraction exercises to ensure consistency in interpretation and application of the extraction tool. Discrepancies were discussed and refinements made before the full dataset was divided among dyads for extraction. Each dyad included one of the lead reviewers (B.L. and M.S.).

Data were extracted regarding the year of publication, country, participants involved in the codesign process, study aims and design, data collection dates, codesign terms and definitions used, justification for using codesign, theories and models of codesign, activities undertaken by codesign participants, facilitators and barriers to codesign and ethical issues relating to codesign. Discrepancies in extracted data were resolved by referring to the study and in consultation with two reviewers (B.L. and M.S.).

Data analysis

Following JBI guidance, data were inductively analysed in a recursive process that followed the steps of content analysis as outlined by Elo and Kyngäs [35]. Specifically, reviewers (B.L. and M.S.) independently immersed themselves in the extracted data, reading and rereading data to get a sense of the whole; the data was then coded into categories and subcategories. These review authors came together regularly and assessed if there were any discrepancies. All discrepancies were discussed, and consensus was achieved.

Results

The search yielded 1334 publications. After duplicate removal, title and abstract screening and full-text review, 49 publications were included as depicted in Fig. 1. Included publications are detailed in Table 1.

Characteristics of included publications

A total of 19 studies were undertaken in the United Kingdom (UK) [36–54], 9 in Australia [55–63], six in Canada [64–69] and 5 in the United States [70–74]. One study was undertaken in Northern Ireland [75], one in South Africa [76], one in the United Kingdom and New Zealand [77], one in the United Kingdom and Norway [78] and one across the United Kingdom, India, Pakistan, Turkey, Kenya, South Africa, Brazil and Portugal [79]. In total, 33 of the studies used qualitative methods (for example, focus groups and interviews) [36–39, 41, 43–48, 50, 54, 59–64, 66–69, 71, 72, 74–79] and 5 used mixed methods [49, 56, 58, 70, 73]. A total of four studies were systematic reviews [19, 80–82], two were scoping reviews [42, 83], three were text and opinion [40, 55, 84] and two combined qualitative methods with text and opinion [52, 57]. A 20-year timespan was established for the search. Interestingly, almost all included publications were published in the last 10 years, with the exception of Soleimpour et al. [72], published in 2008, and Kramer et al. [70], published in 2013.

The included age range varied somewhat across studies, with most studies including individuals between the ages of 14–29 years. However, one study included individuals as young as 10 years (range 10–24 years) in their review [83], while another included individuals up to age 36 years (range 14–36 years) in their study [52]. Several studies did not define their age range, but rather referred to young people [49, 55, 59–61, 64, 84] or children and adolescents [81].

The included studies focused on a wide range of populations. In total, 11 studies focused on young people with lived experiences of mental ill-health and/or mental health conditions [36, 42, 43, 45, 48–50, 58, 66, 68, 79].

