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Effects of consumers and health providers working in partnership on health services planning, delivery and evaluation.
Cochrane Database of Systematic Reviews 2021, Issue 9. Art. No.: CD013373.
DOI: [10.1002/14651858.CD013373.pub2](https://doi.org/10.1002/14651858.CD013373.pub2).

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[Intervention Review]

Effects of consumers and health providers working in partnership on health services planning, delivery and evaluation

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ABSTRACT

Background

Health services have traditionally been developed to focus on specific diseases or medical specialties. Involving consumers as partners in planning, delivering and evaluating health services may lead to services that are person-centred and so better able to meet the needs of and provide care for individuals. Globally, governments recommend consumer involvement in healthcare decision-making at the systems level, as a strategy for promoting person-centred health services. However, the effects of this 'working in partnership' approach to healthcare decision-making are unclear. Working in partnership is defined here as collaborative relationships between at least one consumer and health provider, meeting jointly and regularly in formal group formats, to equally contribute to and collaborate on health service-related decision-making in real time. In this review, the terms 'consumer' and 'health provider' refer to partnership participants, and 'health service user' and 'health service provider' refer to trial participants.

This review of effects of partnership interventions was undertaken concurrently with a Cochrane Qualitative Evidence Synthesis (QES) entitled *Consumers and health providers working in partnership for the promotion of person-centred health services: a co-produced qualitative evidence synthesis*.

Objectives

To assess the effects of consumers and health providers working in partnership, as an intervention to promote person-centred health services.

Search methods

We searched the CENTRAL, MEDLINE, Embase, PsycINFO and CINAHL databases from 2000 to April 2019; PROQUEST Dissertations and Theses Global from 2016 to April 2019; and grey literature and online trial registries from 2000 until September 2019.

Selection criteria

We included randomised controlled trials (RCTs), quasi-RCTs, and cluster-RCTs of 'working in partnership' interventions meeting these three criteria: both consumer and provider participants meet; they meet jointly and regularly in formal group formats; and they make actual decisions that relate to the person-centredness of health service(s).

Data collection and analysis

Two review authors independently screened most titles and abstracts. One review author screened a subset of titles and abstracts (i.e. those identified through clinical trials registries searches, those classified by the Cochrane RCT Classifier as unlikely to be an RCT, and those

identified through other sources). Two review authors independently screened all full texts of potentially eligible articles for inclusion. In case of disagreement, they consulted a third review author to reach consensus. One review author extracted data and assessed risk of bias for all included studies and a second review author independently cross-checked all data and assessments. Any discrepancies were resolved by discussion, or by consulting a third review author to reach consensus. Meta-analysis was not possible due to the small number of included trials and their heterogeneity; we synthesised results descriptively by comparison and outcome. We reported the following outcomes in GRADE 'Summary of findings' tables: health service alterations; the degree to which changed service reflects health service user priorities; health service users' ratings of health service performance; health service users' health service utilisation patterns; resources associated with the decision-making process; resources associated with implementing decisions; and adverse events.

Main results

We included five trials (one RCT and four cluster-RCTs), with 16,257 health service users and more than 469 health service providers as trial participants. For two trials, the aims of the partnerships were to directly improve the person-centredness of health services (via health service planning, and discharge co-ordination). In the remaining trials, the aims were indirect (training first-year medical doctors on patient safety) or broader in focus (which could include person-centredness of health services that targeted the public/community, households or health service delivery to improve maternal and neonatal mortality). Three trials were conducted in high income-countries, one was in a middle-income country and one was in a low-income country. Two studies evaluated working in partnership interventions, compared to usual practice without partnership (Comparison 1); and three studies evaluated working in partnership as part of a multi-component intervention, compared to the same intervention without partnership (Comparison 2). No studies evaluated one form of working in partnership compared to another (Comparison 3).

The effects of consumers and health providers working in partnership compared to usual practice without partnership are uncertain: only one of the two studies that assessed this comparison measured health service alteration outcomes, and data were not usable, as only intervention group data were reported. Additionally, none of the included studies evaluating this comparison measured the other primary or secondary outcomes we sought for the 'Summary of findings' table.

We are also unsure about the effects of consumers and health providers working in partnership as part of a multi-component intervention compared to the same intervention without partnership. Very low-certainty evidence indicated there may be little or no difference on health service alterations or health service user health service performance ratings (two studies); or on health service user health service utilisation patterns and adverse events (one study each). No studies evaluating this comparison reported the degree to which health service alterations reflect health service user priorities, or resource use.

Overall, our confidence in the findings about the effects of working in partnership interventions was very low due to indirectness, imprecision and publication bias, and serious concerns about risk of selection bias; performance bias, detection bias and reporting bias in most studies.

Authors' conclusions

The effects of consumers and providers working in partnership as an intervention, or as part of a multi-component intervention, are uncertain, due to a lack of high-quality evidence and/or due to a lack of studies. Further well-designed RCTs with a clear focus on assessing outcomes directly related to partnerships for patient-centred health services are needed in this area, which may also benefit from mixed-methods and qualitative research to build the evidence base.

PLAIN LANGUAGE SUMMARY

When healthcare consumers (patients, carers and family members) and healthcare providers work together as partners to plan, deliver and evaluate health services, what effects does this have?

What are person-centred health services?

Traditionally, health services have been developed by healthcare providers and focus on specific diseases or medical specialties. Involving consumers as partners in planning, delivering and evaluating health services may lead to services that are better able to meet the needs of and provide care for individuals.

Why we did this Cochrane review

Governments worldwide recommend that healthcare providers work with consumers to promote person-centred health services. However, the effects of healthcare providers and consumers working together are unclear.

We reviewed the evidence from research studies to find out about the effects of healthcare providers and consumers working together to plan, deliver and evaluate health services.

Specifically, we wanted to know if consumers and healthcare providers working together in partnership – in the form of regular meetings in which consumers and providers were invited to contribute as equals to decisions about health services – had an impact on:

- changes to health services;
- the extent to which changes to health services reflected service users' priorities;
- users' ratings of health services;
- health service use; and
- time and money needed to make or act on decisions about health services.

We also wanted to find out if there were any unwanted (adverse) effects.

What did we do?

First, we searched the medical literature for studies that compared:

- consumers and healthcare providers working in partnership against usual practice or other strategies with no partnership; or
- different ways of working in partnership (for example, with fewer or more consumers, or with online or face-to-face meetings).

We then compared the results, and summarised the evidence from all the studies. Finally, we rated our confidence in the evidence, based on factors such as study methods and sizes, and the consistency of findings across studies.

What did we find?

We found five studies that involved a total of 16,257 health service users and more than 469 health service providers. Three studies took place in high income-countries and one each in middle- and low-income countries.

The studies compared:

- working in partnership against usual practice without partnership working (2 studies); and
- working in partnership as part of a wider strategy to promote person-centred health services, against the same wider strategy without partnership working (3 studies).

No studies evaluated one form of working in partnership compared to another.

What are the main results of our review?

The studies provided insufficient evidence to determine if working in partnership had any effects compared to usual practice or wider strategies with no working in partnership.

No studies investigated:

- impacts on the extent to which changes to health services reflected service users' priorities, or
- the resources needed to make or act on decisions about health services.

Few studies investigated:

- impacts on changes to health services;
- users' ratings of health services;
- health service use; and
- adverse events.

The few studies that did investigate these outcomes either did not report usable information or produced findings in which we have very little confidence. These studies were small, used methods likely to introduce errors in their results and focused on specific settings or populations. Their results are unlikely to reflect the results of all the studies that have been conducted in this area, some of which have not made their results public yet.

What does this mean?

There is not enough robust evidence to determine the effects of consumers and providers working in partnership to plan, deliver or evaluate health services.

This review highlights the need for well-designed studies with a clear focus on evaluating the effects of partnerships for promoting person-centred care in health services. This area of research may also benefit from studies that investigate why certain partnerships between consumers and healthcare providers may be more successful than others, and an accompanying qualitative evidence synthesis addressing this aspect is forthcoming.

How up-to-date is this review?

The evidence in this Cochrane Review is current to April 2019.

SUMMARY OF FINDINGS

Summary of findings 1. Consumers and providers working in partnership compared with usual practice

Comparison 1

Patients or population: consumer and provider partnership participants or trial participants

Settings: community, policy, teaching or health care setting

Intervention: working in partnership

Comparison: usual practice

Outcomes	Impacts	No. of studies	Certainty of the evidence (GRADE)
Health service alterations (changes to services resulting from decisions)	No studies that comparatively evaluated this outcome were found ¹ .	-	-
Degree to which health service alterations reflect health service user (trial participant) priorities (demand responsiveness)	No studies that evaluated this outcome were found.	-	-
Health service user (trial participant) health service performance ratings (local accountability)	No studies that evaluated this outcome were found.	-	-
Health service user (trial participant) health service utilisation patterns	No studies that evaluated this outcome were found.	-	-
Resources associated with decision-making process	No studies that evaluated this outcome were found.	-	-
Resources associated with implementing decisions (e.g. changed services)	No studies that evaluated this outcome were found.	-	-
Adverse events	No studies that evaluated this outcome were found.	-	-

GRADE Working Group grades of evidence

High certainty: We are very confident that the true effect lies close to that of the estimate of the effect.

Moderate certainty: We are moderately confident in the effect estimate: The true effect is likely to be close to the estimate of the effect, but there is a possibility that it is substantially different.

Low certainty: Our confidence in the effect estimate is limited: The true effect may be substantially different from the estimate of the effect.

Very low certainty: We have very little confidence in the effect estimate: The true effect is likely to be substantially different from the estimate of effect.

¹One study (Persson 2013) identified problems and actions taken to address these in the intervention group only.

Summary of findings 2. Multi-component intervention with consumers and providers working in partnership compared to the same intervention without partnership

Comparison 2

Patients or population: consumer and provider partnership participants or trial participants

Effects of consumers and health providers working in partnership on health services planning, delivery and evaluation (Review)

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Settings: community, policy, teaching or health care setting

Intervention: multi-component intervention that includes working in partnership

Comparison: same intervention without partnership

Outcomes	Impacts	No. of studies	Certainty of the evidence (GRADE)
Health service alterations (changes to services resulting from decisions)	We are uncertain about the effects of multi-component interventions on this outcome.	2	+000 VERY LOW a,b,c,d
Follow-up: 12 months (Wu 2019) to 21 months (O'Connor 2019)	Two studies (862 participants) were identified, both reporting little to no difference between groups, but results could not be pooled in meta-analysis due to differences in outcome measures.		
Degree to which health service alterations reflect health service user (trial participant) priorities (demand responsiveness)	No studies that evaluated this outcome were found.	-	-
Health service user (trial participant) health service performance ratings (local accountability)	We are uncertain about the effects of multi-component interventions on this outcome.	2	+000 VERY LOW a,b,d
Follow-up: 12 months (Greco 2006) to 21 months (O'Connor 2019)	Two studies (one randomised 792 participants, the other randomised 26 clusters with 8967 participants) were identified, both reporting little to no difference between groups, but result could not be pooled in meta-analysis due to differences in outcome measures.		
Health service user (trial participant) health service utilisation patterns	We are uncertain about the effects of multi-component interventions on this outcome.	1	+000 VERY LOW a,b,d,e
Follow-up: 12 months (Wu 2019)	One study (384 participants) reported little to no difference between groups.		
Resources associated with decision-making process	No studies that evaluated this outcome were found.	-	-
Resources associated with implementing decisions (e.g. changed services)	No studies that evaluated this outcome were found.	-	-
Adverse events	We are uncertain about the effects of multi-component interventions on this outcome.	1	+000 VERY LOW a,b,d,e
Follow-up: 12 months (Wu 2019)	One study (384 participants) reported that no harms were observed in either group.		

GRADE Working Group grades of evidence

High certainty: We are very confident that the true effect lies close to that of the estimate of the effect.

Moderate certainty: We are moderately confident in the effect estimate: The true effect is likely to be close to the estimate of the effect, but there is a possibility that it is substantially different.

Low certainty: Our confidence in the effect estimate is limited: The true effect may be substantially different from the estimate of the effect.

Very low certainty: We have very little confidence in the effect estimate: The true effect is likely to be substantially different from the estimate of effect.

^aDowngraded by one level for crucial risk of bias for multiple criteria: high or unclear for methods of sequence generation (O'Connor 2019; Wu 2019); allocation concealment (Greco 2006; O'Connor 2019; Wu 2019); blinding (unclear for participants/providers/outcome assessors (Greco 2006; O'Connor 2019); providers (Wu 2019); loss to follow-up (Greco 2006; O'Connor 2019); selective outcome reporting/analyses (Greco 2006; O'Connor 2019; Wu 2019); and other sources of bias (Greco 2006; O'Connor 2019).

^bDowngraded by one level for some indirectness: compared to the review question one or more studies are restricted in setting and population (O'Connor 2019; Wu 2019).

^cDowngraded by one level for some imprecision: although results were based on studies (Greco 2006; O'Connor 2019) with a total number of events >300; effect sizes are small and suggest little to no effect with the intervention but include benefit or harm. One or more studies didn't explicitly define the MID for this outcome or present CIs.

^dDowngraded by one level as publication bias is strongly suspected: results come from studies unlikely to be representative of the studies that have been conducted, as protocols exist for completed trials not yet published.

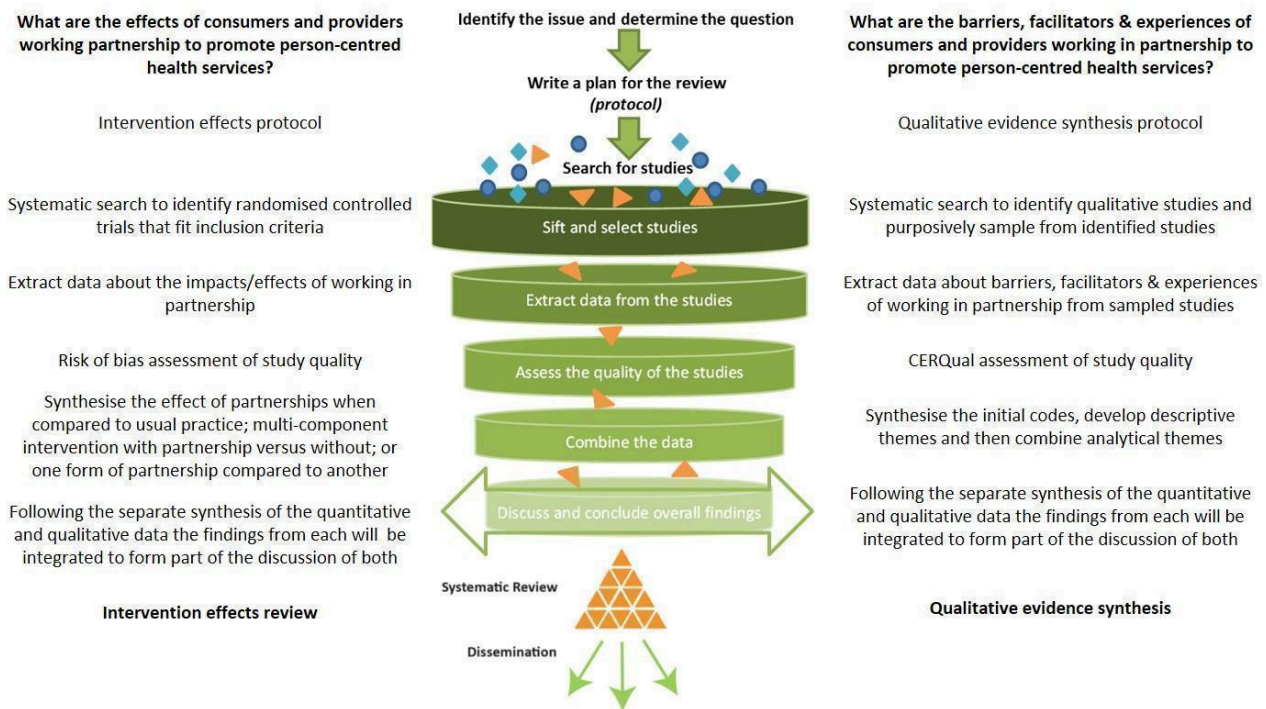
^eDowngraded by one level for some imprecision as the total number of events is less than 300 and the optimal sample size is not clear (Wu 2019).

BACKGROUND

This review assessed the effects of consumers and health providers working in partnership, as an intervention, on health services planning, delivery and evaluation. Such partnerships may lead to more person-centred health services. In this review, we use the term 'consumer' to mean patients, their carers and family members, in recognition of the roles that different people may undertake in health care and health care planning. We define 'working in partnership' as consumers and health providers making

decisions together, in formal group formats (such as committees, councils, boards, or steering groups), about aspects of health service planning, delivery, or evaluation (or a combination), with the aim of making health services person-centred (see Glossary of key terms in [Appendix 1](#)). This review was conducted concurrently with a Cochrane Qualitative Evidence Synthesis (QES) entitled *Consumers and health providers working in partnership for the promotion of person-centred health services: a co-produced qualitative evidence synthesis* ([Merner 2019](#); [Figure 1](#)).

Figure 1. Modified infographic comparing the Intervention effects review process (on the left) and the Qualitative evidence synthesis review process (on the right (Kaufman 2011))



Description of the condition

Historical and theoretical context of working in partnership for the promotion of person-centred care

The concept of consumers and providers working in partnerships in healthcare decision-making is based on paradigms of recovery, empowerment, and human, democratic, or consumer rights. The mental health consumer recovery and empowerment movement explicitly utilises consumer experiential knowledge through working in partnership, to transform and innovate services and policies ([Pelletier 2011](#)). In some countries, the impetus for working in partnership in decision-making at the health service level, in addition to the point of care level (whether consultation or encounter), has been driven by healthcare safety and quality standards and rights. For example, the Australian National Safety and Quality Health Service Standards mandate that health service organisations partner with consumers in health governance, policy, and planning to design, deliver, and evaluate healthcare systems and services ([ACSQHC 2017](#)). The Australian Charter of Healthcare Rights states that people using the Australian healthcare system have the right to participate in decision-making and choices about

their own care, and about health service planning and policies ([ACSQHC 2008](#)). Partnership with consumers at the governance level is also becoming more common internationally ([National Patient Safety Foundation 2014](#)).

Person-centred care definition and features

Worldwide, healthcare sectors are adopting person-centred principles to enhance quality of care, and empower consumers to participate in their care ([Byrne 2020](#); [Delaney 2018](#); [Mockford 2012](#); [Stone 2008](#); [Tritter 2003](#)). There are various definitions of person-centred care, but there is no single, universally accepted definition ([Byrne 2020](#)), and terms such as individualised or personalised, and patient-, family-, or user-centred care are conceptually similar ([Greene 2012](#)). Common to these terms and definitions is the provision of health care that emphasises personhood and partnership ([Edgman-Levitan 2013](#); [Hubbard 2007](#)). This review adopts the following definition of person-centred care: 'planning, delivery, and evaluation of health care that is grounded in mutually beneficial partnerships among healthcare providers, patients, and families' ([IPFCC 2012](#)).

Person-centred care is an overarching concept or ethos, which has often been implemented at the health service level. Its implementation may also affect interactions at the point of care in many different ways. For instance, the Picker Institute identifies the following principles for person-centred care, which underpin interventions at point of care: respecting consumer preferences and values; providing emotional support, physical comfort, information, communication, and education; continuity and transitions, co-ordination of, and access to care; and involvement of the family and friends (Picker Institute 1987). Person-centred care contrasts with systems- or provider-centred care, which has been criticised for being paternalistic, medically dominated, and illness-oriented (Bardes 2012; Berwick 2009).

Working in partnership for the promotion of person-centred health services

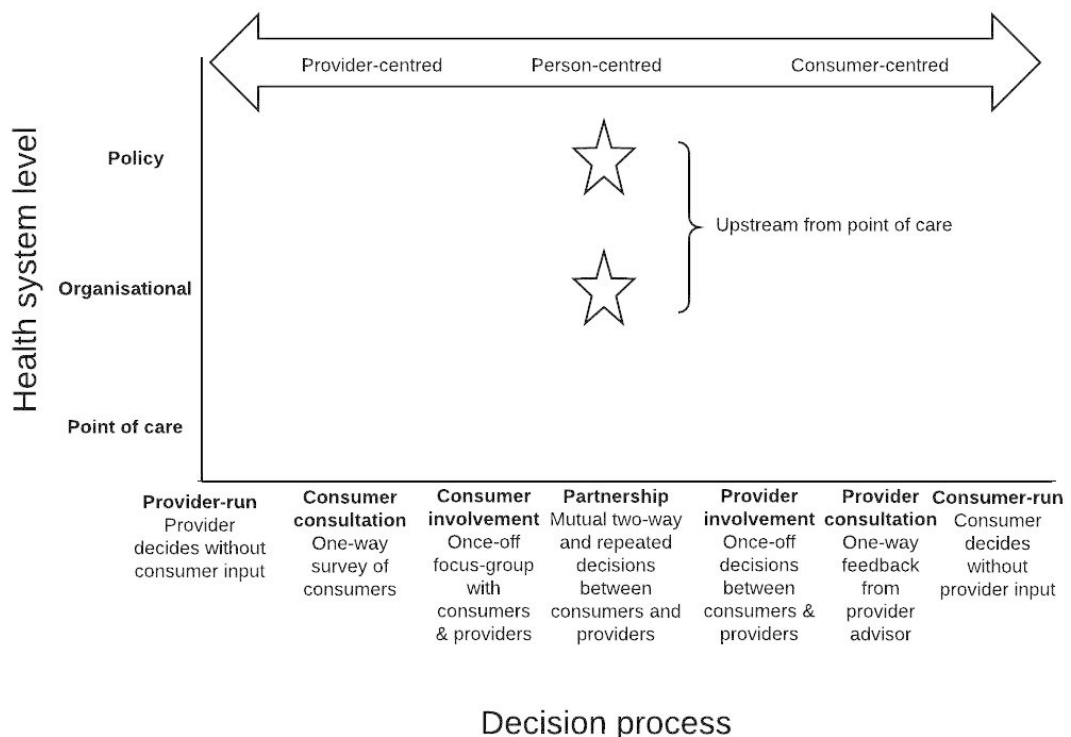
Working in partnership may be a key intervention for the promotion of person-centred health services. It is the focus of this review, but it is also important to note that this is only one of several elements of person-centred care and that other elements exist outside this review's focus. Working in partnership may impact organisational leadership, strategic vision, consumer involvement, measurement and feedback of consumer experience, staff capacity building, incentives, accountability, and a culture supportive of learning and change (Edgman-Levitan 2013; Luxford 2011). Qualitative research

has identified that factors embedded within the broader health service(s) and health system, and policies are important to facilitate person-centred care in the consultation process (i.e. at the point of care delivery (Batalden 2016; Leysdon 2015; Ogden 2017)).

At point of care, person-centred consultations typically have three main features: eliciting and skilfully listening to the consumer's personal narrative; encouraging the consumer's active participation in goal setting; and documenting goals (Moore 2017). Interventions that support one or more of these features include shared decision-making (Legaré 2014), decision aids (Stacey 2017), personalised care planning (Coulter 2011), family-centred care (Shields 2012), or family-initiated care escalation interventions (Mackintosh 2020). These interventions promote person-centred care by focusing on consumer involvement in the clinical consultation process, which influences the responsiveness of care delivery at the level of individual consumers. Interpersonal and communication skills training of providers also helps to promote person-centred care in the consultation process (Dwamena 2012; Gilligan 2021; Repper 2007).

In contrast, the current review focuses on the involvement of consumers in partnership with health providers as one of the key ways in which person-centred care can be promoted at the health service level i.e. upstream, at a higher level than the point of care (Figure 2).

Figure 2. Decision-making at different levels of the health system influences the person-centeredness of health services



Description of the intervention

Defining working in partnership as an intervention

The Australian Commission for Safety and Quality in Health Care defines partnerships as "healthcare organisations, healthcare providers, and policy-makers actively working with people who use the healthcare system, to ensure that health information and services meet people's needs" (ACSQHC 2018). The World Health Organization (WHO) further defines partnership "as a collaborative relationship between two or more parties, based on trust, equality, and mutual understanding, for the achievement of a specified goal. Partnerships involve risks as well as benefits, making shared accountability critical" (WHO 2009). The WHO definition identifies partnerships as a form of collaboration. While 'collaborate' features on the participation spectrum (Arnstein 1969), and partnerships are considered an emergent process (Wildridge 2004; Wolf 2017), working in partnership is a distinct type of collaboration that occurs over a sustained time span to allow for the ongoing process of developing constructive relationships (Ocloo 2021). Hence, one-off consumer participation in collaborations, even when they are intended to promote person-centred care at the health service level, do not fit within the parameters of this review (Armstrong 2018; Fucile 2017; McKenzie 2017).

