Title

The Use and Reporting of Experience-Based Co-Design Studies in the Healthcare Setting: A Systematic Review.

ABSTRACT

Background

Experience-based co-design is an approach to health service design that engages patients and healthcare staff in partnership to develop and improve health services or pathways of care. The aim of this systematic review was to examine the use (structure, process and outcomes) and reporting of experience-based co-design (EBCD) in health service improvement activities.

Methods

Electronic databases [MEDLINE, CINAHL, PsycINFO and The Cochrane Library] were searched to identify peer-reviewed articles published from database inception to August, 2018. Search terms identified peer-reviewed English-language qualitative, quantitative and mixed-method studies that underwent independent screening by two authors. Full texts were independently reviewed by two reviewers and data independently extracted by one reviewer before being checked by a second reviewer. Adherence to the 10 activities embedded within the 8-stage EBCD framework was calculated for each study.

Results

We identified 20 studies, predominantly from the United Kingdom and in acute mental health or cancer services. EBCD fidelity ranged from 40-100% with only three studies satisfying 100% fidelity.

Conclusion

EBCD is used predominantly for quality improvement, but has potential to be used for intervention design projects. There is variation in the use of EBCD, with many studies eliminating or modifying some EBCD stages. Moreover, there is no consistency in reporting. In order to evaluate the effect of modifying EBCD or levels of EBCD fidelity, the outcomes of each EBCD phase (i.e., touchpoints and improvement activities) should be reported in a consistent manner.

Systematic review registration

PROSPERO: CRD[redacted]

INTRODUCTION

There is widespread and active involvement of service-users, their carers and family members in activities relating to healthcare.[1-4] In terms of quality and safety, partnering with service-users is not only required for effective individual care, but also for healthcare service design, overall governance, policy and planning.[4] Active engagement of service-users in the planning and development of healthcare is key to effecting change.[5] As such, research on co-design and co-production with consumers in health care has a relatively long history..[6-9]Evidence from a 2013 systematic review (40 studies) suggests that the patient experience, when robustly collected and analysed, is positively associated with clinical effectiveness and patient safety.[10] A more recent systematic review of 65 co-design studies of health care suggests that co-design encourages shared goals and might improve service-user/–provider relationships and communication, subjective health outcomes and service-user satisfaction with the service provided.[8] However, co-design in healthcare is notoriously difficult to implement. Barriers to its successful implementation include a lack of resources (e.g., funding, co-design facilitators) and managerial support, staff turnover, logistical barriers for engaging vulnerable service-users and cohort retention.[6] Despite these barriers, in the last 5 years there has been an increase in published co-design work.

Experience-based co-design (EBCD) is a relatively newer form of participatory action research that involves service-users, first piloted in 2005 to improve the care and treatment experience of head and neck cancer patients and their carers.[11] It integrates ethnographic research and service-design methods with the principles of consumer engagement to improve patient care and provider experiences of care. Since the pilot study,[11] EBCD has increasingly become a more structured and prescriptive method. Due to the quality improvement nature of EBCD, the stages are viewed as cyclical, continually improving the service or care pathway. According to the Point of Care Foundation (PoCF) Toolkit,[12] EBCD framework consists of eight stages:

1) observe clinical areas, 2) interview service-providers and service-users, 3) develop a trigger film (an edited videotaped interview film highlighting themes from the service-user interviews), 4) service-provider feedback event, 5) service-user feedback event, 6) joint service provider and service user workshop(s), 7) co-design groups, and 8) celebration event. Accelerated EBCD (AEBCD) is an adapted method whereby the co-design process is accelerated by using pre-existing service-user experience narratives from pre-existing interviews.

Despite the availability of EBCD toolkits, [12-14] there are currently no reporting standards or EBCD-specific quality appraisal instruments to guide the appropriate conduct and reporting of these studies. Using all EBCD stages can be resource intensive and researchers might eliminate or adapt EBCD stages to satisfy time and resource constraints of a project. However, the success and quality of EBCD projects likely rely on how closely they adhere to the EBCD framework (i.e., fidelity) as well as adequate scoping of the service-provider and service-user experience and skilled facilitation of co-design events.[15] Despite the increasing number of published EBCD projects, there are currently no systematic reviews describing EBCD use in healthcare services. The aim of this systematic review was to examine the use (structure, process and outcomes) and reporting of EBCD in designing health service improvement activities.

METHODS

This systematic review adheres to the Preferred Reporting Items for Systematic reviews and Meta-Analyses (PRISMA) reporting guidelines[16]. The research questions were informed by the Donabedian evaluation model (Box 1).[17]

BOX 1 Research Questions
Structure-related questions 1. Where were the studies conducted (country, setting)? 2. What was the size and the make-up of each stakeholder group?

3. What was the training or skill set of the facilitators?
4. What training was provided to the participants?
5. What resources were used?

Process-related questions
1. How did the study adhere to the Experience-based Co-design (EBCD) framework [8] (i.e., fidelity)?
2. What were the methods of gathering experience data?
3. What were the methods of the co-design phase?
4. What were the drop-out rates and reasons from the co-design phase?
5. How were EBCD projects being evaluated?
6. How long was the EBCD process from planning to co-design completion?
7. What were the touch-points identified in and across the included studies?

Outcome-related questions
1. What were the deliverables of the EBCD?
2. What were the outcomes of the EBCD process evaluations?
3. What were the participant views on the EBCD process?

Eligibility criteria

Due to the expected variations in using and describing EBCD, we defined the minimum requirements to be considered EBCD for this review as including 2 phases where service-users were participants in both phases. During phase 1, relevant service-user experience data must have been identified and summarised to identify touchpoints (or equivalent) either using service-user data from the local service or using previously developed materials such as the accelerated EBCD (AEBCD). During phase 2, co-design workshop(s) must have included at least one service-user participant to develop recommendations or activities that provided professional, organisational and system service improvements.

We included all relevant qualitative, quantitative or mixed-methods studies that used EBCD to design a new or improve an existing healthcare service or pathway, or studies that evaluated the EBCD process. We excluded studies where no service design or improvement was evident. Opinion pieces, editorials/letters, government reports, and conference proceedings were excluded.

Search strategy

To identify potentially relevant reports of EBCD studies, we searched the following electronic bibliographic databases from database inception to 20th August, 2018: MEDLINE, CINAHL, PsycINFO and The Cochrane Library. Searches included combinations of the following MeSH terms and keywords: "participatory action research"; "shared decision making"; "patient decision making"; "experience-based co-design"; "experience-based design"; co-design*; codesign*; "patient engag*"; "patient involv*"; "narrative design"; "co creat*"; "health services research"; patient; consumer; "patient care planning"; "delivery of health care"; "service planning"; "service design"; disease; and health. There was no restriction by date or language. We also searched Google Scholar using search phrases "experience-based co-design" or "experience-based design", and hand-searched the reference lists of relevant articles such as systematic reviews, and the included articles. The references were managed using EndNote Version X8 (Clarivate Analytics, 2018).