Co-design research with young people with disability

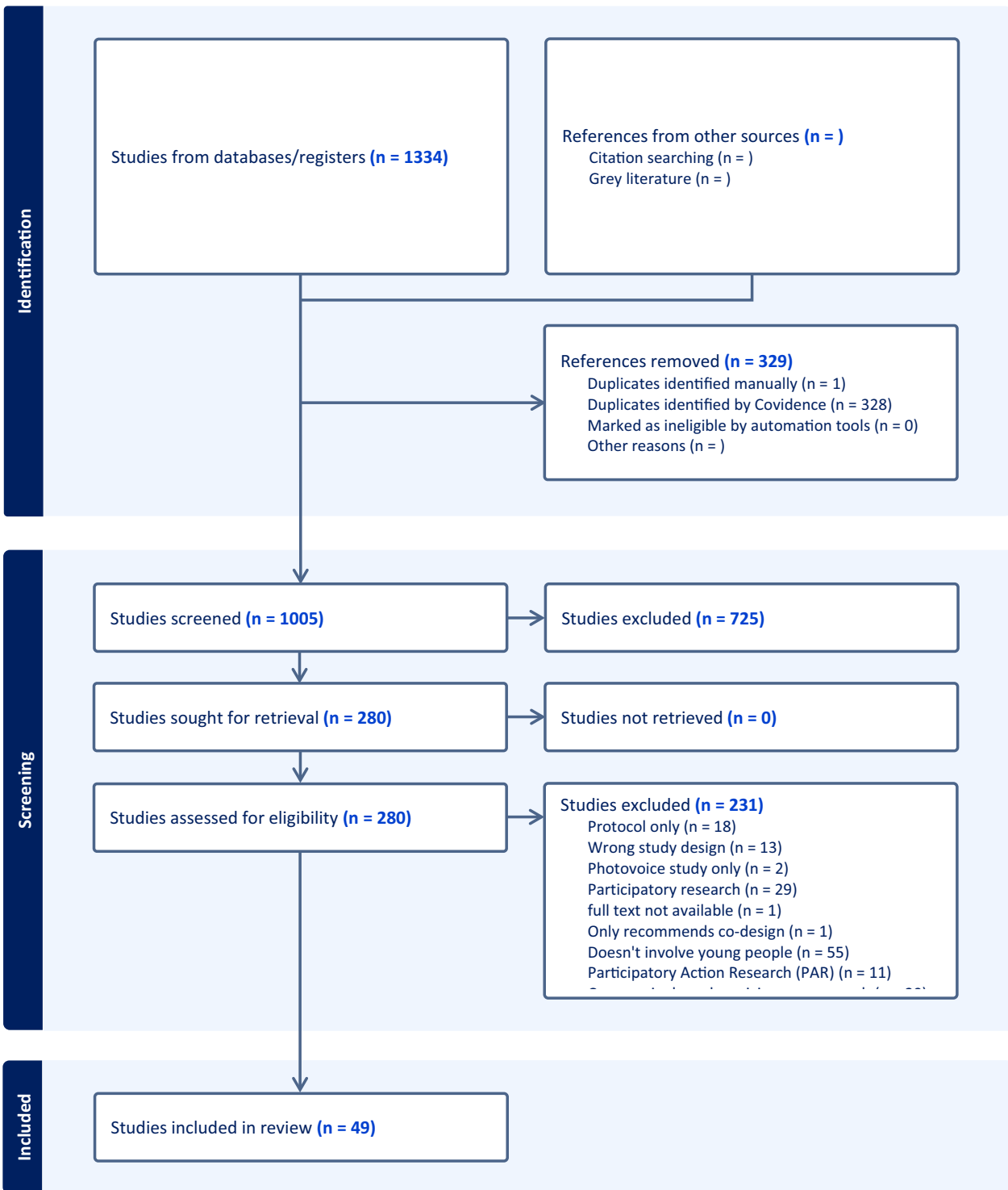


Fig. 1 PRISMA flow chart

Table 1 Description of studies included in the review

First author; year; country	Study design	Purpose of study and study focus	Participant characteristics	Collaboration terminology used	Activities undertaken with participants
Ali; 2023 [83]	Scoping review	Identify approaches to engagement; patient engagement in mental health care research	Adolescents and youth aged 10–24 years	Patient engagement; experience-based codesign, participatory approach, codesign approach, participatory action research	NA – review
Bennett; 2022a; United Kingdom [36]	Qualitative research	Explore impacts of young coresearcher involvement in research; help-seeking, emotional abuse and neglect	Aged 14–18 years; male, female and gender nonconforming; some had lived experience of mental health challenges; white British; most attending state-funded schools	Coproduction, coresearchers	Creating research questions; determining methods; analysing results; participating in workshops; writing papers and reports; giving presentations and talks; facilitating meetings; collecting data; participating in evaluation and reflective exercises
Bennet; 2022b; United Kingdom [37]	Qualitative	Develop coproduced methodologies to analyse data; help-seeking	Aged 14–18 years	Coproduction, coresearchers, codevelop	Creating research questions; determining methods; analysing results; giving presentations and talks; working as coresearchers; participating in reflective exercises
Blanchard; 2017; Australia [55]	Text and opinion	Codesigning solutions with young people; mental health and wellbeing	Young people (age not reported)	Youth participation	Providing input into research agenda; design, testing and dissemination; assisting in developing other projects; ensuring outputs were relevant; assisting as media spokespeople; helping to recruit new staff; participating in workshops
Boswell; 2021 [82]	Systematic review	Investigate facilitators and barriers of coproduction of services; coproduction methods	Child or young person ≤ 25 years with special educational needs and disability or ≤ 18 years without special educational needs and disability	Coproduction	NA – review
Brady; 2019; United Kingdom [47]	Qualitative	Describe co-led research process; defining quality and rights-based education, health and care plans	Aged 16–23 years; all with disabilities	Coresearcher, co-led	Facilitating interviews/focus groups; working as coresearchers; attending conferences; contributing to team meetings; attending training and fieldwork visits
Canas; 2019; Canada [64]	Qualitative	Evaluate youth engagement; participatory evaluation of engagement	Young people with prior experience in organizations (age not reported)	Knowledge mobilization (network), participatory evaluation	Creating research questions; analysing data; participating in interviews; reviewing drafts

Table 1 (continued)

First author; year; country	Study design	Purpose of study and study focus	Participant characteristics	Collaboration terminology used	Activities undertaken with participants
Culbong; 2022; Australia [56]	Mixed methods	Improve cross-sector collaboration; mental health services for Aboriginal and Torres Strait Islander young people	Aboriginal or Torres Strait Islander young people aged 16–25 years	Codesign, participatory research, Indigenous and participatory action research, coresearch	Collecting data; working as coresearchers; designing how mental health partners should work with Aboriginal and Torres Strait Islander young people in their services
Davison; 2022; Northern Ireland [75]	Qualitative	Provide guidance for participatory research methods; adapting self-report measures of wellbeing	Aged 11–17 years; male and female; all with intellectual disabilities	Participatory research	Participating in workshops
Dewa; 2021a; United Kingdom [48]	Qualitative	Describe coproduction approach; mental health	Aged 18–25 years; male and female; white British, British Asian and Black British ethnicities; lived experience of mental health difficulties	Patient and public involvement (PPI), coproduction	Creating surveys; creating interview/focus group guides; facilitating interviews/focus groups; collecting data; analysing results; writing papers and reports; giving presentations and talks; working as coresearchers
Dewa; 2021b; United Kingdom [49]	Mixed methods	Examine mental health and coping during coronavirus disease 2019 (COVID-19) lockdown; mental health impacts of COVID-19	Age not reported; coresearchers had experiences of mental health difficulties	Coproduction, coresearchers	Creating research questions; determining methods; creating surveys; creating interview/focus group guide; facilitating interviews or focus groups; collecting data; analysing results; writing papers and reports; working as coresearchers
Dunn; 2017; United Kingdom [50]	Qualitative	Coproduce a transition preparation program; mental health services	Aged 16–22 years; male, female and gender-fluid; had transitioned or were approaching transition from child and adolescent mental health services and were involved in participation networks; experiencing a variety of mental health and other conditions	Coproduce, participatory research, coresearch	Facilitating interviews/focus groups; participating in workshops; writing papers and reports; giving presentations and talks; working as coresearchers