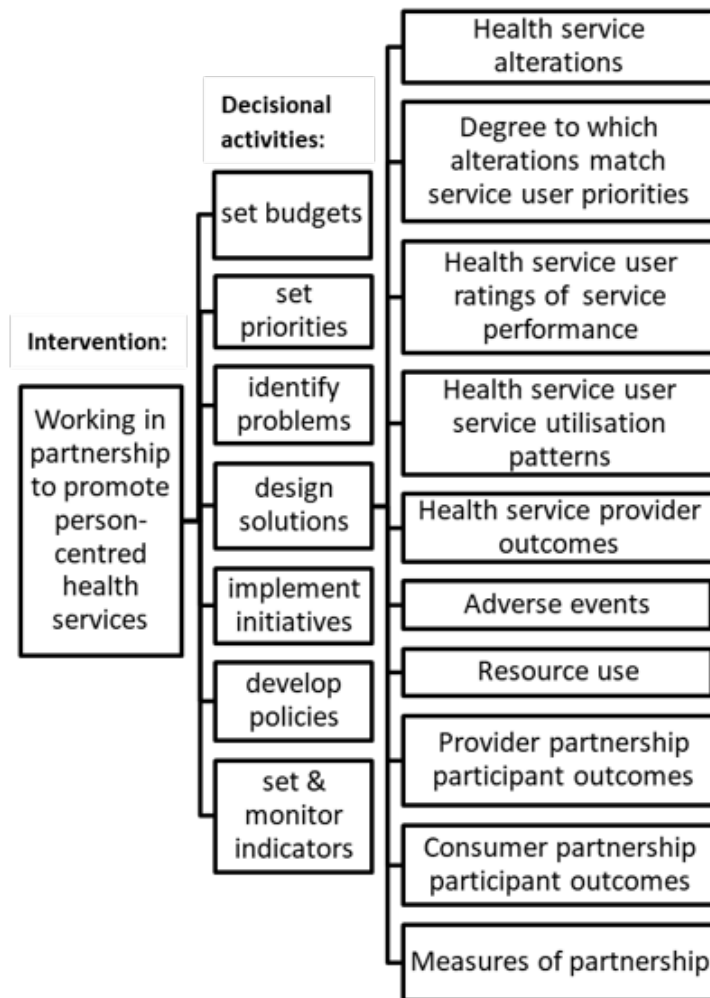
We included trials that evaluate the effects of working in partnership (i.e. collaborative relationships between at least one

consumer and health provider, meeting jointly and regularly in formal group formats, to equally contribute to and collaborate in real-time), on decisions intended to promote person-centred care in one or more areas of a health service or services. These formal group formats could include committees, councils, boards, or steering groups, which meet more than once (either for an ongoing or time-limited duration) in real-time (face-to-face or virtually).

Purpose(s) of working in partnership

Promoting person-centred care at the health service level may be achieved by working in partnership to set priorities, identify problems, design solutions, or implement initiatives that reorient the responsiveness of health services towards the information and service delivery needs and experiences of consumers (Figure 3). Partnership approaches to develop policies or identify and monitor performance indicators may also influence person-centred care at the health service level. Working in partnership on such decisions may improve health service performance ratings of affordability, physical accessibility, acceptability, safety, quality, service availability, and accountability. Working in partnership may improve the responsiveness of health services to the consumers who use them (ACSQHC 2011; Doyle 2013; Edgman-Levitan 2013; National Patient Safety Foundation 2014; Rathert 2012). Working in partnership on these decisional activities may result in changes that promote person-centred health services.

Figure 3. How working in partnership may influence person-centred care outcomes at the health service level



In research, numerous terms connote working in partnership at the health service level. Working in partnership underpins participatory action research, co-production, user-centred design, experience-based design, and co-design (Batalden 2016; Cooke 2016; Jun 2018; Sanders 2008). Common to these collaborative decision-making approaches is that they empower consumers at the health service level (Sanders 2008) and may reorient health services from a ‘provider-focus’ to a ‘patient-focus’ (Luxford 2011). Partnership approaches to decision-making are frequently illustrated by the maxim ‘nothing about me, without me’ (Berwick 2009; Coulter 2011; Delbanco 2001; Nelson 1998) and a move from the clinical paradigm of ‘what is the matter?’ to ‘what matters to you?’ (Edgman-Levitan 2013).

Optimising partnership working

Ottmann and colleagues caution that engagement and participation of consumers alone does not suffice to enable this shift. They argue that to ensure truly collaborative decision-making, the contribution of stakeholder voices requires monitoring and amplification where necessary, in order to account for intrinsic power imbalances (Ottmann 2011). For example, in their research, administrative and operational ‘imperatives’ dominated consumers’ voices; to address this power imbalance, the researchers adopted the role of consumer advocate (Ottmann

2011). We planned to conduct a subgroup analysis that focused on the effects of attempts to address intrinsic power imbalances in preparation for partnerships, for example, by providing a salary or financial reimbursement, orientation, training, coaching, or support (via an advocate, facilitator, moderator, or mentor). However, there were insufficient trials to do so.

How consumers are selected can also contribute to power imbalances, for example, by handpicking or inviting ‘appropriate’ or ‘acquiescent’ representatives, or by overlooking class or ethnic groups from whom comments are seldom heard (Ocloo 2016). Another power imbalance to be considered is whether the partnership is professionally dominated (Ocloo 2016). Therefore, in subgroup analysis, we planned to consider the methods of recruitment, whether the researchers ensured the inclusion of a diverse consumer or provider participant group (e.g. caregivers, vulnerable people, range of health providers) and the ratio of consumers to providers (e.g. consumer majority, provider majority, or equal). Due to too few included trials, we were unable to conduct planned subgroup analyses.

How the intervention might work

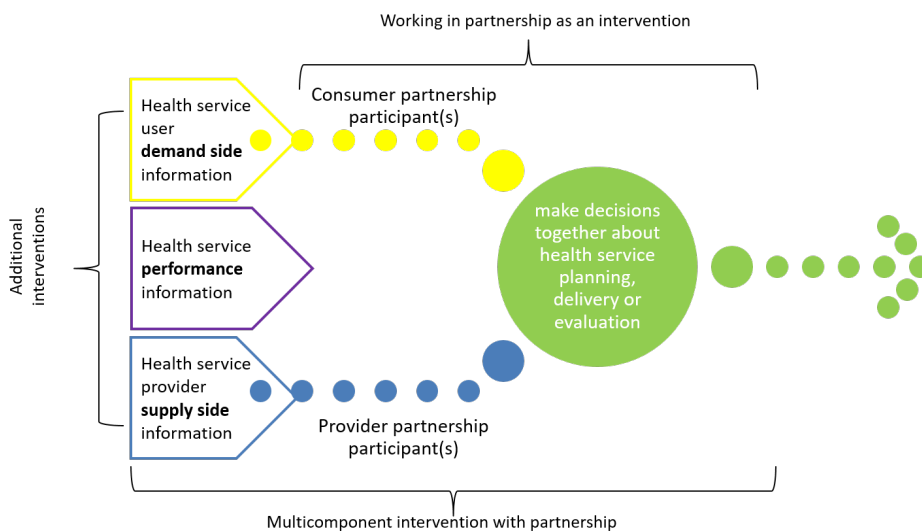
Working in partnership interventions might work by strengthening the demand responsiveness and local accountability of health

services, by including consumers in health service planning and policy decision-making (Björkman Nyqvist 2017). Responsiveness and accountability require information about (1) the needs, preferences, experiences, and priorities of consumers of the service, as well as (2) ratings of health service(s), such as performance indicators. Consumers and health providers working in partnership, means that both consumer and provider perspectives are available, and feed into health service decision-making (Edgman-Levitan 2013).

Recent trials focusing on working in partnership vary in the frame of reference for partnership decision-making. In some

trials, the consumers and health providers directly involved in the partnership (the partnership participants) approach decision-making using their own experience as a point of reference (Björkman Nyqvist 2017; Ong 2017; Palmer 2015; Palmer 2016). In other trials, the partnership participants are explicitly required to incorporate additional information that has been gathered systematically, as part of the trial, into their decision-making (Björkman 2009; Greco 2006; Gullo 2017; Waiswa 2016). This additional information may include the broader health service user perspectives (demand side), the broader provider perspectives (supply side), or health performance information (see Figure 4).

Figure 4. 'Working in partnership' interventions alone and as a component of multi-component interventions



We differentiated between working in partnership as an intervention on its own, which only incorporates the viewpoints of the consumer and provider partnership participants into their decision-making; and working in partnership as part of a multi-component intervention, in which partnership participants consider additional information (e.g. demand side, supply side, or performance information) that has been gathered systematically, as part of the trial, into their decision-making.

Why it is important to do this review

The primary objective of this review is to identify whether a common type of partnering with consumers (meeting together in formal group formats) is effective in achieving person-centred health services. This review parallels a Cochrane QES that explores consumers' and health providers' experiences of the same format (Merner 2019). We anticipate that combining the results of both reviews will provide guidance for consumers, health providers and policymakers about this form of partnership and together form a comprehensive and cohesive assessment of the evidence on partnering.

Trials evaluating the effects of upstream interventions of consumer involvement in developing health care policy, research, and services have been synthesised in other systematic reviews (Hubbard 2007; Nilsen 2006). Nilsen and colleagues focus on all

forms of consumer engagement (i.e. consult, involve, collaborate and empower) (Nilsen 2006). We limit our focus to partnership approaches (i.e. collaborate but with an ongoing or time-limited duration, excluding one-off collaborations). We also limit our focus to decisional activities intended to promote person-centred care in one or more areas of a health service(s), whereas Nilsen 2006 and Hubbard 2007 both focus on broader types of activities in all areas of research, policy, and healthcare services, with consumers broadly (Nilsen 2006), and people affected by cancer (Hubbard 2007). An overview of reviews of the theory, barriers and enablers for consumer and public involvement across health, social care and consumer safety has also recently been published (Ocloo 2021). However, no reviews have specifically evaluated the effects of consumers working in partnership, as an intervention to promote person-centred health services, which is the focus here.

An earlier review in this area explored the effects of involving consumers in the planning and development of health care, but at that time, there were no comparative or experimental studies available (Crawford 2002). Crawford and colleagues identified that involving consumers contributed to changes to services. However, they also noted that the effects of involvement on quality of care (accessibility and acceptability of services) or impact on consumers' satisfaction, health, or quality of life, had not been examined (Crawford 2002). In the absence of trial evaluations,

reviews based on research in this upstream context have focused on consumer participation and involvement predominantly as an agenda or aspiration, with guidance based on case studies of one-off collaboration examples. Sharma and colleagues identified that engaging people in partnerships, shared decision-making, and meaningful participation in health system improvement, all promoted person-centred care (Sharma 2015).

Given recently conducted or planned trials in the area (Greco 2006; Palmer 2015; Palmer 2016), a systematic review is timely. The Cochrane Consumers and Communication Group has also identified the promotion and implementation of person-centred care as a priority review topic (Synnot 2018; Synnot 2019).

By focusing on partnership activities, our review contributes to Cochrane's growing evidence base for interventions to promote person-centred care, which currently has an exclusive focus on consumer participation in interventions occurring at the point of care (Coulter 2015; Dwamena 2012; Legaré 2014; Mackintosh 2020; Shields 2012; Stacey 2017).

OBJECTIVES

To assess the effects of consumers and health providers working in partnership, as an intervention to promote person-centred health services.

METHODS

Criteria for considering studies for this review

Types of studies

We included randomised controlled trials (RCTs), cluster-RCTs, and quasi-RCTs (a trial in which randomisation is attempted, but subject to potential manipulation, such as allocating participants by day of the week, date of birth, or sequence of entry into the trial), as we anticipated that few, properly conducted RCTs will have focused on consumers and health providers working in partnership.

Types of participants

We included trials in which the following groups were participants.

- 1. Consumer partnership participants.** Consumer partnership participants refers to people who are fulfilling an advisory or representative role within the partnership. These roles might include a consumer or patient representative; consumer consultant; consumer with acute or chronic condition(s), their caregiver or family member; community members, general public or citizens; representatives, consultants, or members of consumer organisations.
- 2. Health provider partnership participants.** Health provider partnership participants refers to people who are fulfilling an advisory or representative role within the partnership. These roles might include, for example: a clinician (such as doctor, nurse, allied health, or community health worker from any discipline), health service manager, supervisor or administrator (including quality coordinators, chief executives, etc.), health policy-maker, or consumer liaison officer. As we are interested in partnerships between consumers and health providers, we will exclude partnerships in which health providers take on the role of consumer, or partnerships between consumers and providers who are primarily health researchers or academics.

- 3. Health service users and health service providers.** Health service users and health service providers refers to the consumers and providers who are not directly involved in the partnership intervention, but are participants in trials that evaluate the effects of the partnership intervention.

Partnership groups could include multiple stakeholders, as long as the goal was to make decisions to promote person-centred care. Partnerships could be committees that developed in-service training or vocational education curriculum directed towards post-registration or post-graduate level students, as long as they included at least one consumer.

Types of interventions

We included trials evaluating the effects of consumers and health providers working in partnership as an intervention, to make decisions with the aim of promoting person-centred care in one or more areas of a health service or services. We included trials of working in partnership in formal groups that meet face-to-face or virtually, more than once.

We defined person-centred care as “planning, delivery, and evaluation of health care that is grounded in mutually beneficial partnerships among healthcare providers, patients, and families” (IPFCC 2012). Examples of person-centred care decisions at the health service level included: identify appropriate and responsive healthcare indicators; improve continuity or follow-up of care; service (re)development, (re)design of physical spaces, or improve coordination of care across providers and settings (or a combination).

We included trials evaluating the effects of consumers and providers working in partnership in formal groups or committees to develop in-service training or vocational education curriculum directed towards post-registration or post-graduate level students (i.e. student cohort likely to be existing providers, and therefore partnership intervention may influence person-centredness of health service).

We defined health services as public or privately funded services that provide direct care to consumers in primary (e.g. community health centres, general practitioner practices, private practices, dispensaries), secondary (e.g. specialist outpatient clinics), or tertiary settings (e.g. hospitals). We included home and residential services only when they primarily provide health or nursing care (e.g. home-based nursing services, nursing homes, residential rehabilitation services, or hospices).

Working in partnership has three key components (see Table 1): (1) both consumer and provider participants meet (2) jointly (e.g. face-to-face, online, phone) in a formal group format regularly (e.g. over time, more than once), to (3) to consider or make an actual decision that relates to the person-centredness of health service(s).

We assess three comparisons in this review. Comparisons 1 and 2 assess the effects of partnership versus no partnership (with no other differences between groups), while Comparison 3 compares the effects of different versions of partnership.

Comparison 1. Consumers and health providers working in partnership compared to usual practice without partnership

(i.e. usual ways of decision-making may contain some but not all key components of working in partnership).

Studies for this comparison answer the question: ‘compared to usual practice without partnership, what is the effectiveness of consumers and health providers working in partnership, as an intervention?’. For example, ‘what is the effect of facilitated partnership (intervention) compared to no partnership (usual practice)?’ illustrates this comparison (Palmer 2015).

Examples of usual practice may include:

- decision-making involves some consumer input, but decisions are not made jointly;
- providers independently make decisions;
- decision-making meets some key components, but group format is informal, meets once-off, or does not meet together in real-time.

Comparison 2. Consumers and health providers working in partnership, as part of a multi-component intervention, compared to the same multi-component intervention without consumers and health providers working in partnership.

Studies for this comparison answer the question: ‘what is the effectiveness of a multi-component intervention that includes consumers and health providers working in partnership, compared to the same multi-component intervention without partnership?’. For example, ‘what is the effect of facilitated partnership plus health service consumer (demand side) information (multi-component intervention with partnership) compared to health service consumer (demand side) information without partnership (same multi-component intervention without partnership)?’ serves to illustrate this comparison (Greco 2006).

For example, a multi-component intervention may include co-interventions, such as health service consumer or provider information (demand and supply), or health service performance information (or both). Working in partnership would be part of one multi-component intervention arm, but not the other.

Comparison 3. One form of consumers and health providers working in partnership, compared to another form of consumers and health providers working in partnership.

Studies for this comparison answer the question: ‘what is the effectiveness of one form, versus another, of consumers and health providers working in partnership, as an intervention?’. For example, both groups have working in partnership interventions that fulfil all key components, but the intervention and comparator groups differ in the nature of a key feature, such as partnership participant composition (ratio of consumers and providers), or frequency, or format (online format versus face-to-face) of the meetings.

Excluded interventions

We excluded trials where the comparison did not enable us to isolate the effects of consumers and providers working in partnership. This included:

- consumers and health providers working in partnership as part of a multi-component intervention compared to usual practice; or

- consumers and health providers working in partnership, compared to an active control that does not include working in partnership (i.e. comparator is a different intervention).

In these cases, the comparisons will not allow us to evaluate the effect of working in partnership as an intervention, as the intervention and comparator groups differ on more than just the partnership component. An example illustrative of an excluded comparison is, ‘what is the effect of health service consumer (demand side) information plus partnership (multi-component intervention with partnership) compared to no health service consumer (demand side) information and no partnership (usual practice)?’ (Boivin 2014).

As working in partnership is a distinct type of collaboration that occurs over time, we excluded one-off collaborations involving consumers in group formats, even when they are intended to promote person-centred care. We excluded studies that involve partnering with consumers for decision-making about an individual's care or treatment. We also excluded studies about partnering with consumers for health services research (planning, undertaking, or disseminating research), including a health service's management of research (research funding panels, setting research priorities, research ethics and research governance (Gray-Burrows 2018)).

We excluded trials that examine committees that develop educational programmes or training for pre-registration or undergraduate students, as we are interested in working in partnership as a strategy to promote person-centred health services. Undergraduate students may not yet be employed as providers, and therefore less able to either directly or indirectly influence the person-centredness of the health service as part of the intervention (Klein 1999).

As we are interested in consumer-provider partnerships, we excluded studies of researchers or academics working in partnership with consumers if providers were not also partnership participants. Similarly, we excluded studies in which researchers or academics were working in partnership with health providers, if consumers were not partnership participants.

Types of outcome measures

This is the first Cochrane Review on this topic and so included a wide range of outcomes to inform future conceptual development and research. We did not identify from trials any additional outcomes that we did not anticipate at the protocol stage and that we considered important to consumers or health providers making decisions.

Health service alterations (changes to services resulting from decisions)

- Addition, rationalisation, substitution, expansion, or revision of health services (e.g. changes to policies, performance indicators, resources, processes or systems, programmes, settings (e.g. relocating a stroke rehabilitation service from the hospital to the community), education, information, physical structures, or culture or values of services)

Degree to which health service alterations reflect health service user (trial participant) priorities (demand responsiveness)

- Comparability of partnership decision(s) with health service user preference(s) or priorities

Health service user (trial participant) health service performance ratings (local accountability)

- Physical accessibility, e.g. simplified appointment procedures, extended opening times, transport to unit, parking, signage, security
- Affordability
- Acceptability e.g. satisfaction, retention or disengagement of existing consumers, attracting new consumers, appointment attendance or nonattendance
- Safety
- Quality
- Accountability

Health service user (trial participant) ratings of health service utilisation patterns

- Uptake of altered services or changes in coverage

Health service provider (trial participant) outcomes

- Satisfaction, staff engagement, retention or turnover, well-being

Adverse events

- Measures of complaints, harms, litigation, damage to health service reputation, staff disengagement or turnover, increased rate of consumer failure to attend appointments, etc.

Resource use

- Cost (time, money) associated with decision-making process (e.g. cost of organising and running meetings, training (providers and consumers), remuneration, coordination, or meeting space)
- Cost (time, money) associated with implementing new or changes in service

Consumer (partnership participant) outcomes*

- Attendance and retention rates in formal group formats
- Preparedness to participate (e.g. feeling informed, motivation or empowerment to be involved, attitudes towards partnership, etc.)
- Experiences of participation (e.g. satisfaction, preferences, knowledge, well-being, involvement, etc.)
- Adverse outcomes and experiences (e.g. isolation, exploitation, uncertainty, conflict, decreased well-being, disengagement from health service)

Provider (partnership participant) outcomes*

- Attendance and retention rates in formal group formats
- Preparedness to participate (e.g. feeling informed, confidence, attitudes towards partnership, etc.)
- Experiences of participation (e.g. satisfaction, preferences, job satisfaction, well-being, etc.)
- Adverse outcomes and experiences (e.g. dissatisfaction, worsening attitudes towards consumers, emotional exhaustion,

work overload, decreased well-being, disengagement or resigning from employment, and conflict)

Measures of partnership among provider and consumer partnership participants*

- Degree of shared decision-making involvement, capacity building, trust, etc

We expected that outcomes denoted above with a star (*) would likely be measured for both the intervention and control groups only in Comparison 3 (e.g. in head-to-head comparison of partnership interventions).

We did not exclude studies based on the presence or absence of outcomes reported.

Two review authors independently assigned the outcomes reported in each included study to the review's outcome categories, and resolved any differences in categorisation by involving a third review author.

Where more than one outcome measure was available in one trial for the same outcome we planned to:

- select the primary outcome that has been identified by the study authors;
- where no primary outcome was identified, we planned to select the one specified in the sample size calculation;
- if there were no sample size calculations, we planned to rank the effect estimates (i.e. listed them in order from largest to smallest) and select the median effect estimate;
- where there were an even number of outcomes, we planned to select the outcome whose effect estimate is ranked $n/2$, where n is the number of outcomes.

We planned to use the selection steps above to inform the statistical analysis (i.e. pooling, synthesis). However, as there were insufficient trials for statistical analysis, we collected data on more than one outcome measure per category per trial to inform descriptive findings. Where a study reported multiple outcome measures for the same outcome, we extracted all. Review authors then met to discuss and reach consensus on the most relevant outcome measure for evaluating partnering with consumers (whether objective or subjective). This outcome was selected to take forward for the analysis of intervention effectiveness.

Timing of outcome assessment

We grouped time points into short-, medium-, and long-term time points. For the purpose of meta-analysis, we planned to select one time point for each outcome from each study. However, as we did not have sufficient numbers of trials measuring the outcomes to be able to conduct meta-analyses, we chose to report descriptively the longest-term time point because this was most likely to be relevant to consumers and decision makers.

Main outcomes for 'Summary of findings' tables

We reported the following outcomes in the 'Summary of findings' tables.

- Health service alterations (changes to services resulting from decisions).

- Degree to which changed service reflects health service user priorities (demand responsiveness).
- Health service user (trial participant) ratings of health service performance (local accountability).
- Health service user (trial participant) health service utilisation patterns.
- Resources associated with decision-making process.
- Resources associated with implementing decisions (e.g. changed services).
- Adverse events.

Search methods for identification of studies

Electronic searches

We searched the following electronic databases (searches were initially conducted in April 2019 and then updated on 23 February 2021):

- the Cochrane Central Register of Controlled Trials (CENTRAL, The Cochrane Library, to 8 April 2019);
- MEDLINE Ovid* (1946 to 8 April 2019);
- Embase Ovid* (1947 to 8 April 2019);
- PsycINFO Ovid* (1806 to April Week 1 2019);
- CINAHL EBSCO Host* (1937 to 8 April 2019);
- PROQUEST Dissertations and Theses Global* (2016 to 8 April 2019).

Studies identified as potentially relevant from the updated searches run in February 2021 are listed as [Studies awaiting classification](#), to be considered in future updates to the review.

The outputs of databases denoted above with a star (*) were sorted by the Cochrane RCT Classifier. The RCT Classifier assigned a probability (from 0 to 100) to each citation for being a true randomised trial. The titles and abstracts of any records determined by RCT Classifier to be unlikely to be an RCT (or quasi-RCT) with the classifier scores of nine or less were screened by one review author for potential inclusion. Two authors independently screened the citations classified as likely to be an RCT. All records determined to be relevant in terms of scope at title and abstract screening stage were then screened in full text by two review authors.

We searched online trial registers including [ClinicalTrials.gov](#) at the US National Institutes of Health (from 2000 to 23 February 2021), and the WHO International Clinical Trials Registry Platform (ICTRP) (from 2000 to September 2019). For the updated search in February 2021, it was assumed that both registries were covered by updated searches of other databases, as registry records have been made available via CENTRAL since April 2019).

We present the strategy for MEDLINE Ovid in [Appendix 2](#). We tailored this strategy to other databases and report them in [Appendix 3](#), [Appendix 4](#), [Appendix 5](#), [Appendix 6](#), [Appendix 7](#) and [Appendix 8](#).

We also searched Web of Science (2000 to 8 April 2019) using the 'All databases' option to search forward on citations of 14 selected references, used to validate the search strategy; see [Appendix 9](#).

We restricted the search period, as the qualitative review scoping searches of this topic showed a proliferation of studies about partnering with consumers published after 2000. Additionally, the definition of person-centred care has developed considerably over the past decades to include aspects broader than partnering with individuals during consultations. Our assessment shows that a consistent and recognisable definition of working in partnership to promote person-centred health services has been used most often since 2000. We aimed to assess and build the evidence on what is currently accepted as partnering in the context of person-centred health services. Therefore, in this review, we searched from 2000 onwards to exclude older, conceptually inconsistent studies. We excluded publications in languages other than English.

Searching other resources

We searched relevant grey literature sources, such as websites (e.g. the WHO, Health Quality Improvement Partnership UK, Involve UK, Health Foundation UK, Beryl Institute, James Lind Alliance, International Association for Public Participation, Institute for Patient- and Family-Centered Care (formerly Picker Institute Europe), Health Issues Centre Australia, Planetree, The King's Fund, Consumer Health Organisation of Canada, Canadian Institutes of Health Research (CIHR), and the patient group - One Voice Patient & Family Advisory Council, Mayo Clinic USA) during September 2019.