Study selection

Titles and abstracts of articles retrieved from the search strategy were independently screened by two reviewers who assessed the eligibility of relevant full-text articles. Disagreements were resolved through consensus among the two reviewers with third review author as arbiter.

Data collection

A standardised data extraction form of open and closed questions was developed, piloted for two included studies and adjusted accordingly before extraction of the remaining data. Data extraction included closed questions such as size and make-up of stakeholder groups, EBCD toolkits, facilitator and stakeholder training, completion of each stage of EBCD, mode of stage delivery, time to complete EBCD and recruitment and dropout rates. Open questions included author details, stated aims, setting, geographical location, resources allocated to study, EBCD framework details, analysis method for experience data, improvement activities and EBCD

evaluations. Data were independently extracted by one reviewer and 100% of the data extraction was checked by a second reviewer. Any discrepancies identified by the second reviewer were checked against the study publications in the first instance and any resulting disagreements were resolved through consensus among the reviewer group.

Critical appraisal

As action research contributed to the development of EBCD,[18] we used the draft *Guidance for assessing action research proposals and projects* [19] which comprises 20 questions used to guide critical reflection. Critical appraisal was not used as part of the eligibility criteria, but to describe the studies. Each study was independently appraised by two reviewers. Percentage agreement was calculated between reviewers and any discrepancies between appraisals were resolved by a third reviewer.

Synthesis of results

Frequencies of closed questions from data extraction were calculated to provide descriptive information about studies. Studies were first synthesised to address the use of EBCD (i.e., structure- and process-related questions [17]) relating to aims and settings, resourcing, participant characteristics and methods used in the included articles. We further examined the use of EBCD by exploring the fidelity of the included studies against the 8-stage PoCF EBCD framework. We identified the 10 activities as these related to each stage of the PoCF EBCD framework and calculated how closely each study adhered to the framework (EBCD fidelity**)**.[12] Each study activity scored 1 (completed) or 0 (not completed or unclear) per activity and calculated as mean EBCD activity score x 100%. Outcome-related questions relating to EBCD deliverables, strengths and weaknesses and participant views on the EBCD process were reviewed narratively. Where possible, improvement activities were categorised using the framework as defined by Locock, et al. [20] into: small scale changes; process redesign at the team level; process redesign between services; and process redesign between

organisations (adapted from Adams, et al. [21]). We examined reporting of EBCD studies by identifying whether each activity as outlined above was clearly reported in the publications.

RESULTS

The search strategy yielded 647 records, of which 38 full text articles were reviewed. We excluded 11 articles, predominantly for being the wrong publication type (**Supplementary Table 1**). We identified 27 articles reporting 19 completed and one 'in progress' study that met eligibility criteria and were included in this review (**Figure 1**).

Critical Appraisal

Critical appraisal was completed by two reviewers with 93.5% agreement (**Supplementary Table 2**). All critical appraisal items were satisfied by two studies, with 10, five and three studies meeting at least 80%, 60% and 40% of the criteria respectively. Only half of the studies adequately described the relationship between the researchers and participants. Twelve studies (60%) either reported ethics approval or discussed ethical issues relating to the project. Thirteen studies (65%) reported funding to support the project as well as successfully completing the project without issue. Thirteen studies (65%) discussed the extent to which the aims and objectives of each stage were achieved.

Structural characteristics

Settings

Structure-related characteristics are summarised in **Table 1**. Most studies were conducted in acute hospital settings in the United Kingdom. Healthcare areas using EBCD were mostly mental health (five studies), cancer (six studies including one study of cancer and intensive care unit), paediatrics (three studies), emergency departments (two studies including one study of the geriatric palliative care experience) and one study each in palliative/end of life

care, maternity, geriatric outpatient services, and primary care for service users with multi-morbidities.

Stakeholder groups

Of the 20 included studies, 12 described the project team including descriptions of advisory committees, key stakeholders or site personnel. Stakeholder involvement was not always clear as participant groups often changed after experience data were collected and analysed. Where reported, service-provider experiences were represented by nurses, doctors and allied health with some including 'managers', clerical staff, receptionists and other 'staff'. Service-user experiences were represented by patients, caregivers, family and/or service-user advocates.

Facilitation, training and resources

Of the 20 included studies, 17 described the facilitators (**Table 1**), 11 of which described facilitator training and/or qualifications. No study reported training the EBCD participants. Financial support was acknowledged in 16 studies, two of which were specific to travel costs to attend EBCD training or conduct non-participant site observations.[22, 23] Half of the studies reported using an EBCD toolkit.

Table 1 Structure-related experience-based co-design elements of included studies in chronological publication order.

Study	Country	Setting	Health service area	Funded	Method	EBCD Toolkit used	Facilitators described (n)		
							SP/SU experience collection (n)	Co-design (n)	Trained
Bate & Robert cancer study [11]	UK	Acute	Head and neck cancer	Yes	EBCD	No	≥2	≥2	Yes
Bowen geriatric outpatient study [24-27]	UK	Acute	Outpatient services for older people	Yes	EBCD	No	NR	NR	NR
Boyd breast service study [14]	NZ	Acute	Breast service	NR	EBCD	NR	2	3	Yes
Piper ED study [28, 29]	Australia	Acute		NR	EBCD	NR	NR	NR	NR
Programme 1									
Site 1			ED						
Site 2			ED						
Site 3			ED						
Programme 2									
Site 1			ED + MAU						
Site 2			ED + cardiology						
Site 3			ED + radiology/theatre/ orthopaedics						
Site 4			ED + radiology						
Cheshire & Ridge palliative care study [30, 31]	UK	Acute	Palliative and end of life care pathway	Yes	AEBCD	NR	NR	NR	Yes
Tsianakas cancer study [32]	UK	Acute	2 Breast cancer services 2 Lung cancer services	Yes	EBCD	Yes	1	NR	Yes
Locock ICU/ cancer study [33-35]	UK	Acute	2 Lung cancer services 2 ICU services	Yes	AEBCD	Yes	NR	NR	Yes
Gustavsson neonatal study [36-38]	Sweden	Acute	Neonatal	Yes	EBCD	NR	2	1	Yes
Fenton mental health study [39-41]	UK	Acute	Early psychosis	Yes	EBCD	NR	1	NR	NR
Gustavsson diabetes study [37, 38]	Sweden	Acute	Juvenile diabetes	Yes	EBCD	NR	2	1	Yes
Springham & Robert mental health study [18]	UK	Acute	1 Mental health ward	Yes	EBCD	Yes	NR	NR	NR
Wright geriatric ED study [22, 42, 43]	UK	Acute	Geriatric palliative care (ED)	Yes	EBCD	NR	1	3	Yes