Table 1 (continued)

First author; year; country	Study design	Purpose of study and study focus	Participant characteristics	Collaboration terminology used	Activities undertaken with participants
Edwards; 2022; United Kingdom [51]	Qualitative	Explore experiences of special educational needs and disabilities; supported internship programs	Aged 18–25 years; male and female; had learning disabilities and some other disabilities; members of ethnic minority groups; have education, health and care plan and be enrolled in a supported internship programme	Participatory research, participatory design, coresearch	Creating research questions; determining methods; creating interview/focus group guides; giving presentations and talks; working as coresearchers; commenting on and refining themes; participating in evaluation and feedback sessions
Fox; 2019; Australia [57]	Qualitative; text and opinion	Examine critical methodologies; experiences of young primary carers in rural Australia; experiences of LGBTQI young people in rural Australia	Study 1: 12–17 years; male and female; primary carers in rural Australia Study 2: young people identifying as LGBTQI and living in rural Australia	Community critical methodologies, participatory group, participatory approach, coresearcher, coproduction	Creating research questions; determining methods; analysing results
Goodey; 2022; United Kingdom [52]	Qualitative; text and opinion	Explore understanding of a construct; how disabled young people understand capital in their lives	Aged 14–36 years; male and female, including transgender individuals; sought to include young people with learning disability and those identifying as men	Coproduce, codesign	Creating research questions; creating interview/focus group guides; facilitating interviews or focus groups; collecting data; analysing results; participating in workshops
Hodson; 2022; Canada [84]	Text and opinion	Explore how participatory design can be more inclusive; supporting decision-making	Nursing students with learning disabilities (age not reported)	Participatory design, codesign	Participating in interviews; creating interactive diaries; refining diaries; giving presentations
Kendal; 2017; United Kingdom [53]	Qualitative	Develop participatory research method; emotional health support needs	Aged 16–18 years; predominantly female; most in full-time education	Participatory research, coproduction, coresearchers	Facilitating interviews/focus groups; analysing results; participating in workshops; writing papers and reports; working as coresearchers; young person advisor contributing to all stages of the study
King; 2022 [19]	Systematic review	Identify current state of codesign as theory and praxis; codesign with young Indigenous people and other marginalized groups	Children and young people ≤ 24 years; focused on young people who were Indigenous or from other priority social groups (for example, disability, LGBTQIA+ and migrant)	Codesign	NA – review

Table 1 (continued)

First author; year; country	Study design	Purpose of study and study focus	Participant characteristics	Collaboration terminology used	Activities undertaken with participants
Knowles; 2022; United Kingdom, New Zealand [77]	Qualitative	Determine priorities for systematic review; codesign to design interventions	Aged 16–25 years; male, female and nonbinary young people; Māori young people included in New Zealand study; lived experience of both or either individual experience of self-harm or indirect experience of self-harm or suicide as a friend or family member	Participatory codesign	Creating research questions; participating in workshops
Kramer; 2013; United States [70]	Mixed methods	Program development and evaluation; rehabilitation approaches	Ages 12–17 years; male and female, variety of disabilities, all white	Participatory research	Creating surveys; creating interview/focus group guides; facilitating interviews/focus groups; collecting data; analysing results; working as coresearchers
Kramer; 2018; United States [71]	Qualitative	Develop and refine measurement tool; patient-reported outcomes measurement	Aged 14–21 years; developmental disabilities	Long-term participatory collaboration	Creating interview/focus group guides; facilitating interviews/focus groups; analysing results; using photovoice techniques
Lapadat; 2020; Canada [66]	Qualitative	Describe opportunities and challenges of co-collaboration; self-management for youth with bipolar disorder	Aged 20–25 years; male and female; had diagnosis of bipolar disorder	Community-based participatory research, youth-driven research project	Creating research questions; determining methods; facilitating interviews or focus groups; participating in workshops; writing papers and reports; giving presentations and talks; working as coresearchers
Lee; 2023; Australia [58]	Mixed methods	Describe a pilot evaluation; Lived Experience Working Group protocol	Aged 16–30 years; lived experience of mental ill-health	Participatory processes and involvement, participatory action research	Determining study methods; creating surveys; facilitating interviews/focus groups; collecting data; analysing data; participating in workshops; writing papers and reports

Table 1 (continued)