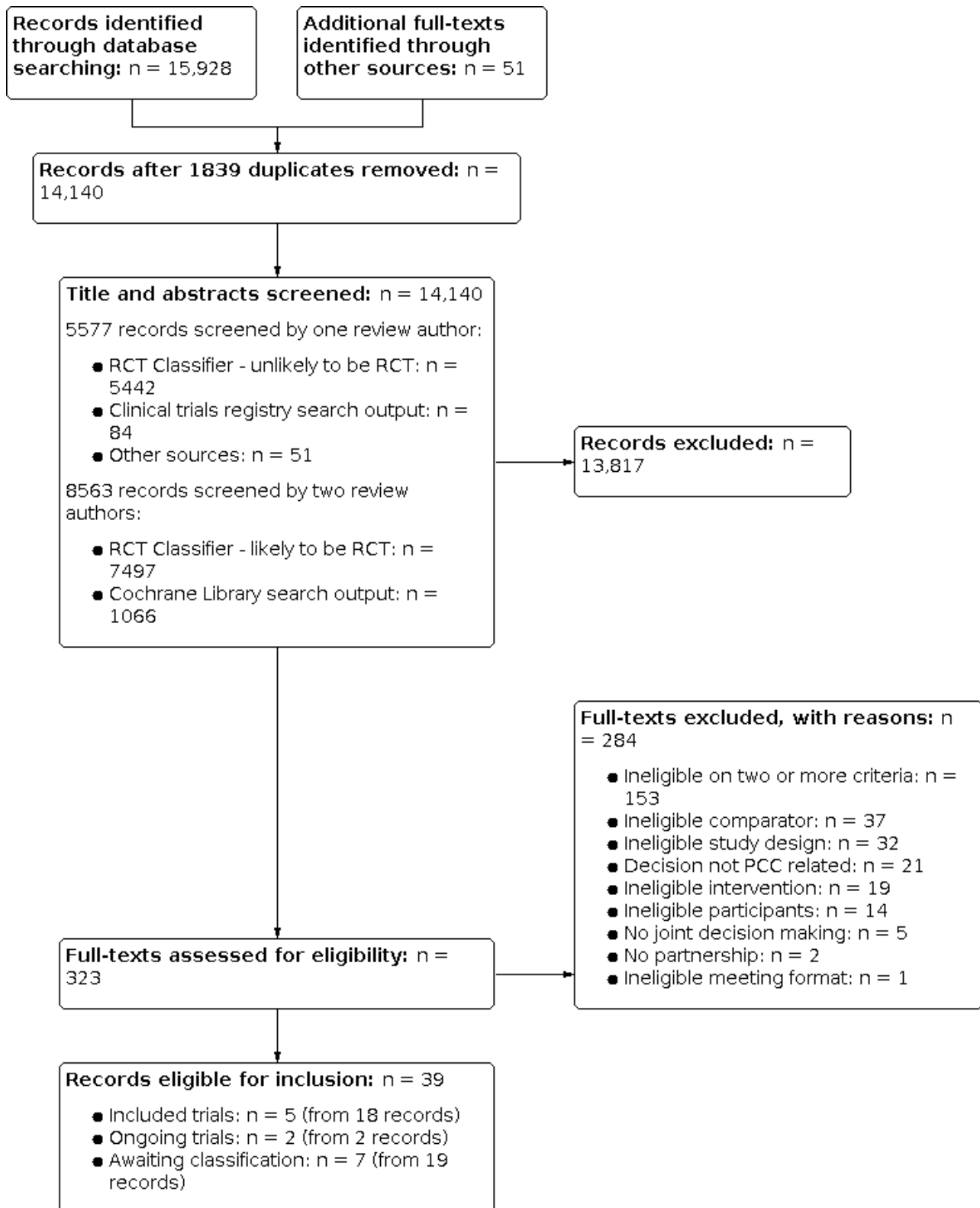
We attempted to contact experts in the field and authors of included studies to identify other potentially relevant studies. We searched reference lists of included studies and relevant systematic reviews.

Data collection and analysis

Selection of studies

To determine titles and abstracts that met the inclusion criteria, a subset of citations identified by searches were screened by one review author (records classified as unlikely to be RCTs by the RCT Classifier or identified through search of the clinical trials registries or other sources) and the remainder (records classified as likely to be RCTs by the RCT Classifier and those identified through the Cochrane Library search) were independently screened by at least two review authors, with consensus decisions made by a third review author. All the references identified at title and abstract stage and considered relevant by one or more review author were retrieved in full text. Two review authors independently screened all full-text articles for inclusion or exclusion, with discrepancies resolved by discussion, and by consulting a third review author, if necessary, to reach consensus. We list all potentially relevant papers excluded from the review at this stage, with reasons provided in the '[Characteristics of excluded studies](#)'. We also provide citation details and any available information about ongoing studies, and collate and report details of duplicate publications, so that each study (rather than each report) is the unit of interest in the review. We report the screening and selection process in an adapted PRISMA flow chart in [Figure 5 \(Liberati 2009\)](#).

Figure 5. PRISMA diagram



Data extraction and management

One review author extracted data for all included studies and a second review author independently cross-checked all data.

Any discrepancies were resolved by discussion until consensus was reached. We developed and piloted a data extraction form, using Cochrane Consumers and Communication's [data extraction template](#). We extracted data on the following items: details of the

study; risk of bias items; criteria related to precision of the study (e.g. use of a power calculation); funding source and the declaration of interests for the primary investigators; details of consumers and providers; and setting. One review author entered all extracted data into Review Manager 5; a second review author independently checked entered data for accuracy against the data extraction sheets (Review Manager 2014).

Assessment of risk of bias in included studies

We assessed and report on the methodological risk of bias of included studies in accordance with the *Cochrane Handbook for Systematic Reviews of Interventions*, and the Cochrane Consumers and Communication guidelines, which recommend the explicit reporting of the following individual elements for RCTs: random sequence generation; allocation sequence concealment; blinding (participants, personnel); blinding (outcome assessment); completeness of outcome data, selective outcome reporting (Higgins 2011; Ryan 2013).

For cluster-RCTs, we also assessed and report the risk of bias associated with an additional domain, selective recruitment of cluster participants.

We planned to assess and report quasi-RCTs as being at a high risk of bias for random sequence generation.

We considered blinding separately for different outcomes (for example, blinding may have the potential to differently affect subjective versus objective outcome measures). We judged each item as being at high, low, or unclear risk of bias as set out in the criteria provided by Higgins 2011, and provide a quote from the study report and a justification for our judgement for each item in the 'Risk of bias' table.

We deemed studies to be at the highest risk of bias if we scored them as at high or unclear risk of bias for either the sequence generation or allocation concealment domains, based on growing empirical evidence that these factors are particularly important potential sources of bias (Higgins 2011).

One review author assessed risk of bias for all included studies and a second review author independently cross-checked all assessments, consensus was reached by resolving any disagreements through discussion. We attempted to contact study authors for additional information about the included studies, or for clarification of the study methods. We incorporated the results of the 'Risk of bias' assessment into the review through standard tables, descriptive synthesis, and commentary about each of the elements. We provide an overall assessment of the risk of bias of included studies and a judgment about the internal validity of the review's results.

Measures of treatment effect

For dichotomous outcomes, we planned to analyse data based on the number of events and the number of people assessed in the intervention and comparison groups. We planned to use these to calculate the risk ratio (RR) and 95% confidence interval (CI). For continuous measures, we planned to analyse data based on the mean, standard deviation (SD), and number of people assessed for both the intervention and comparison groups to calculate mean difference (MD) and 95% CI. If the MD was reported without individual group data, we used this to report the study results. If

more than one study measured the same outcome using different tools, we planned to calculate the standardised mean difference (SMD) and 95% CI using the inverse variance method in Review Manager 5 (Review Manager 2014).

Unit of analysis issues

For any included cluster-RCTs, we checked for unit-of-analysis errors. Where we found errors, and sufficient information was available, we planned to re-analyse the data using the appropriate unit of analysis, by taking account of the intracluster correlation (ICC). We planned to obtain estimates of the ICC by contacting authors of included studies, or imputing them using estimates from external sources. It was not possible to obtain sufficient information to re-analyse the data, so we reported effect estimates and annotated any unit-of-analysis errors.

Dealing with missing data

For participant data, where possible, we conducted analysis on an intention-to-treat basis; otherwise, data were analysed as reported. We reported on the levels of loss to follow-up and reasons, and assessed this as a source of potential bias.

For missing outcome or summary data, we planned to impute missing data, and report any assumptions in the review. We planned to investigate, through sensitivity analyses, the effects of any imputed data on pooled effect estimates; however, there were too few studies to do so.

Assessment of heterogeneity

We planned to examine the heterogeneity across studies, to determine if there were considerable differences in settings, interventions, participants, and outcomes, and used this descriptive analysis to determine the most appropriate groupings of studies within each of the review's main comparisons. Where studies were considered similar enough (based on consideration of these factors) to allow pooling of data using meta-analysis, we planned to assess the degree of heterogeneity by visual inspection of forest plots, and by examining the Chi² test for heterogeneity. Heterogeneity was to be quantified using the I² statistic. An I² value of 50% or more was to be considered to represent substantial levels of heterogeneity, and this value was to be interpreted in light of the size and direction of effects and the strength of the evidence for heterogeneity, based on the P value from the Chi² test (Higgins 2011). As there were insufficient studies pool effect estimates, we did not explore possible reasons for variability by conducting subgroup analysis.

Included studies were too dissimilar due to substantial clinical, methodological or statistical heterogeneity to pool statistically, therefore we did not report pooled results from meta-analysis, but instead used a descriptive approach to data synthesis. There were too few studies to group studies with similar populations, intervention and methodological features to explore differences in intervention effects.

Assessment of reporting biases

We assessed reporting bias qualitatively, based on the characteristics of the included studies (e.g. to determine if only small studies that indicate positive findings are identified for inclusion).

We did not identify sufficient (i.e. 10 or more) studies for inclusion in the review, and therefore we did not construct a funnel plot to investigate small study effects, which may indicate the presence of publication bias. Therefore, we did not formally test for funnel plot asymmetry (Higgins 2011). Instead, publication bias was assessed by determining whether the included studies were likely to be representative of all relevant studies that have been conducted and where there were completed trials not yet published we considered this suggestive of publication bias.

Data synthesis

We could not conduct meta-analyses as planned due to an insufficient number of studies identified within each comparison and each outcome. We decided not to meta-analyse data as the included trials were not similar enough in terms of participants, settings, intervention, comparison, and outcome measures to ensure meaningful conclusions from a statistically pooled result.

As we were unable to pool the data statistically using meta-analysis we conducted a descriptive synthesis of results. We present the major outcomes and results, organised by intervention categories according to the major types or aims (or both) of the identified interventions. Due to lack of trials, it was not possible to explore the possibility of organising the data by population, and explore heterogeneity in the results by investigating the subgroups identified below. Within the data categories, we explore the main comparisons of the review:

- partnership intervention versus usual practice (without partnership);
- multi-component intervention with partnership versus multi-component intervention without partnership;
- one form of partnership intervention versus another.

If we had identified studies assessing the effects of more than one intervention, we would have compared each separately with usual practice, and with one another.

Using the synthesised quantitative findings to supplement the Cochrane qualitative evidence synthesis (QES)

The QES informed development of this review (Merner 2019). While we planned at the outset of these two pieces of work to integrate qualitative and quantitative findings from this review in the discussion (Harden 2018), the sparse data available and small number of trials included in this review did not lend itself to an in-depth interpretation through a qualitative lens. Future updates of this review may consider looking at contextual and other information offered by the accompanying QES, but only if it is meaningful to do so.

Subgroup analysis and investigation of heterogeneity

A statistical subgroup analysis was not possible, nor was it possible to examine explanatory factors to explore the effects of interventions descriptively.

Sensitivity analysis

There were too few included studies to undertake planned sensitivity analyses.

Ensuring relevance to decisions in health care

Both the protocol for this review and the related QES protocol were co-designed with a stakeholder advisory panel who were also to be directly involved in the production of the QES at the review stage (Merner 2019). A draft of the protocol for this review was shared with the stakeholder advisory panel prior to a stakeholder workshop day. During the workshop, the stakeholders provided the following feedback on the protocol.

- Refine definitions to reflect practice e.g. consumers and health providers often ‘make decisions together’ rather than ‘sharing responsibility for decisions’.
- Define terms in understandable, or lay language.
- A diagram or infographic showing the differences between the effectiveness review and the QES is needed to help with clarity.
- Explain the differences between point of care versus partnership in health service.
- Clarify if Consumer Liaison Officer has a complaints role or advocate role.
- Consider (in subgroup analyses) the role of power differentials, consumer representatives, whether led or chaired by consumers or professionals, who initiated the group, who leads partnerships, and hierarchies within service (e.g. palliative care – multidisciplinary care).
- Relevant outcomes might include: participatory outcomes, such as cohesion or collaboration (perhaps in measures of increasing involvement or capacity building); consumer participation as stepping stone to higher-level participation and involvement (i.e. capacity building, which benefits the individual consumer and the system); and personal well-being. Decisions might result in: changes in systems or services; improved accessibility (of parking, signage, security and reduced theft); more dissemination of changed services and outcomes; rationalised services (i.e. increased focus on those that consumers want, on those that add value); growth in services (i.e. may demonstrate increased need); change of setting (e.g. hospital service to community, hospital to home setting); staff engagement, retention, etc; and financial cost savings (i.e. if experienced staff stay on, this may be more cost-effective than adding new staff). Adverse events might include stakeholder disengagement, negative impacts on reputation, noncompliance, and failure to attend at point of care.
- Relevant grey literature search sites might include: Beryl Institute, Health Foundation UK; work in Canada with First Nations (i.e. indigenous) people have led the way with community-led engagement.

The stakeholder panel feedback resulted in the following changes to the protocol.

- Changed ‘sharing responsibility for decisions’ to ‘make decisions together’ or alternatively ‘jointly make decisions’.
- Glossary added to define terms (see Appendix 1).
- Modified the infographic of the funnel diagram to outline the different steps in the qualitative and quantitative systematic review approaches (see Figure 1).
- Developed figure to highlight the level of the health system where partnership-based decision-making might impact the person-centeredness of health services (i.e. national, state, regional (policy) level, or local health service governance

(organisational) level, as opposed to the direct care (point of care) level (see [Figure 2](#))).

- Removed the term 'Consumer Liaison Officer' as an example in the background, and referred instead to a consumer advocate role as a support component of facilitated partnerships.
- Added to the methods our intent to consider the identified potential sub-group analyses, if number of included trials allows.
- Added the identified outcomes.
- Added the grey literature resources.

A content expert provided feedback on the protocol and review, as part of Cochrane Consumers and Communication's standard editorial process.

Summary of findings and assessment of the certainty of the evidence

Two review authors independently assessed the certainty of the evidence, using the GRADE criteria described in [Schünemann 2011](#): methodological limitations, inconsistency, imprecision, indirectness and publication bias. We planned to prepare a 'Summary of findings' table for each of the three comparisons outlined above. However, we did not prepare a table for Comparison 3, as none of the included studies examined one form of partnership intervention versus another. We did not use GRADEpro software ([GRADEpro GDT](#)) to present the results of the meta-analysis, as the findings were limited to descriptive synthesis. The seven key outcomes outlined in the [Types of outcome measures](#) section are presented in 'Summary of findings' tables for Comparison 1: Partnership intervention versus usual practice and Comparison 2: Multi-component intervention with partnership versus multi-component intervention without partnership.

RESULTS

Description of studies

See [Characteristics of included studies](#), [Characteristics of excluded studies](#), [Characteristics of ongoing studies](#), and [Characteristics of studies awaiting classification](#).

Results of the search

The combined database searches yielded 15,928 records. We obtained an additional 51 full-text records through other sources. After removing duplicates ($n = 1839$), we screened 14,140 titles and abstracts. Of the title and abstracts screened, 8563 records were screened by two review authors (i.e. records classified as likely to be RCTs by RCT Classifier, $n = 7497$; and records obtained through Cochrane Library search, $n = 1066$). One review author screened 5577 other records (i.e. those classified as unlikely to be RCTs by the RCT Classifier, $n = 5442$; those identified by search of clinical trials registries, $n = 84$; and those identified through other sources, $n = 51$). Two review authors independently screened 323 full-text articles. We excluded 284 full-text records that did not meet the inclusion criteria and recorded our reasons for exclusion (see [Characteristics of excluded studies](#)).

We included five studies (reported in 18 records). One is an RCT ([Jha 2015](#)), and four are cluster-RCTs ([Greco 2006](#); [O'Connor 2019](#); [Persson 2013](#); [Wu 2019](#)). Two studies ([Kjellström 2019](#); [Sawtell 2018](#)) are ongoing (see [Characteristics of ongoing studies](#)). Studies

identified as potentially relevant from the updated searches run in February 2021 are listed as [Studies awaiting classification](#). Seven studies ([English 2018](#); [Gai 2019](#); [James 2013](#); [Lindquist 2020](#); [Morrison 2020](#); [Palmer 2015](#); [Shrestha 2011](#)) reported in 19 records are awaiting classification (see [Characteristics of studies awaiting classification](#)). See [Figure 5](#) for PRISMA diagram.

Included studies

Participants

A total of 16,257 health service users and at least 469 health service providers were trial participants in the five included studies (the number of included provider trial participants was unknown in [Wu 2019](#)). In two studies, the trial participants were health service users only (mothers with live births ([Persson 2013](#)) and pregnant women or mothers of children aged under five ([O'Connor 2019](#))); in one study, the trial participants were health service providers only (first-year medical trainee doctors employed in hospitals; [Jha 2015](#)); and in two studies, both health service users and providers were trial participants ([Greco 2006](#); [Wu 2019](#)).

In two studies, all health service users were female ([O'Connor 2019](#); [Persson 2013](#)), reflecting the trials' focus on maternal and child health; and in the other two studies the majority (63% to 68%) of health service users were female ([Greco 2006](#); [Wu 2019](#)). None of the three studies including health service providers as trial participants provided demographic details ([Greco 2006](#); [Jha 2015](#); [Wu 2019](#)), although in [Jha 2015](#) all participants were doctors in their first year after medical school and so were all considered to be at the same level. See [Table 2](#) for more details of participants.

Setting

Included studies were carried out in Sierra Leone ([O'Connor 2019](#)), UK ([Greco 2006](#); [Jha 2015](#)), USA ([Wu 2019](#)) and Vietnam ([Persson 2013](#)). Studies included communities in high-income settings (urban: [Jha 2015](#); [Wu 2019](#); coastal and rural: [Greco 2006](#)); middle-income settings (village: [Persson 2013](#)); and low-income settings (urban slum: [O'Connor 2019](#)). Three studies were based in primary care ([Greco 2006](#); [Jha 2015](#); [Wu 2019](#)) and two were based in communities, focusing on improving maternal and neonatal healthcare in communities with high neonatal, child and/or maternal mortality rates ([O'Connor 2019](#); [Persson 2013](#)).

Interventions

To be eligible for inclusion, the intervention 'working in partnership' was required to have three key components: (1) both consumer and provider participants meet; (2) they meet jointly and regularly in formal group formats; (3) they make actual decisions that relate to the person-centredness of health service(s). Although all included studies meet this definition, they differed greatly in terms of the participants involved, meeting purpose, formats, duration and decisions; see [Table 3](#) for details.

Consumer partnership participants included patients and carers with experience of harm or error during healthcare either to themselves or their families ([Jha 2015](#)); lay women members of a women's union ([Persson 2013](#)); health service patients ([Greco 2006](#)); peer supervisors of community health workers (CHWs) ([O'Connor 2019](#)) and community leaders from not-for-profit community-based organisations serving adults and addressing social determinants of health ([Wu 2019](#)).

Provider partnership participants included clinicians involved in education at graduate medical schools (Jha 2015); commune health centre staff (physician, midwife, nurse), village health workers, chairpersons/vice chairpersons and women's union representatives (village and commune levels) (Persson 2013); healthcare community practice staff (Greco 2006); peripheral health unit (government primary health care facility) staff; health management committee and ward development committee members (O'Connor 2019); and Johns Hopkins Health System (JHHS) staff members (Wu 2019).

Although meetings were all formalised, they varied in purpose. Partnership meetings included: curriculum co-designed and delivered teaching sessions at five hospital sites (Jha 2015); maternal and newborn health group meetings in each of 44 communes (Persson 2013); 'Critical Friends Group' meetings in 28 health services (Greco 2006); community health data review meetings in ten communities (O'Connor 2019); Baltimore 'Community-based Organizations Neighborhood Network: Enhancing Capacity Together' (CONNECT) participatory action research meetings with JHHS staff for 20 community-based organisations (CBOs) (Wu 2019).

Decisions made in partnerships also differed in terms of directly or indirectly influencing the person-centredness of health services. In the curriculum co-designed and co-delivered by consumers and providers, participants jointly developed and delivered the patient safety curriculum for first-year postgraduate medical trainees, which influenced the person-centredness of health service indirectly (Jha 2015). In the remaining trials, decisions and activities had a more direct impact. For instance, in maternal and newborn health group meetings, consumers and providers jointly identified local problems and agreed on actions to support the commune health centre staff and key commune stakeholders in improving perinatal health care practices. Actions were directed towards health services but also to pregnant women and their households, and to members of the general public (Persson 2013). Similarly, in 'Critical Friends Group' meetings, consumers and providers jointly interpreted systematic patient feedback and agreed on an action plan to enable practices to make changes that were more patient focused. This directly aimed to influence the person-centredness of the health services (Greco 2006).

All partnership meetings took place face-to-face. Meeting length ranged from one to two hours (Jha 2015; Persson 2013; Wu 2019), and frequency and duration ranged from twice over 12 weeks (Greco 2006; Jha 2015) to monthly for three years (Persson 2013).

Training for partnership participants was reported in four studies (Greco 2006; Jha 2015; O'Connor 2019; Persson 2013). This took different forms, including a series of preparatory workshops facilitated by consumer and carer members from the Patient Voice Group at University of Leeds (Jha 2015); a facilitation manual and ten-day training program for consumer partners (facilitators) delivered by researchers (Persson 2013); preliminary consumer-only and provider-only (where requested) group meetings facilitated by a researcher (Greco 2006); and training by project staff for consumer partners (peer supervisors) (O'Connor 2019).

Support for consumer partnership participants was also reported in four studies (Jha 2015; O'Connor 2019; Persson 2013; Wu 2019). This included opportunities to debrief with a consumer from the

Patient Voice Group after co-delivered teaching (Jha 2015); field supervision by two researchers and monthly two-day meetings for consumer partners (facilitators) (Persson 2013); oversight and assistance from at least one local health management committee and ward development committee member (O'Connor 2019), and a student research assistant assigned to each intervention consumer site (CBOs) (Wu 2019).

Less common were explicit attempts to address intrinsic power imbalances (Jha 2015; Persson 2013). Where this occurred, strategies included providing travel expenses and financial reimbursement for attending teaching and training sessions, (Jha 2015) and payment on a full-time basis for the three years of the intervention (Persson 2013).

Primary outcomes

Three trials measured health service alterations (changes to services resulting from decisions). In one trial this was in terms of problems identified and actions taken to address these (Persson 2013) but data were reported for the intervention arm only. Another study (O'Connor 2019) reported data from two outcome measures in this category: the number of mothers ever having had a visit from a CHW and number of mothers having had a home health visit from a CHW in the last year in which the CHW performed all roles. The third study (Wu 2019) measured CBO staff reports of the number of times they had received one or more referrals from healthcare staff.

No studies measured the degree to which health service alterations reflect health service user (trial participant) priorities (demand responsiveness).

Two studies measured outcomes related to health service user (trial participant) health service performance ratings (local accountability). O'Connor 2019 reported the number of mothers having had a CHW visit in the past year who found the visit helpful or somewhat helpful. In Greco 2006, overall satisfaction with this general practice (a subscale of the 'Improving Practice Questionnaire'; scale range zero to five, higher scores better) was reported.

One study (Wu 2019) identified the number of participants referred from the healthcare system to a CBO (via client report), relating to the category of health service user (trial participant) uptake of altered services or changes in coverage.

Three trials measured health service provider (trial participant) reported outcomes. Jha 2015 reported 'Attitudes to Patient Safety Questionnaire' scores from a 26-item questionnaire with total scores ranging from 26 to 182 (higher scores indicating a more positive attitude). Persson 2013 measured healthcare staff knowledge on perinatal care, availability of equipment and drugs at health facilities, but did not report any data. The third trial (Wu 2019) reported several relevant outcomes (e.g. JHHS staff barriers to referring patients to CBOs, capacity for CBOs and healthcare organizations to work together) but data presented was not extractable for the comparison of intervention and control groups.

One study reported adverse events by descriptively reporting that no harms were observed in either group (Wu 2019).

Secondary outcomes

No studies measured resource use such as costs (time, money) associated with the decision-making process (e.g. cost of organising and running meetings) or costs associated with implementing new or changes in services.

Consumer (partnership participant) reported outcomes were measured in three included trials (O'Connor 2019; Persson 2013; Wu 2019), but for one the data were not comparative (Persson 2013). O'Connor 2019 reported the ratio of peer supervisors reporting versus those trained which we identified as a proxy for consumer partnership participant retention rates. The third study (Wu 2019) reported the mean number of CBO staff rating that they worked together with health service moderately or extremely well.

Provider (partnership participant) outcomes were measured in two studies (O'Connor 2019; Persson 2013), but data for Persson 2013 was not comparative. O'Connor 2019 reported the health management committee's rating of their ability to fulfil their role of using health information in planning.

Two studies assessed measures of partnership among provider and consumer partnership participants. O'Connor 2019 reported on Health Management Committee (provider) rated ability to fulfil their role of reviewing and contributing to CHW activity plans. The

other did not report comparative data but measured satisfaction with the partnership for consumer participants in the intervention group only (Wu 2019).

