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Lived experience codesign of self-harm interventions: a scoping review

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ABSTRACT

Objectives This study aims to map existing literature describing how people with lived experience of self-harm have engaged in codesigning self-harm interventions, understand barriers and facilitators to this engagement, and how the meaningfulness of codesign has been evaluated.

Design Scoping review by Joanna Briggs Institute methodology. A protocol was published online (http://dx.doi.org/10.17605/OSF.IO/P52UD).

Data sources PubMed, Embase, PsycINFO, Web of Science, Cochrane Library, PROSPERO, ClinicalTrials.gov and relevant websites were searched on 24 December 2022 (repeated 4 November 2023).

Eligibility criteria We included studies where individuals with lived experience of self-harm (first-hand or caregiver) have codesigned self-harm interventions.

Data extraction and synthesis Results were screened at title and abstract level, then full-text level by two researchers independently. Prespecified data were extracted, charted and sorted into themes.

Results We included 22 codesigned interventions across mobile health, educational settings, prisons and emergency departments. Involvement varied from designing content to multistage involvement in planning, delivery and dissemination. Included papers described the contribution of 159 female, 39 male and 21 transgender or gender diverse codesigners. Few studies included contributors from a minoritised ethnic or LGBTQIA+ group. Six studies evaluated how meaningfully people with lived experience were engaged in codesign: by documenting the impact of contributions on intervention design or through postdesign reflections. Barriers included difficulties recruiting inclusively, making time for meaningful engagement in stretched services and safeguarding concerns for codesigners. Explicit processes for ensuring safety and well-being, flexible schedules, and adequate funding facilitated codesign.

Conclusions To realise the potential of codesign to improve self-harm interventions, people with lived experience must be representative of those who use services. This requires processes that reassure potential contributors and referrers that codesigners will be safeguarded, remunerated, and their contributions used and valued.

STRENGTHS AND LIMITATIONS OF THIS STUDY

⇒ Comprehensive search strategy with no restriction on publication date to capture breadth of evidence.
⇒ All papers screened at title/abstract and full-text level by two researchers independently.
⇒ Protocol uploaded to the Open Science Framework prior to conducting scoping review.
⇒ Did not check all published self-harm intervention papers for evidence of codesign, so instances where codesign was not mentioned in the title or abstract could have been missed.
⇒ Only the development paper for each intervention was included— follow-up papers were excluded at full-text level, which may have overlooked additional codesign details.

INTRODUCTION

As health services shift from paternalistic to person-centred care, there is an increasing focus on engaging patients and caregivers with lived experience in designing services.[1] Codesigned services are more efficient and relevant for end-users, foster positive emotions and increase service-user knowledge.[2] Gold standard codesign is both active and embedded, where those with lived experience are equal partners with a meaningful role incorporating creativity, problem-solving and decision-making.[3] Coproduction comprises codesign alongside codelivery.[4 5] Coproduction guidelines state experiential knowledge should be respected by sharing both decision-making and power, so research is jointly owned between researchers and those with lived experience. Building and maintaining relationships should be prioritised through continued dialogue and reflection. Establishing ground rules, valuing reciprocity and flexibility are crucial. Diverse perspectives should be sought, especially from under-represented groups.[6]

Involvement of experts by experience in mental healthcare design is widespread across early psychosis, eating disorders, adult psychological therapies and youth mental health.[7 8] However, the state of the field of codesigned self-harm interventions has not to our knowledge been the topic of a published review.

Self-harm is defined as direct, deliberate harm to one's own body in the absence of suicidal intent, for reasons not socially

sanctioned.[9] The most prevalent forms are cutting, burning, hitting and banging.[10] Self-harm is common. A nationally representative estimate of self-harm in England revealed a lifetime prevalence of 6.4%, with especially high rates in women aged 16–24, a quarter of whom self-harmed.[11]

Self-harm is prevalent in patients with Complex Emotional Needs,[12] with prevalence rates of 95% and 90% in adolescent and adult samples diagnosed with emotionally unstable personality disorder.[13] Self-harm behaviour occurs across a wide range of psychiatric diagnoses. People with depression, substance use and anxiety disorders are at particularly high risk.[14] Self-harm is also present in the absence of comorbidities,[15] prompting the inclusion of non-suicidal self-injury disorder as a condition in the Diagnostic and Statistical Manual of Mental Disorders, Fifth Edition (DSM-V).[16] High-risk groups include the lesbian, gay, bisexual, transgender, queer, questioning, intersex, or asexual (LGBTQIA+) population[17] and those with chronic physical illnesses.[18] A previous systematic review reported significant differences in self-harm rates between ethnic groups, with Asian males being least likely to self-harm and black females being most likely to self-harm. Black and South Asian people were less likely to repeat self-harm relative to white people.[19]

Self-harm can serve to regulate distressing emotions and escape from negative internal states, communicate distress and self-punishment, and can serve an antisuicide function for some.[20 21] However, self-harm is a strong risk factor for future non-suicidal self-harm and completed suicide, with suicide risk up to 49 times the general population.[22 23]

All patients presenting with self-harm should receive information, have family/caregivers involved, undergo psychosocial assessment and have a personalised care plan and risk assessment.[24] A series of Cochrane reviews question the efficacy of existing psychological interventions. In children and adolescents, consistently positive outcomes were found for dialectical behaviour therapy only,[25] and in adults only cognitive behavioural therapy-based psychotherapy and mentalisation-based therapy showed promise.[26 27]