First author; year; country	Study design	Purpose of study and study focus	Participant characteristics	Collaboration terminology used	Activities undertaken with participants
Liddiard; 2019a; United Kingdom [54]	Qualitative	Coproduce theoretical knowledge; lives and aspirations of young people with life-limiting and life-threatening impairments	Aged 19–30 years; female; living with life-limiting and life-threatening impairments	Coresearchers; coproduction	Creating interview/focus group guides; facilitating interviews/focus groups; analysing results; participating in workshops; writing papers and reports; giving presentations and talks; working as coresearchers; supporting research design and planning; recruiting participants; coleading research process and collaborative analysis; producing other dissemination materials
Liddiard; 2019b; United Kingdom [38]	Qualitative	Describe coproduced disability research; living with life-limiting and life-threatening impairments	Aged 19–30 years; female; living with life-limiting and life-threatening impairments	Coproduction, coresearchers	Creating research questions; creating interview/focus group guides; analysing results; writing papers and reports; working as coresearchers; supporting research design; recruiting participants; planning project-impact strategy; building relationships with partner organizations
Liebenberg; 2017; Canada [67]	Qualitative	Exploring facilitating youth engagement; mental health	Aged 12–18 years; First Nations	Participatory action research (PAR), knowledge mobilization	Determining methods; creating interview/focus group guides; facilitating interviews or focus groups; collecting data; analysing results; giving presentations and talks; applying for funding
Mannell; 2023; South Africa [76]	Qualitative	Challenging power relations in coproduction; human immunodeficiency virus (HIV) and intimate partner violence prevention	Aged 18–29 years; men and women; living in informal settlements and rural communities; not currently in school or formal work	Coproduction	Codesigning intervention; participating in workshops; working as coresearchers
Mawn; 2015; United Kingdom [39]	Qualitative	Describe establishment of youth research group; mental health	Aged 14–24 years	Patient and public involvement (PPI), patient researchers, involvement, research collaboration	Creating research questions; giving presentations and talks; being coapplicants on grant applications
McCabe; 2023 [80]	Systematic review	Describe impacts of young engagement; mental health research	Aged 8–25 years for included studies in review Youths aged 19–24 years acted as consultants for review; male; Canadian citizens	Coproduction, patient engagement, participatory action research	Youth consultants contributed to interpretation of results and discussion

Table 1 (continued)

First author; year; country	Study design	Purpose of study and study focus	Participant characteristics	Collaboration terminology used	Activities undertaken with participants
Meldahl; 2022; United Kingdom, Norway [78]	Qualitative	Explore perspectives on healthcare; mental healthcare services	Aged 17–22 years	Coresearchers	Creating research questions; creating surveys; collecting data; analysing results; writing papers and reports; working as coresearchers
Mulvale; 2019; Canada [68]	Qualitative	Evaluation of elicitation techniques; mental health care; transitions to adult care; employment supports	Aged 16–25 years; male and female; experiencing mental health problems	Experience-based codesign (EBCD)	Participating in data collection as a participant; codesigning prototypes
Norton; 2021 [81]	Systematic review	Review evidence on concept of coproduction; coproduction in child and adolescent mental health	Children and adolescents (age not reported)	Coproduction	NA – review
Pavarini; 2019; United Kingdom [40]	Text and opinion	Provide model of young people's advisory group; guidance on coproduction process	Aged 15–18 years; shared interest in ethics and mental health; included individuals with mental health difficulties and from socially marginalized groups or with special needs	Coproduction	Creating interview/focus group guides; analysing results; writing papers and reports; giving presentations and talks; with group available to support refining research questions, designing materials and tools and recruiting
Ramey; 2019; Canada [69]	Qualitative	Evaluation of advisory group; participatory research evaluation	Aged 15–29 years	Participatory research, action research, knowledge in action	Determining methods; analysing results; writing papers and reports; working as coresearchers; supporting implementation of research study; identifying practices; publishing results
Robinson; 2023; Australia [59]	Qualitative	Exploring challenges to centering young people's voices; lived experience of family violence	Included one young coresearcher with lived experience of significant disability	Codesign, coresearcher	Analysing results; writing papers and reports; working as a coresearcher
Rome; 2015; United Kingdom [41]	Qualitative	Explore transitions in schooling and services; transition services for young people with disability and adult-free research spaces for young people	Aged 12–19 years; lived experience of disability; male and female	Participatory research	Creating research question; determining study methods; facilitating interviews/focus groups; participating in workshops; writing papers and reports; giving presentations and talks; disseminating research; planning and running conference with stakeholders

Table 1 (continued)