Excluded studies

We excluded 284 studies in total (see [Characteristics of excluded studies](#)). The most common reasons for exclusion were: ineligible on two or more criteria (n = 153); ineligible comparator (n = 37); ineligible study design (e.g. no attempt at randomisation) (n = 32) and decision not related to person-centredness of health service (n = 21).

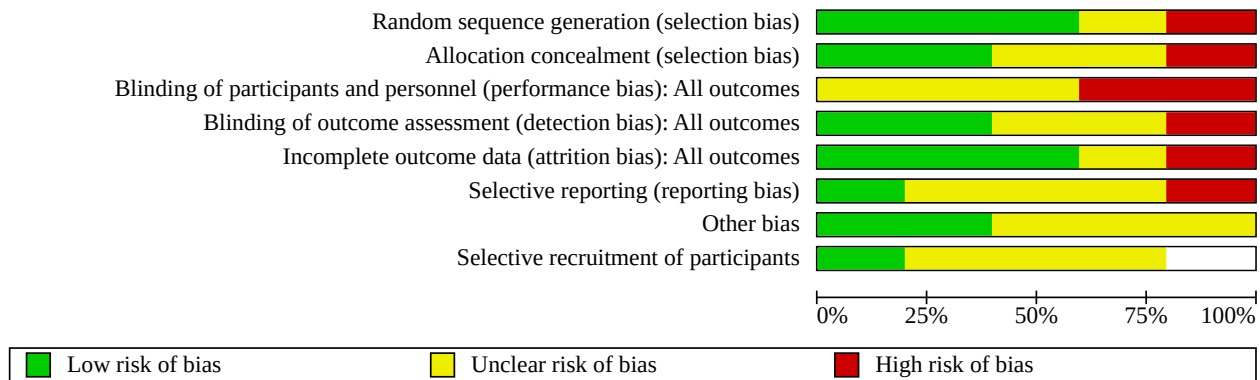
Risk of bias in included studies

See [Characteristics of included studies](#), [Figure 6](#) and [Figure 7](#) for a summary assessment of the risk of bias in the included studies (Jha 2015 is not a cluster-RCT and judgement on the domain 'selective recruitment of participants' is thus non-applicable in [Figure 6](#) and [Figure 7](#)). Overall, three of the five included studies were considered at highest risk of bias due to being rated at high or unclear risk of bias for the sequence generation and/or allocation concealment domains. Additionally, most of the studies had methodological limitations in the following domains: performance bias, detection bias, other sources of bias and selective recruitment of participants.

Figure 6. Risk of bias summary: review authors' judgements about each risk of bias item for each included study

	Random sequence generation (selection bias)	Allocation concealment (selection bias)	Blinding of participants and personnel (performance bias): All outcomes	Blinding of outcome assessment (detection bias): All outcomes	Incomplete outcome data (attrition bias): All outcomes	Selective reporting (reporting bias)	Other bias	Selective recruitment of participants
Greco 2006	+	?	?	?	+	?	?	+
Jha 2015	+	+	-	-	-	-	?	
O'Connor 2019	?	?	?	?	?	?	?	?
Persson 2013	+	+	-	+	+	+	+	?
Wu 2019	-	-	?	+	+	?	+	?

Figure 7. Risk of bias graph: review authors' judgements about each risk of bias item presented as percentages across all included studies



Allocation

Risk of bias for random sequence generation was adequately described and rated as low in three studies (Greco 2006; Jha 2015; Persson 2013). It was unclear in one study (O'Connor 2019) as the process for the random allocation to the intervention and control group for the ten communities was not described, and high in another study (Wu 2019), as although a restricted randomisation process was conducted that constrained the allocation of organisations based on a range of factors (their ZIP code, client population size and the type of service offered) even if balance was managed on these factors there might be other potential confounders which were not considered. Allocation was adequately concealed in two studies (Jha 2015; Persson 2013), inadequate in one (Wu 2019) and measures taken were judged as unclear in two studies (Greco 2006; O'Connor 2019).

Selective recruitment of cluster participants was assessed for the four cluster-RCTs. One was considered to be at low risk of bias, as there did not appear to be differential participant recruitment in clusters (Greco 2006), and at unclear risk of differential participant recruitment, as timing of recruitment was not mentioned (O'Connor 2019; Persson 2013; Wu 2019).

Blinding

Either participants (Jha 2015) or personnel (Persson 2013) were aware of their assignment in two studies, and as outcomes were subjective, this was judged as leading to a high risk of performance bias. For the remaining studies, blinding and potential effects on outcomes were rated as being at unclear risk of bias (Greco 2006; O'Connor 2019; Wu 2019).

One study stated that there was no blinding of outcome assessment (Jha 2015); we considered this study to have high risk of detection bias. Information provided by the trial authors for two further studies indicated that primary outcomes were assessed electronically, with statisticians analysing the data blind to group assignment (Wu 2019), or that data collectors were blind to group allocation and had no contact with those administering the intervention (Persson 2013). Both were therefore rated as at low risk of bias. We assessed the remaining two studies as having unclear risk of detection bias as there was no description of whether or not adequate steps were taken to blind outcome assessors (Greco 2006; O'Connor 2019).

Incomplete outcome data

One study was considered to have incomplete outcome data (due to 68% of participants missing from primary outcome (Attitudes to Patient Safety Questionnaire, APSQ) analysis at follow-up; and because this was somewhat unbalanced between groups; 74% missing in the intervention and 62% in the control) and therefore at high risk of attrition bias (Jha 2015). One study was assessed as having unclear risk of attrition bias due to insufficient details on participant numbers over the course of the trial (O'Connor 2019). Three studies were considered to have low risk of attrition bias as there were no losses to follow-up (Persson 2013); minimal incomplete outcome data (1.23% questionnaire responses excluded due to being incomplete; Greco 2006); or acceptable levels of attrition (7% both groups), for similar reasons across groups (Wu 2019).

Selective reporting

One study was considered to have high risk of reporting bias: it reported an additional outcome not mentioned in the protocol and did not report comparative data for the course evaluation mentioned in the study protocol (Jha 2015). Three studies were considered to be at unclear risk of reporting bias because although data were reported for all outcomes mentioned in the methods, we were not able to identify a trial protocol in two studies (Greco 2006; O'Connor 2019), and in the third, the protocol only listed the primary outcome measure; and there are additional outcomes in the publication (Wu 2019). The remaining trial reported all outcomes as planned, based on the protocol (Persson 2013), and was therefore assessed as having a low risk of selective reporting.

Other potential sources of bias

Three studies were considered to have unclear risk of other types of bias for the following reasons: a greater proportion of control group providers were the subject of the survey for their first time during the follow-up, potentially explaining why overall mean scores were worse in the control group and better in the intervention group (Greco 2006); no characteristics were provided to assess baseline imbalance, participants with incomplete data for each time point were excluded from analysis, and there may have been communication between intervention and control participants (Jha 2015); there was substantial movement between communities

(in and out) (O'Connor 2019). Two studies were considered to be at low risk of other potential sources of bias (Persson 2013; Wu 2019).

Effects of interventions

See: [Summary of findings 1 Consumers and providers working in partnership compared with usual practice](#); [Summary of findings 2 Multi-component intervention with consumers and providers working in partnership compared to the same intervention without partnership](#)

Comparison 1: consumers and health providers working in partnership compared to usual practice

Two included studies assessed this comparison (Jha 2015; Persson 2013). See [Table 4](#) for extracted data and [Summary of findings 1](#) for a summary of key findings.

No studies reported the following outcomes: degree to which health service alterations reflect health service user (trial participant) priorities (demand responsiveness); health service user (trial participant) health service performance ratings (local accountability); adverse events; resource use associated with decision-making process, resource use associated with implementing new or changed services; or measures of partnership among provider and consumer partnership participants. Additionally, [Persson 2013](#) measured the following outcomes relevant to this comparison but the data were not comparative: health service alterations (problems and actions taken to address these); consumer (partnership participant) reported outcomes (consumer partner attendance at meetings); and provider (partnership participant) reported outcomes (provider partner attendance at meetings). We are uncertain about the effects of the intervention on these outcomes, including those reported in [Summary of findings 1](#), because of a lack of evidence.

Below we present findings organised by outcomes with comparative data.

Health service provider (trial participant) reported outcomes

Two trials assessed health service provider-reported outcomes (Jha 2015; Persson 2013), but [Persson 2013](#) did not present usable data; [Jha 2015](#) reported little or no effect of the intervention on health service providers' overall attitudes to patient safety (e.g. self-reported opinion towards the causes, reporting and management of errors) at three to six weeks.

In summary, very low-certainty evidence indicates that we are unsure about the effects of working in partnership compared to usual practice on health service provider reported outcomes. We had serious concerns about risk of bias for multiple domains (performance bias, detection bias, attrition bias, reporting bias, other sources of bias and selective recruitment of participants) as well as indirectness, imprecision and publication bias.

Comparison 2: multi-component intervention with consumers and providers working in partnership compared to the same intervention without partnership

Three included studies assessed this comparison ([Greco 2006](#); [O'Connor 2019](#); [Wu 2019](#)). See [Table 5](#) for extracted data and [Summary of findings 2](#) for a summary of key findings. The timing of longest follow-up ranged from 12 months ([Greco 2006](#); [Wu 2019](#)) to 21 months ([O'Connor 2019](#)).

No studies reported the following outcomes: degree to which health service alterations reflected health service user preference(s) or priorities; resource use associated with decision-making process or resource use associated with implementing new or changed services. One study ([Wu 2019](#)) measured outcomes reported by the health service providers (trial participants), but the data were not comparative; rather, data were reported in trial as pre-post for inpatient staff and outpatient staff separately. Below we present findings, organised by outcomes with data.

Primary Outcomes

Health service alterations

Two studies ([O'Connor 2019](#); [Wu 2019](#)) assessed health service alterations. These studies reported little or no effect of the intervention on the number of mothers who reported ever having a CHW visit; the number of mothers who reported having a home health CHW visit in the last year in which the CHW performed all roles; or the number of CBO staff who reported receiving one or more referral from healthcare staff.

In summary, very low-certainty evidence indicates that we are unsure whether multi-component interventions with partnership compared to without partnership result in health service alterations. We had serious concerns about risk of bias or lack of clarity across all domains (all items rated as at unclear or high risk of bias for at least one of the two studies). We also graded down for indirectness, imprecision and risk of publication bias.

Health service user (trial participant) health service performance ratings (local accountability)

Two studies ([Greco 2006](#); [O'Connor 2019](#)) assessed the acceptability of health services to trial participants. Studies reported little or no effect of the intervention on the number of mothers who had a home health CHW visit in the past year who found the visit helpful or somewhat helpful; or health service user overall satisfaction with the general practice.

In summary, very low-certainty evidence (due to serious concerns about risk of bias or lack of clarity across all domains (all items rated as at unclear or high risk of bias for at least one of the two studies), indirectness and publication bias) indicates that we are unsure about the effects of multi-component interventions with partnership compared to without partnership on health service user (trial participant) health service performance ratings.

Health service user (trial participant) health service utilisation patterns

One study ([Wu 2019](#)) assessed trial participant health service utilisation patterns. There was little or no effect of the intervention on the number of clients who reported they were referred from the healthcare system to a CBO.

In summary, very low-certainty evidence (due to serious concerns about methodological limitations (high risk of selection bias or lack of clarity across domains of performance bias, reporting bias and selective recruitment of participants), indirectness, imprecision and publication bias) indicates that we are unsure about the effects of multi-component interventions with partnership compared to without partnership on trial participant health service utilization patterns.

Adverse events

One study (Wu 2019) descriptively reported that no harms were observed in either group.

Secondary outcomes

Consumer (partnership participant) reported outcomes

Two studies (O'Connor 2019; Wu 2019) assessed consumer partnership participant reported attitude or behaviour outcomes. There was little or no effect of the intervention on the ratio of peer supervisors reporting versus peer supervisors trained (a proxy measure for consumer partnership participant retention rates); or on community-based organisation staff ratings of working together with health service moderately or extremely well.

In summary, very low-certainty evidence (due to serious concerns about methodological limitations (risk of bias or lack of clarity across all domains, with all items rated as at unclear or high risk of bias for at least one of the two studies), indirectness, imprecision and publication bias) indicates that we are unsure about the effects of multi-component interventions with partnership compared to without partnership on consumer partnership participant reported outcomes.

Provider (partnership participant) reported outcomes

One trial (O'Connor 2019) assessed provider partnership participant behaviour or attitude outcomes. There was little or no effect with the intervention on health management committee use of health information in planning.

In summary, very low-certainty evidence indicates that we are unsure about the effects of multi-component interventions with partnership compared to without partnership on provider partnership participant-reported outcomes. We had serious concerns about risk of bias across all domains, as well as indirectness, imprecision and publication bias.

Measures of partnership among provider and consumer partnership participants

One trial (O'Connor 2019) assessed measures of partnership among provider and consumer partnership participants, reporting a small decrease with the intervention on the number of times health management committees reviewed and contributed to CHW activity plans. A second trial (Wu 2019) reported data about partner satisfaction with the partnership for consumer participants reported for the intervention group only.

In summary, very low-certainty evidence indicates that we are unsure about the effects of multi-component interventions with partnership compared to without partnership on measures of partnership among provider and consumer partnership participants. We had serious concerns about methodological limitations (all risk of bias domains items rated as at unclear or high risk of bias for at least one of the two studies), as well as indirectness, imprecision and publication bias.

Comparison 3: one form of consumers and health providers working in partnership, compared to another.

No included studies assessed this comparison.

DISCUSSION

Summary of main results

We identified five studies; two that evaluated working in partnership interventions compared to usual practice without partnership (Comparison 1), and three that evaluated working in partnership as part of a multi-component intervention, compared to the same intervention without partnership (Comparison 2). No studies evaluated one form of working in partnership compared to another (Comparison 3).

Our findings indicate that we are uncertain of the effects of working in partnership as an intervention to promote person-centred health services. Primarily, this is because only a limited number of trials met our tightly defined inclusion criteria and those included were disparate in terms of settings, populations and context, outcomes measured, as well as the purpose and nature of the partnerships evaluated.

Predominantly, the evidence included in this review evaluated the effects of working in partnership as an intervention to promote person-centred health services indirectly. For instance, only two studies examined ways to directly influence decisions about the person-centredness of health services: Greco 2006 examined decision-making to improve the person-centredness of health service planning, while Wu 2019 assessed decisions about delivery related to discharge co-ordination. In all other trials, the partnership decision-making was either indirectly related to health service delivery or planning (e.g. via educating first-year doctors on patient safety; Jha 2015); or the partnership aim was broader, with the health service only one of many avenues of decision-making influence (e.g. public, households, community; O'Connor 2019 and Persson 2013).

Additionally, some studies were not primarily focused on partnership as a means of achieving person-centredness of health services but instead used partnering as a way of achieving clinical endpoints (such as maternal and neonatal mortality; O'Connor 2019 and Persson 2013). For this reason, many of the outcomes we sought related to person-centredness of health service delivery were not measured.

While this review can only conclude that there are uncertain effects of partnership on a range of outcomes, there may be potential benefits or effects that are not yet adequately examined in trial-based literature. Mixed-methods or qualitative research methods may be particularly suited to better understanding elements of successful partnerships, and so to inform development of effective approaches. A qualitative evidence synthesis on this topic is currently underway (Merner 2019).

Overall completeness and applicability of evidence

Overall we identified a limited number of trials evaluating interventions with partnership compared to without partnership (Comparisons 1 and 2) and none for Comparison 3. Partnership decisions in the included studies influenced planning or delivery; none of the partnership decisions influenced evaluation of health services.

Many of the outcomes that we sought were not measured in the included studies. Often, this was because the partnerships evaluated had far broader aims than to improve person-

centredness of services. Some included trials aimed to improve clinical endpoints rather than examining the influence of partnering on the person-centredness of the health service. Even where relevant outcome measures were reported in such trials, these were most often examined in the intervention group only and therefore were not comparatively evaluated. Taken as a body of evidence, this review highlights the general lack of trials directly assessing the effects of partnership interventions and indicates that more research in the area is needed.

Although few studies were included, most were conducted very recently suggesting this is a burgeoning area of research. Additionally, we identified some protocols for trials that were very recently completed but not yet published, and some ongoing trials. Therefore, we know the evidence is growing and there is likely to be new emerging evidence that may help to build our understanding and certainty about the effects of these interventions. However, the effects of such interventions may also be usefully understood by alternative research approaches to trials: mixed-methods and qualitative research may also help to unpack the complex effects of these complex interventions (Merner 2019).

It is also important to note that there are limitations inherent in conceptualising partnership as an intervention. This configures engagement and partnership as a process initiated by health services, decision makers and others, rather than a model arising from consumers and the community itself. Future research may wish to explore this in more depth, rather than necessarily adopting the definitions and inherent constraints of this current review related to this point.

Most included studies were from high-income countries (Greco 2006; Jha 2015; Wu 2019), with two in middle-income (Persson 2013) or low-income countries (O'Connor 2019). This may also limit the applicability of the research. Further, none of the included studies measured resources associated with decision-making process or with implementing decisions; and very few measured consumer- or provider-partner reported outcomes or measures of partnership. These are important outcomes for health service decision-making and may have profound impacts on the effects of these interventions.

Resources, including both time and money, required for the establishment of partnership interventions and their maintenance over time are also important considerations for this review. Neither were addressed by the included studies, but existing literature highlight the importance of both (Edgman-Levitan 2013; National Patient Safety Foundation 2014). For instance, establishing respectful and trusting partnerships can take a long time, and therefore interventions built on such approaches are not quickly implemented (Boivin 2014). Such interventions, for instance aiming to identify health service priorities and to then inform implementation and evaluation on health and related outcomes, also imply an extended time course between conceptualisation and outcome. The trials included in this review were conducted, and outcomes measured, at relatively short time points and this may have contributed to the lack of effects seen across studies.

In terms of costs, engaging consumers in partnership activities to design and evaluate health services has the potential to save money by avoiding interventions that might be poorly designed, unnecessary or unacceptable to the people they are designed to

help (Edgman-Levitan 2013; National Patient Safety Foundation 2014). Future evaluations should include a cost analysis of these interventions to inform decision-making about their usage, including costs to consumers and to organisations, particularly if interventions are intensive (e.g. requiring multiple face-to-face meetings) and/or conducted over long time periods (e.g. months to years). Considerations of costs and time required for partnership are important as there is a wide range of approaches through which consumer feedback might be incorporated into the design and evaluation of health services. This includes mechanisms such as consumer surveys to feed into system redesign, or consumer review of patient portals and education materials. Such flexible, relatively quick approaches may be easier to implement, and may also offer the advantage of potentially allowing a wider, more diverse range of consumers to participate and engage with these mechanisms to shape systems responses than might be possible through a structured series of face to face meetings like partnership.

This current review cannot answer all of these questions, and given the narrowness of the selection criteria the trials identified here represent only a sliver of existing consumer and provider partnership intervention evaluations, and this in turn represents only a small piece of the wider consumer engagement research available to inform systems' move towards delivery of person-centred care. Other trials exist that are beyond the focus of this review, such as one-off partnerships as an intervention to improve person-centredness of health services and partnerships in research and/or at the point of care contexts or more pragmatic trials where partnership is a component of the intervention but the effect of partnership as an intervention on its own is not able to be determined. As research in this area continues to develop, it will be critical for studies to adequately consider the changing landscape (Byrne 2020). As an example of this, with the shift towards collaborative models of different people working together (variously called co-design or co-production) there is growing emphasis on the need for all parties (both consumers and health providers, as well as decision-makers) to receive training and support so that they have adequate skills to undertake these roles (Edgman-Levitan 2013). This contrasts with earlier models of consumer engagement, where the focus was on upskilling or informing consumer partners in order to address power imbalances. With recognition of the desirability of truly collaborative models of engagement has come recognition of the different challenges such models of working together entail for the different parties involved (Boivin 2018) – both consumers and others.

Quality of the evidence

We assessed risk of bias using the Cochrane 'Risk of bias' tool, and certainty of evidence using the GRADE approach. The certainty of evidence was downgraded to very low for all outcomes. These judgements were based primarily on methodological limitations identified in relation to one or more risk of bias criteria (risk of selection bias, performance bias, detection bias and reporting bias), and due to concerns over imprecision (where studies did not explicitly define the optimal sample size or minimally important difference, or did not report confidence intervals). Publication bias was also strongly suspected, as results are from studies unlikely to be representative of all relevant studies that have been conducted; we are also aware of completed trials not yet published. Finally, compared to the review question, several studies were restricted

in setting and population, leading to downgrading over concerns about indirectness.

Potential biases in the review process

Where multiple outcomes were measured within an outcome category, we selected the outcome measure we judged to be most directly related to the partnership decision made. For example, for the outcome category 'Health service user (trial participant) health service utilisation patterns', we selected 'Client-reported referral from the healthcare system' over "CBO client healthcare utilisation (health system billing claims) data" (Wu 2019). This was because the decision made in partnership between health services and community-based organisation leaders was designed to influence the co-ordination between health and social services (CBOs) at discharge. Although these judgements were made through discussion and consensus between at least two review authors, it is possible that others may reach different decisions about the reporting and relative importance of such outcomes.

Our searches were comprehensive and systematic, but given the complexity of the intervention and the variety of terms in use, we may have missed potentially eligible studies. Additionally, as we limited our search to publications since 2000, there may be a small number of earlier trials that we have missed. Finally, we excluded studies published in languages other than English, and so may have not included some relevant papers. The typically low level of certainty of evidence from trials in this area suggests that any such trials are unlikely to change the conclusions of the review; however, we cannot discount this as a potential source of bias, and this decision may be revised in future updates of the review.

Agreements and disagreements with other studies or reviews

While there are several systematic reviews on relevant topics, e.g. public involvement in health care policy (Conklin 2015); healthcare planning, development and redesign (Crawford 2002; Dalton 2016; Haldane 2019; Milton 2012; Mockford 2012; Nilsen 2006; Tempfer 2011); and safety and quality of care delivery (Bombard 2018; McMillan 2013; Ocloo 2021), this is the first review to examine 'working in partnership' as an intervention to promote person-centred health services. One of the earlier reviews in this area explored the effects of involving consumers in the planning and development of health care (not specifically working in partnership as defined here) and identified no comparative or experimental studies (Crawford 2002). We have identified five included trials and nine ongoing or recently completed trials.

These reviews support our conclusion that there is currently a lack of robust evidence to determine the effects of consumers and providers working in partnership as an intervention to promote person-centred health services. However, consumer involvement is underpinned by moral and political imperatives (Esmail 2015), including democratic principles and patient rights to be informed, active partners in the health care system (Conklin 2015; Hart 2004).

AUTHORS' CONCLUSIONS

Implications for practice

This review indicates there is uncertainty about the effects of consumers and providers working in partnership as an intervention to promote person-centred health services. However, the lack

of large, well-designed trials with a primary focus on this intervention and purpose should not be interpreted as implying that these approaches have no value. Although effectiveness remains uncertain, partnership approaches are already warranted on political and moral grounds. The benefit of building the evidence base for effectiveness in the future is that it may help to provide guidance to health services about the best partnership approaches to adopt.

Implications for research

In future, research might further investigate whether partnership approaches influence the person-centredness of health services, and under what conditions. Such studies could be designed with a closer focus on the aim of partnership interventions and directly relevant outcomes, particularly interim outcomes of partnership interventions, resource use and measures of participation in decision-making.

Future studies might meaningfully contribute to this area in many ways, and some of the questions that most need to be answered may not be best addressed in randomised trials. A role for pragmatic, mixed-methods research in this area, to identify the best approaches, and to build on current understanding of enablers and barriers to the development and implementation of person-centred health services, are needed. To ensure that data from comparative studies is most useful and meaningful, outcomes should be collected from both intervention and control groups.

To be most meaningful, future studies might consider a range of outcomes relevant to health services and to consumers, including both potential positive and negative (adverse) outcomes. A scan of the literature and stakeholder advice used to inform outcome selection for this review identified that such partnership evaluations could include measures of satisfaction with decisional process; attendance at meetings; costs associated with decision-making and implementing new or changed services (for health care organisations and for consumers); degree to which health service alterations reflect service user priorities (demand responsiveness) and capacity to work together. Potential cost savings of partnership and consumer engagement approaches by ensuring that interventions and health services are appropriately designed to meet people's needs might also be usefully assessed in future research.

ACKNOWLEDGEMENTS

Cochrane Consumers and Communication supported the authors in the development of the protocol and review. Cochrane Central Editorial Service (<https://community.cochrane.org/review-production/production-resources/cochranes-central-editorial-service>) conducted the editorial and peer-review process for this review. Contributors to the editorial process were: Sign-off Editor (final editorial decision): Lisa Bero, Senior Editor, Research Integrity and Cochrane Public Health and Health Systems; Handling Editor (selecting peer reviewers, collating peer-reviewer comments, providing editorial guidance to authors, editing): Joey Kwong, Cochrane Central Editorial Service; Editorial Assistant (editorial policy checks and supporting editorial team): Leticia Rodrigues, Cochrane Central Editorial Service; Copy Editor (copy-editing and production): Hacsí Horvath, Cochrane Copy Edit Support; Peer-reviewers (providing comments and a recommendation): Antoine

Boivin, Canada Research Chair in Partnership with Patients and Communities, University of Montreal, Canada (clinical/content); Amy-Louise Byrne, Lecturer in Nursing, School of Nursing, Midwifery and Social Sciences, Central Queensland University (clinical/content); Susan Edgman-Levitan, Executive Director, MGH Stoeckle Center for Primary Care Innovation; Lecturer in Medicine, Harvard Medical School (clinical/content); Vijayluxmi Bose, Health Communication Specialist, Independent Consultant (consumer); Jennifer Hilgart, Associate Editor, Cochrane Editorial & Methods Department (methods); Robin Featherstone, Information Specialist, Cochrane Editorial & Methods Department (search).