Several streams of evidence suggest existing self-harm interventions are not fit for purpose. There are accounts of patients being refused pain relief in the emergency department due to the self-inflicted nature of their wounds—'I thought you liked pain',[28] or denied medical treatment under assumptions they would re-engage in self-harm.[29] Patients recount stigmatising attitudes from healthcare professionals, labelled 'attention-seeking' for seeking help.[30] Given the rise in self-harm in young people, it is particularly concerning that this age group report feeling let down by clinical services and dropped on discharge.[31]

Patients' perceptions are not unfounded. Clinical staff across emergency departments, general medical and psychiatric settings had feelings of irritation and anger towards those presenting with self-harm.[32] Unfortunately, these experiences are not unique to healthcare settings. Prison officers, nurses and doctors reportedly exhibited hostility towards prisoners who engaged in self-harm.[33]

Collaboration with patients and caregivers to design and implement new approaches and interventions may improve their acceptability and efficacy and build relationships with staff. While one systematic review noted that service-user evaluation of predesigned psychosocial self-harm interventions was rare,[34] there have been no attempts to synthesise research regarding whether and how people with lived experience have codesigned self-harm interventions. Given the stigma surrounding self-harm from medical professionals, as well as self-stigma and the high number of people who self-harm who are not in contact with services,[35] engaging this lived experience group may be particularly challenging. A review in this area is important to identify how codesign has been conducted and unique requirements and challenges to lived experience involvement.

Objectives

The primary objective of this scoping review was to map the extent of lived experience involvement in codesigning self-harm interventions. We also sought to describe how representative codesigners have been of intervention end-users and explore benefits, challenges, barriers and facilitators to codesign. Additionally, we aimed to examine how the meaningfulness of codesign has been evaluated. Given that codesign is an emerging field, we conducted a scoping review, as we considered it the method most suited to our aim of identifying and mapping the breadth of codesign evidence in the area of self-harm. Scoping afforded flexibility and the ability to identify gaps in the literature.[36]

METHODS

This work followed the Joanna Briggs Institute methodology for scoping reviews.[37] Reporting followed the Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) extension for Scoping Reviews Checklist.[38] The protocol is published (http://dx.doi.org/10.17605/OSF.IO/P52UD, online supplemental material 1).

Eligibility criteria

We included studies where individuals with first-hand or caregiver experience of self-harm codesigned interventions, materials or guidelines for self-harm. There were no restrictions on age, gender, diagnosis or publication date. Primary studies, systematic reviews, meta-analyses and grey literature were included. Only English language studies were included. Various collaborative design concepts such as codesign, coproduction, cocreation and patient and public involvement were incorporated. Interventions solely for self-harm where the intention was to die were excluded. Involvement restricted to consultation

or giving feedback on pre-existing interventions was excluded.

Information sources

On 24 December 2022, we searched the following databases using a comprehensive search strategy comprising three concepts ('codesign', 'self-harm' and 'intervention'): PubMed, Embase, PsycINFO, Web of Science and Cochrane Library, as well as grey literature in PROSPERO, and ClinicalTrials.gov. Online supplemental materials 2 and 3 detail the complete search strategy and example search. Websites were also scoped for relevant content: Department of Health, National Institute for Health and Care Research (NIHR), National Institute for Health and Care Excellence, The McPin Foundation, Royal College of Psychiatrists, Harmless, YoungMinds, MQ Mental Health Research and Mind. The search was updated on 4 November 2023.

Procedures for analysis

Following deduplication, all records were screened for eligibility at title and abstract level, then at full-text level, by two researchers independently (LCW and NLC). Disagreements were resolved via discussion with a third person (CC). Decisions were recorded using Rayyan (https://www.rayyan.ai/).

We conducted a qualitative content analysis.[39] LCW extracted the following data from included articles: authors, year and publication type, country, setting, intervention, self-harm definition, aims, methods, population, extent of codesign involvement, benefits/challenges and facilitators/barriers. During extraction, we decided that remuneration and evaluation of codesign activities should also be extracted. Frequency counts were made of types of publication, country, definition of self-harm and demographics of codesigners. A deductive approach was used to map before, during and after codesign data against key principles in NIHR guidelines for coproduced work including sharing power, including all perspectives, valuing contributor knowledge, reciprocity, and building and maintaining relationships.[6] Data were categorised into intended user group, intended setting, aims, methods, role of the codesigner and barriers/facilitators, for reporting.

Patient and public involvement

Patients or the public were not involved in conducting this review.

RESULTS

Database searching returned 2737 records. Following deduplication, 1814 titles and abstracts were screened for eligibility. 71 full texts were assessed, of which 17 were included. Two additional materials were identified through web searches and one through references. The updated search yielded 328 results. After deduplication, 210 titles and abstracts were screened and 4 papers were read at full text level, of which 2 were included. A final 22 studies were included. The PRISMA flow chart in figure 1 summarises the selection process.

Details of codesigned interventions, materials and guidelines are outlined separately for young people[40–51] (table 1) and adults[52–61] (table 2). We included 14 qualitative studies, 2 quantitative, 1 mixed methods, 1 commentary, 2 protocols (for future codesign and evaluation of self-harm interventions) and 2 web pages outlining coproduced materials. Thirteen studies took place in the UK, the rest in Australia, India, the USA, New Zealand, Canada and Taiwan. All were published between 2005 and 2023.

Four interventions were for non-suicidal self-harm,[40 47 54 61] while eight interventions did not discriminate based on suicidal intent.[43–46 48 50 51 60] The remaining sources did not define self-harm or the definition did not reference intent.

What interventions have been codesigned?