First author; year; country	Study design	Purpose of study and study focus	Participant characteristics	Collaboration terminology used	Activities undertaken with participants
Sellers; 2021; United Kingdom [42]	Scoping review	Review youth-focused health studies; use of young people's advisory groups in health research	Aged 12–18 years; lived experience of mental health challenges; all were members of NeuroX Young People's Advisory Group (YPAG)	Young People's Advisory Groups (YPAGs)	NeuroX YPAG was involved in conceptualizing and disseminating this review
Soleimanpour; 2008; United States [72]	Qualitative	Reflections on youth-led research; school health programs	Middle and high school students (grades 8–11) (age not reported); female and male; represented racial and ethnic diversity of school	Community-based participatory research (CBPR)	Creating research questions; determining study methods; creating surveys; collecting data; writing papers and reports; giving presentations and talks; working as coresearchers
Spears; 2021; Australia [60]	Qualitative	Describe participatory design processes; health campaigns and bullying prevention	Young people (age not reported)	Participatory design (PD)	Conceptualizing topic; designing intervention; participating in workshops
Spies; 2021; Australia [61]	Qualitative	Experience of services; youth residential rehabilitation services	Young people (age not reported)	Participatory action research; collaborative autoethnography	Creating research question; determining methods; analysing results; participating in workshops; writing papers and reports; working as coresearchers
Spuerck; 2023; United Kingdom, India, Pakistan, Turkey, Kenya, South Africa, Brazil, Portugal [79]	Qualitative	Explore how to meaningfully involve young people in research; barriers and enablers of peer researcher roles in mental health	Aged 14–24 years; lived experience of depression and anxiety	Coproduction, participatory research, peer researchers	Facilitating interviews/focus groups; analysing results; participating in workshops; writing papers and reports; giving presentations and talks; working as coresearchers
Swist; 2022; Australia [62]	Qualitative	Document research process; establish adolescent health research community of practice	Aged 13–26 years; males and females from diverse cultural backgrounds	Coproduction, living lab, participatory research approach, cocreation, coresearch, codesign, research-practice partnerships	Facilitating interviews/focus groups; participating in workshops; writing papers and reports
Taggart; 2022; United Kingdom [43]	Qualitative	Develop training program; service assessment and training implementation	Project aimed at those aged 16–25 years; had experience of complex mental health needs	Action research, coproduction	Determining methods; participating in group discussions and activities; developing training program; delivering training program
Taylor; 2022; United Kingdom [44]	Qualitative	Define research priorities; youth mental health	Aged 16–24 years; with care experiences and/or identifying as LGBTQ+	Coproduction	Creating research questions; participating in workshops

Table 1 (continued)

First author; year; country	Study design	Purpose of study and study focus	Participant characteristics	Collaboration terminology used	Activities undertaken with participants
Thomson; 2022; United Kingdom [45]	Qualitative	Explore engagement in research process; patient and public involvement program development	Aged 16–24 years; lived experience of mental illness	Coproduction, patient and public involvement (PPI)	Establishing research priorities; participating in workshops; writing papers and reports
Villa; 2018; United States [73]	Mixed methods	Document recent youth participatory action research (YPAR) projects; gender-based violence, bullying and coping	Aged 13–21 years; all People of Colour	Youth participatory action research (YPAR)	Creating research questions; determining methods; creating surveys; creating interview/focus group guides; facilitating interviews or focus groups; collecting data; analysing results; participating in workshops; writing papers and reports; giving presentations and talks
Woods-Jaeger; 2022; United States [74]	Qualitative	Develop prevention strategy; health inequities and racism	Ages 12–17 years; men and women; Black youth	Youth participatory action research; community based participatory research, critical consciousness	Creating research question; determining methods; collecting data; participating in workshops; writing papers and reports; giving presentations and talks; working as coresearchers
Wright; 2019; Australia [63]	Qualitative	Explore engagement with services; youth mental health services	Aged 15–34 years; Aboriginal and Torres Strait Islander young people living on Wadjuk Nyoongar country (Perth, WA, Australia)	Participatory action research, codesign, coresearchers, storytelling	Working as coresearchers
Zlotowitz; 2016; United Kingdom [46]	Qualitative	Ethnography of coproduced intervention; building relationships to address needs	Aged 16–22 years; predominantly male; living in inner city housing estate; primarily white British ethnicity; identified by community agencies as gang-affiliated	Coproduction, partnership, codesign, sequential and dynamic coproduction, street therapy	Determining study methods and activities; participating in workshops; participating in program activities

A total of 11 studies included young people with disabilities [38, 41, 47, 51, 54, 59, 70, 71, 75, 82, 84], including 1 study involving young people with intellectual disabilities [75], 1 among young people with developmental disabilities [71], 2 with young people with learning disabilities [51, 84] and 2 including individuals with life-limiting and life-threatening impairments [38, 54]. In total, two studies included Aboriginal and Torres Strait Islander young people in Australia [56, 63], and one study included First Nations young people in Canada [67]. Several studies focused on specific programs, such as supported internships [51] and transitions from child and adolescent mental health services [50].

A variety of terms were used to describe the nature of the research conducted in the included studies, with nearly all studies using multiple terms. The most commonly used terms were coproduction (21 studies) [36–38, 40, 43–46, 48–50, 52–54, 57, 62, 76, 79–82], coresearch/coresearcher (used in 15 studies) [36–38, 47, 49–51, 53, 54, 56, 57, 59, 62, 63, 78], participatory research (10 studies) [41, 50, 51, 53, 56, 62, 69, 70, 75, 79], codesign (used in 9 studies) [19, 46, 52, 56, 59, 62, 63, 83, 84] and participatory action research (7 studies) [56, 58, 61, 63, 67, 80, 83]. Further details related to the focus of the studies, populations, terminology used and collaborative actions are presented in Table 1.

Co-concepts and definitions

Within the 49 included publications, over 40 different terms were used. While most publications ($n=36$) offered some form of description or definition of the terms they used, the level of detail provided varied significantly across publications [19, 36, 38, 40, 42, 44, 45, 48, 50, 53, 55–64, 66–68, 71–77, 79–84]. The remaining 13 publications did not give a description or definition [37, 39, 41, 43, 46, 47, 49, 51, 52, 54, 69, 70, 78]. Many publications offered multiple terms to describe their project. For instance, Goodley et al. used the terms codesign, coproduction and coresearch [52]. Swist et al. used the terms codesign as well as coproduction, coresearch and research practice partnerships [62]. Culbong et al. used the term codesign along with participatory research and Indigenous participatory action research [56]. Ali et al. used codesign and patient engagement [83], and Fox, Nic Giolla Easpaig and Watson used participatory research, coproduction and coresearch [57]. In this results section, we focus on the most commonly used terms. The order of terms presented below reflects their relative frequency in literature, beginning with coproduction and followed by coresearch, participatory research, codesign and participatory design.