We thank Anne Parkhill for developing the search strategy. We also thank the authors of three of the included trials ([Jha 2015](#), [Persson 2013](#) and [Wu 2019](#)) for providing additional information about their studies upon request.

We gratefully acknowledge the input and guidance of the Stakeholder Advisory Panel formed for the QES ([Merner 2019](#)). The Australian-based Stakeholder Advisory Panel consists of consumers, healthcare professionals, and health policy-makers. The members of the Panel are: Leslie Arnott (Consumer Representative, Victoria), Susan Biggar (Australian Health Practitioner Regulation Agency (AHPRA), Victoria, and Consumer Representative, Victoria), Noni Bourke (Chief of

Organisational Support & Development, Bass Coast Health, Victoria), Paul Bryden (Consumer Representative, Queensland), Renee Chmielewski (Manager, Planning and Patient Experience, The Royal Victorian Eye and Ear Hospital, Victoria), Leia Earnshaw (Consumer Representative, Australian Capital Territory), Marie Gill (Consultant, Gill and Wilcox Consultancy, Victoria), Fiona Martin (Clinical Practice Lead/Health Psychologist, Catholic Care, Victoria), Nathalie Martinek (Practitioner Trauma & Fatigue: Prevention & Recovery Professional Mentor & Mediator for Physicians and Other Health Professionals (until October 2018)), Louise McKinlay (Director, Patient Experience & Partnerships, Safer Care Victoria), David Menzies (Manager, Chronic Disease Programs, South Eastern Melbourne Primary Health Network, Victoria), Nancy Messino (Clinical Trials Quality Officer, Victorian Comprehensive Cancer Centre, Victoria), Anne Mussared (Consumer Representative, South Australia), Naomi Poole (Program Manager, Partnering with Consumers, Australian Commission on Safety and Quality in Health Care, New South Wales), Nora Refahi (Consumer Representative, Victoria), Lorraine Smith (School of Pharmacy, Faculty of Medicine and Health, University of Sydney, Camperdown, New South Wales), Roshni Sonawane (Consultant Paediatrician, Rockingham General Hospital and Wexford Specialist clinics, Murdoch, Western Australia), and Cheryl Wardrope (Patient Safety and Quality Service, Children's Health Queensland Hospital and Health Service, South Brisbane, Queensland).

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* Indicates the major publication for the study

CHARACTERISTICS OF STUDIES
Characteristics of included studies [ordered by study ID]

Greco 2006
Study characteristics
Methods

Study design: Cluster-RCT; Unit of randomisation: health service practices.

- Unclear how many assessed for eligibility
- 42 practices eligible
- 14 not randomised
 - 6 practices refused (reasons: transient patients; existing patients group; staff negative, too busy; staff sickness; bad previous experience with patient involvement)
 - 8 practices did not provide a decision
- 28 practices randomised.

Sample size/power calculation: Power calculations at the 5% significance level determined that 15 intervention and 15 control practices with at least 83 patient participants in each would provide 80% power to find a difference in Improving Practice Questionnaire "capacity" score of 2%.

Country of study: North and East Devon; England

Setting: Coastal and rural Healthcare Community Practices (unclear if publicly/private funded)

Study duration: Unclear

Greco 2006 (Continued)

Broader consumer involvement: none described

Participants

Consumer partnership participants: (n = 46): health service patient members. Practices were encouraged to choose patients with differing patterns of attendance at surgery and to include patients from those attending branch surgeries as well as the main health centres (no other inclusion/exclusion criteria description)

- Age: 39.1% >65; 32.6% 40-65; 28.3% <40 years
- Sex: 65.2% female; 34.8% male
- Education level: not described
- Socioeconomic status (SES): not described
- Diagnosis: not described
- Other: not described

Provider partnership participants: (n = 57): practice staff members.

- Age: not described
- Sex: 78.9% female; 21.1% male
- Education level: not described
- SES: not described
- Years practising: not described
- Other: Role (%): 29.8% GPs; 19.3% practice managers; 10.5% practice nurses; 3.5% health visitors; 21.1% receptionists; 7.0% administrators and 8.8% other (includes other manager; dispensing staff; nursing assistant)

Health service user trial participants: (n = unclear how many were eligible; 7537 patients completed baseline questionnaire and 8967 patients completed 12 month follow-up)

- Age - mean (SD): Intervention: 51.47 (18.49); Control: 50.69 (18.84)
- Sex: Intervention: 68.5% female; Control: 68.3% female
- Education level: not described
- SES - Jarman Material Deprivation Score (Mean range): Intervention: 2.97 (-6.74 to 11.47); Control: 1.09 (-9.76 to 13.3)
- Other: Service users who saw their usual Doctor- Intervention: 73.2%; Control: 72.6%. Service users attending < 5 years - Intervention: 24.0%; Control: 24.5%. Attending 5-10 years - Intervention 23.7%; Control: 17.5%. Attending > 10 years - Intervention: 52.4%; Control 58.0%.

Health service provider trial participants: (n = 279 providers eligible and 186 providers participated: 109 of these participated both at baseline and 12 month follow-up).

- Age: not described
- Sex: not described
- Education level: not described
- SES: not described
- Years practicing: not described
- Other: Mean (SD) Whole Time Equivalent GPs - Intervention: 3.91 (1.89); Control: 4.59 (2.11). Median (IQR) # doctors per practice - Intervention: 6 (3); Control: 5 (2.5). Median (IQR) # of nurses - Intervention: 2 (2); Control 1.5 (1.5). Median (IQR) # AHPs - Intervention: 1.5 (1); Control: 1 (0.5)

Interventions

Randomised to intervention: 14 health practices; 4396 patients completed baseline questionnaire (analysed at 12 months: 14 practices with 5000 patients); a total of 107 providers (80 GPs, 20 nurses, 7 AHPs) participated and 66.4% (71/107) participated both at baseline and follow-up.

Nature of intervention: Critical Friends Group (CFG) meetings between patients and providers who in partnership interpret results of Improving Practice Questionnaire (IPQ: systematic patient feedback) and decide on an action plan that enables practices to make patient focused changes.

Intervention aim: to assess whether CFG enables practices to interpret IPQ results and devise an action plan that enables practices to make changes that are more patient focused.

Greco 2006 (Continued)

Context of partnering: CFGs met twice combined (practice staff and patients) following separate preliminary meetings. During the first meeting, which took place 2 weeks following the initial preliminary meetings, group members exchanged information about themselves, their roles, and identified areas for attention and improvement within practice based on IPQ results. Meeting notes were distributed to participants a few days later. In the second meeting 8-10 weeks following the preliminary meetings, improvement strategies were reviewed.

Decision-making activity: During the first CFG meeting, members interpreted the IPQ results and agreed on 3-5 improvement strategies. During the second meeting, members reviewed progress on earlier identified improvement strategies. Topics most frequently discussed at CFGs, after reviewing baseline IPQ feedback were - privacy at the reception desk (6/14 meetings) and waiting time to see the doctor (12/14 meetings).

Meeting format, duration, frequency and location: face-to-face; two combined meetings; the preliminary meeting (in patient only and provider only groups) was facilitated by researchers, the nature of the two subsequent combined meetings was not described. Meetings were held at participating practices, duration unknown, no further description provided.

Partnership duration: Time-limited over approximately 12 weeks: preliminary meeting; two weeks later first combined meeting; 8-10 weeks later second combined meeting

Training/support: Preliminary meetings were held with patient-only groups and with practice staff only groups at intervention sites that requested this. During preliminary meetings a researcher provided background information about the project, purpose of future meetings and IPQ results.

Decision-making process, attempts to resolve conflict: not described

Diversity and ratio of consumer and provider participants: diversity not described; across all 14 CFGs the ratio of consumers to providers was 46:57 (ratio not provided for each CFG). Practices were advised to select equal numbers of practice staff and patients to participate within the CFG.

Attempts to address intrinsic power imbalances: not described

Theoretical basis for partnering: UK National Health Service (NHS) outlines ways to develop the role of patients within the new NHS as equal partners, whose voice and concerns can be heard, and British General Medical Services contract stipulates patient experience as a domain within the Quality and Outcomes Framework. The rationale for the intervention is to match the requirements of these governing bodies and find a way to move the patient involvement agenda towards engaging patients in the processes of change and improvement in healthcare.

Tailoring/modification/adapting: Unclear

Fidelity/integrity: Not assessed. No control groups discussed IPQ results with patients during the research period.

Randomised to control: 14 health practice sites with 3141 patients completed baseline questionnaires (analysed at 12 months: 12 practices, and 3967); a total of 79 providers (55 GPs, 17 nurses and 7 AHPAs) participated and 48.1% (38/79) participated both at baseline and follow-up.

Nature of comparison: multifaceted intervention minus partnership: control sites received no assistance (or encouragement) from researchers in setting up a CFG. Practice managers were contacted at 12 months to find out about any patient involvement initiatives that had taken place since their first and second IPQ.

Co-intervention: Both intervention and control sites were given IPQ pilot study results. The initial pilot involved 42 GP practices (206 GPs and 8600 patients completed the IPQ) within the North and East Devon Healthcare Community.

Outcomes

Outcomes measured at Baseline (T0) and follow-up (12 months post-intervention - T1):

Outcome measures relevant to the review (reporting available comparative data for longest time point measured):

Greco 2006 (Continued)

- **Health service user (trial participant) health service performance ratings (local accountability):** Overall satisfaction with this general practice (a subscale of the Improving Practice Questionnaire) (scale: 0-5, higher scores better) (T1).

Other study outcome measures (data extracted but not reported in review):

Other subscales of service user experience via Improving Practice Questionnaire: 27 item survey. Items scored on a scale of 0 (poor) to 5 (excellent)

Notes

Funding: NHS Modernisation Agency and the former North East Devon Regional Health Authority

Conflict of interest: None disclosed (nor were affiliations disclosed)

Other: Subscale was selected by review authors as the most relevant subscale from those reported of the IPQ.

Risk of bias

Bias	Authors' judgement	Support for judgement
Random sequence generation (selection bias)	Low risk	"Thirty practices were randomly selected from a pool of 42 practices (using a random number generator)... and were invited to participate in the study. If a practice declined to participate in the project another practice was randomly selected from the pool. Then, practices that agreed to participate were assigned randomly to either the treatment or control group by selecting a chip from an envelope. 15 chips in the envelopes were marked "T" for treatment group and the other 15 marked "C" for control". (p 488, Greco 2006)
Allocation concealment (selection bias)	Unclear risk	Unclear whether intervention allocations could have been foreseen during enrolment.
Blinding of participants and personnel (performance bias) All outcomes	Unclear risk	No information provided for blinding of participants or personnel.
Blinding of outcome assessment (detection bias) All outcomes	Unclear risk	No information provided.
Incomplete outcome data (attrition bias) All outcomes	Low risk	Two (out of 14) control practice sites failed to carry out a follow-up survey because they lacked the necessary time and resources. 208/8967 (1.23%) of questionnaire responses were excluded because less than half the questions on the questionnaire had been answered (p 495, Greco 2006).
Selective reporting (reporting bias)	Unclear risk	All outcomes mentioned in study publication are reported however, no protocol has been identified for the trial.
Other bias	Unclear risk	No baseline imbalances. Of the 152 eligible providers 'in the intervention group, significantly more were involved in the IPQ survey both at baseline and at the 12 month follow-up (66.4% (71/107)) than compared with the 127 (eligible) control group providers (48.1% (38/79)). Therefore in the control group, a greater proportion of providers were the subject of the survey for their first time during the follow-up, potentially explaining why overall mean scores got worse in the control group and better in the intervention group'. (p 495, Greco 2006). This trial allocated clusters but analysed at individual level; does not seem to have been adjustment for clustering.
Selective recruitment of participants	Low risk	Does not appear to be differential participant recruitment in clusters for different interventions or baseline imbalances.

Jha 2015
Study characteristics
Methods

Study design: RCT; Unit of randomisation: all trainee doctors employed at 5 hospital sites in their first year following graduation

- training mandatory for progression, 313 total eligible
- 313 trainee doctors from 5 sites eligible
- 30 not randomised
 - 5 declined
 - 25 did not attend
- 283 trainee doctors randomised

Sample size/power calculation: factoring in a clustering effect within each centre a sample size of 115 gave 80% power to detect an effect size of 0.53

Country of study: Yorkshire and Humer region, England, UK

Setting: predominately urban postgraduate medical schools at Scarborough, Hull, York, Grimsby and Scunthorpe hospital sites, unclear if public/private funded

Study duration: 2011 - 2012

Broader consumer involvement: "The patients ... provide feedback on documents, e.g. our interview guide for trainee doctors and will take part in focus groups after the teaching sessions to refine the intervention" (p 4, Winterbottom 2010). Consumers were involved in training the patients and carers in a preparatory patient learning journey workshop. The facilitators of these preparatory workshops were members of the Patient Voice Group at the University of Leeds and patients and carers themselves. Patients and carers who co-developed and co-facilitated the training to the foundation year trainees were also provided with support and opportunity to debrief following training sessions with a consumer (member of the Patient Voice Group). Two consumers were involved in analysing the qualitative data and interpreted the lessons learned in light of the coding frame provided (Jha 2015).

Participants

Consumer partnership participants: (n = 6 patients and 5 carers), people who had experienced harm or error during healthcare either to themselves or their families; recruited through the National Patient Safety Agency, Action for Victims of Medical Accidents and local press advertisements.

- Age: not described
- Sex: not described
- Education level: not described
- Socioeconomic status (SES): not described
- Diagnosis: not described
- Other: not described

Provider partnership participants: (n = 8), clinicians involved in medical education of foundation year trainees (7 doctors, 1 pharmacist)

- Age: not described
- Sex: not described
- Education level: not described
- SES: not described
- Years practicing: not described
- Other: not described

Health service user trial participants: (none)

Health service provider trial participants: (n = 283), first year (postgraduate/foundation year) medical trainee doctors employed by 5 hospitals sites

Jha 2015 (Continued)

- Sex: not described
- Education level: not described
- SES: not described
- Years practising: not described
- Other: not described

Interventions

Randomised to intervention: 142 trainee doctors at 5 sites; (analysed: 126 trainee doctors; 16 excluded due to incomplete data)

Nature of intervention: consumer and provider partners collaboratively co-developed and co-delivered patient safety curriculum to first year trainee medical graduates.

Intervention aim: to assess whether facilitating trainees to reflect on safety from the patient's perspectives and their experience of patient safety influences their beliefs, attitudes and intention of future behaviour.

Context of partnering: following consumer partner training in 4 preparatory Patient Learning Journey workshops facilitated by consumers and carers (from Patient Voice Group, University of Leeds), consumer and provider partners co-developed and co-delivered the patient safety curriculum in two sessions.

Decision-making activity: partnership participants defined teaching session aims and objectives, decided on key narrative aspects and facilitated a discussion between patients and trainees.

Meeting format, frequency and location: face-to-face, 2 x 1 hour sessions of co-developed patient safety curriculum presenting 1 patient narrative 15-18 minutes in duration, followed by facilitated discussion delivered on site in groups of 7-10 trainee doctors.

Partnership duration: time-limited to during the preparatory Patient Learning Journey workshops and in the development and delivery of the training session.

Training/support: Consumer partners provided with 4 preparatory Patient Learning Journey workshops facilitated by consumer and carer members from Patient Voice Group, University of Leeds; also given support and opportunity to debrief with a consumer (from Patient Voice Group) following training sessions.

Decision-making process, attempts to resolve conflict: not described

Diversity and ratio of consumer and provider participants: not described

Attempts to address intrinsic power imbalances: consumer partners provided with travel expenses and financial reimbursement for teaching and training attendance and 2 consumer partners co-delivered each teaching session with a third consumer partner attending to observe and serve as a reserve in case one consumer partner unable to attend.

Theoretical basis for partnering: draws on the conceptual framework by Kumagai which is underpinned by theories of empathy and moral development and Mezirow's transformative learning theory. Transformative learning occurs when there is a process of effecting change in a frame of reference and other people's stories may help trainee doctors develop empathy and new understanding of the meaning of patient safety from the patient's perspective.

Tailoring/modification/adapting: broad learning outcomes were standardized but examples of key incidents in narratives patients shared varied.

Fidelity/integrity: aimed to standardise intervention across sites by using same co-facilitators (patients and a trained independent chairperson) and by asking consumer partners to maintain consistent narratives.

Randomised to control: 141 trainee doctors at 5 sites; (analysed: 110 trainee doctors; 31 excluded due to incomplete data)

Jha 2015 (Continued)

Nature of comparison: usual practice of standard patient safety curriculum in clinician-led teaching sessions (included regulatory and procedural, ethical and legal issues and communication with patients and record keeping handovers).

Co-intervention: common learning objectives derived from UK Foundation Program Curriculum were adhered to during sessions and issues related to the objectives discussed even if they did not naturally arise.

Outcomes

Outcomes measured at Baseline (T0); immediately post intervention (T1) and 4 to 6 weeks follow-up (post-intervention – T2):

Outcome measures relevant to the review (reporting available comparative data for longest time point measured):

- **Health service provider (trial participant) reported outcomes:** Attitudes to Patient Safety Questionnaire overall score (T2) 26-item attitude to patient safety questionnaire rated from 1 (strongly disagree) to 7 (strongly agree); possible overall scores range 26-182, higher scores indicate positive attitude. Questions 11, 13-17 and 25 worded negatively and reversed for analysis.

Other study outcome measures (data extracted but not reported in the review):

- Subscale scores of the Attitudes to Patient Safety Questionnaire (APSQ) (T0, T1);
- Overall and subscale Positive Affect, Negative Affect Scores (T0, T1): 20-item survey (10 items on the positive affect scale and 10 items on the negative affect scale), rated from 1 (very slightly or not at all) to 5 (extremely); possible overall score range 10-50 for both Positive Affect and Negative Affect, higher scores indicate more Positive Affect and more Negative Affect;
- Knowledge of patient safety (T0, T1, T2) 7-item measure of medical trainee knowledge of patient safety rated from 1 (low) to 7 (high); and
- three learning point takeaways (T1)

Notes

Funding: National Institute for Health Research Program Grant for Applied Research Reference Number RP-PG-0108-10049

Conflict of interest: The authors declared they have no competing interests.

Other: For outcomes not reported in this review, data for APSQ subscales was not reported for each subscale; nor for subscale groupings such as Knowledge of patient safety; or in extractable form for the PANAS data. Learning point takeaways was reported as qualitative data.

Risk of bias

Bias	Authors' judgement	Support for judgement
Random sequence generation (selection bias)	Low risk	"Simple randomisation was carried out at an individual level on a 1:1 basis ... this was done on-site at the training day by an independent administrator using a randomisation sequence generated using randomly ordered envelopes containing allocations." (p 25-6, Jha 2015).
Allocation concealment (selection bias)	Low risk	"The assignment in the first envelope was given to the first individual as defined by registration and so on." (p 26, Jha 2015).
Blinding of participants and personnel (performance bias) All outcomes	High risk	Participants were aware of their assignment due the sessions having different formats (rated as high risk); blinding not described for personnel (rated unclear risk). Performance bias rated high risk overall.
Blinding of outcome assessment (detection bias) All outcomes	High risk	No attempt to blind outcome assessors, and the outcomes were subjective (self-reported); also for the qualitative analysis trainees were identifiable and so there was no blinding.

Jha 2015 (Continued)

Incomplete outcome data (attrition bias) All outcomes	High risk	For the primary outcome (APSQ) analysis was conducted on 122/283 participants immediately post intervention due to missing data: 56/142 in the intervention arm, and 66/141 in the control arm; and 90/283 participants at follow-up of between 3-6 weeks: 37/142 in the intervention and 53/141 in the control. While there were fewer participants missing data for the post intervention PANAS (138/142 in intervention and 125/141 in control) the data presented is not overall mean and SD, rather it is change in overall score from baseline; therefore it is not usable data for this review. Additionally the trial report mentions a secondary outcome of APSQ scored using subscales grouped by attitudes towards "patient safety training"; "confidence in reporting errors"; "working hours as a cause of error"; "error inevitability"; "professional incompetence as a cause of error"; "disclosure responsibility"; "team functioning"; "patient responsibility in reducing errors"; "importance of training" and "knowledge of patient safety". These were not reported.
Selective reporting (reporting bias)	High risk	The protocol does not mention PA&NA which is presented in the trial findings; additionally the protocol and trial mentions a course evaluation at the end of the teaching session to assess overall effectiveness for which data is not presented and a 7 item self rating of how knowledgeable participants feel about aspects of patient safety for which data is not provided in the trial report (it looks to be added as a subscale into the APSQ).
Other bias	Unclear risk	No characteristics of the participants randomised between groups were provided so not able assess baseline imbalance; the analysis presented is only for the participants with complete data for each time point (i.e. if missing data from baseline or post intervention or follow-up the participants were excluded from analysis) this means that the data is largely not usable, additionally where change in overall score from baseline is reported it is not usable data for this review; there may have been communication between members of study groups post-intervention, which may have lessened the likelihood of there being a difference between groups.

O'Connor 2019
Study characteristics
Methods

Study design: Cluster-RCT; Unit of randomisation: community sites

- Unclear how many assessed for eligibility
- Unclear how many eligible
- Unclear how many not randomised
- 10 community sites randomised

Sample size/power calculation: "The sampling methodology provided a 95% confidence interval of +/-8% or less for the prevalence of indicators measure in the population." (p 7, [O'Connor 2019](#)) "The number of CHWs trained was calculated using a Child Survival Project- and community-led census and policy-mandated population-to-CHW ratios." (p 4, [O'Connor 2019](#))

Country of study: Freetown, Western Urban District, Sierra Leone

Setting: Low-income Urban slum communities within Freetown Municipal area with the highest maternal mortality ratio in the world (136/10,000 live births) and under-5 mortality rate was fourth highest in the world (114/1000 live births) (p 3, [O'Connor 2019](#)). Communities are served by government primary health care facilities (Peripheral Health Units) at the sub-district level and these are supervised by District Health Management Team (consisting of 15 members) which is also responsible for coordinating public health interventions in the community, the Freetown City Council also supports the delivery of community health services. Each Peripheral Health Unit is supported by the Health Management Committee which liaises between the service and the community. Each community spans 1-2 wards. Wards

O'Connor 2019 (Continued)

within Freetown Municipal area have an elected Ward Development Committee responsible for engaging community members on general development activities; the chair of the Ward Development Committee is also a Councillor on the Freetown City Council.

Study duration: 2011 - 2017

Broader consumer involvement: None described

Participants

Consumer partnership participants: (n = 49), peer supervisors of CHWs participating in Community Health Data Review (CHDR) meetings, each community had 5-12 Peer Supervisors. Peer Supervisors were selected by Child Survival Project staff together with community leaders, based on their performance during initial CHW training. CHW were selected by a community-level process according to the National CHW Program selection criteria. Criteria included currently living in and have close connections to their geographical community; accepted by community members, and ability and motivation to serve their community. Note that the data presented here is overall for all CHW (not just Peer Supervisors)

- Age: about two thirds were 18-34; 21% 35-54; and 4% 55+ years
- Sex: 46% female; 54% male
- Education level: Almost 60% completed some secondary school
- Socioeconomic status (SES): not described
- Diagnosis: not described
- Other: 5% classified themselves as non-literate

Provider partnership participants: (n = unknown 30-50 participants in each of the 10 CHDR meetings; includes Peer Supervisors), Peripheral Health Unit (government primary health care facility) staff; Health Management Committee members, and Ward Development Committee members participating in CHDR meetings.

- Age: not described
- Sex: not described
- Education level: not described
- SES: not described
- Years practising: not described
- Other: not described

Health service user trial participants: (n = 599 at baseline; 792 at 21 months), household respondents were pregnant women and mothers of children under 5 years targeted by CHW. Household respondents were selected randomly from 10 random households in each of the 60 clusters. Clusters were also randomly selected using a probability proportional to size methodology based on population projections from the most recent Government of Sierra Leone census.

- Age: not described
- Sex: not described
- Education level: not described
- SES: not described
- Other: not described

Health service provider trial participants: none

Interventions

Randomised to intervention: 5 communities. Baseline data were collected from: 299 household respondents; 509 Community Health Workers (CHW); 49 Peer Supervisors; 80 Ward Development Committees and 75 Health Management Committees. Follow-up data were collected from: 379 household respondents; 509 CHW; 49 Peer Supervisors; 80 Ward Development Committees and 75 Health Management Committees.

Nature of intervention: In the Operation Research Study the Participatory Community-based Health Information System intervention consisted of Community Health Data Review meetings every two months to support Health Management Committees, Ward Development Committees and CHW Peer Supervisors to undertake two activities (1. review of data collected by CHWs and actions in response to

O'Connor 2019 (Continued)

this data and 2. after 6 months, verbal autopsies for deaths under 5 years) in addition to the Child Survival Project activities.

Intervention aim: "to 1) assess the extent to which the Participatory Community-based Health Information System facilitated local community structures to use data to plan and implement actions for improving maternal, neonatal and child health and 2) assess the extent to which this contributed to improved community-level maternal, neonatal and child health outcomes." (p 4, [O'Connor 2019](#))

Context of partnering: Findings from monthly reports submitted by volunteer community health workers and verbal autopsy findings for deaths of children aged less than 5 years were processed and shared at Community Health Data Review (CHDR) meetings in each intervention community. These bi-monthly meetings were attended by community leaders, including members of the Ward Development Committee and Health Management Committee, the Peer Supervisors, and representatives of the Peripheral Health Unit. Following a review of the information, attendees proposed actions to strengthen community-based health services in their community.