Of the 12 interventions designed by and for children and young people, 4 were mobile health technologies.[42–45] Four were resources to support care providers—primary care practitioners,[40] general hospital children's nurses,[41] parents and teachers,[49] and school staff.[48] In educational settings, young people codesigned and co-ran a self-injury group[47] and codesigned outcomes for self-harm interventions, which informed a Cochrane review.[50] Youth in India codesigned a psychological intervention for use in low-income and middle-income countries.[46] Young people also codesigned guidelines for safe online communication about self-harm.[51]

Mobile health interventions were also the focus of three interventions codesigned by adults with lived experience of self-harm,[52–54] and one protocol for a planned brief contact intervention.[55] Adults also codesigned materials to aid professionals and caregivers, including a handbook for mental health trusts[61] and self-harm awareness training delivered by experts by experience.[57] Women's prisons were the focus of three interventions.[58–60] Finally, adults codesigned an activity workbook for self-harm recovery.[56]

To what extent, and using which methods, were individuals with lived experience involved?

Before codesign

Three studies describe how people with lived experience were involved in planning how studies would be conducted or evaluated, or in securing funding. In one study, people with lived experience identified the need for a co-run self-injury group within their American college campus.[47] Service-users were also involved in the grant phase and protocol development,[52] and informed study outcomes.[60]

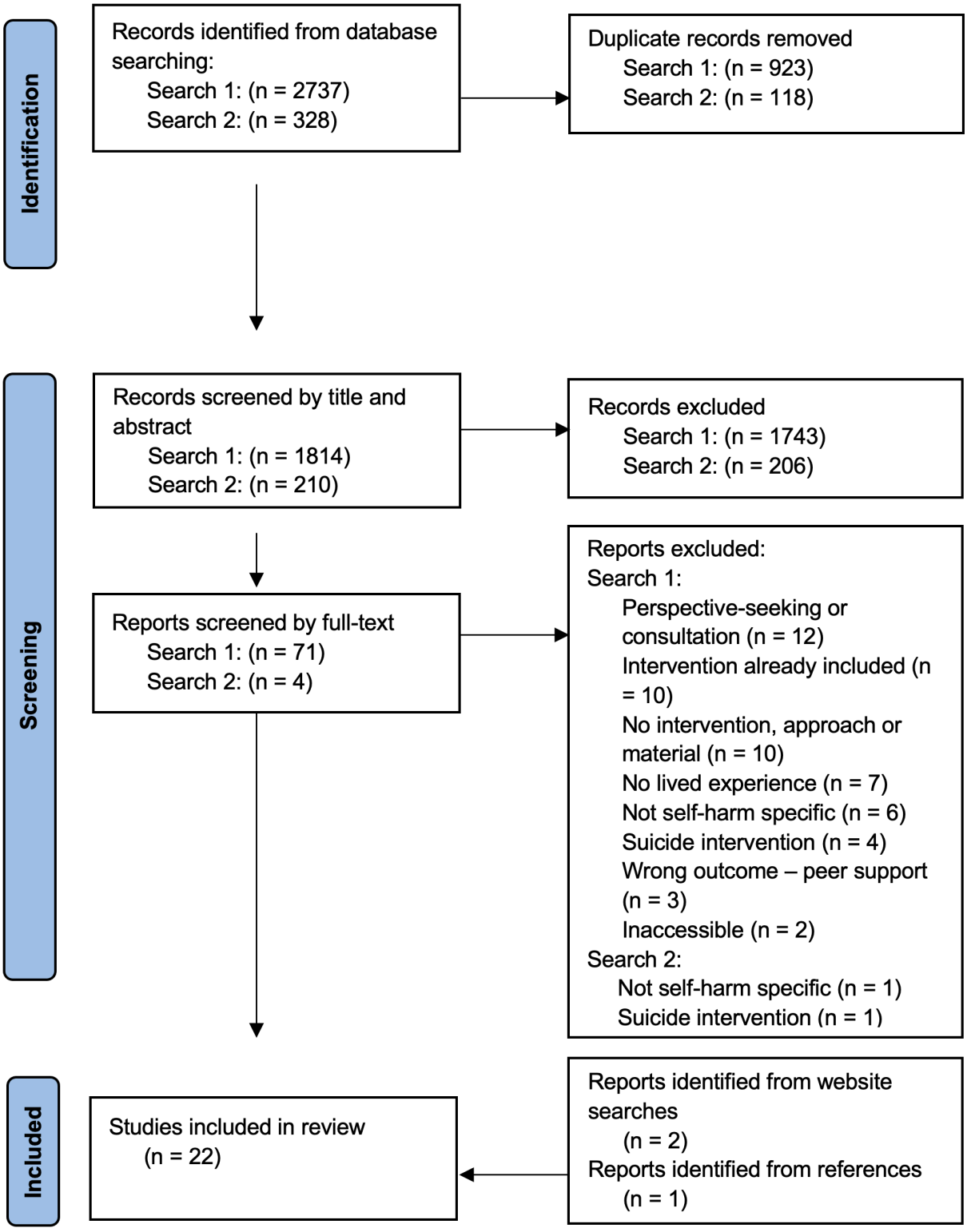

Figure 1 PRISMA flow chart of the screening process. Search 1 conducted 24 December 2022. Search 2 conducted on 4 November 2023. PRISMA, Preferred Reporting Items for Systematic Reviews and Meta-Analyses.