Kenyon caesarean study [44]	UK	Acute/ community	Caesarean section care pathway	Yes	EBCD	Yes	1	NR	NR
Van Deventer paediatric study [23]	South Africa	Acute	Paediatric malnutrition and HIV services	Yes	EBCD	Yes	4	4	NR
Cranwell mental health study [45-47]	Australia	Acute/ primary	Mental health care	Yes	EBCD	NR	1	1	Yes
Cooper mental health study [48]	UK	Community	Adult psychological therapies	NR	EBCD	Yes	1	2	NR
Fucile cancer study [49]	Canada	Community	Local oncology centre	NR	EBCD	NR	NR	NR	NR
Hackett mental health study [50]	Canada	Community	Youth mental health	Yes	EBCD	NR	NR	NR	Yes
Weston cancer study [51]	UK	Acute/ community	Adolescent/young adult cancer	Yes	EBCD (INC)	Yes	1	NR	NR
Knowles multimorbidity study [52]	UK	Primary	Multimorbidity care	Yes	AEBCD	NR	3	3	Yes

Abbreviations: SP, service-provider; SU, service-user; UK, United Kingdom; NZ, New Zealand; ICU, Intensive care unit; ED, emergency department; HIV, Human Immunodeficiency Virus; MAU, Medical Assessment Unit; EBCD, experience-based co-design; AEBCD, accelerated EBCD; INC, incomplete EBCD; NR, not reported.

Process characteristics

EBCD duration and fidelity

The EBCD activities as they relate to each stage of EBCD are described in **Figure 2** and the process-related data are presented in **Table 2**. The EBCD studies, from Stage 1 to 8, took a median (range) of 9 (8-19) months and AEBCD took a median of 8 (4-8) months. EBCD fidelity (**Figure 2**) across all studies was median 75% (25-100%) with only 2 studies achieving 100%. The stages most often omitted or lacking description were Stages 1 (observation) and 8 (celebration event). Where celebration events were held, EBCD participants as well as additional stakeholders external to the project were involved. Due to the inconsistent reporting of outcomes, we did not evaluate the effect of fidelity on implementation activities.

Data collection methods

Site observations were conducted for 5-20 hours per site with the exception of Tsianakas, et al. [32] who observed two service areas for 219 hours in total. The individual experiences of service-users and -providers were collected in all 20 studies. The predominant method used was stakeholder interview with median 15.5 (5-40) service-users (14 studies) and 24 (4-54) service-providers (13 studies). Joint- or stakeholder-specific focus groups, workshops or meetings involved median 14 (6-38) service-users (three studies) and seven (5-17) service-providers (five studies). Three studies used national archived service-user interviews [i.e., AEBCD] with one study supplementing archive data with local service-user interviews.

Data analysis and touchpoints

Fourteen of the 20 studies systematically analysed experience data. Analysis methods varied; including thematic analysis (one study), colour-coding themes (one study), interpretative phenomenological analysis (three studies), framework analysis (three studies), qualitative content analysis (two studies) or thematic discourse analysis (one study), constant comparative

188 method (two studies), and Burden Treatment Theory (one study). Touchpoints were identified
189 by 13 studies although these were often presented as summaries with only examples provided.

190 Twelve studies created a trigger film of video- or audio-recorded interview excerpts. Other
191 formats used to 'trigger' discussion (eight studies) during the joint workshop included
192 touchpoint lists and experience maps of service-user experiences (six studies). Interview quotes
193 (three studies) and lists of improvement areas (one study) of service-provider experiences were
194 also used.

195 Stakeholder feedback events (used by 16 studies) included median seven (4-39) service-users
196 (reported in 16 studies) and 17 (3-64) service-providers (reported in nine studies). Improvement
197 priorities were identified by participants (16 studies), researchers (one study) and not reported
198 in two studies.

Table 2 Reporting and completion of experience-based co-design activities, duration and fidelity of included studies in chronological publication order.

Reference	Experience gathering			Film	Feedback events		Joint SP/SU workshop		Small teams	Celebration event	EBCD fidelity	Duration (months)
	Obs (hours)	With SP (n)	With SU (n)		With SP (n)	With SU (n)	SP (n)	SU (n)				
Bate & Robert cancer study [11]	✓(NR)	✓(NR[d])	✓(NR[d])	✓	✓(NR)	✓(NR)	✓(NR)	✓(NR)	✓	✓	90%	NR
Bowen geriatric outpatient study [24-27]	×	✓(9[d])	✓(13[d])	✓	*unclear*	*unclear*	*unclear*	*unclear*	✓	✓	80%	12
Boyd breast service study [14]	×	✓(5[e,f])	✓(14[e], 182[f])	✓	×	×	✓(14)	✓(12)	✓	×	50%	NR
Piper ED study [28, 29]							~15-50/site				80%	
Programme 1												
Site 1	✓(5)	✓(54[d])	✓(20[d])	×	×	×	✓(NR)	✓(NR)	*unclear*	*unclear*		9
Site 2	✓(5)	✓(45[d])	✓(40[d])	×	×	×	✓(NR)	✓(NR)	*unclear*	*unclear*		9
Site 3	✓(20)	✓(28[d])	✓(16[d])	×	✓(NR)	×	✓(NR)	✓(NR)	*unclear*	*unclear*		9
Programme 2												
Site 1	✓(8)	✓(36[d])	✓(19[d])	×	✓(NR)	×	✓(NR)	✓(NR)	*unclear*	*unclear*		9
Site 2	×	✓(30[d])	✓(22[d])	×	×	×	✓(NR)	✓(NR)	*unclear*	*unclear*		9
Site 3	✓(20)	✓(53[d])	✓(25[d])	×	✓(NR)	×	✓(NR)	✓(NR)	*unclear*	*unclear*		9
Site 4	✓(13)	✓(28[d])	✓(27[d])	×	✓(NR)	×	✓(NR)	✓(NR)	*unclear*	*unclear*		9
Cheshire & Ridge palliative care study [30, 31]	×	✓(15)	✓(NR[b])	✓	×	×	✓(7)	✓(15)	✓[c]	×	50%	8
Tsianakas cancer study [32]	(219 total)										100%	
Breast cancer	✓(NR)	✓(37[d])	✓(23[d])	✓	✓(NR)	✓(NR)	✓(NR)	✓(NR)	✓	✓		NR
Lung cancer	✓(NR)	✓(26[d])	✓(13[d])	✓	✓(NR)	✓(NR)	✓(NR)	✓(NR)	✓	✓		NR
Locock ICU/ cancer study [33-35]		(42[d] total)			(46 total)	(49 total)					100%	
ICU	✓(NR)	✓(NR)	✓(78[b])	✓	✓(NR)	✓(NR)	✓(NR)	✓(NR)	✓	✓		8
Lung Cancer	✓(NR)	✓(NR)	✓(45[b])	✓	✓(NR)	✓(NR)	✓(NR)	✓(NR)	✓	✓		8
Gustavsson neonatal study [36-38]	×	✓(7[d])	✓(5[d])	×	✓(7)	✓(5)	*unclear*	*unclear*	✓	✓	90%	9
Fenton mental health study [39-41]	×	✓(9[d])	✓(12[d])	×	✓(NR)	✓(NR)	(50 total) ✓(NR)	✓(NR)	✓	×	70%	NR