Decision-making activity: Typically, data for the preceding 4-6 months were reviewed in CHDR meeting. The Operation Research Study staff analysed CHW collected data with the Child Survival Project staff prior to the meeting and determined topics and data to present in CHDR meetings. "The Operation Research Study staff prepared simple data sheets to be used by participants, and participants used them to draw and interpret bar charts in front of the group. Records were kept of discussion topics." (p5, [O'Connor 2019](#)) "Following the review of data, CHDR participants developed action points. Action points were documented during the meeting on flip chart paper which the Health Management Committee chairman kept after the meeting. Action points from previous meetings were reviewed in subsequent meetings and discussions held on the extent to which actions had been completed." (p 6, [O'Connor 2019](#))

Meeting format, duration, frequency and location: face-to-face, duration unknown, every two months, location unclear

Partnership duration: 20 months

Training/support: Based on their performance during initial training, community leaders and Child Survival Project staff together selected 106 Peer supervisors from the CHWs receiving training. Peer supervisors were given additional training by project staff and were assigned 8-12 CHWs to supervise. At least one Health Management Committee and Ward Development Committee member from the same zone as the Peer Supervisor provided oversight and assistance.

Decision-making process, attempts to resolve conflict: not described

Diversity and ratio of consumer and provider participants: Each community had 5-12 Peer Supervisors and there were 30-50 participants in Community Health Data Review meetings. Generally, the same District Health Management Committee members, Ward Development Committee members and Peer Supervisors attended each meeting. Although Government primary health care facility (Peripheral Health Unit) In-Charges rarely attended meetings, they generally sent the same representative to each meeting. At the beginning, Peripheral Health Unit staff attendance was not strong, but attendance improved after Health Management Committee members engaged Peripheral Health Unit staff. Ratio of consumer and provider participants not described.

Attempts to address intrinsic power imbalances: not described

Theoretical basis for partnering: Sierra Leone Government highlights the need for community engagement in policy document "Basic Package of Essential Health Services, 2015-2020", it focus on CHWs to fulfil this role. The policy document also recognises Health Management Committees (that support each Peripheral Health Unit) and Ward Development Committees (that are responsible for engaging community members on general development activities and the chair is also a Councillor on the Freetown City Council) but does not outline roles or the ways in which they should fit into the health system.

Tailoring/modification/adapting: not described

Fidelity/integrity: not described

O'Connor 2019 (Continued)

Randomised to control: 5 communities. Baseline data were collected from: 300 household respondents, 710 CHW; 57 Peer Supervisors; 75 Ward Development Committees and 75 Health Management Committees. Follow-up data were collected from: 413 household respondents, 710 CHW; 57 Peer Supervisors; 75 Ward Development Committees and 75 Health Management Committees

Nature of comparison: multifaceted intervention minus partnership: control sites of the Operation Research Study consisted of usual practice in addition to Child Survival Project activities

Co-intervention: The Concern Worldwide Child Survival Project was implemented in all 10 communities. In the broader Child Survival Project, 1325 volunteer CHWs were recruited and trained with the Ministry of Health and Sanitation 2012 National CHW Program training materials by Child Survival Project staff and the Western Area District Health Management Teams. CHWs were assigned 25 households to visit monthly and disseminate health messages, check for danger signs of illness and collect vital event and morbidity data using Ministry of Health and Sanitation registers.

Outcomes

Outcomes measured at Baseline (T0) and follow-up (21 months post-intervention - T1):

Outcome measures relevant to the review (reporting available comparative data for longest time point measured):

- **Health service alterations data (changes to services resulting from partnership decisions):** Number of mothers who have ever had a community health worker (CHW) visit (T1); and Number of mothers who had a home health visit from a CHW in the last year in which the CHW performed all roles (T1)
- **Health service user (trial participant) health service performance ratings (local accountability):** Number of mothers who had a CHW visit in the past year who found the visit helpful or somewhat helpful (T1)
- **Consumer (partnership participant) reported behaviours/attitudes outcomes:** Number of peer supervisors reporting/number of peer supervisors trained (T1)
- **Provider (partnership participant) reported behaviours/attitudes outcomes:** Health Management Committee review and contribute to CHW activity plans (T1)

Other study outcome measures (data extracted but not reported in review):

- Health Institution capacity Assessment Process (assessed separately by Ward Development Committees and Health Management Committees);
- Measures of functionality of the CHW program;
- CHW and Peer Supervisory reporting rates;
- Key household level survey results on Maternal, Neonatal and Child health practices; and
- Household survey results on illness care seeking.

Notes

Funding: United States Agency for International Development (USAID); Irish Aid and Concern Worldwide.

Conflict of interest: "The authors completed the Unified Competing Interests Form ... and declare no competing interests"

Other: For other outcomes reported not reported further in this review, choice of outcomes was made jointly by review authors according to measure(s) most representative of the outcome concept(s) sought. Data for other outcomes was reported by the trial but not extracted and considered further for analysis in this review.

Risk of bias

Bias	Authors' judgement	Support for judgement
Random sequence generation (selection bias)	Unclear risk	"The study was a cluster-randomised controlled trial, with [10 previously selected] communities randomly selected [assigned] to either the intervention or comparison area. Within the 10 communities 30 clusters in the intervention and comparison areas each were selected at random using a probability proportional to size methodology based on population projections from the most

O'Connor 2019 (Continued)

recent Government of Sierra Leone census. Ten interviews were conducted in each cluster through a random selection of households and a random selection of the respondent within the household." (p 7, [O'Connor 2019](#)).

Allocation concealment (selection bias)	Unclear risk	Method use to conceal the allocation sequence not described.
Blinding of participants and personnel (performance bias) All outcomes	Unclear risk	No information on blinding of participants or personnel provided.
Blinding of outcome assessment (detection bias) All outcomes	Unclear risk	No information on blinding of outcome assessors.
Incomplete outcome data (attrition bias) All outcomes	Unclear risk	No information about attrition or exclusions were reported.
Selective reporting (reporting bias)	Unclear risk	No protocol identified; all results for all outcomes mentioned in trial reported.
Other bias	Unclear risk	There was substantial movement between communities (in and out).
Selective recruitment of participants	Unclear risk	No information on recruitment bias (differential participant recruitment in clusters)/loss of clusters.

Persson 2013
Study characteristics
Methods

Study design: Cluster-RCT; Unit of randomisation: commune (geopolitical sites)

- 187 communes (from 14 districts) assessed for eligibility;
- 90 eligible (districts with neonatal mortality rate (NMR) 24/1000 in 2005)
- 97 communes excluded (districts with NMR <15/1000 in 2005)
- 90 communes (from 8 districts) randomised

Sample size/power calculation: "The sampling strategy was one-stage cluster sampling with a probability proportional to size of the clusters. The Probability proportional to size, in this case number of births per year, was chosen to obtain similar distribution of sizes of clusters across intervention and control communes. Sampling was neither blocked nor paired. A sampling frame was established with a cumulative list of number of births in each of the communes in the 2005 survey. ... The design effect was arbitrarily estimated to be 1.5 [taking into account] the high number clusters and low average cluster size. A 3-year sample would allow detection of 7/1000 neonatal mortality rate with 80% at 0.05 significance". (p 2-3, [Persson 2013](#))

Country of study: Quang Ninh province, Vietnam (Middle-income country)

Setting: Commune Health Centres in with 3-6 staff members provide primary health care including reproductive and antenatal care to approximately 1000-18,000 people. Delivery care is offered by Commune Health Centres, or by hospital at district, province and regional levels. Each Commune Health Centre has a Village (community) Health Worker who provides basic healthcare in the villages. Private alternatives for antenatal care in addition to governmental health care system exist but in this province the private or non-governmental sector plays a limited role in relation to delivery services.

Study duration: 2008 - 2011

Persson 2013 (Continued)

Broader consumer involvement: Members from the Women's Union were also members of the intervention steering board (chaired by the hospital director of the regional Uong Bi hospital and the Provincial Health Bureau)

Participants

Consumer partnership participants: (n = 11), Pairs of lay women were facilitators for the 44 Maternal and Newborn Health Groups (MNHGs). Each facilitator was responsible for 5-8 MNHGs. Recruitment criteria included being an experienced Women's Union member, having completed secondary school and having children. Facilitators were recruited using local newspaper adverts and recommendations from communes. "Originally the Women's Union office in each of the 8 study districts selected two individuals among the applicants for further interview [by two researchers and the chairwomen of the Women's Union]... Out of the 16 applicants interviewed 8 were selected for further training" (p 5, Eriksson 2016). Three additional facilitators were recruited during the trial to replace facilitators leaving because of childbirth or new employment. *The Women's Union is an organisation with high national coverage, working on a range of welfare issues relevant for women in Vietnam, especially those related to health-care. Data below relates to only the facilitators (not the Women's Union members of the MNHGs)

- Age (mean): 32 years
- Sex: female only
- Education level: eligible to participate if completed secondary school
- Socioeconomic status (SES): not described
- Diagnosis: not described
- Other: 9/11 from ethnic majority Kinh; 2/11 from ethnic minority Tay

Provider partnership participants: (n = 352; each of the 44 MNHGs had 8 members), Commune Health Centre staff (physicians, midwives, nurses); a commune Village Health Worker, a population collaborator, a chairperson/vice chairperson of the commune; and two Women's Union representatives

- Age (mean): 42 years
- Sex: 76% female
- Education level: not described
- SES: not described
- Years practicing: not described
- Other: 71% from ethnic majority Kinh group

Health service user trial participants: (n = 1243 mothers randomly sampled from 22,377 live births located within 90 communes during first 3 years of trial July 2008-June 2011). The demographic details below were from a random sample of mothers (398/7033) with live births during first year of trial. ("A 6% random sample of all registered live births, surviving the neonatal period, was continuously selected (each month) in order to represent the entire birth cohort") (p 4, Persson 2013). The demographic details below are for Intervention: n = 213; Control: n = 185 mothers

- Age (%<20 years): intervention: 8.9%; control: 9.2%
- Sex (female): all
- Education level (Lacks formal education): intervention: 15%, control: 21%
- SES (Poor household): intervention: 19%; control: 27%;
- Other: Ethnic minority household- intervention: 33%; Control: 38%; Mother farmer- Intervention: 42%; Control 51%; First-born child- Intervention: 39%; Control 38%

Health service provider trial participants: none

Interventions

Randomised to intervention: 44 communes; analysed during years 1-3: 656 mothers randomly sampled from 11,818 live births in 44 communes.

Nature of intervention: laywomen facilitation of MNHGs during which members collaborated to decide which problems to focus on and what actions to take directed towards pregnant women and their households, health services, or general public in order to address those problems.

Intervention aim: to reduce neonatal mortality and improve maternal delivery, and newborn care indicators. Stillbirth was defined as birth of a dead foetus after an estimated 28 weeks of gestation. Live

Persson 2013 (Continued)

birth was defined as birth of a foetus with any sign of viability. Neonatal death was defined as death of a live birth during the first 28 days of life.

Context of partnering: "MNHGs were constituted in each intervention commune (by directives from the Provincial Health Bureau). ...The facilitators primarily used the plan-do-act cycle in mobilising the groups in identifying and prioritising local perinatal health problems and accomplishing improvement cycles that included concrete actions on prioritized problems directed towards pregnant women and their households, the health services, or the general public. Such improvement cycles on different problems were performed continuously over the intervention period in all MNHGs. Where possible one facilitator performed monthly meetings with the same MNHG over the 3 year period. Each facilitator was responsible for 5-8 MNHGs. Twenty groups kept the same facilitator the whole period, 22 changed facilitator once, and two groups changed facilitator twice. When appropriate, facilitators were recommended to highlight recommendations provided by the Vietnamese National Standard and Guidelines on Reproductive Health Care Services." (p 4, [Persson 2013](#))

Decision-making activity: In MNHGs Plan-Do-Study-Act discussions centred on individual and common experiences in the local setting, the facilitator supported the group in critical reflection, problem identification, finding solutions and developing change strategies. The intervention aimed to achieve local ownership and "bottom-up" approach in empowering healthcare staff to improve practice. When appropriate, the facilitators would highlight recommendations in the National Guidelines. "The groups identified 32 unique problems and implemented 39 unique actions. The identified problems targeted health issues concerning both women and neonates. Actions implemented were mainly communication activities." (p 1, Eriksson 2016)

Meeting format, duration, frequency and location: Monthly face-to-face meetings lasting on average 2 hrs (110 mins), meetings located at commune centre or health care centre.

Partnership duration: 3 years (31 months)

Training/support: The facilitators were trained in problem solving, participatory and enabling approach in a 10 day training program which "included theoretical sessions, group discussion, role-plays, and field practice. It covered topics such as group dynamics, quality improvement methods (e.g. brainstorming and the plan-do-study-act cycle); and evidence based perinatal care. A facilitation manual and a specific diary were developed to guide the work of the facilitators. Two research team members coordinated the facilitation process and acted as supervisors of the facilitators, i.e. field supervision and performing 2 day meetings with all facilitators once a month during the entire trial period." (p 3-4, [Persson 2013](#))

Decision-making process, attempts to resolve conflict: facilitators were trained on brainstorming, the nominal group technique, the plan-do-study-act cycle and the strengths-weaknesses-opportunities-threats diagnostic tool.

Diversity and ratio of consumer and provider participants: MNHGs consisted of 8 members: 3 Commune Health Centre staff (physician, midwife, nurse); a commune Village Health Worker, a population collaborator, the chairperson/vice chairperson of the commune; and two Women's Union representatives (from village and commune levels).

Attempts to address intrinsic power imbalances: The MNHG facilitators were paid on a full-time basis for the 3 years of the intervention. Except for the Village Health Worker and the Women's Union employee (who were reimbursed travel expenses to and from the meetings), other members were neither paid nor received allowances - as implementation work was assumed to be part of their normal duties.

Theoretical basis for partnering: study draws from "the Promoting Action on Research Implementation in Health Services Model. This middle range theory highlights three major ingredients for being successful in implementing research into practice: 1) the nature of the evidence being used, 2) the quality of the context in terms of coping with changes, and 3) the types of facilitation needed to ensure a successful change process. Implementation is conceived as a multifaceted intervention, rather than a more straightforward, linear process of translating knowledge from experts to the local level. In the trial the authors analysed the effect of facilitation of local stakeholder groups focusing maternal and neonatal health problems and actions." (p 7, [Persson 2013](#))

Tailoring/modification/adapting: Each MNHG was context-specific and continuously negotiated and interpreted among stakeholders.

Persson 2013 (Continued)

Fidelity/integrity: "Two research team members coordinated the facilitation process and acted as supervisors of the facilitators; i.e. field supervision and performing 2 day meetings with all facilitators once a month during the entire trial period. The intervention process was monitored continuously. Issues like MNHG's choice of improvement topics, activities for improving practice, the interaction between facilitators and group members, and progress of the facilitation process at all intervention sites were examined using several approaches, like interviews with facilitators and focus group discussions with MNHG members, analyses of facilitators diaries from MNHG meetings and the notes from the monthly meetings with the supervisors." (p 5, Eriksson 2016); 1508 (out of 1584; 95%) of the planned MNHG meetings with a facilitator were completed; during the intervention a facilitator joined the MNHG activity in a commune 294 times; a facilitator supported a co-facilitator at a MNHG meeting 122 (8%) of the time; a NeoKIP researcher supported a facilitator at a 95 MNHG meetings (6%); and 35 (97%) monthly meetings between supervisor and facilitators took place (p 12, Eriksson 2016). Overall attendance at the meetings was 86%; the Head of the Women's Union (village level) attended 97%; the Head of the Community Health Centre attended 95%; midwives attended 94%; Community (Village) Health Workers attended 90%; Nurse attended (88%); Population collaborator (87%); Chairwomen of the Women's Union (commune level) (87%); and Vice chairperson of peoples committee attended 61% (p 7, Eriksson 2016). "No deviations from the protocol were observed except from one out of 44 MNHGs that ended the facilitation intervention two-thirds of the way into the trial. The facilitated intervention with MNHGs maintained a high activity with a large number of problems identified and actions taken, in spite of no extra financial benefits to the group members" (p 6, Eriksson 2016). "However, the NeoKIP intervention was a new approach for local stakeholders, who were not used to collaborate in this kind of group activity. This type of approach requires active and disciplined stakeholders who assess, discuss, and find ways to overcome contextual barriers that may impede the process of implementation." (p 8, Eriksson 2016)

Randomised to control: 46 communes; analysed during years 1-3: 587 mothers randomly sampled from 10,559 live births in 46 communes

Nature of comparison: usual practice; baseline perinatal care comprised the following: 'At primary care level communal health centres (CHC) provide antenatal care (ANC), delivery services and postnatal care staffed by 3–6 persons (physician, nurses, midwife). The primary health care level is also supported by at least one part-time village health worker (VHW) in each village, who mainly takes part in preventive services. Delivery services are also offered at hospitals at district, provincial and regional levels with more skilled staff and resources available at the higher levels' (p.1479, Nga 2010)

Most women (76%) received 3+ ANC visits, in line with national guidelines. 92% of births occurred in health care facilities (regional, provincial or district hospitals, community health centres); 8% occurred at home (accounting for 20% of neonatal deaths).

Co-intervention: none

Outcomes

Outcomes measured at Baseline (T0) and follow-up (during first year of intervention - T1; second year T2; third year T3; sixth year T4):

Outcome measures relevant to the review (reporting available comparative data for longest time point measured):

- **Health service alterations data (changes to services resulting from partnership decisions):** *Intervention process:* number of identified problems relating to perinatal health, process in working with these problems, interaction between group and facilitator, methods used during process. N.B. data reported in trial for intervention group only, not comparative.
- **Health service provider (trial participant) reported outcomes:** healthcare staff knowledge on perinatal care. N.B. no data reported in trial.
- **Consumer (partnership participant) reported behaviours/attitudes outcomes:** Consumer partner attendance at meetings. N.B. data reported in trial for intervention arm only, not comparative
- **Provider (partnership participant) reported behaviours/attitudes outcomes:** Provider partner attendance at meetings. N.B. data reported in trial for intervention arm only, not comparative

Other study outcome measures (data extracted but not reported in review):

- Neonatal Mortality: surveillance data and case-referent interviews

Persson 2013 (Continued)

- Intervention coverage: number of participants at intervention meetings, topics discussed at meetings, frequency of meetings
- Health care process data: antenatal care usage: frequency and time of antenatal care, ultrasound examination rate, antenatal care quality measurement; delivery care utilisation (delivery preparedness, home delivery rate and care-seeking patterns)
- Delivery care: caesarean section rate, transfer patterns, assistance at delivery
- Immediate postnatal care at place of delivery: resuscitation rate, temperature control, breast feeding initiation, rate of exclusive breast feeding at two months
- Postnatal care at home: umbilical care, prevalence and duration of skin-to-skin, exclusive breast feeding rate and frequency and timing of home visits by midwife
- Causes of neonatal death
- Healthcare resources: availability of equipment and drugs at health facilities
- Sex ratio at birth

Notes

Funding: Swedish International Development Cooperation Agency (SIDA), Swedish Research Council and Uppsala University.

Conflict of interest: Authors have declared that no competing interests exist.

Other: For other outcomes reported by the trial but not reported in the review, these were judged, through author consensus, to be outside the scope of the selection criteria (e.g. neonatal mortality) and/or less relevant measures of an outcome for which multiple measures were reported.

Risk of bias

Bias	Authors' judgement	Support for judgement
Random sequence generation (selection bias)	Low risk	"A random number list was used to subsequently allocate "intervention" or "control" to the list of communes, and 44 out of the 90 communes were allocated to intervention and 46 to control. The randomisation was preformed by one of the involved researchers at Uppsala University." (p 3, Persson 2013).
Allocation concealment (selection bias)	Low risk	"The sequence generation was concealed until the intervention was assigned; otherwise allocation was not masked." (p 3, Persson 2013)
Blinding of participants and personnel (performance bias) All outcomes	High risk	Unclear whether study participants were blind from knowledge of which intervention cluster they were assigned to; not able to blind personnel from knowledge of which intervention cluster they were assigned to.
Blinding of outcome assessment (detection bias) All outcomes	Low risk	No description of measures used, if any, to blind outcome assessors from knowledge of which intervention a participant received; The following relates to the outcome neonatal births/mortality "One (out 10) of the Village health Workers in the commune were involved in the Maternal and Newborn Health groups while all Village Health Workers were informants in the data collection system. The information on births and/or neonatal deaths provided by the village health workers who were involved in the intervention was most likely not biased since the updated list of pregnant women enabled a systematic enquiry on a monthly basis on pregnancy outcomes, as well as a triangulation of information sources and cross-checking of data." (p 6, Persson 2013) "Six data collectors were trained for 2 weeks. They attended monthly meetings at all commune health centres, all district hospitals, and the two provincial level hospitals in the area to collect data on live births and neonatal deaths. Further the data collectors met all Village Health Workers in the communes to collect data on live births and neonatal deaths in their villages. Triangulation was systematically performed of live births and neonatal deaths from all included sources (records and reports from the district, provincial and regional hospitals, commune health centres and village health workers) to ascertain that all data were

Persson 2013 (Continued)

		registered and secure that no duplication of information occurred." (p 777, Eriksson 2018).
		Author contact confirms that data collectors were blinded to group allocation and had no contact with those involved in intervention delivery.
Incomplete outcome data (attrition bias) All outcomes	Low risk	Zero losses to follow-up.
Selective reporting (reporting bias)	Low risk	Outcomes appear to be reported as planned based on those identified in protocol.
Other bias	Low risk	Groups were mostly balanced at baseline (except slightly more poor households in intervention group). Data collection was separated and verified by triangulation from different sources (and by analysts unaware of group assignment for at least some outcomes).
Selective recruitment of participants	Unclear risk	Not sure when participants were recruited to clusters.

Wu 2019
Study characteristics

Methods	<p>Study design: Cluster-RCT; Unit of randomisation: community based organisations (CBOs)</p> <ul style="list-style-type: none"> • 150 CBOs assessed for eligibility • 22 CBOs eligible and • 22 CBOs randomised; 20 operating once trial began <p>Sample size/power calculation: none identified</p> <p>Country of study: Baltimore, Maryland, US</p> <p>Setting: urban privately funded academic health care system (Johns Hopkins Health System (JHHS)). JHHS comprises Johns Hopkins University School of Medicine; The Johns Hopkins Hospital (1177 patient beds; 2230+ full-time attending physicians) Johns Hopkins Bayview Medical Centre (448 patient beds; 710+ attending physicians).</p> <p>Study duration: 2014 - 2016</p> <p>Broader consumer involvement: two community leaders were paid co-principal investigator and co-investigator on the study team. Both reviewed and approved all stages of proposal and helped identify and recruit CBOs for participation, and recruited members to be interviewed. Both were involved in the partnership intervention co-development process, implementation and evaluation. The community based co-principal investigator led meetings with CBO leaders. Both contributed to paper writing and submission.</p>
Participants	<p>Consumer partnership participants: (n = unknown), community leaders from not-for-profit CBOs that served adults and addressed one or more social determinants of health, located within the zip code of East or Southeast Baltimore</p> <ul style="list-style-type: none"> • Age: not described • Sex: not described • Education level: not described • Socioeconomic status (SES): not described • Diagnosis: not described

Wu 2019 (Continued)

- Other: not described

Provider partnership participants: (n = unknown), Johns Hopkins staff members as part of study team

- Age: not described
- Sex: not described
- Education level: not described
- SES: not described
- Years practicing: not described
- Other: not described

Health service user trial participants: (n = 6491 patients assessed for eligibility; 5255 eligible patients), high-risk Medicare and Medicaid Johns Hopkins Community Health Partnership (J-CHIP) outpatient patients (adults, at least one chronic condition, at least one visit to J-CHIP site, high risk for future hospitalisation). Patients with monthly healthcare utilization data, including emergency department visits and days hospitalised during both pre and post intervention and known home address were included.

- Age (mean): intervention 62 years; control 62 years
- Sex (female): intervention 65%; control 63%
- Education level: not described
- SES (Insurance type): intervention: Medicare 64%; Priority Partners MCO 36%; control: Medicare 65%, Priority Partners MCO 35%;
- Other (race): intervention: African American 59%; Asian 1%; White 35%; Hispanic 1%; Native American 0%; Unknown/other 5%; control: African American 52%; Asian 1%; White 42%; Hispanic 0%; Native American 0%; Unknown /other 4%.

Health service provider trial participants: (n = unknown), outpatient staff (case managers, community health workers, health educators and behavioural health specialists) and inpatient staff (social workers, case managers, hospitalists and nurse who help discharge patients to home) from JHHS.

- Sex: not described
- Education level: not described
- SES: not described
- Number of years practising: not described
- Other: not described

Interventions

Randomised to intervention: 11 CBOs; 1997 patients (analysed: 10 CBOs; 1864 patients)

Nature of intervention: After randomisation the partnership Baltimore CONNECT (Community-based Organisations Neighbourhood Network: Enhancing Capacity Together) co-developed an intervention/toolkit (Healthify).

Intervention aim: to "enhance the capacity of both CBO staff and frontline hospital workers to address client needs by strengthening the bidirectional flow of information about health and social services and building networks that span both entities." (p e32, Wu 2019)

Context of partnering: Partnership based on the African Partnerships for Patient Safety Engagement (ACE) Framework which is underpinned by Community Based Participatory Research and Participatory Action Research approaches.