During codesign

One study engaged people in online workshops[50] while the remaining codesign was face-to-face via workshops, focus groups and interviews. Using sticky notes, codesigners wrote and thematically sorted triggers, urge-reduction messages, and characteristics of groups who self-harm for Txt4shs, with further workshops to personalise and refine the intervention.[53] Over four workshops young people sketched intervention features as individuals, obtained group feedback, then prioritised optimal features for the

Table 1 Description of included studies involving young people in codesign of self-harm interventions

Author/year/country	Intervention/guideline/resource	Intended setting	Codesign aims	Methods	Stakeholders	Extent of involvement
Bailey *et al* (2019) UK [40]	Self-help materials for young people	Primary care	Develop materials to aid general practice self-harm consultations	Participatory action research: focus groups with young people, general practitioners, practice nurses; thematic analysis on focus group transcripts	N=15 aged 16–25 years with experience of self-harm recruited by snowball sampling 1 mixed race, 14 white; 8 M, 7 F 14 GPs and 16 practice nurses	Review and create materials, share help-seeking experiences
Latif *et al* (2017) UK [41]	Our Care through Our Eyes e-learning for rCNs	General hospital	Coproduce a digital educational programme for rCNs caring for CYP who self-harm	rCN workshop: set priorities for their learning CYP workshop: generate ideas for e-learning	4 CYP admitted to CAMHS for self-harm treatment in past 12 months Mean age 15 years. All F 19 nurses	Development workshop—shared hospital experiences, used flip charts and storyboards to design training package, suggested how e-learning could be more engaging
Hetrick *et al* (2018) Australia[42]	Symptom monitoring app 'Well-being tracker' Safety features	App for those in face-to-face treatment	Codesign app for young people with major depression/ at risk of self-harm to self-monitor mood	4 codesign workshops with young people 2 codesign workshops with clinicians—identify concerns	Current/former mental health service clients, treated for depression which may have included self-harm Gender: 3 M, 8 F; Mean age 21.4 years 16 clinicians	Designed app features, individually and as group. 1 young person presented design to clinicians App designers sorted focus group notes into themes
Owens and Charles (2016) UK[43]	TeenTEXT: self-management text-messaging intervention	App for adolescents under CAMHS clinician	Redevelop adult text-messaging intervention for adolescents	Redevelopment: tailored components of adult intervention Adapt intervention through its use Focus group with CAMHS team—understand barriers to implementation	Development work: CAMHS patients with experience of self-harm, 3 clinicians Feasibility work: 1 clinician–client dyad	Development work: creative workshops to alter adult intervention; delivery design by researchers, software developers, clinicians. Feasibility work: use intervention for 6 months and provide feedback

Continued

Table 1 Continued

Author/year/country	Intervention/guideline/resource	Intended setting	Codesign aims	Methods	Stakeholders	Extent of involvement
Stallard *et al* (2018) UK[44]	BlueIce smartphone app: toolbox of CBT/DBT strategies	App for 12–17 year olds in face-to-face therapy	Create, refine, evaluate smartphone app Evaluate BlueIce	Coproduction between young people, clinical staff, academics, app developers Workshops with clinicians Phase 1 evaluation of acceptability, safety	Development: young people with lived experience of self-harm and clinicians (n unknown, recruitment source unknown) Evaluation: 40 young people with current/past self-harm	Coproduced app—design, layout, flow, content
Thabrew *et al* (2023) New Zealand[45]	Village: communication app for low mood, self-harm, suicidal ideation	App for young people	Codesign app with young people and family/friends to connect young people to self-nominated support network	6-month iterative process 'Sprints'—rapid cycles of designing, developing, testing Deliverable product at end of each sprint	N=40 youth including many who had experienced low mood, self-harm, suicidal ideation N=20 family members N=3 mental health clinicians N=6 IT specialists	'Scrums'—regular team meetings with 1 person with authority, 1 facilitator, rest of team. Team holds joint responsibility for product Mental health content drafted by psychiatrist and users provided feedback
Aggarwal *et al* (2021) India[46]	ATMAN: counsellor delivered psychological intervention	Youth in LMIC	Codesign a scalable psychological intervention to reduce self-harm and improve functioning	Phenomenological thematic analysis of interviews; systematic review—identify effective elements of existing interventions 2 rounds of development workshops	Youth aged 15–24 who presented to psychiatry department after self-harm (n=15); caregivers (n=4) Development work: N=6 young people, N=5 MHPs Finalising structure: N=7 young people, N=5 MHPs	Interviews on self-harm experience—identify intervention outcomes Workshop round 1—reflect on experiences, feedback on review, identify missing elements Workshop round 2—feedback to finalise structure
Kokaliari and Lanzano (2005) USA[47]	Consumer-therapist co-run self-injury group	American colleges	Design and run group for self-injury on principles of consumer empowerment	Plan and facilitate group	Members of consumer-run, campus mental health organisation with experience of self-injury 2 student consumers, 2 counsellors	Brainstormed solutions to increased self-injury Planned group, delivered with professionals Equal team members, all decisions made jointly