Coproduction

Coproduction tended to emphasise shared ownership throughout the research process, including design, implementation and dissemination. Coproduction was referred to most frequently in studies included in our review ($n=21$) [36–38, 40, 43–46, 48–50, 52–54, 57, 62, 76, 79–82]. These publications emphasized the significance of collaboration between academics and various partners to produce outcomes that cannot be achieved in isolation. They highlighted the principles of equity, partnership and meaningful collaboration in coproduced research, emphasizing the importance of empowering communities and giving them control over the research process. Several publications addressed the importance of the integration of ideas and the involvement of disabled children and young people with long-term illnesses and their families in the research process [36, 37, 40, 44, 45, 53, 76, 81]. Boswell and Woods defined coproduction as “an equal relationship between people who use services and the people responsible for services” through which they “work together from design to delivery, sharing strategic decision-making about policies, as well as decision around the best way to deliver services” ([82] p. 42).

Coresearch

A total of 15 studies cited coresearchers as part of their methodology [36–38, 47, 49–51, 53, 54, 56, 57, 59, 62, 63, 78]. The concept of coresearch or coresearchers is where young people are involved as equal research partners. They share decision-making, power and responsibility throughout the research process, shifting the role of young people from research participants to codesigners. Publications using coresearchers used various methods, including online platforms, face-to-face workshops, arts workshops, exhibitions and public festivals, were used to engage with disabled young people in the research process.

Robinson et al. used codesign and also “employed a coresearcher throughout the project” ([59] p1196) to centre the voices and perspectives of young people and avoid tokenism. Kendal et al. included a young person on their research team and considered the young people involved in their study as coresearchers who both created and analysed data and produced knowledge in partnership with researchers [53]. Goodley et al. also explored knowledge with coresearchers drawing on theories related to posthuman disability studies, to emphasize the complex relationships between human (for example, professionals, caregivers, allies and family members) and nonhuman entities (for example, wheelchairs, iPhones and services) in the lives of disabled young people [52].

Participatory research

In the included studies, participatory research was framed as a collaborative process that values young people's lived experience and seeks to centre their voices in shaping research goals, methods and outcomes. Participatory research ($n=10$) [41, 50, 51, 53, 62, 63, 69, 70, 75, 79] and its application in various contexts emphasized the importance of creating spaces for young people [70] "to initiate and conduct their own research in ways that are manageable and meaningful to them" ([41] p. 290). The publications that adopted the term participatory research often delved into other specific approaches and techniques used in participatory research with children and adolescents, including codesign workshops and inclusive participatory research methods (such as photovoice). Overall, participatory research was described as a democratic and collaborative approach that aims to address power imbalances and involve subjective experts in the research process.

In total, nine studies reported one or more theory-based framework broadly incorporating some form of participatory design or participatory research. The most commonly used were Hart's Ladder of Children's Participation ($n=2$) [39, 60], Arnstein's Ladder of Participation ($n=4$) [39, 58, 81, 84] and Hussain's Design Participation Ladder ($n=1$) [84]. These ladders describe the extent and conditions of participation in participatory-designed projects reflecting a continuum of power.

Codesign

Codesign ($n=9$) appeared less frequently than other coterms but was typically associated with involving stakeholders in the early stages of research design, often to ensure relevance and usability [19, 46, 52, 56, 59, 62, 63, 83, 84]. However, only three studies provided definitions of what they meant by the term [19, 56, 59]. In these publications, such as Robinson et al. the primary intention of codesign was to meaningfully "include relevant stakeholders in design and implementation so that research processes and outcomes are relevant, valuable and acceptable to those who engage with them" ([59] p. 1194). King et al. identified multiple relevant definitions of codesign in broader literature, but found that most studies included in their review of the current state of codesign theory and praxis did not define what they meant by the use of the term codesign [19]. The remainder of studies using the term codesign in our review ($n=6$) provided no description of what was meant by their use of the term codesign [46, 52, 62, 63, 83, 84]. Among these publications, young people were typically engaged in design workshops, consultations or feedback sessions. However, most did not detail decision-making processes

or how youth perspectives shaped research outcomes, raising concerns about the depth of their involvement. Of the publications using the term codesign, few provided detail on how decision-making power was shared. In several cases, young people were consulted or participated in design activities; however, there was limited evidence of coownership of decisions, suggesting that some instances may more accurately reflect consultation rather than codesign.

Participatory action research

Participatory action research (PAR) was typically framed as a socially engaged approach with a focus on empowerment and action. PAR was used in seven publications [56, 58, 61, 63, 67, 80, 83]. PAR involves actively involving participants or coresearchers in all stages of the research process, with a focus on local contexts and working towards action and social change [63]. There were also a number of variations of this methodology, including Indigenous participatory action research [56], community-based participatory research (CBPR) [66, 72] and youth participatory action research (YPAR) [73, 74].