Decision-making activity: "To begin, iCBO (intervention CBO) leaders completed a needs assessment to identify commonly faced challenges. The most salient issues identified were: referring clients to organisations for support, developing a stronger relationship with other CBOs to better serve clients, and interfacing with JHHS. Results of needs assessment were directly linked to formation of strategies to enhance co-ordination of health and social services." (p 302, Wu 2018)

Meeting format, duration, frequency and location: face-to-face (plus email and phone calls); each meeting 1.5 to 2 hours in duration; conducted monthly (for 6 months of co-development and 12 months of the trial), with location rotated among iCBOs.

Wu 2019 (Continued)

Partnership duration: 6 months

Training/support: no training described; each iCBO assigned a student research assistant

Decision-making process, attempts to resolve conflict: not described

Diversity and ratio of consumer and provider participants: not described

Attempts to address intrinsic power imbalances: not described

Theoretical basis for partnering: Draws from the following 8 concepts of the ACE Framework: establish a community engagement advisory board; know the community; establish an enabling community engagement environment; raise patient quality and safety awareness locally and nationally; collect community knowledge and experiences; ensure robust communication mechanisms; feed into monitoring and evaluation; and develop a community ripple effect.

Tailoring/modification/adapting: reverse innovation of the ACE Framework by adapting the ACE approach to partner with iCBO leaders to co-develop and implement a set of interventions, or toolkit

Fidelity/integrity: No assessment of fidelity, but there was survey data on trust, partnership etc (secondary outcomes). Some contamination effects possible, as intervention and control CBOs may have shared some clients and provided services to the J-CHIP cohort of patients. Healthify also listed both intervention and control CBOs.

Randomised to control: 11 CBOs, 3258 patients (analysed: 10 CBOs, 3053 patients)

Nature of comparison: usual practice plus J-CHIP - no other description

Co-intervention: Johns Hopkins Community Health Partnership (not described)

Outcomes

Outcomes measured at Baseline (T0) and follow-up (12 months after intervention had ended - T1):

Outcome measures relevant to the review (reporting available comparative data for longest time point measured):

- **Health service alterations data (changes to services resulting from partnership decisions):** CBO staff reported receiving 1+ referral from healthcare staff (T1)**
- **Health service user (trial participant) health service utilisation patterns:** Client reported referred from the healthcare system to a CBO (T1)
- **Health service provider (trial participant) reported outcomes:** Healthcare staff barriers to referring patients to CBOs, capacity for CBOs and healthcare organizations to work together, confidence in knowledge about community resources, confidence in the capacity of CBOs to meet their clients' needs, and number of referrals to iCBOs and cCBOs (T1). Data reported as pre-post separately for in-patient and outpatient staff (but not comparatively for intervention vs. control group)
- **Adverse events:** "no harm was done to any of the participants in either group" (p e36, Wu 2019)
- **Consumer (partnership participant) reported behaviours/attitudes outcomes:** CBO staff ratings of working together with health service moderately or extremely well (T1)**
- **Measures of partnership among provider and consumer partnership participants:** iCBO partner satisfaction with the partnership self-assessment tool (T1). Data reported for intervention consumer partners only.

Other study outcome measures (extracted but not reported in review):

- CBO client healthcare utilisation (health system billing (claims) data) (Mean and Standard Error*)
- CBO client reported (survey in-person/by phone) attitudes and behaviours (%)**
- CBO staff reported (online/paper survey) attitudes and behaviours (%)**

Following outcomes were not comparative (reported pooled data only):

- Healthcare staff reported (online/paper survey) attitudes (J-CHIP outpatient staff) (%)
- Healthcare staff report (online/paper survey) attitudes (hospital staff) (%)

Following outcomes measured at T1 for intervention arm only:

Wu 2019 (Continued)

- iCBO partner (online/paper survey) satisfaction with the partnership (partnership self-assessment tool)
- iCBO staff use of Healthify (Healthify analytics usage data)
- In/out patient staff and iCBO staff (post event survey) usefulness of meet and greet sessions (% agree or strongly agree)

Notes

Funding: Patient-Centred Outcomes Research Institute project grant (CD-12-11-4948). Viva Dadwal supported by Fulbright Canada and the U.S Department of State's Fulbright Scholarship Programme.

Conflict of interest: No financial disclosures reported by authors

Other: *calculated standard deviation from standard error; ** calculated events from % data. For outcomes reported by the trial but not included in this review, authors identified through consensus that such outcomes were less relevant to the outcomes of the review (where multiple measures of an outcome were reported).

Risk of bias

Bias	Authors' judgement	Support for judgement
Random sequence generation (selection bias)	High risk	Cluster-RCT "a restricted randomization process was conducted that constrained the allocation of organisations based on their ZIP code, client population (small, medium or large) and the type of service offered. There was purposeful balance in the number of churches, neighbourhood associations, and Hispanic serving organisation in each group as well as the primary type of services provided (e.g. food, housing, clothing)" (p e33, Wu 2019). Rated as at high risk - even if balance was managed on these factors there might be other potential confounders which were not considered.
Allocation concealment (selection bias)	High risk	"The assignment of CBOs could not be blinded which introduced potential for bias." (p 305, Wu 2018)
Blinding of participants and personnel (performance bias) All outcomes	Unclear risk	CBO clients were not likely to be aware of an individual CBO's group assignment; blinding of personnel not described. CBOs were randomised and therefore in the intervention group the leadership (at least) were aware of the intervention; control group may not have been aware of assignment.
Blinding of outcome assessment (detection bias) All outcomes	Low risk	Not described in manuscript. Author response indicates that primary outcomes were all electronic data, with statisticians blinded to assignment.
Incomplete outcome data (attrition bias) All outcomes	Low risk	A total of 205 and 133 patients were excluded from the comparison and interventions arms respectively who did not have any utilisation data available either in the pre- or post intervention period; these losses were about 7% in both groups; reasons were similar, and numbers remaining for analysis still large.
Selective reporting (reporting bias)	Unclear risk	All outcomes measured reported in published methods are reported and trial protocol is registered NCT02222909 but protocol only lists primary outcomes measured i.e. Emergency Department visits + hospital days [Time Frame: Up to 1 year]; Number of Emergency Department Visits + Number of Hospital Days in the past 6 months for patients enrolled in the Johns Hopkins Community Partnership; and Change in number of clients seen per month [Time Frame: September 2014 - September 2015] Change in median number of clients seen by Community Based Organizations per month; additional outcomes are reported in publications.
Other bias	Low risk	None.

Wu 2019 (Continued)

Selective recruitment of participants	Unclear risk	"For allocation of J-CHiP patients to a treatment arm, those who lived closer to an iCBO were allocated to the intervention group, and those who lived closer to a cCBO were allocated to the control group. Google application programming interfaces were used to determine the distance between each patient's residence and each of the participating CBOs." (p e33, Wu 2019); timing not mentioned.
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ACE: African Partnerships for Patient Safety Engagement Framework; **ANC:** Antenatal Care; **APSQ:** Attitudes to Patient Safety Questionnaire; **CBO:** COmmunity Based Organisation; **CHC:** Communal Health Centres; **CFG:** Critical Friends Group; **CHDR:** Community Health Data Review; **CHW:** Community Health Worker; **CONNECT:** Community-based Organisations Neighbourhood Network: Enhancing Capacity Together; **IPQ:** Improving Practice Questionnaire; **J-CHiP:** Johns Hopkins Community Health Partnership; **JHHS:** Johns Hopkins Health System; **MNHG:** Maternal and Newborn Health Groups; **NMR:** Neonatal Mortality Rate; **VHW:** Village Health Worker.

Characteristics of excluded studies [ordered by study ID]

Study	Reason for exclusion
Abbey 2017	Ineligible intervention (some other intervention evaluated)
Abelson 2003	Ineligible on two or more criteria
Abelson 2016	Ineligible study design (no attempt at randomisation)
Aboumatar 2017	Ineligible intervention (some other intervention evaluated)
Acharya 2015	Ineligible intervention (some other intervention evaluated)
Ackermann 2010	Ineligible participants (no provider or no consumer)
Aggett 2009	Ineligible on two or more criteria
Aibinuomo 2011	Ineligible on two or more criteria
Aimola 2016	Ineligible intervention (some other intervention evaluated)
Aldiss 2011	Ineligible on two or more criteria
Alhassan 2015	Ineligible on two or more criteria
Alhassan 2016	Ineligible on two or more criteria
Alhassan 2016a	Ineligible on two or more criteria
Alhassan 2016b	Ineligible on two or more criteria
Alhassan 2017	Ineligible on two or more criteria
Alhassan 2019	Ineligible on two or more criteria
Aliyu 2013	Ineligible on two or more criteria
Allen 2012	Ineligible study design (no attempt at randomisation)
Allen 2013	Ineligible on two or more criteria

Study	Reason for exclusion
Allen 2018	Ineligible study design (no attempt at randomisation)
Allender 2016	Ineligible on two or more criteria
Alvarado 1999	Ineligible on two or more criteria
Andersson 2015	Decision not PCC related
Andersson 2017	Decision not PCC related (dengue control)
Angwenyi 2014	Ineligible on two or more criteria
Anonymous 2005	Ineligible participants (no provider or no consumer) (abstract of Manandhar 2004)
Armstrong 2018	Ineligible meeting format (do not meet jointly or not formal group or once off)
Arunachalam 2012	Decision not PCC related
Ayles 2013	Ineligible on two or more criteria
Azad 2010	Decision not PCC related (strengthen community)
Balcazar 2009	Ineligible on two or more criteria
Balcazar 2010	Ineligible on two or more criteria
Bashir 2019	Ineligible on two or more criteria
Batterham 2014	Ineligible on two or more criteria
Bedford 2014	Ineligible on two or more criteria
Belin 2008	Ineligible comparator
Beuermann 2018	Decision not PCC related
Bitton 2018	Ineligible study design (no attempt at randomisation)
Björkman 2009	Ineligible comparator
Björkman 2010	Ineligible on two or more criteria
Björkman Nyqvist 2017	Ineligible study design
Blank Wilson 2014	Ineligible on two or more criteria
Bloom 2014	Ineligible study design (no attempt at randomisation)
Bogart 2009	Ineligible on two or more criteria
Boivin 2011	Ineligible on two or more criteria
Boivin 2014	Ineligible comparator
Boivin 2014b	Ineligible comparator

Study	Reason for exclusion
Boivin 2018	Ineligible on two or more criteria
Bos 2007	Ineligible on two or more criteria
Bower 2015	Ineligible participants (no provider or no consumer)
Bramble 2011	Ineligible on two or more criteria
Brooker 2005	Ineligible on two or more criteria
Brundage 2010	Ineligible on two or more criteria
Burnell 2015	Decision not PCC related
Cabassa 2014	Ineligible on two or more criteria
Campbell-Scherer 2014	Ineligible on two or more criteria
Capara 2015	Ineligible on two or more criteria
Cardoso 2017	Ineligible intervention (some other intervention evaluated)
Carmen 2015	No joint decision making
Castillo 2018	Ineligible comparator
Castro 2012	Ineligible on two or more criteria
Chaney 2011	Ineligible on two or more criteria
Chang 2015	Ineligible comparator
Cheever 2007	Ineligible on two or more criteria
Chiew 2008	Ineligible on two or more criteria
Chin 2007	Ineligible on two or more criteria
Choi 2011	Ineligible intervention
Choi 2016	Ineligible intervention
Choi 2019	Ineligible comparator
Chomat 2019	Ineligible study design
Chumbley 2002	No partnership
Chung 2010	Ineligible comparator
Chung 2014	Ineligible comparator
Chung 2015	Ineligible comparator
Clarke 2014	Ineligible on two or more criteria

Study	Reason for exclusion
Clausen 2018	Ineligible study design (no attempt at randomisation)
Coker 2016	Decision not PCC related
Coker 2019	Ineligible intervention (some other intervention evaluated)
Colbourn 2013	Decision not PCC related
Cooper 2016	Ineligible study design (no attempt at randomisation)
Corrigan 2017	No joint decision making
Decat 2013	Ineligible on two or more criteria
de la Torre 2013	Ineligible on two or more criteria
Donato 2019	Ineligible on two or more criteria
Dowrick 2016	Ineligible intervention (some other intervention evaluated)
Drummond 2014	Ineligible on two or more criteria
El Ansari 2001	Ineligible study design (no attempt at randomisation)
Elstad 2009	Ineligible study design (no attempt at randomisation)
Erwin 2018	Ineligible intervention
Esienumoh 2018	Ineligible study design (no attempt at randomisation)
Farmer 2006	Ineligible on two or more criteria
Fenenga 2015	Ineligible on two or more criteria
Fottrell 2013	Ineligible on two or more criteria
Fottrell 2016	Ineligible on two or more criteria
Frank 2018	Ineligible on two or more criteria
Fujimori 2014	Ineligible on two or more criteria
Fulkerson 2021	Ineligible study design
Galiatsatos 2017	Ineligible study design (no attempt at randomisation)
Gellatly 2018	Ineligible on two or more criteria
Gholipour 2016	Ineligible on two or more criteria
Gitaka 2018	Ineligible on two or more criteria
Gloppen 2012	Ineligible on two or more criteria
Glynn 2015	Ineligible on two or more criteria

Study	Reason for exclusion
Goldfinger 2012	Ineligible on two or more criteria
Goodkind 2017	Ineligible on two or more criteria
Gram 2018	Ineligible on two or more criteria
Greenfield 2012	Ineligible on two or more criteria
Gregory 2011	Ineligible intervention (some other intervention evaluated)
Groene 2014	Ineligible on two or more criteria
Grogan 2012	Ineligible study design (no attempt at randomisation)
Gual 2012	Ineligible on two or more criteria
Gullo 2017	Ineligible comparator
Gullo 2018	Ineligible comparator
Gummersbach 2013	Ineligible on two or more criteria
Haines 2015	Ineligible on two or more criteria
Hamilton 2017	Ineligible on two or more criteria
Hanson 2014	Ineligible study design (no attempt at randomisation)
Harding 2016	Ineligible on two or more criteria
Harris 2013	Ineligible on two or more criteria
Henderson 2017	Ineligible intervention (some other intervention evaluated)
Hernandez 2013	Ineligible on two or more criteria
Hobbs 2000	Ineligible study design (no attempt at randomisation)
Hoffman 2018	Ineligible on two or more criteria
Holt 2014	Ineligible comparator
Hoos 2015	Ineligible study design (no attempt at randomisation)
Houweling 2011	Ineligible on two or more criteria
Houweling 2013	Ineligible on two or more criteria
Huppelschoten 2015	Ineligible comparator
Hwang 2012	Ineligible comparator
Hynes 2017	Ineligible study design (no attempt at randomisation)
Iezzoni 2018	Ineligible comparator

Study	Reason for exclusion
Izquierdo 2016	Ineligible comparator
Izquierdo 2018	Ineligible comparator
Jha 2013	Ineligible study design (no attempt at randomisation)
Källander 2015	Ineligible comparator
Kang 2017	Ineligible on two or more criteria
Kelly 2010	Ineligible on two or more criteria
Khadyakov 2014	Ineligible comparator
Khodyakov 2014	Ineligible comparator
Khodyakov 2017	Ineligible on two or more criteria
Khodyakov 2018	Ineligible comparator
Kim 2014	Ineligible on two or more criteria
Kim Yeary 2017	Ineligible on two or more criteria
Kneipp 2011	Decision not PCC related
Ko 2015	Decision not PCC related
Ko 2016	Decision not PCC related
Koerner 2014	Ineligible on two or more criteria
Kogan 2017	Ineligible comparator
Koniotou 2015	Ineligible on two or more criteria
Krishnan 2017	Ineligible intervention
Krist 2013	Ineligible on two or more criteria
Lalonde 2011	Ineligible on two or more criteria
Lam 2016	Ineligible comparator
Lamb 2010	Ineligible on two or more criteria
Lamontagne 2014	No partnership
Landry 2017	Ineligible comparator
Lawton 2016	Ineligible on two or more criteria
Lawton 2017	Ineligible on two or more criteria
Lewycka 2010	Ineligible on two or more criteria

Study	Reason for exclusion
Lewycka 2013	Ineligible on two or more criteria
Liddy 2011	Ineligible on two or more criteria
Lippeveld 2017	Ineligible on two or more criteria
Livingston 2013	Ineligible on two or more criteria
Lodewijckx 2012	Ineligible on two or more criteria
Loignon 2018	Ineligible on two or more criteria
Lovell 2018	Ineligible on two or more criteria
Luna 2015	Ineligible study design (no attempt at randomisation)
Ma 2018	Ineligible on two or more criteria
Machline-Carrion 2019	Ineligible participants
MacLeod 2012	Ineligible on two or more criteria
Malfait 2018	Ineligible study design (no attempt at randomisation)
Manandhar 2004	Ineligible participants (no provider or no consumer)
Martinez Garcia 2013	Ineligible on two or more criteria
Martínez-Jaikel 2019	Ineligible intervention
McCabe 2018	Ineligible participants
McElfish 2017	Decision not PCC related (research)
McKay 2011	Ineligible intervention (some other intervention evaluated)
Mehta 2017	Ineligible comparator
Mendel 2011	Ineligible on two or more criteria
Mendel 2021	Ineligible comparator
Mendenhall 2007	Ineligible on two or more criteria
Meynard 2011	Ineligible intervention (some other intervention evaluated)
Michaels 2017	Ineligible participants (no provider or no consumer)
Miller 2017	Ineligible on two or more criteria
Miller 2020	Ineligible on two or more criteria
Mirza 2009	Ineligible on two or more criteria
More 2008	Ineligible intervention (some other intervention evaluated)

Study	Reason for exclusion
Morrison 2011	Ineligible comparator
Mourad 2011	Ineligible on two or more criteria
Nahar 2012	Ineligible on two or more criteria
Nair 2015	Ineligible comparator
Namazzi 2015	Ineligible on two or more criteria
NCT02286193	Ineligible on two or more criteria
NCT03035474	Ineligible on two or more criteria
NCT03044145	Ineligible on two or more criteria
NCT03222466	Ineligible on two or more criteria
NCT04514133	Ineligible on two or more criteria
Newman Owiredu 2017	Ineligible on two or more criteria
Ngo 2016	Ineligible comparator
Noel 2014	Ineligible on two or more criteria
Ogbuoji Osondu 2018	Ineligible participants
Ojerholm 2016	Ineligible on two or more criteria
Oliver 2009	Ineligible study design (no attempt at randomisation)
Ong 2013	Ineligible participants (no provider or no consumer)
Ong 2017	Ineligible comparator
Orozco-Beltran 2013	Ineligible on two or more criteria
Osrin 2003	Ineligible on two or more criteria
Parchman 2013	Ineligible on two or more criteria
Patel 2019a	Ineligible study design
Patel 2019b	Ineligible study design
Paton 2013	Ineligible study design (no attempt at randomisation)
Patzer 2014	Ineligible comparator
Peremans 2010	Ineligible intervention
Peter 2015	Ineligible on two or more criteria
Peterson 2018	Ineligible on two or more criteria

Study	Reason for exclusion
Pramanik 2018	Decision not PCC related
Prost 2018	Ineligible on two or more criteria
Protik Ali 2018	Decision not PCC related
Rai 2018	Ineligible on two or more criteria
Raynes-Greenow 2010	Ineligible on two or more criteria
Reeves 2013	Ineligible on two or more criteria
Reinhardt 2012	Decision not PCC related
Rogers 2007	Ineligible on two or more criteria
Sarmiento 2018	Ineligible participants (no provider or no consumer)
Sauers-Ford 2016	Ineligible on two or more criteria
Scholl 2018	Ineligible on two or more criteria
Schweitzer 2015	Ineligible on two or more criteria
Segal 2010	Decision not PCC related
Sepuchra 2003	Ineligible on two or more criteria
Shagi 2008	Ineligible on two or more criteria
Sherbourne 2017	Ineligible comparator
Shukla 2018	Ineligible study design (no attempt at randomisation)
Simonsen 2017	Ineligible on two or more criteria
Singh 2020	Ineligible study design
Sirilak 2013	Ineligible on two or more criteria
Smiddy 2015	Ineligible on two or more criteria
Smout 2016	Ineligible on two or more criteria
Solomon 2017	Ineligible on two or more criteria
South 2016	Decision not PCC related
Spencer 2011	Decision not PCC related
Springgate 2018	Ineligible on two or more criteria
Springgate 2018b	Ineligible comparator
Stanhope 2013	Ineligible on two or more criteria

Study	Reason for exclusion
Stephens 2018	Ineligible on two or more criteria
Stockdale 2016	Ineligible comparator
Storm 2011	Ineligible study design (no attempt at randomisation)
Svetaz 2016	Decision not PCC related
Taylor 2017	Ineligible on two or more criteria
Thilly 2003	Ineligible participants (no provider or no consumer)
Thornton 2003	Ineligible on two or more criteria
Tondora 2010	Ineligible on two or more criteria
Tran 2004	Ineligible on two or more criteria
Tran 2018	No joint decision making
Treloar 2015	Ineligible on two or more criteria
Tripathy 2010	Ineligible on two or more criteria
Tripathy 2011	Ineligible on two or more criteria
Tripathy 2016	Ineligible on two or more criteria
Tsianakas 2012	Ineligible study design (no attempt at randomisation)
Tumiel-Berhalter 2011	Ineligible on two or more criteria
Uding 2007	Ineligible on two or more criteria
Uding 2009	Ineligible on two or more criteria
Vale 2018	Decision not PCC related
Vanderboom 2014	Ineligible participants (no provider or no consumer)
Van Malderen 2017	No joint decision making
Van Malderen 2017a	No joint decision making
von dem Knesebeck 2002	Ineligible on two or more criteria
Waiswa 2016	Ineligible comparator
Wathne 2018	Ineligible on two or more criteria
Watson 2001	Ineligible on two or more criteria
Weinstein 2006	Ineligible study design (no attempt at randomisation)
Wells 2013	Ineligible comparator

Study	Reason for exclusion
Werner 2019	Ineligible on two or more criteria
Wheatley 2002	Ineligible on two or more criteria
Williams 2013	Ineligible intervention (some other intervention evaluated)
Winters 2016	Ineligible on two or more criteria
Wolf 2008	Ineligible on two or more criteria
Wolfe 2019	Ineligible participants
Wood Dauphinee 2011	Ineligible on two or more criteria
Yano 2016	Ineligible on two or more criteria
Younes 2012	Ineligible on two or more criteria
Young 2005	Ineligible study design (no attempt at randomisation)
Zhang 2020	Ineligible participants
Zimmerman 2017	Decision not PCC related
Zwar 2008	Ineligible on two or more criteria

PCC: person-centred care.

Characteristics of studies awaiting classification [ordered by study ID]

English 2018

Methods	Cluster-RCT; unit of randomisation - geographic regions n = 26
Participants	Inclusion Criteria: 18-89 years, all sexes. Enrolled primary care staff (including physicians, nurse practitioners and physician assistants). Primary care practice must be family medicine or general internal medicine practices with a maximum of ten lead clinicians; and independent, or if in part of a larger organisation, must demonstrate on careful screening that they do not received significant quality improvement support from the larger organisation. Exclusion Criteria: Primary care practices with more than 10 lead clinicians; non-independent primary care practices that receive significant quality improvement support from their system organisation.
Interventions	Multi-component intervention with partnership (enhanced facilitation: standard facilitation plus community engagement in developing resources) compared with multi-component intervention without partnership (standard facilitation intervention)
Outcomes	Primary outcomes: Timing: Baseline, 3, 6, 9, 12, and 15 months from baseline: Change in documentation of the following practice level indicators: aspirin therapy in patients with ischaemic vascular disease; blood pressure in patients with a diagnosis of hypertension; blood pressure in patients with adequately controlled blood pressure; fasting LDL in patients with a fasting LDL at or below the LDL goal; patients who had a fasting LDL test performed and prescribed a statin based on risk; and patients screened about tobacco use. Secondary outcomes: Timing: Baseline, 9 and 15 months from baseline: change of the documentation in primary care practices (based on practice-level scores of change process capacity, adaptive reserve, clinician experience and implementation of patient-centred medical home components).