Continued

Table 1 Continued

Author/year/country	Intervention/guideline/resource	Intended setting	Codesign aims	Methods	Stakeholders	Extent of involvement
Meinhardt *et al* (2022) New Zealand[48]	New Zealand-specific guidelines for school staff managing self-harm	New Zealand high schools (age 12–19 years)	Develop culturally responsive guidelines for school staff supporting students who self-harm, consistent with bicultural principles	Delphi expert consensus method: Literature review Interviews with school staff Expert panels (youth and stakeholders) chose items for guidelines Rōpū Mātanga Māori resolved discrepancies	N=30 youth: aged >16 (2 no self-harm experience, 15 lived experience, 22 knew someone, 19 supported someone; 24 F, 5 M, 1 trans woman) recruited from youth advisory group. N=34 researchers, MHPs, school staff (1 no experience, 6 lived experience, 26 know someone, 28 supported someone) 46.9% European, 28.1% Māori, 18.8% Pacific Peoples, 6.3% Asian	Questionnaires—suggest new recommendations Voted on which recommendations included in guideline Acknowledged as guideline contributors
Bush (2016) UK[49]	No Harm Done: digital information pack, 3 short films	Variety	Cocreate resources for people supporting those who self-harm	Collaboration between YoungMinds, The Charlie Walker Memorial Trust, Royal College of Psychiatrists	Young people, parents	Shared their stories
Knowles *et al* (2022) New Zealand and UK[50]	Outcomes for Cochrane review of self-harm interventions for educational settings	Educational settings	Identify methods to generate outcomes, design outcomes important to young people, compare to typical review outcomes	Participatory codesign workshops Thematic analysis on generated ideas	N=28 young people with individual or friend/family experience of self-harm New Zealand: 5 M, 8 F between 16–23 years: 6 Māori, 4 New Zealand Europeans, 4 Asian UK: 11 F, 3 M, 1 non-binary Recruited from professional networks and young people's organisations	Workshops: design review and generate outcomes Pick 3 'must include' and 'must exclude' outcomes Collaboration to reach final 6 outcome themes Input on how outcomes could be measured

Continued

Table 1 Continued

Author/year/country	Intervention/guideline/resource	Intended setting	Codesign aims	Methods	Stakeholders	Extent of involvement
Robinson *et al* (2023) Australia[51]	#chatsafe guidelines for online communication about self-harm	Online	Update existing suicide guidelines to include guidance on safe creation and consumption of online self-harm content	Delphi expert consensus method: Literature review Roundtables with stakeholders Expert panel formation Guideline development Dissemination	Roundtables: N=7 young people (5 F; mean age 20.7 years) Expert panels: N=74 young people (59.5% F; 25.7% trans or gender diverse; 14.7% M; mean age 21.3 years; 82.4% living or lived experience of self-harm or suicide; 54.1% LGBTQIA+; 23% from culturally/linguistically diverse background) N=29 professionals (experts in self-harm or suicide)	Roundtable discussion regarding online communication about self-harm/suicide and suggestions for the guidelines Expert panellists voted on items for inclusion Young people will codesign a national social media campaign to disseminate guidelines

CAMHS, child and adolescent mental health services; CBT, cognitive behavioural therapy; CYP, children and young people; DBT, dialectical behavioural therapy; F, female; GP, general practice; LGBTQIA+, lesbian, gay, bisexual, transgender, queer, questioning, intersex, or asexual; LMIC, low-income and middle-income country; M, male; MHPs, mental health professionals; rCN, registered children's nurses.

Table 2 Description of included studies involving adults in codesign of self-harm interventions

Author/year/country	Intervention/guideline /resource	Intended setting	Codesign aims	Methods	Stakeholders	Extent of involvement
MacLean *et al* (2018) Canada[52]	BEACON Smartphone assisted problem solving therapy	Emergency department (ED)	Design self-harm intervention for men and develop recruitment strategy to engage men who present to ED with self-harm	Design intervention and subsequent randomised controlled trial Held conference—discuss service user–researcher collaboration	Unknown for app development Coinvestigators: 2 service-users with lived-experience of self-harm	Designed intervention Involved in all stages: grant phase, development of protocol, steering committee, creation of Service User and Caregiver Research Interest Group in suicide prevention
Owens *et al* (2011) UK[53]	Txt4shs (Text for Self-Harm Support): personal coping statements on demand	ED	Develop text-messaging intervention to reduce self-harm Decide right message, right person, right time	6 participatory workshops	8 mental health service-users with history of self-harm (6 F, 2 M, aged 18–50+ years, all self-harmed for >5 years), 1 carer Recruited from existing networks 3 clinicians	Workshops to discuss style, content and time of messages Shaped intervention to be tailored to the individual Changed from push to pull messaging
Birbeck *et al* (2017) UK[54]	7 digital designs including mood tracker, digital stress ball, harm reduction intervention, platform for caregivers	Variety of settings	Conduct a hackathon involving those who would use self-harm technologies	'Self Harmony' hackathon—create new self-harm digital interventions Outputs presented to statutory and voluntary service providers for feedback	N=8 with lived experience of self-harm Medical trainees (n=4), researchers (n=4), technologists (n=15), designers (n=5), charity workers (n=5), members of public (n=4) N=3 lived experience mentors Recruited via advertisements	Provide accounts of self-harm to be incorporated into study design Lived experience speaker to inspire participants Involved in intervention design process Mentors ensured sensitive engagement with self-harm
Chang (2022) Taiwan[55]	Text and web-based Brief Contact Intervention	Mobile health	Codesign and evaluate feasibility of BCI to reduce repeated self-harm	Establish codesign team Evaluate feasibility in 30 participants through delivery of BCI for 5 months	Aiming for 4–6 service users, 4–6 service providers	Focus groups—design content, frequency, setting, outcome measures Interviews on participation in codesign team
Harmless (n.d.). UK[56]	Self-harm workbook	Variety	–	–	Service users, therapists	Workbook developed collaboratively with service users, therapists and Institute of Mental Health
NICE (2012) UK[57]	Changing Minds training course, staff awareness training	Variety	Trainers to design and codeliver mental health awareness training courses	9-month part-time training course—develop skills to codesign and codeliver training	Previous secondary mental healthcare inpatients or in contact with secondary mental health services	Deliver training on self-harm awareness Once experienced design own courses, provide support and mentor
Ward *et al* (2012) UK[58]	At Arm's Length: staff self-harm awareness training	Women's prison	Develop staff awareness training session about self-harm	Participatory action research: planning, action and critical reflection stages	Women prisoners with lived experience of self-harm (N=6 for focus group, N=2 for development)—self-selection Prison staff	Questionnaires/ interviews—identify need for training Focus group—helpful management, responses from staff, key messages Development of training package Codelivery of the training sessions with researcher
Ward and Bailey (2013) UK[59]	Self-harm management pathway: training package, sensory room, in-cell activities, trauma service	Women's prison	Outline service user involvement conducted in a custodial setting to develop a care pathway for self-harm	Participatory action research Literature review on self-harm in prisons	Prisoners with recorded history of self-harm invited to take part Process mapping events: N=9 women, N=7 staff Interviews: N=15 women, N=13 staff	Share narrative accounts of self-harm Questionnaires and interviews on self-harm, suggestions for care development Combined with review data Focus groups to discuss themes