Gustavsson diabetes study [37, 38]	×	✓(6[d])	✓(7[d])	×	✓(6)	✓(7)	*unclear*	*unclear*	✓	✓	90%	9
Springham & Robert mental health study [18]	×	✓(NR[d])	✓(NR[d])	✓	✓(NR)	✓(NR)	✓(NR)	✓(NR)	✓	*unclear*	70%	8
Wright geriatric ED study [22, 42, 43]	✓(150[a])	✓(15[d])	✓(10[d])	✓	✓(64)	✓(10)	✓(7)	✓(2)	×	×	80%	19
Kenyon caesarean study [44]	×	✓(22[d])	✓(15[d])	×	✓(17)	✓(7)	✓(6)	✓(5)	×	✓	80%	12
van Deventer paediatric study [23]	✓(10)	✓(14[d])	✓(9[d])	✓	✓(24)	✓(5)	✓(16)	✓(5)	✓	✓	100%	9
Cranwell mental health study [45-47]	×	✓(21[e])	✓(16[d])	✓	✓(17)	✓(16)	✓(6)	✓(7)	×	×	70%	NR
Cooper mental health study [48]	×	✓(NR[e])	✓(6[d])	✓	*unclear*	✓(6)	✓(8)	✓(4)	×	×	60%	NR
Fucile cancer study [49]	×	✓(9[e])	✓(6[e])	×	×	×	(15 total) ✓(NR)	✓(NR)	×	×	40%	8
Hackett mental health study [50]	×	✓(14[d], 4[f])	✓(19[d], 12[f])	×	×	×	✓(6)	✓(11)	×	×	50%	18
Weston cancer study [51]	×	✓(6[d])	✓(6[d])	*unclear*	✓(3)	✓(3)	INC	INC	INC	INC	INC	INC
Knowles multimorbidity study [52]	×	✓(5[e])	✓(38[e])	✓	✓(5)	✓(11)	*unclear*	*unclear*	×	×	70%	4

Abbreviations: Obs, observations; SP, service-provider; SU, service-user; EBCD, experience-based co-design; NR, not reported; ICU, intensive care unit; INC, incomplete EBCD.

× EBCD activity not completed

✓ EBCD activity completed

'*unclear*' Insufficient information to determine whether the EBCD activity was completed.

[a] Non-participating site observation

[b] Sourced from a national archive of lung cancer patient interviews (n=45) and ICU patient interviews (n=40) and ICU patient caregiver (n=38) interviews

[c] Service-providers only

[d] Interview

[e] Workshop or focus group

[f] Survey

Joint workshop

Nineteen of the 20 studies had completed EBCD to at least the joint workshop stage (one incomplete) although only one study described the framework used to run their workshop (MAXIMUM framework).[52] Workshop delivery was face-to-face for all studies, with twelve studies reporting between 2-15 service-users participants and 2-16 service-provider participants per meeting (ratio of three service-users to every four service-providers), and one facilitator to every five participants.

Small co-design teams

Half of the included studies described using the small co-design team stage of EBCD. The number of teams formed, and the number and mode of meetings, were highly variable and largely dependent on the number of improvement priorities identified. All but one study used mixed teams of service-users and -providers.

Drop-out

It was often unclear whether the same participants were involved in both the data collection and the co-design workshops. Throughout the co-design workshops researchers often emphasised voluntary participation, resulting in a small core group (usually service-providers) with others participating on an ad hoc basis. In two studies the protocol was amended to recruit an additional cohort for co-design, which was attributed to the transitory nature of the service-users, high service-provider turnover, or time delays between EBCD Stages.

Outcome characteristics

EBCD deliverables

Studies aimed to improve a service or care pathway (12 studies), evaluate the EBCD process (2 studies) or reported both improvement and evaluation (six studies) (**Supplementary Table 3**). Only two studies pre-determined EBCD outcomes: a) improving informational and

educational resources or b) the number of formal complaints on a specific ward. Project costs were only evaluated in one publication, which compared the cost of AEBCD with EBCD, and reported that AEBCD was cheaper than EBCD at £8,289 GBP vs £30,485 GBP respectively.[20, 33]

The studies that listed the improvement activities (11 studies) indicated 1-38 improvement activities per site, service or care pathway (**Supplementary Table 3**) were generated by EBCD. Where improvement activities could be categorised, most were attributed to a redesign within team (6 studies), small scale changes (4 studies) or redesign between services (1 study) and one study had an even distribution of changes across categories.

Participant perception of EBCD

Process evaluation data were available for eight studies, with evaluation for Gustavsson's neonatal and diabetes studies reported together.[38] Both service-users and -providers had positive views of the EBCD process[30, 33, 48] and reported that SMART (specific, measurable, achievable, relevant, time-bound) goals reflected their service improvement needs.[48] Wright's geriatric ED study [22] found that staff had changed their personal practice and had developed ongoing multidisciplinary team collaborations as a result of EBCD.[43] In the Cheshire & Ridge palliative care study,[30, 31] commissioners had commented that EBCD was run as a change management process that felt more engaging and less tokenistic in service-user participation. Participants in the Tsianakas cancer study [32] stated that the collaborative nature of EBCD gave service-users a greater sense of direct responsibility for the work and its outcomes built a strong relationship between service-users and -providers and noted a higher level of clinical engagement in the improvement effort than is usually observed in other projects. Service-user participants from the Gustavsson's neonatal and diabetes studies[38] reported that the diversity of views, when presented face-to-face, resulted in a common perspective of patient processes. Participants also noted that the power relationship between

professionals and patients was more equal in the EBCD than in actual care relationships. In contrast, service provider participants in Piper's ED study [28] study found it difficult to balance EBCD activities with other work commitments despite being positive about the EBCD approach.