Culbong et al. used Indigenous research methods as part of PAR to amplify diverse voices and promote meaningful action, incorporating the use of cultural engagement activities to establish trust and safety between researchers and research participants [56]. The authors explored the principles underlying participatory research methods, such as open and meaningful participation, shared decision-making and minimizing researcher bias and used a decolonizing research framework which prioritized Indigenous worldviews. The engagement process included an On Country event and the use of shared story experiences to explore points of difference and mutual benefits. Critical consciousness [74] as well as knowledge mobilization [64, 67] are further examples of novel theories used to describe participatory research. Canas et al. [64] and Liebenberg et al. [67] acknowledged the importance of knowledge mobilization in research projects with young people, bridging the gap between academic research and practical application.

In community-based participatory research (CBPR) [66, 72], all partners are equally involved in the research process, recognizing the strengths, responsibilities and learning opportunities that each brings to the partnership. Through a collective empowering process, community members, stakeholders and researchers share responsibility to define problems, collect and interpret data and implement strategies to address these problems ([72] p. 710).

Youth participation [55] and youth participatory action research (YPAR) [73, 74] involve young people as active

citizens. These methodologies value youth researchers as experts in their lives, build empathic understanding of lived experiences and encourage skill-building and healing through radical inquiry ([73] p. 598). Blanchard and Fava defined the young people in their research as codesigners, involved as active participants throughout the design process from problem-setting to problem-solving [55].

Participatory design

Participatory design was used in a smaller number of studies and emphasized collaboration during the design phase, often drawing directly from design and creative disciplines. Participatory design (PD) ($n=3$) was described as specifically involving the people who will benefit from or use a system in its design, emphasizing cocreation and collaboration [55, 77, 84]. A total of two publications that used the term codesign also provided a cited definition of participatory design (PD) (that included the word codesign as part of the definition) [55, 84]. For Hodson, Svanda and Dadashi, PD highlighted a shift from participants being informants to becoming legitimate and acknowledged participants in the design process [84]. Blanchard and Fava also emphasized that PD shifts beyond simply involving young people to a place of cocreating or codesigning with young people [55].

Knowles et al. [77] adopted the term participatory codesign, which, alongside collaboration, blends different forms of knowledge in the design process. Participatory codesign highlights the importance of recognizing lived experiences as valuable knowledge and expertise. As described by Knowles et al., the term codesign is used to describe the collective creativity and working together in the design development process. Knowles et al. describe codesign as collaborating and connecting different knowledge to carry out a design task and explain that coproduction goes further in its participation of people in the delivery process [77]. The publication also mentions the involvement of people in decisions and reviews related to the design.

Discussion

This review focuses on clarifying the concept of codesign as a method for engaging in research with young people in the health and social sciences. Despite codesign being increasingly valued in health sciences for involving historically excluded groups, such as young people, we found a lack of definitions related to codesign. We also found that codesign was not the most frequently used term in the publications identified for inclusion in our review. Additionally, we found that many publications used multiple terms to refer to the collaborative methods

they used, and many studies did not clearly define what they meant by those terms, how those approaches fit together or why they picked those approaches.

Our results align with those of previous reviews (for example, [13, 19]) finding a lack of definitions of codesign or justification for using codesign in included studies. In literature, codesign has been characterized as both a philosophy and a method [85] as well as a process, a set of practical tools and a set of principles [10]. Definitions vary widely, however, with some authors considering codesign as “a tool of human-centred design and design thinking” with “methods involve[ing] bringing together key users, designers and subject matter experts who participate in iterative workshops to understand and empathize with users” ([86], para 5). Others, such as Gilbert et al., define “codesign as a participatory approach to the development of interventions that brings together technical expertise and lived experience from users” ([87] p. 180). Ideally, codesign is “an equal relationship between people who use services and the people responsible for services [through which] they work together from design to delivery, sharing strategic decision-making about policies, as well as decision around the best way to deliver services” ([82] p. 42). Nonetheless, questions remain about the relationship between codesign and other co-terms, with some considering codesign as “part of coproduction, which also includes cocommissioning, codelivery and coassessment of services” ([88] p. 727).

Broadly speaking, a key principle for undertaking participatory research with young people is that any collaborations or proposed interventions must be understood and continually evaluated from the perspective of whether they are relevant, meaningful and engaging to the young people who stand to benefit from them, as well as taking into consideration the potential for harm and their anticipated impact on mental health and well-being outcomes [89]. For instance, knowledge mobilization, as cited by Canas et al. [64] and Liebenberg et al. [67], requires active partnerships and is often cited alongside PAR approaches to effectively disseminate research findings and improve the well-being of communities.

Taken together, our results indicate that the overarching understanding of codesign is that it refers to a collaborative approach where people who will ultimately benefit from or use a system play a critical role in designing it. It involves actively involving participants, often referred to as coresearchers or codesigners, throughout the design process, from problem-setting to problem-solving, and diverse forms of expertise and lived experience are crucial to enhancing health services and outcomes.

Our review highlights that codesign is not necessarily the singular go-to method of choice when engaging young people in research. Rather, a suite of well-established participatory methods are used in conjunction with an intention to collaboratively design, create or produce. For example, Blanchard and Fava used youth participatory action research (YPAR), where young people contribute as design partners, participating in idea generation as well as providing opinions and feedback on existing design concepts [55]. In several cases, the methods and terminology used may shift, such as in Wright et al.'s participatory action research project, whose first stage is referred to as an engagement process and where codesign is used in subsequent project stages [63].