Continued

Table 2 Continued

Author/year/country	Intervention/guideline /resource	Intended setting	Codesign aims	Methods	Stakeholders	Extent of involvement
Mitchell *et al* (2019) UK[60]	COVER: Medical skin camouflage (MSC) clinics for self-harm scarring	Women's prison	Train long-term prisoners to deliver intervention Assess feasibility and acceptability of MSC	Patient and public involvement (PPI) Phase 1) Focus groups Phase 2) adaptation of MSC intervention, develop training/ intervention protocols Training of long-term prisoners Randomised controlled trial (RCT)	Separate focus groups (N=10 women prisoners with self-harm experience; N=10 prison staff) 2 experts by experience Aim to train 6–10 long-term prisoners with personal experience of self-harm and at least 10 years left on sentence, who already hold a prison position of responsibility	PPI—informed outcome measures Select women-centred outcomes, decision to be trained by other prisoners, use of diary. Codesigned all materials for participants Will train long-term prisoners to deliver MSC Will design dissemination event to present RCT outcomes. Post-RCT reflective focus groups
Pengelly *et al* (2008) UK[61]	Alternatives to Self-harm Service User Handbook	Adult mental health trusts	Develop a handbook to promote collaborative working between people who repeatedly self-harm and front-line health professionals	Content from: Literature search and website searches Interviews with service users Input from mental health staff	N=6 service users with long histories of self-harm (recruitment source unknown) N=6 nurses and N=4 managers from self-harm teams Feedback from N=6 service-users (from user groups) and N=13 professionals	Content determined by literature, interviews, correspondence with self-harm teams Modified handbook based on feedback Service users involved in training on handbook's use

BCI, brief contact intervention; F, female; M, male; MSC, medical skin camouflage; NICE, National Institute for Health and Care Excellence; PPI, patient and public involvement.;

final group design.[42] Young people and their families were involved in 'sprints' and 'scrums' to iteratively develop the Village app—working as a team to a deadline.[45]

Using information gleaned from other stakeholders or literature alongside service-user design was common.[61] Themes emerging from statistical analysis of medical records and challenges identified by general practice staff guided focus groups to source and create self-help materials for self-harm consultations.[40] Registered children's nurses identified their training needs, on which workshops were held with children and young people who used storyboards to reflect on their experiences and decide what should be included.[41]

Voting was frequently used in decision-making. Designing a psychological intervention, youth added missing elements to those identified through interviews and a systematic review, voted on elements for inclusion and built elements into modules.[46] Young people codesigned a review for self-harm interventions by anonymously suggesting review outcomes which were combined with typical outcomes recorded in trials and voted on for inclusion.[50] Two studies employed the Delphi expert consensus method whereby stakeholders voted on items obtained from literature searches and interviews with professionals and experts by experience for inclusion in guidelines for school self-harm management[48] and online communication about self-harm.[51]

The Self Harmony hackathon uniquely included people with lived experience as designers, as inspiration through sharing their experiences, and as mentors to ensure sensitive engagement with self-harm.[54] No Harm Done materials were also unique since sharing self-harm stories on film was the cocreation contribution, using real-life experiences to dispel myths.[49]

Extent of codesign involvement was less clear when interventions were not afforded a separate development paper,[52] involving creative workshops,[43] creating, refining and evaluating an app,[44] and collaborative development of a prison self-harm pathway[59] and self-harm workbook.[56] Service-users will be involved in developing the content, settings and outcomes of a brief contact intervention.[55]

Four studies involved codelivery. Students planned topics for and facilitated a college self-injury group alongside counsellors.[47] People with lived experience also designed and codelivered self-harm awareness training.[57] In prisons, women designed outcomes for an existing intervention[60] and a staff training package,[58] which will be delivered by other prisoners with self-harm experience.

All decisions regarding the co-run self-injury group were made between consumers and counsellors who were viewed as equals.[47] However, elements of some interventions were determined prior to lived experience involvement—content type and web-based nature,[55] mood monitoring features,[42] and an existing intervention for redevelopment.[43]

After codesign

App design ideas,[42] guidelines,[51] handbook training[61] and findings[60] were (or planned to be) codisseminated. Only one paper explicitly stated those with lived experience were acknowledged as contributors on final guidelines.[48] Continued dialogue was rare, though people with lived

experience not only codesigned the BEACON intervention but were coinvestigators in a subsequent randomised controlled trial.[52]

Remuneration

This varied from a certificate[48] to travel reimbursement and food provision,[54] vouchers,[41 48 50] hourly pay[42 53] and unspecified payment for involvement.[51 57] More attractive incentives were proposed to encourage recruitment.[41] Prison settings did not detail reimbursement, but stated the intervention would not interfere with women's income.[60] Others offered training opportunities such as conference attendance.[52] No papers outlined the rationale for their chosen reimbursement, nor the time commitment of contributors.