DISCUSSION

We identified 19 complete and one 'in progress' published EBCD projects aimed at improving healthcare services. As expected, the largest uptake for EBCD was in its country of origin (UK) and there is an increasing application of this method with most studies published after 2014 (15 studies). Despite the recommendation to complete all stages of EBCD,[12, 15] our review indicates that EBCD fidelity remains less than 100%. This might be attributed to authors' perceptions of the flexibility of the EBCD framework , [12] barriers to implementing co-design (i.e., lack of resources and managerial support, staff turnover, logistical issues, cohort retention, information asymmetry),[6, 8] or the lack of evidence demonstrating that higher fidelity leads to better service-user experiences (a limitation of the wider healthcare service co-design literature).[6, 8]

Palumbo's systematic review of coproduction in healthcare [8] indicates that conflicting priorities and beliefs between service-providers and –users as well as information asymmetry to be major barriers to co-design. The PoCF EBCD framework[12] attempts overcome these via site observations and sharing experiences during the joint workshop. Both methods provide insight into the healthcare service, help contextualise the touchpoints raised and move preconceptions about the service experience from *what should be* to *what is*. To this end, formally presenting the service-provider experience during the joint workshop in addition to that of the service-users could mitigate information asymmetry. However, few studies presented the service-provider perspective, potentially contributing to conflicting design priorities and limiting engagement.

Similarly, few studies implemented site observations, none of which were carried out by the service-providers. The PoCF[12] encourage service-providers to undertake observations so that they gain insight into the day-to-day delivery and experience reality of health services. However, making time for service-provider observations without managerial support might limit service-provider engagement in EBCD, as they are often required to volunteer time in addition their existing workload expectations.[6] Issues that were otherwise unreported by participants during interviews and focus groups (Stage 2) might have been missed in studies that failed to complete observations;[12] especially when researchers were not familiar with the service area. Where completed, observations were conducted in-person by the researchers so the reliability of observation data was dependent on the method of data recording, coding scheme, observer experience and training and the nature of the work environment.[53] The effects of selectivity and observer-related factors (e.g. fatigue, inattention) could be lessened by using pairs of observers or video-recording EBCD activities could be considered as a means of obtaining comprehensive and consistent data. This method facilitates greater flexibility in the time and duration of data collection.

In this review, we argued that any EBCD studies must at least involved two key phases, namely experience-gathering phase and co-design phase with patient participation in both phases. Nevertheless, any non-adherence with activities or stages outlined by the PoCF EBCD framework could potentially compromise the extent of participation of service-users and other stakeholders, and the quality of the experience-gathering and co-design processes. Future studies should explore the relationships between fidelity as prescribed by the PoCF EBCD framework and service-user experiences.

Consistent with the PoCF EBCD framework, interviews were often used in favour of focus groups to gather participant experiences. EBCD facilitators have reported that individual

interviews engage service-providers and enhance their commitment to the EBCD process.[35] Compared with focus groups, individual interviews require fewer participants and data collectors per data collection event, are easier to schedule, and take less time to organise and transcribe.[54] As such, focus groups might not have been adequate to identify all relevant touchpoints. However, we were unable to evaluate the effectiveness of focus groups versus interviews in generating touchpoints due to limited touchpoints data. The generation of touchpoints and interview analyses varied across studies and was not always conducted in a systematic way. This could be due to the lack of guidance in the PCoF EBCD toolkit (among others).

For co-design to be successful in healthcare there must be cohort retention and a reconfiguration of the power dynamic between the service-users and –providers. Co-design studies with formally engaged and funded facilitators are more likely to maintain momentum, engage and retain participants and generate improvement priorities.[6] Although the majority of included studies used a facilitator, facilitator training was apparent in just over half. Facilitation is particularly important during the co-design stages (stage 6 and 7) as they are pivotal for successful EBCD as it is during these stages that improvement priorities are set and activities are designed. However, although all completed EBCD studies included Stage 6, only half of the studies completed EBCD to Stage 7; often reporting that service-providers experienced difficultly balancing EBCD with work commitments. Consistent with previous reviews,[6, 8] authors cited a lack of funding, support and time as barriers to co-design workshops and teams. Although participant views on involvement in EBCD were generally positive with service-users reporting a more equal power dynamic than exists in the care relationship,[38] the significance of these stages should not be understated as they allow for power relations between service-providers and -users to equalise over time. By omitting workshops and/or small co-design teams, the voice of service-users is less likely to be heard,

and service-providers remain expert providers rather than working as partners in a co-design process. Therefore, emphasising to participants the flexible nature of attendance and level of participation in the Stage 7 might enhance involvement and reduce drop-out. [35]

There was a lack of consistency in the reporting of EBCD projects which may be due to no standardised reporting guideline. Many studies failed to report the project outcomes (i.e., touchpoints and planned improvement activities) and recruitment and drop-out rates or ability to maintain participants when transitioning from experience-gathering to co-design phases. Therefore, it is challenging to identify how the varied use of EBCD affected its success. Often projects were reported across multiple publications, and published data were limited and needed to be supplemented with reports in the grey literature to understand the method. Future reporting should include adequate detail so the reader can evaluate quality.

Our review demonstrates that EBCD has predominantly been used for service improvement in local settings. With the increasing expectation of service-user engagement in healthcare, we recommend explorations of extending the use of EBCD to the development or redesign of healthcare policy. This would require adequate resourcing and the involvement of healthcare executives and policy makers throughout EBCD, especially during Stages 6 and 7 of the process.

In light of the increasing recognition of engaging consumers and end-users in research design, EBCD could be a useful method for designing complex research interventions[55, 56] and maximising both person-centeredness in healthcare and the likelihood of successful use.[1-3] Within the Medical Research Council complex intervention framework,[57] the EBCD method could be used to design components of a complex intervention as a Phase I study, which can subsequently be tested in Phase II – IV studies. The authors are aware of only one study whereby EBCD was used to design a complex intervention to improve breast and lung cancer

services. Tsianakas, et al. [58] reported that although the touchpoints were shared across diagnoses, they translated into improvement priorities that were specific to the healthcare service. This emphasises the importance of Stages 6 and 7 where service-users and providers discussed priorities for improvement.