In this regard, codesign appears not dissimilar to other participatory research methods. However, the variability in terminology can result in confusion and misinterpretation of the methods and outcomes, hindering the ability to build a cohesive understanding of the research landscape. Nonetheless, the breadth of definitions speak to a desire for researchers to consider the wants and needs of research subjects or users and also contribute to the rich landscape of so-called co-approaches employed within the fields of health and social sciences. We argue that the application of codesign is very much context- or project-specific and must involve genuine and equitable collaboration among stakeholders in projects that are emergent, adaptable and iterative.

Moreover, our review highlights how terms such as codesign, coproduction and participatory research are used interchangeably, despite stemming from distinct traditions. This ambiguity may relate to where a project sits along a research continuum – for example, codesign is often linked to earlier ideation stages, while coproduction may refer to longer-term collaboration during implementation and evaluation. However, most studies in our review did not make such distinctions explicit, reflecting a broader need for clarity in defining and justifying these approaches.

Limitations

Our scoping review has several limitations. The search strategy employed may have overlooked relevant articles, as it was restricted to studies involving young people, those that were peer-reviewed and those published in English. Additionally, we did not include grey literature, which might have resulted in the findings not fully representing the existing body of research. Another significant limitation is that young people, who are key stakeholders, were not involved in the review process. The review was not conducted using codesign or related principles, potentially limiting its relevance and impact.

Despite these limitations, an a priori protocol was developed before undertaking the scoping review to ensure clear objectives and transparency throughout the process. The review involved two independent reviewers who conducted screening, full-text review and data extraction and analysis. Our scoping review also conducted an extensive and interdisciplinary search with inclusive criteria, considering a wide array of so-called co-terms such as coproduction and coresearch, alongside designations such as experience-based design and human-centred design and established research methods such as participatory action research and community-based participatory research. This enabled us to gain a broad understanding of the context in which codesign has become popular and a comprehensive understanding of the method around codesign.

Additionally, our decision not to include terms such as cocreation, integrated knowledge translation or experience-based design may have resulted in the exclusion of relevant studies. Future reviews may benefit from including a broader range of participatory terms to further map the evolving conceptual terrain of codesign and related approaches.

Implications

While we focused on conceptual clarity of codesign, what is often left out from such definitions are the realities of the ethical negotiations that take place throughout the codesign journey. Moll et al. [85] found that the growing popularity of the term codesign and its methods has made it difficult to determine if the term has been watered down in ways that avoid addressing foundational principles, namely, power distribution in research, enhancement of the human experience and positive societal impact.

We found that codesign is often purported to reduce power differentials between researchers and participants, giving communities greater control over the research process. It promotes the harnessing of diverse expertise and experiences, allowing for ongoing reflection, critique and the integration of ideas. The goal is to create meaningful and engaging interventions that are relevant to the needs and desires of the participants. Codesign can be applied in various contexts, such as research, service development and product design, and it emphasizes collaboration, equity and social change.

Standardized frameworks or models of codesign could help improve definitional clarity as well as evaluation and ethical standards. Several publications in our review cited frameworks or models of participation and engagement. These frameworks, such as Hart's Ladder of Children's Participation, describe levels of decision-making agency, control and power that can be given to

children and youth by adults [90, 91]. Hart's Ladder has become an influential and widely applied model in the fields of child development, education, civic participation and democratic decision-making. The use of frameworks or stepwise codesign processes (that is, trauma-informed approaches [92, 93], CONSIDER statement for working with First Nations peoples [94]) should be carefully considered and tailored to the specific populations of young people involved in the research process.

Conclusions

The aim of this paper was to find conceptual clarity on codesign in research with young people in the health and social sciences. Acknowledging previous review studies (for example, [19]) and recent criticisms of codesign in research [1, 10], we broadened our scoping review search to include publications which may have referred to potential instances of codesign using alternative terms.

We found that codesign has become a popular choice of method in the past decade but is often poorly defined in literature. Codesign was not the most frequently used term in the publications included in our review, and many publications used multiple terms to refer to the collaborative methods they used in their research. There was little justification in our included publications for why certain collaborative approaches were selected or how multiple approaches may fit together. However, the included publications generally emphasized the importance of collaboration, inclusivity and shared decision-making in the research process.

Our findings highlight that, although there is no single, agreed-upon definition of codesign, it is nevertheless essential for researchers to clearly articulate how they understand and apply the term, including its relationship to other participatory approaches. This includes justifying methodological choices in relation to project goals and participant roles and reflecting on how different co-methods intersect or diverge. While coherence and consistency are important for effective communication, flexibility and adaptation remain critical. Codesign can take many forms – particularly in interdisciplinary research – so long as it remains grounded in its core principles of equity, inclusion and active collaboration.

Supplementary Information

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Supplementary material 1.
Supplementary material 2.
Supplementary material 3.

Author contributions

All authors were involved in planning the study. B.L. conducted the searches and B.L. and M.S. completed screening. All authors were involved in data extraction. B.L. and M.S. drafted the manuscript, and all authors were involved in critical revision of the work.

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Availability of data and materials

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Declarations

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Not applicable.

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Competing interests

The authors declare no competing interests.

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