Who is involved in codesign?

Most work included individuals with personal self-harm experience recruited via services,[41 46] existing team networks,[42 48 53] young people's organisations,[49 50] advertisements,[54] social media[51] or college mental health organisations.[47] Snowball sampling was common.[40 42 52] To manage risk, some studies excluded individuals who self-harmed in the past 3 months[42] or were receiving acute hospital care for their self-harm.[41] There was some gatekeeping to involvement by healthcare professionals and prison staff who excluded people if they were not deemed suitable for workshops[41] and selected prisoners who were most 'suitable' for intervention delivery or already held positions of responsibility.[58 60] Six studies also involved family or caregivers.[45 46 48–50 53] In some studies, codesigners varied across the development process[53] or new individuals were added to make final modifications.[46]

In studies reporting demographics of lived experience codesigners, 159 were female and 39 were male.[40–42 48 50 51 53 58–60] In one study, 19 codesigners were trans or gender diverse—over a quarter of the sample.[51] In other studies, only one non-binary person and one transwoman were included.[48 50] Few studies reported ethnicity. Young people who codesigned materials for UK general practice were overwhelmingly white,[40] while two New Zealand studies sought Māori and non-Māori representation and recruited a Rōpū Mātanga Māori (clinical cultural governance group) to ensure Māori-centred work, given higher self-harm rates among this population.[48 50] A study based in India recruited from the local population to develop an intervention for low-income and middle-income countries.[46] Only one study reported details of employment, educational level and sexual orientation—with over half of their codesigners identifying as LGBTQIA+.[51] No studies presented information on self-harm frequency (besides meeting an inclusion cut-off) or comorbidities.

What were the barriers and facilitators to self-harm intervention codesign?

Barriers and facilitators fell broadly into the categories of recruitment, safeguarding, enabling collaborative involvement, time and funding, and placement within the wider mental health system (see table 3).

Was codesign meaningful?

Meaningfulness of lived experience involvement may be discerned from how codesign benefited the intervention or reports from codesigners on the impact of their involvement. Several papers outlined positive impacts of their codesign efforts but did not report how these were assessed, for example, enabling the lived experience voice to be heard[41 42 47 50] and making interventions relevant to end-users.[41 48 52] Codeliverers reportedly broke down barriers to professional-run groups, served as role models for attendees,[47] developed transferable skills,[57] provided meaningful work and addressed the inmate-officer divide of a prison setting.[59 60] However, few studies quantified the degree or success of these activities.

Three studies explicitly documented how lived experience contributions impacted intervention design. Young people identified more asset-based outcomes for self-harm interventions ('better coping' and 'safer environment to talk about self-harm') than typical self-harm reduction/cessation, prompting researchers to transform their review.[50] Researchers were challenged on their preconceived idea to subcategorise people who self-harm and send generic support messages at prespecified times. Highlighting the personal nature of self-harm and potentially detrimental effects of receiving blanket messages paved the way for the highly personalised Txt4shs app.[53] The Self Harmony hackathon informed a platform where digital mental health tools will be open-sourced.[54]

Three studies involved reflections on the codesign process. Assessments conducted with Changing Minds cotrainers revealed involvement gave them a valued role, increased self-esteem and confidence to develop supportive social networks and challenge discrimination.[57] One codeliverer of prison self-harm awareness training reflected how the experience increased their self-esteem, confidence and acceptance of their own self-harming frequency. Additionally, most staff recipients reflected that the lived experience perspective was the most useful element.[58] Reflective focus groups with young people and clinicians highlighted short consultations as a limiting factor of their codesigned materials.[40] Some studies conducted debriefing but did not include what was discussed.[47 50]

DISCUSSION

In this scoping review, we identified 22 codesigned interventions, approaches and materials for self-harm across settings. Though codesign arose in the 1970s,[62] most studies were published in the 2010s, in the UK. This surge in codesign publications is perhaps unsurprising given increasing self-harm prevalence, particularly in young people and the recent push towards lived experience involvement.[63 64] 12 interventions were designed by and for children and young people and 10 by adults. Where

Table 3 Barriers and facilitators to codesign of self-harm interventions by people with lived experience

Factor	Barriers	Facilitators
Recruiting people with lived experience	► Recruitment challenges[41] ► Parents/guardians, clinical or prison staff had to deem codesigners suitable[41 58 60] ► High attrition due to: – Being too unwell[43] – Fluctuations in mental state and personal circumstances[53] – Study length[48]	► Support to withdraw and rejoin[52] ► More incentives[41] ► Online opportunities for involvement[41]
Safeguarding	► Feared repercussions: – Peers becoming aware of self-harm history[42] – Relationship issues between prisoners and staff[58] – Self-harm exacerbation[59] ► Intense and draining nature of involvement[47]	► Ground rules regarding personal disclosure[46 50] ► Completion of a "wellness plan" (not elaborated on) prior to participation[42] ► Support from youth workers and clinical psychologists[50] ► Mental health charity input to ensure codesign activities are sensitive[54] ► Provision of safe spaces to relax or obtain support from volunteers[54] ► Follow-up debriefing and phone calls to check well-being[47 50]
Enabling collaborative involvement	► Methods too didactic or formal with minutes and agendas were difficult to engage with[50 52] ► Skills deficits for example in scientific literature searching limited lived experience involvement[53] ► Power imbalances within the prison system[59] ► Competing preferences between younger adolescents and older adolescents[45]	► Use of a 'persona' method to overcome challenges eliciting review outcomes: cases of young people self-harming are presented, and codesigners asked how cases would be better after a successful intervention[50] ► Creating a safe space[52] ► Assuring there are no right or wrong answers[41] ► Placing service-users in leadership roles to avoid tokenistic involvement[57 59] ► Ensuring a two-way relationship where service-users benefit from: – Skill development[42] – Training opportunities[52] – Payment[57]
Time and funding	► Radical revision of pre-determined ideas slows app development[53]	► Flexibility from funding bodies who are willing to tolerate uncertainty[53] ► Adequate funding to build relationships with clinical teams and cover timespan necessary to incorporate lived experience input[43 57]
Wider mental health system	► Clinician availability may not permit service-user designs[42] ► Professional views may not align with service-user designs[51 61] ► TeenTEXT unable to go through further codevelopment due to burden of new technology on burnt-out Child and Adolescent Mental Health Services[43] ► Institutional stigma regarding capacity of service users to deliver training[57]	► Presence of professionals to support individuals who may otherwise be reluctant to run a self-injury group[47] ► Anticipate and rectify barriers, for example, service capacity early[43] ► New practices rather than trying to fit codesign into typical research practices[52]