Strengths and Limitations

As far as the authors are aware, this is the first systematic review to evaluate the use and reporting of EBCD for the design or improvement of healthcare services. This complex review was informed by multiple frameworks (i.e., PRISMA,[16] Donabedian model,[17] *Guidance for assessing action research proposals and projects*[19]) presenting a comprehensive overview on this increasingly used method. However, publications relating to co-design activities likely exist in design or co-design journals and the grey literature not abstracted to the major healthcare-related databases used in this search. Given this review is limited to the published literature, we recognise that some publications may have been missed.

Key recommendations and rationale

According to the findings of this review, several recommendations have been outlined in Box 2 in relation to future use, reporting and use of EBCD studies. While we recognise the resource-, time- and engagement-related feasibility issues of conducting EBCD with 100% fidelity, at least 2 phases are required to ensure that any co-design is based on the experiences of service-users and -providers. First, experiences should be scoped via site observations (Stage 1) and collecting individual experiences of service-users and –providers (Stage 2). Second, the design of improvement activities needs to be a collaborative effort between service-users and –providers based on the data collected in the first phase, preferably using co-design teams (Stage 7) or a more accelerated approach during the joint workshop. However, we would argue that the exclusion of any EBCD stage would mean the minimum requirements to be considered EBCD were not met and could compromise study quality.

BOX 2 Key Recommendations
Recommendations for using Experience-Based Co-Design (EBCD) • Preference individual interviews over focus groups when gathering experience data from stakeholders • Consider supplementing service-user experiences with those of service-providers during the joint workshop to minimise information asymmetry. • Limit the time between information-gathering phase and co-design phase to minimise the risk of drop-out **Recommendations for Reporting** • Provide an adequately detailed report so the reader can evaluate quality. Common areas lacking information in the report include: o the relationship between the researchers and participants o details on project management o how the project was funded and supported o the length and timetable of the project • List outcomes for each phase of the project (i.e., touchpoints and improvement activities) and dichotomise them as locally relevant or generalisable • Publish a complete EBCD results paper and refer to the published research protocol (if relevant)

A better way to improve feasibility could be the adaptation of EBCD activities to limit resource use. For example, video cameras can provide a means of obtaining comprehensive observation data. However, researchers should strike a balance between objectivity and engagement. By removing the presence of the researcher observer, the project would be less visible to the service resulting in a lost opportunity for engagement. Irrespective of the method of observation, ethical considerations remain and researchers must consider additional consent and privacy concerns, as well as having a clear analytic plan.[59] Individual interviews might prove more resource-effective than focus groups in terms of time to arrange although it is unlikely to reduce analytical time.[54] Individual interviews with service-providers could improve stakeholder commitment in the project and minimise drop-out, particularly in the transition between the experience-gathering and co-design phases. Irrespective of the method, the facilitators should be well-trained in the approach being used to ensure the best outcomes from the project and participants.

To ensure the EBCD process is representative of all stakeholder views, trigger films should be supplemented with data from the service-provider analyses after the feedback events. Feedback events (Stages 4 and 5) serve to emphasise service-user and -provider autonomy by allowing self-censoring aspects of their interviews or trigger films and correcting misinterpretation of their data, similar to a member checking process.[12] Included studies often reported issues with maintaining their participant cohort from the experience-gathering phase to the co-design phase. The time to complete the EBCD process and gaps in moving from stage to stage need to be as short as possible to overcome issues relating to transient participants (particularly unwell service-users), high workforce turnovers and other improvement activities detracting attention from EBCD .

Reporting is particularly important as there is variability in the use of EBCD in these projects, and adaptations often occur as the project progresses. Although more generic reporting frameworks exist for quality improvement work in healthcare (e.g., SQUIRE II [60]), it appears that no studies are using this guide to report EBCD. An EBCD-specific guideline would improve the quality of reporting and would ensure studies are easily understood, comparable and able to be replicated.[61] Such a guide could also serve to inform the design of EBCD projects. Until an EBCD reporting guideline is established, researchers need to publish adequately detailed reports and should consider publishing a protocol paper prior to conducting the study[57] followed by one EBCD publication once the study is completed.

CONCLUSIONS

When conducted well and properly resourced, EBCD might enable effective co-design. EBCD is a useful tool for service redesign and has potential to be used for design of interventions in the research or policy development setting. A reporting guideline needs to be established to encourage researchers to conduct and report EBCD projects in a consistent manner, comparable with other research which would enable replication.

FIGURE LEGENDS

Figure 1. PRISMA flow diagram of the search strategy.

Figure 2. The 8 stages of experience-based co-design (EBCD) [developed by the review authors as informed by The Point of Care Foundation [8] EBCD toolkit]

CONTRIBUTIONS OF AUTHORS

The corresponding author attests that all listed authors meet authorship criteria and that no others meeting the criteria have been omitted. Authors [redacted] and [redacted] conceptualised the review. Authors [redacted], [redacted], [redacted] and [redacted] developed the protocol which was reviewed by all authors. Author [redacted] conducted the search and all articles were screened and [redacted], [redacted] and [redacted] reviewed the full text to determine inclusion of studies. Data extraction was conducted by [redacted] and checked by [redacted]. All authors completed quality appraisal and contributed to and approved the manuscript.