characteristics were reported, codesigners were predominantly women and were in contact with mental health or prison services. Only those studies in which the impact of codesign on the end-product was clearly documented,[50 53] and where codesigners were involved in all stages of the research,[52] appear to closely align with gold-standard guidelines.[6] However, inconsistent detail of reporting between studies makes this difficult to assess. This was the first review to explore depth of lived experience involvement in the self-harm field, factors that help and hinder codesign and meaningfulness of involvement. A robust search strategy across multiple databases enabled a thorough examination of the literature.

Our findings indicate lived experience codesign varied from designing aspects of interventions with considerable input from the literature and other stakeholders, through to multistage involvement in design, delivery and dissemination, with equal decision-making say. It

may be misinformed to aim for equal involvement in all decisions—guidelines state there can still be a leader, whether they are a service-user or another stakeholder.[6] Few studies fostered involvement beyond initial design activities which may be viewed as tokenistic if codesigners are unable to see the impact of their involvement, particularly having shared personal information.[65 66]

Many stated benefits of codesign such as making interventions relevant to end-users and breaking down the staff—service-user divide lacked tangible empirical or qualitative evidence. Barriers and facilitators of codesign fell into themes of recruitment, safeguarding, involvement methods, time and funding, and mental health services. Meaningful coproduction should be 'equitably remunerated'[67] and 'commensurate with the nature and demands of the activity'[68] though, where reported, remuneration varied from a certificate of participation to hourly pay and did not meet recommendations.[69 70]

Unrepresentative stakeholders or involvement activities that exclude the most vulnerable in society could perpetuate power imbalances in self-harm interventions. Codesigners were predominantly cisgender women, especially in prison systems where codesign only took place in women's institutions. While this gender imbalance reflects self-harm prevalence, a significant number of men are affected.[71 72] Ethnicity was infrequently reported. Higher-risk groups including those acutely unwell, those with physical or mental health comorbidities and the LGBTQIA+ population[73] were under-represented, except in one study where over half of codesigners identified as LGBTQIA+, in line with their over-representation in self-harm statistics.[51] Self-harm may present differently in the context of certain conditions and tailored interventions may be required. Additionally, since self-harm is a somewhat hidden phenomenon, interventions designed by those in contact with services may not represent the needs of the wider population who self-harm.[64] While online workshops remove geographical constraints to participation, they may be prohibitive for those lacking technology access. Indeed, research suggests experts by experience should be provided with the necessary equipment to remove barriers to involvement.[65]

Strategies such as snowball sampling and recruitment via existing networks may explain the lack of diversity in these lived experience samples. There was an element of clinician gatekeeping such that only those deemed suitable to take part acted as codesigners, though the criteria for suitability were often not reported. It is conceivable that ethics committees may have prohibited the involvement of those at greatest risk to themselves, but greater transparency documenting the inclusion process is required to confirm this.

We see the crucial next step as breaking down barriers to inclusion of the most vulnerable groups with lived experience of self-harm to ensure a representative set of voices are heard. We suggest that future publications of codesigned self-harm interventions describe: how codesigners are recruited, their demographics, time commitment and the rationale behind remuneration decisions. More transparency is needed regarding any inclusion criteria employed when recruiting codesigners, their comorbidities, contact with services and frequency of self-harm, to assess inclusivity. Researchers should outline barriers and facilitators to codesigning their intervention to inform subsequent practice. Continued dialogue and reflection after the design phase enable evaluation of the impact of coproduction activities and prevent tokenism.

Limitations

We recognise that the dichotomy between non-suicidal self-injury and self-harm with the intent to die is contentious, particularly given the increased risk of suicide following self-harm.[74] For this reason, we included interventions for self-harm where the intent was not specified, however, we excluded interventions for self-harm where the intent was to die as we believe this speaks to a different literature on suicide, where there is a host of codesigned interventions beyond the scope of this review. Though our search strategy was comprehensive across multiple databases, papers where search terms were not referenced in the title or abstract may have been overlooked. Our exploration of the representativeness of codesigners was limited by several papers not describing characteristics of those involved. Given the imperative for codesign of services in many countries, the relative paucity of evidence found suggests many codesign activities may be unpublished.

CONCLUSIONS

Codesign of self-harm interventions is becoming more frequent, but work is required to improve representation, in particular from ethnically diverse, male and higher-risk individuals. Additional safeguarding measures and support from relevant mental health or LGBTQIA+ champions to ensure sensitive involvement could empower a wider group to have their voices heard. Addressing financial, technological and systemic barriers and raising awareness of codesign opportunities could increase accessibility, as could greater transparency in documenting codesign decisions.

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