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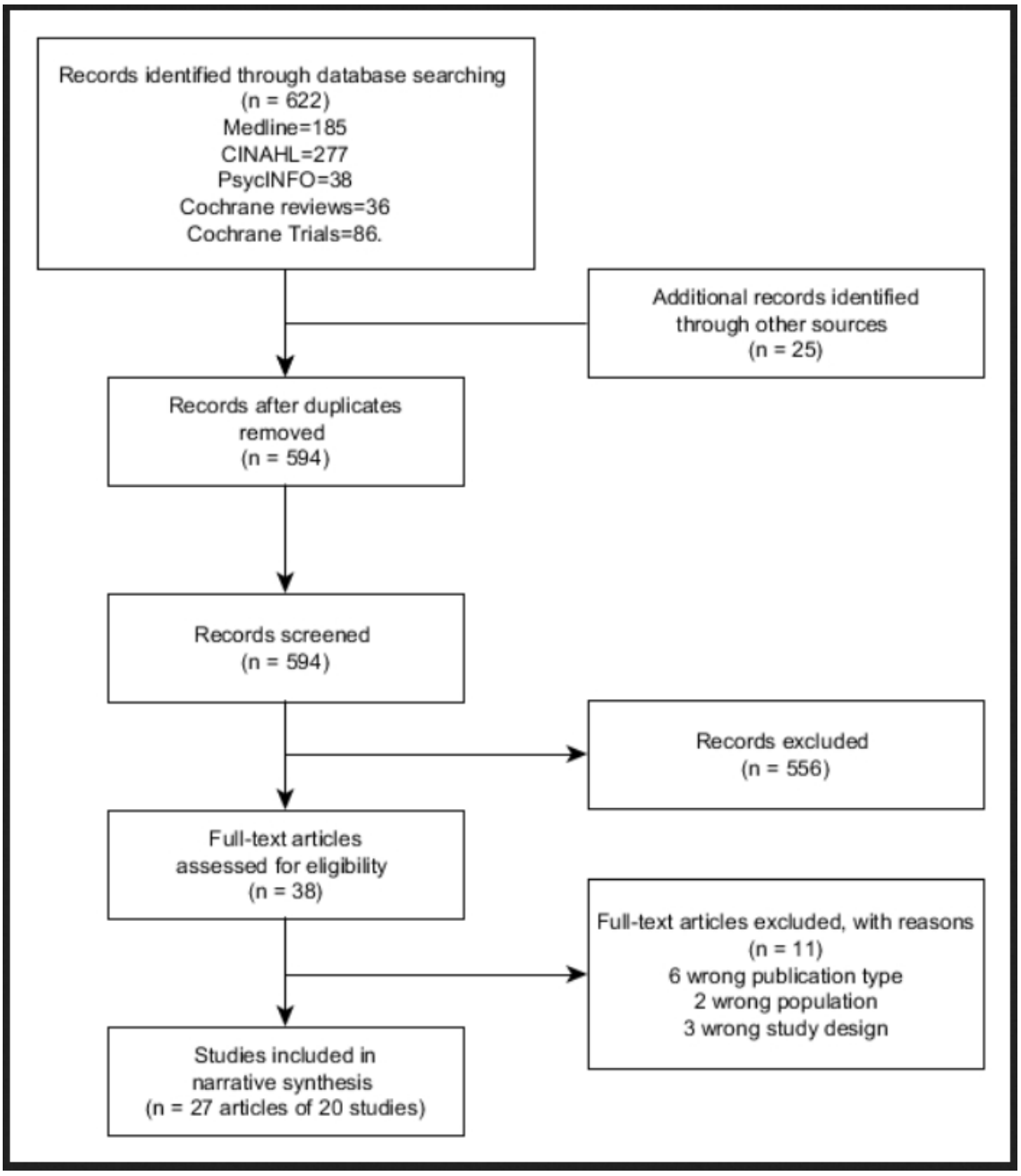
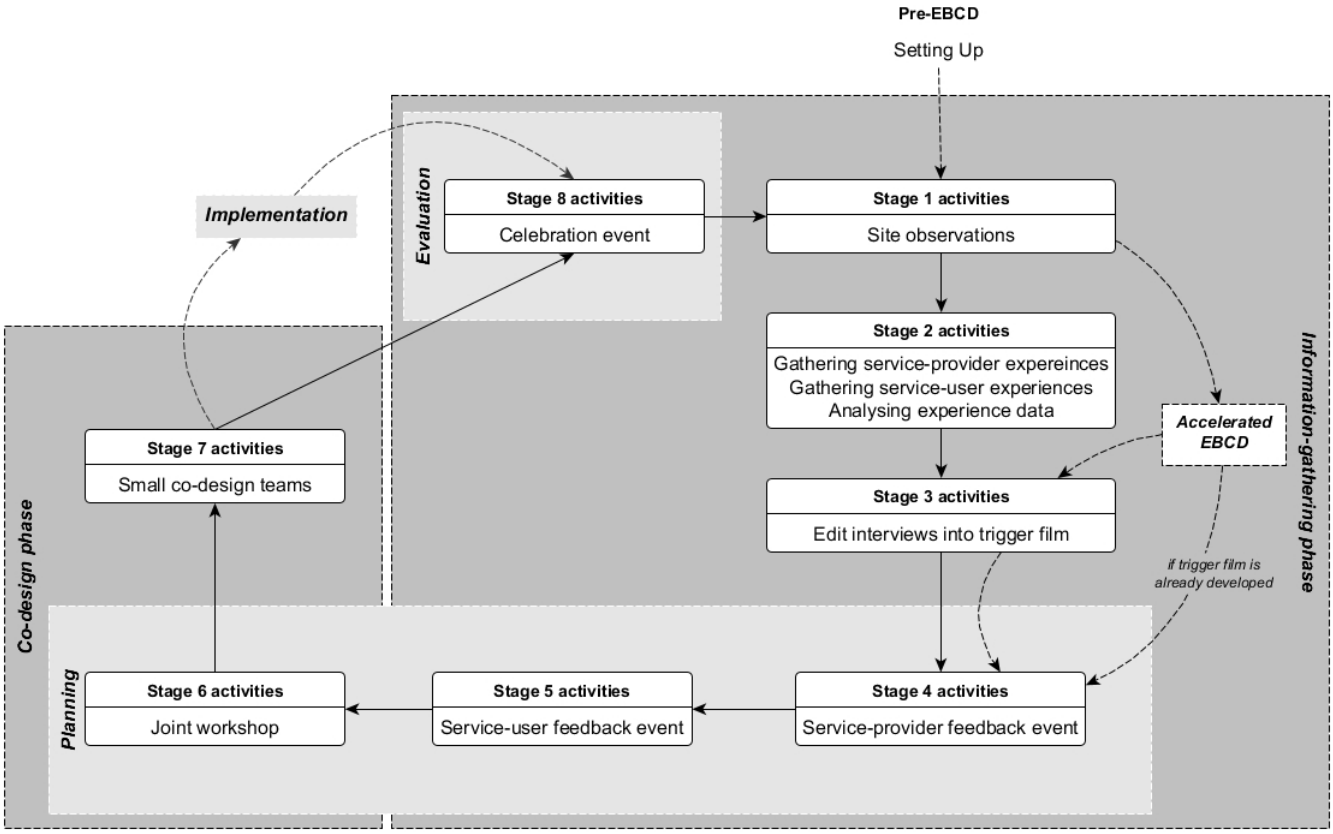

Records identified through database searching
(n = 622)
Medline=185
CINAHL=277
PsycINFO=38
Cochrane reviews=36
Cochrane Trials=86.
Additional records identified through other sources
(n = 25)
Records after duplicates removed
(n = 594)
Records screened
(n = 594)
Records excluded
(n = 556)
Full-text articles assessed for eligibility
(n = 38)
Full-text articles excluded, with reasons
(n = 11)
6 wrong publication type
2 wrong population
3 wrong study design
Studies included in narrative synthesis
(n = 27 articles of 20 studies)


Pre-EBCD
Setting Up
Implementation
Evaluation
Stage 8 activities
Celebration event
Stage 1 activities
Site observations
Stage 2 activities
Gathering service-provider expereinces
Gathering service-user experiences
Analysing experience data
Accelerated EBCD
Stage 3 activities
Edit interviews into trigger film
if trigger film is already developed
Information-gathering phase
Co-design phase
Stage 7 activities
Small co-design teams
Planning
Stage 6 activities
Joint workshop
Stage 5 activities
Service-user feedback event
Stage 4 activities
Service-provider feedback event

Supplementary Table 1 Excluded studies with reasons

Reference	Reason for exclusion
Paton , et al. (2013)[53]	Wrong publication type – letter
Williams (2011)[54]	Wrong publication type – not a journal article
Dietrich, et al. (2017)[55]	Wrong study design – no experience-gathering, only design.
Truman and Raine (2002)[56]	Wrong study design – no design, only experience gathering.
Vechakul, et al. (2015)[57]	Wrong study design – experiences of the design team only
Outlaw, et al. (2018)[58]	Wrong population – no design , only experiences gathered
Palmer, et al. (2018)[59]	Wrong publication type – description of a model, not a study
Palmer, et al. (2015)[60]	Wrong publication type – protocol only
Harrington, et al. (2018)[61]	Wrong population – only service-users involved (no co-design), conference paper
Davies, et al. (2016)[62]	Wrong publication type – no health service design
Richard, et al. (2017)[29]	Wrong publication type – protocol only

Supplementary Table 2 Critical Appraisal of included studies using Waterman, et al.[16] Guidance for assessing action research proposals and projects.

Questions	1	2	3	4	5	6	7	8	9	10	11	12	13	14	15	16	17	18	19	20
Locock [15, 19, 35]	✓	✓	✓	✓	N/A	×	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	×
Write [16, 23, 36]	✓	✓	✓	✓	✓	✓	✓	✓	×	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓
Gustavsson[a] [20, 37, 38]	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	?
Gustavsson[b] [20, 38]	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	?
Larkin [39-41]	✓	✓	✓	×	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	?
Cooper [21]	×	✓	✓	✓	✓	?	?	✓	?	?	✓	✓	×	✓	✓	✓	✓	×	?	✓
Fucile [42]	✓	✓	✓	✓	✓	×	✓	×	?	?	✓	×	✓	✓	✓	✓	✓	×	✓	×
Hackett [43]	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓
Kenyon [44]	✓	✓	✓	✓	✓	×	?	×	?	✓	✓	✓	✓	✓	N/A	N/A	✓	N/A	N/A	✓
Weston [45]	×	✓	✓	✓	?	?	✓	×	✓	×	✓	✓	✓	?	×	×	×	×	?	?
Piper [25]	✓	✓	✓	✓	✓	✓	✓	×	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	?
Cheshire [22, 46]	✓	✓	×	×	✓	✓	?	✓	?	✓	✓	?	?	✓	×	✓	✓	×	?	?
Tsianakas [24]	✓	✓	✓	✓	✓	?	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	×	✓
Springham [13]	✓	✓	✓	✓	×	×	✓	×	?	?	✓	×	×	×	✓	✓	×	×	✓	×
van Deventer [17]	✓	✓	✓	✓	?	✓	✓	✓	✓	✓	✓	?	✓	✓	✓	✓	✓	✓	✓	✓
Cranwell [47-49]	✓	✓	✓	✓	✓	?	?	×	✓	?	✓	✓	?	✓	✓	✓	✓	✓	✓	✓
Boyd [10]	✓	✓	✓	×	✓	?	✓	✓	✓	✓	✓	✓	?	✓	?	✓	✓	✓	✓	✓
Knowles [18]	✓	✓	✓	✓	✓	✓	✓	×	✓	✓	✓	×	✓	✓	✓	✓	✓	✓	?	✓
Bate [7]	✓	✓	✓	×	×	×	?	×	?	?	✓	✓	✓	✓	✓	✓	✓	×	✓	✓
Bowen[50-52]	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓

Abbreviations: N/A, not applicable; ?, unclear.

[a]Neonatal study

[b]Juvenile diabetes study

Critical appraisal questions:

1. Is there a clear statement of the aims and objectives of each stage of the research?
2. Was the action research relevant to practitioners and/or users?
3. Were the phases of the project clearly outlined?
4. Were the participants and stakeholders clearly described and justified?
5. Was consideration given to the local context while implementing change?
6. Was the relationship between researchers and participants adequately considered?
7. Was the project managed appropriately?

8. Were ethical issues encountered and how were they dealt with?
9. Was the study adequately funded/supported?
10. Was the length and timetable of the project realistic?
11. Were data collected in a way that addressed the research issue?
12. Were steps taken to promote the rigour of the findings?
13. Were data analyses sufficiently rigorous?
14. Was the study design flexible and responsive?
15. Are there clear statements of the findings and outcomes of each phase of the study?
16. Do the researchers link the data that are presented to their own commentary and interpretation?
17. Is the connection with an existing body of knowledge made clear?
18. Is there discussion of the extent to which aims and objectives were achieved at each stage?
19. Are the findings of the study transferable?
20. Have the authors articulated the criteria upon which their own work is to be read/judged?

Supplementary Table 3 Outcome-related experience-based co-design characteristics: improvement activities implemented categorized as per the Locock, et al.[17] Framework

References	Small scale change	Redesign within the team	Redesign between services	Redesign between organisations	Total improvement activities
Locock [15, 19, 35]					
ICU	20	15	3	-	38
Lung cancer	1	6	2	1	10
Write [16, 23, 36]	-	3	1	-	4
Gustavsson[a] [20, 37, 38]	?	?	?	?	?
Gustavsson[b] [20, 38]	?	?	?	?	?
Larkin [39-41]	2	7	1	-	10
Cooper [21]	4	2	1	-	7
Fucile [42]	-	5	-	-	5
Hackett [43]	-	-	1	-	1
Kenyon [44]	-	8	-	-	8
Weston [45]	NA	NA	NA	NA	NA
Piper [25]	?	?	?	?	?
Cheshire [22, 46]	?	?	?	?	?
Tsianakas [24]					
Breast cancer	5	9	2	-	16
Lung cancer	7	3	-	2	12
Springham [13]	?	?	?	?	?
van Deventer [17]	?	?	?	?	?
Cranwell [47-49]	-	1	1	1	3
Boyd [10]	7	-	-	-	7
Knowles [18]	?	?	?	?	?
Bate [7]	?	?	?	?	?
Bowen[50-52]	2	2	1	-	5

Abbreviations: NA, not applicable; ?, unclear.

[a]Neonatal study

[b]Juvenile diabetes study