English 2018 (Continued)

Notes trial registration #:NCT02515578 [new references Dickinson 2020 and Fernald 2020 identified 21/12/2020]

Gai 2019

Methods	<p>Cluster-RCT; unit of randomisation: community clinic level</p> <p>Objectives: To evaluate the effects of a community-based intervention on the utilisation of maternal and neonatal care provided by qualified facilities and skilled providers, in the context of the Safe Mothering Promotion Project (Phase II).</p> <p>'The objective of SMPP Phase II was to improve maternal and neonatal health outcomes by: improving maternal and neonatal health (MNH) service delivery at health facilities; strengthening CSGs to implement community led actions for saving mother and newborn lives; involving the local government bodies to support MNH services; and empowering women, through awareness building, to obtain participation and accountability for overcoming barriers to access healthcare services' (p. 4).</p>
Participants	<p>Eligible: women having given birth in the year preceding data collection; residing in study areas (intervention or control areas) and able to give written informed consent.</p> <p>Location: Kalaroa Upazila of Satkhira District, Bangladesh</p> <p>Total n = 4675 women (intervention group: n = 2407 (1102 baseline, 1305 at follow up); control group: n = 2268 (1237 baseline, 1031 at follow up).</p>
Interventions	<p>Multicomponent intervention at healthcare facilities and community levels, involving Community Support Groups embedded within Community Clinics and serving to create demand and mobilise the community, working in collaboration with a Community Group (governing and management body, ensuring quality of care). Purpose is to promote better maternal and neonatal health outcomes; comparison with usual practice.</p>
Outcomes	<p>Primarily clinical and related outcomes, reflecting use of services for antenatal care, delivery, postpartum care and neonatal care by pregnant and post-partum women.</p> <p>'The major indicators of the expected outcomes were:</p> <ul style="list-style-type: none"> • Proportion of women received any and 4+ ANC from skilled health care providers; • Met need (proportion of women with complications received services from EmOC facilities) during pregnancy, childbirth and post-partum period; • Delivery attended by skilled birth attendants; • Delivery conducted at health facilities; • Proportion of postpartum women received PNC from skilled providers within 42 days of delivery; • Proportion of sick newborns received services from skilled provider <p>Information related to maternal and neonatal complications and care seeking were obtained from the respondents through face-to-face interview using a structured questionnaire' (p.9).</p>
Notes	<p>UMIN Clinical Trial Registry UMIN000031789.</p>

James 2013

Methods	<p>Cluster-RCT: unit of randomisation - Community Health Centres, n = 16 (11 enrolled?)</p>
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James 2013 *(Continued)*

Participants	Community Health Centres are eligible if they serve mostly Medicaid, uninsured, or lower-income patients; be willing to be randomised to intervention or comparison, and willing to allow the research team access to Community Health Centres managers/directors, patients, and providers. Participants were eligible if they spoke English or Spanish and were aged 49 or older.
Interventions	Using a Community-Based Participatory Research approach, collaborated with partners to implement and evaluate a systems-level intervention for its effectiveness in increasing CRC screening rates vs usual practice
Outcomes	Timing: baseline, six months, and twelve months. Primary outcome: colorectal cancer screening by patient self-report, with a chart-audit in a sub-sample of patients. Other outcomes: evaluated according to the Reach, Efficacy/Effectiveness, Adoption, Implementation, and Maintenance (RE-AIM) conceptual framework. Six-month and 12-month surveys include self-reported CRC screening, healthcare utilization, and awareness of screening or educational efforts
Notes	Trial registration #: NCT01299493 [new reference Muthukrishnan 2018 - identified 21 December 2020]

Lindquist 2020

Methods	Multi-site RCT; n = 400 Objective: To assess the effectiveness of a long term support services (LTSS) planning tool for older adults and to involve community partners in disseminating information about the tool within the community.
Participants	Older adults and their family members; community partners (5 newly trained) Dissemination amongst diverse community groups in Chicago, Indiana and Hawaii
Interventions	LTSS planning tool, with community partner engagement to increase dissemination about the tool in patient partners. Train the trainer model.
Outcomes	Engagement of patient partners in dissemination activities. Dissemination activities (locations, dates; newly created accounts, web sessions and daily visitors to tool site). Assessed at 1 week and 1 month after dissemination activities.
Notes	Conference abstract only. Not clear if partnership is evaluated through randomised trial (may be in parent trial of tool effectiveness).

Morrison 2020

Methods	Cluster-randomised trial; 21 intervention Village Development Committee (VDCs) clusters and 22 control clusters; stratified (4 groups) based on previous women's group activity exposure. Objectives: To evaluate the impact of strengthened health management committees (HMCs) and community mobilisation through women's groups on deliveries (institutional deliveries and those by trained health workers).
Participants	Eligible: women aged 12-49 years, who had delivered a baby between 1 October 2010 and 30 September 2012.

Morrison 2020 (Continued)

	<p>Makwanpur District, rural Nepal; containing 43 geopolitical VDCs.</p> <p>Complete data were recorded for 13,721 deliveries during the study period (intervention and control sites).</p>
Interventions	<p>Multicomponent intervention versus control.</p> <p>Strengthening health management committees (HMCs), via 4-day workshop based on principles of Appreciative Inquiry.</p> <p>Women's group intervention: training of female community health volunteers in facilitation skills, participatory learning and action cycle process, and running meetings; provided with manual to guide discussions, and supervision.</p> <p>Women's groups run approximately monthly; discussions included those about barriers to institutional delivery and how to address these; followed by community and cluster meetings to garner support for implementation of strategies to address barriers; following implementation groups reflected on progress and planned and implemented further strategies or modified those already in place.</p>
Outcomes	<p>Primary outcomes: deliveries conducted by trained health workers; institutional deliveries</p> <p>Secondary outcomes: uptake of antenatal and postnatal care; live births; stillbirths</p>
Notes	<p>Current Controlled Trials ISRCTN99834806. Date of registration: 28 September 2010</p>

Palmer 2015

Methods	<p>Stepped wedge cluster-RCT; unit of randomisation - Community Support Services</p>
Participants	<p>Consumers: English speaking, aged 16 years or older, attends a program that is part of the Mental Health Community Support Service at the participating service provider; received a diagnosis of mental illness.</p> <p>Carers: English speaking, aged 18 years or older, supports someone who attends a program that is part of the Mental Health Community Support Service at the participating service provider.</p> <p>Staff: employed at the mental health service (any time fraction) and are involved in planning and/or the delivery of services related to the Mental Health Community Support Services.</p>
Interventions	<p>Mental Health Experience Co-design (MH ECO) is a structured process for service users (consumers), carers and mental health staff to come together to identify improvements to service planning and delivery and co-design the solutions to these improvements compared to clusters awaiting intervention as controls i.e. usual practice</p>
Outcomes	<p>Timing: 9, 18, and 27 months after intervention. Primary outcome: Psychosocial Recovery Assessment Scale - Revised 24 Item RAS-R; Secondary outcome: mental health and well-being for consumers and carers (EUROHIS - Quality of Life 8 Item Scale) and change in staff attitudes to recovery (RSA, Recovery Self Assessment Scale - Provider Version and STARS Staff Attitudes to Recovery Scale)</p>
Notes	<p>The CORE study Principal Investigator: A/Prof, Dr Victoria Jane Palmer, Department of General Practice, Melbourne Medical School. Trial registration #: ACTRN12614000457640</p>

Shrestha 2011

Methods	Cluster-RCT; unit of randomisation - village development committee clusters, n = 60
Participants	Main target population: Women of reproductive age; infants under a year of age and pregnancies in the district
Interventions	Two community-based interventions involving Female Community Health Volunteers (1) MIRA Dhanusha community groups: a participatory intervention with women's groups and (2) MIRA Dhanusha sepsis management: training of community volunteers in the recognition and management of neonatal sepsis
Outcomes	Primary outcome: neonatal mortality rates. Secondary outcomes: MIRA Dhanusha community group: stillbirth, infant and under-two mortality rates, care practices and health care seeking behaviour, maternal diet, breastfeeding and complementary feeding practices, maternal and under-2 anthropometric status. MIRA Dhanusha sepsis management: identification and treatment of neonatal sepsis by community health volunteers, infection-specific neonatal mortality
Notes	ISRCTN: ISRCTN87820538; Principal investigator: Prof Anthony Costello, UCL Centre for International Health and Development

CHC: Community Health Centre; **CRC:** Colorectal Cancer; **EUROHIS-QoL:** shortened version of the WHO Quality of Life Instrument-Abbreviated version; **LDL:** Low-density lipoprotein; **MH ECO:** Mental Health Experience Co-design; **RSA:** Recovery Self Assessment Scale; **RAS-R:** Psychosocial Recovery Assessment Scale - Revised; **RE-AIM:** Reach, Efficacy/Effectiveness, Adoption, Implementation, and Maintenance; **STARS:** Staff Attitudes to Recovery Scale.

Characteristics of ongoing studies [ordered by study ID]

Kjellström 2019

Study name	'Samskapa' research programme protocol
Methods	Various study designs; mixed-method evaluations of at least nine case studies of coproduction
Participants	Various participants
Interventions	Coproduction in the health and social care sectors
Outcomes	Various studies measuring other outcomes
Starting date	Various start dates during a 5-year period (2019–2024)
Contact information	Professor Sofia Kjellström; doctoral students taking part in the 9 studies: Andreas Gremyr (Jönköping University), Sarah McAllister (King's College London), Sofia Persson (Jönköping University), Anne-Marie Suutari (Jönköping University), Mary Tanay (King's College London) and Pontus Wallin (Jönköping University).
Notes	

Sawtell 2018

Study name	A pragmatic cluster population-level randomised controlled trial of a community-level intervention to increase early uptake of antenatal care (REACH Pregnancy Programme, Work Package 1)
Methods	Matched cluster-RCT; unit of randomisation: electoral ward n = 10

Sawtell 2018 (Continued)

Participants	<p>Wards: electoral wards, covered by maternity care providers enrolled on the study, where the proportion of women who have their first antenatal appointment by 12 weeks is below the NHS national target of 90%</p> <p>Participants: women in the selected electoral wards who give birth, at a hospital enrolled in the study, over a 12-month period</p>
Interventions	Using a co-production process engages with local communities to identifying their perceptions/views on the issues and solutions to increase early booking for antenatal care; tailoring the design of the intervention and form and content of key intervention messages; and facilitating the communication of the intervention messages through community self-help and local social networks compared with usual practice
Outcomes	Timing: baseline; first follow-up (2-7 months) and second follow-up (8-12 months): gestation at booking, antenatal admissions, emergency caesarean rates, gestation/weight at delivery, maternal/infant death, APGAR score, smoking, feeding; Other outcomes: feasibility, acceptability, fidelity and economics via interview/observations and reach, exposure, and acceptability via survey.
Starting date	1 April 2015 to 1 April 2020; intention to publish date: 1 May 2021
Contact information	Principal Investigator: Ms Mary Sawtell, University College London
Notes	ISRCTN63066975

ADDITIONAL TABLES
Table 1. Key components of working in partnership versus usual practice

Key components of working in partnership	(1) Partnership participant types		(2) Joint formal group format, meets over time		(3) Decision relates to person-centeredness of health service	
Working in partnership as an intervention	At least one consumer	At least one health service provider	Opportunity to influence deliberation and decision-making by meeting jointly (e.g. f2f, online, phone)	Formal group format (e.g. board, committee, council, steering or work group)	Meets more than once (e.g. time-limited or ongoing)	Joint decisions about health service planning, delivery, or evaluation
Usual practice – may contain some, but not all, key components of working in partnership	e.g. no consumer participant, or consumer(s) involved, but not in decision-making	(or) no health service provider participant, or provider(s) involved, but not in decision-making	(or) group does not meet jointly e.g. independent deliberation and decision-making	(or) group is informal or ad-hoc	(or) group meets only once	(or) either the consumer or health service provider participant provides feedback, or acts in an advisory or consultative capacity, rather than decision-making, for health service planning, delivery, or evaluation

Table 2. Study demographics

<i>Study</i>	<i>Country; Degree of regional development; Healthcare setting</i>	<i>Partnership participants</i>	<i>Trial participants</i>	<i>Demographic details</i>
<p>Jha 2015</p> <p>RCT</p> <p>283 first year trainee doctors randomised to partnership and usual practice</p>	<p>Country: England</p> <p>Regional development: High-income country; predominantly urban sites</p> <p>Healthcare setting: Post graduate medical schools at 5 hospital sites (unclear if public/private funded)</p>	<p>Consumer partners: 6 patients and 5 carers who had experienced harm or error during healthcare either to themselves or their families</p> <p>Provider partners: 8 clinicians involved in medical education of foundation year trainees</p>	<p>Health service users: none</p> <p>Health service providers: 283 first year medical trainee doctors employed by 5 hospitals sites</p>	<p>Consumer partners: None available (N/A)</p> <p>Provider partners: N/A</p> <p>Health service users: none; not relevant (N/R)</p> <p>Health service providers: N/A</p>
<p>Persson 2013</p> <p>Cluster-RCT</p> <p>90 communes* (a geopolitical unit) were randomised to partnership and usual practice</p> <p>*with 6306 births and neonatal mortality rate of 24/1000 live births in 2005. Communes with a lower mortality rate were excluded from the trial.</p>	<p>Country: Vietnam</p> <p>Regional development: Middle-income country; village sites</p> <p>Healthcare setting: Communities served by Commune Health Centres with 3-6 staff members providing primary health care including reproductive and antenatal care to approximately 1000-18,000 people. Delivery care is offered by Commune Health Centres, or by hospitals at district, province and regional levels. Each Commune Health Centre has a Village Health Worker who provides basic healthcare in the villages.</p>	<p>Consumer partners: 11 members of the Women's Union recruited as lay women facilitators of Maternal and Newborn Health Groups (MNHG)</p> <p>Provider partners: Commune Health Centre staff (physician, midwife, nurse); a commune Village Health Worker, a population collaborator, the chairperson/vice chairperson of the commune; and two Women's Union representatives. Each of the 44 MNHGs had 8 members (352 partnership participants).</p>	<p>Health service users: 1243 mothers randomly sampled from 22,377 live births located within 90 communes during first 3 years of trial July 2008-June 2011</p> <p>Health service providers: none</p>	<p>Consumer partners:</p> <p><u>Age (mean):</u> 32 years</p> <p><u>Sex:</u> female only</p> <p><u>Education level:</u> eligible to participate if completed secondary school.</p> <p>Provider partners: N/A</p> <p>Health service users: details for a random sample of mothers (398/7033) with live births during first year of trial:</p> <p><u>Age (<20 years):</u> intervention 8.9%; control 9.2%</p> <p><u>Sex:</u> all female</p> <p><u>Education level (Lacks formal education):</u> intervention 15%, control 21%</p> <p><u>SES (Poor household):</u> intervention: 19%; control: 27%;</p> <p>Health service providers: N/R</p>
<p>Greco 2006</p> <p>Cluster-RCT</p> <p>28 health services randomised to multi-component intervention with partnership and the same inter-</p>	<p>Country: England</p> <p>Regional development: High-income country; predominately coastal and rural sites</p> <p>Healthcare setting: Healthcare Community Practices (unclear if private or publicly funded)</p>	<p>Consumer partners: 46 health service patients participated in Critical Friends Groups</p> <p>Provider partners: 57 health service staff members participated in Critical Friends Groups</p>	<p>Health service users: 7537 patients completed baseline questionnaire and 8967 patients completed 12 month follow-up</p> <p>Health service providers: 186</p>	<p>Consumer partners:</p> <p><u>Age:</u> 39.1% >65; 32.6% 40-65; 28.3% <40 years;</p> <p><u>Sex:</u> 65.2% female</p> <p>Provider partners:</p> <p><u>Sex:</u> 78.9% female</p> <p>Health service users:</p>

Table 2. Study demographics (Continued)

vention without partnership			providers participated (109 participated both at baseline and 12 month follow-up)	Age (mean SD): Intervention: 51.47 (18.49); Control: 50.69 (18.84)
				Sex (female): Intervention: 68.5%; Control: 68.3%
				SES - Jarman Material Deprivation Score (Mean range): - Intervention: 2.97 (-6.74 to 11.47); Control: 1.09 (-9.76 to 13.3)
				Health service providers: N/A
O'Connor 2019	Country: Sierra Leone	Consumer partners:	Health service users:	Consumer partners:
Cluster-RCT	Regional development:	49 Peer Supervisors of Community Health Workers (CHW) participated in Community Health Data Review (CHDR) meetings. Each community had 5-12 Peer Supervisors.	599 pregnant women or mothers of children under 5 years targeted by CHW (household respondents) at baseline and 792 household respondents at 21 months.	details for CHWs overall (not just Peer Supervisors)
10 communities* randomised to multi-component intervention with partnership and the same intervention without partnership	Healthcare setting: communities served by Peripheral Health Units (Government primary health care facilities); communities already part of the Concern Worldwide Child Survival Project (Al Pikin Fo Liv: All Children Should Live) participated in the Operation Research Study	Provider partners: Peripheral Health Unit staff; and Health Management Committee and Ward Development Committee members participated in CHDR meetings. (30-50 participants in each of the 10 CHDR meetings; includes Peer Supervisors)	none	Age (range): about two thirds 18-34; 21% 35-54 and 4% 55+ years Sex: 46% female Education: almost 60% completed some secondary school.
*with a maternal mortality rate of 136/10,000 live births and under-5 mortality rate 114/1000 live births				Provider partners: N/A Health service users: all female but no other details Health service providers: N/R
Wu 2019	Country: USA	Consumer partners:	Health service users:	Consumer partners:
Cluster-RCT	Degree of regional development:	community leaders from not-for-profit CBOs that served adults and addressed one or more social determinants of health	5255 high-risk outpatient patients (adults, at least one chronic condition, at least one visit to a Johns Hopkins site, high risk for future hospitalisation).	Provider partners: N/A
22 community based organisations (CBOs) randomised to multi-component intervention with partnership and the same intervention without partnership.	Healthcare setting: privately funded academic health care system comprising Johns Hopkins University School of Medicine; The Johns Hopkins Hospital; and Johns Hopkins Bayview Medical Centre	Provider partners: Johns Hopkins staff members as part of study team	Health service providers: Out-patient staff (case managers, community health workers, health educators and behavioural health specialists) and inpatient staff (social workers, case managers,	Health service users: Age (mean): intervention: 62 years; control: 62 years Sex (female): intervention: 65%; control: 63% Education level: N/A
				SES (Insurance type): intervention: Medicare 64%; Priority Partners MCO 36%; control: Medicare 65%, Priority Partners MCO 35%; Health service providers: N/A

Table 2. Study demographics (Continued)

hospitalists and nurse who help discharge patients to home)

Table 3. Description of interventions

Study ID	Partnership intervention aim	Partnership intervention; Comparator; and Co-interventions	Partnership format and location; Frequency and duration; Fidelity; and Tailored/modified	Decision-making activity; Redressing power imbalances; and Training/support
Jha 2015	<p>Partnership intervention aim: to assess if facilitating trainee doctors to reflect on safety from the patient's perspectives and their experience of patient safety influences their beliefs, attitudes and intention of future behaviour.</p>	<p>Partnership intervention: consumer and provider partners jointly co-designed and co-delivered patient safety curriculum.</p> <p>Comparator: usual practice, clinician-led teaching sessions of standard patient safety curriculum (included regulatory and procedural, ethical and legal issues and communication with patients and record keeping handovers).</p> <p>Co-interventions: common learning objectives derived from UK Foundation Program Curriculum adhered to throughout sessions and issues related to objectives discussed even if they did not naturally arise.</p>	<p>Partnership format and location: face-to-face, 2x1 hour sessions of co-developed patient safety curriculum presenting a patient narrative 15-18 minutes in duration, followed by facilitated discussion delivered onsite in groups of 7-10 trainee doctors.</p> <p>Frequency and duration: twice. time-limited to the preparatory Patient Learning Journey workshops and in developing the training session, no other details</p> <p>Fidelity: aimed to standardise intervention across sites by using same co-facilitators (patients and a trained independent chairperson) and by asking consumer partners to maintain consistent narratives.</p> <p>Tailored/modified: broad learning outcomes were standardized but key incidents shared in patient narratives varied.</p>	<p>Decision-making activity: partnership participants defined teaching session aims and objectives, decided on key narrative aspects, and facilitated discussion between patients and trainees.</p> <p>Redressing power imbalances: consumer partners provided with travel expenses and financial reimbursement for teaching and training attendance; and 2 consumer partners co-delivered each session with a third consumer partner attending to observe and serve as reserve in case one consumer partner unable to attend.</p> <p>Training/Support: consumer partners provided with 4 preparatory Patient Learning Journey workshops facilitated by consumer and carer members from Patient Voice Group at University of Leeds; also given support and opportunity to debrief with a consumer (from Patient Voice Group) after co-delivering training sessions.</p>
Persson 2013	<p>Partnership intervention aim: to assess whether lay-women facilitators</p>	<p>Partnership intervention: partnership facilitators empowered and supported the MNHG mem-</p>	<p>Partnership format and location: face-to-face meetings, each lasting on average 2 hr (110 mins); meeting lo-</p>	<p>Decision-making activity: In MNHG Plan-Do-Study-Act discussions centred on individual and common experiences in the local setting, the facilitator supported the group in crit-</p>

Table 3. Description of interventions (Continued)

<p>tion of Maternal and Newborn Health Groups (MNHGs) composed of stakeholders including health care staff, politicians and key persons in the communes can improve perinatal outcomes.</p>	<p>bers to identify local problems and actions in their communes about neonatal health, they collaborated to decide which problems to focus on and what actions to take directed towards pregnant women and their households, health services, or general public in order to address those problems.</p> <p>Comparator: usual practice: not described</p> <p>Co-interventions: none</p>	<p>cated at commune centres or health care centres.</p> <p>Frequency and duration: Monthly over a 3 year period (31 months)</p> <p>Fidelity: "Two research team members coordinated the facilitation process and acted as supervisors of the facilitators; i.e. field supervision and performing 2 day meetings with all facilitators once a month during the entire trial period. The intervention process was monitored continuously. Issues like MNHG's choice of improvement topics, activities for improving practice, the interaction between facilitators and group members, and progress of the facilitation process at all intervention sites were examined using several approaches, like interviews with facilitators and focus group discussions with MNHG members, analyses of facilitators diaries from MNHG meetings and the notes from the monthly meetings with the supervisors." (p 5, Eriksson 2016). See COI table for more details.</p> <p>Tailored/modified: Each MNHG was context-specific and continuously negotiated and interpreted among stakeholders.</p>	<p>ical reflection, problem identification, finding solutions and developing change strategies. The intervention strived to achieve local ownership and "bottom-up" approach in empowering healthcare staff to improve practice. When appropriate, the facilitators would highlight recommendations in the National Guidelines.</p> <p>Redressing power imbalances: MNHG facilitators were paid on a full-time basis for the 3 years of the intervention. Except for the Village Health Worker and the Women's Union employee (who were reimbursed travel expenses to and from the meetings), other members were neither paid nor received allowances - as implementation work was assumed to be part of their normal duties.</p> <p>Training/support: 10 day training program for the facilitators "included theoretical sessions, group discussion, role-plays, and field practice; covering topics such as group dynamics, quality improvement methods (e.g. brainstorming and the plan-do-study-act cycle); and evidence based perinatal care. A facilitation manual and a specific diary were developed to guide the work of the facilitators. Two research team members coordinated the facilitation process and acted as supervisors of the facilitators, i.e. field supervision and performing 2 day meetings with all facilitators once a month during the entire trial period." (p3-4, Persson 2013)</p>
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Greco 2006

Partnership intervention aim: to assess whether Critical Friends Groups (CFGs) enable practices to interpret the results of systematic patient feed-

Partnership intervention: CFG meeting members jointly interpreted systematic IPQ patient feedback, agreed on and progressed improvement strategies.

Partnership format and location: face-to-face at participating practices; meeting length not described

Frequency and duration: twice over a time-limited period of approximately 12 weeks

Decision-making activity: in first CFG meeting members identified areas for attention and improvement within the practice based on IPQ results; agreed on 3-5 improvement strategies for review at the next meeting, with meeting notes distributed to participants within a few days. In second CFG meeting members reviewed progress on improvement strategies identified earli-

Table 3. Description of interventions (Continued)

back (from the Improving Practice Questionnaire (IPQ)) and come up with an action plan that enables practices to make changes that are more patient focused.

Comparator: control sites received IPQ results but no assistance (or encouragement) from researchers in setting up a CFG. Practice managers contacted at 12 months to find out about any patient involvement initiatives that had taken place during the time between their first and second IPQ.

Co-interventions: Control and intervention sites were given IPQ pilot study results

Fidelity: Not assessed. No control groups discussed IPQ results with patients during the research period.

Tailored/modified: not described

er. Topics most frequently discussed at CFGs, after reviewing IPQ feedback, were: privacy at the reception desk (6/14 meetings) and waiting time to see doctor (12/14 meetings).

Attempts to readdress intrinsic power imbalances: not described

Training/Support: preliminary meetings facilitated by researchers held with patient-only groups and with practice staff only groups at intervention sites that requested this. During preliminary meetings a researcher provided background information about the project, purpose of future meetings and the IPQ results.

O'Connor 2019

Partnership intervention aim: "to 1) assess the extent to which the Participatory Community-based Health Information System facilitated local community structures to use data to plan and implement actions for improving maternal, neonatal and child health and 2) assess the extent to which this contributed to improved community-level maternal, neonatal and child health outcomes." (p 4, O'Connor 2019)

Partnership intervention: Community Health Data Review (CHDR) meeting members jointly undertook a review of data collected by Community Health Workers and used the data to plan and implement actions for improving maternal, neonatal and child health practices (actions could target health services directly as well as households or communities) in addition to the Concern Worldwide Child Survival Project activities

Comparator: usual practice in addition to Child Survival Project activities

Co-interventions: The Child Survival Project was implemented in all ten communities. In the broader Child Survival Project, 1325 volunteer CHWs were recruited and trained with the Ministry of Health and Sanitation 2012 National CHW Program training materials by Child Sur-

Partnership format and location: Face-to-face; no details on meeting length or location

Frequency and duration: every two months over a 20 month period

Fidelity: not described

Tailored/modified: not described

Decision-making activity: data for the preceding 4-6 months were reviewed in CHDR meetings. The Operation Research Study staff analysed CHW collected data with the Child Survival Project staff prior to the meeting and determined topics and data to present in CDHR meetings. "The Operation Research Study staff prepared simple data sheets to be used by participants, and participants used them to draw and interpret bar charts in front of the group. Records were kept of discussion topics." (p 5, O'Connor 2019); "Following the review of data, CHDR participants developed action points. Action points were documented during the meeting on flip chart paper which the HMC chairman kept after the meeting. Action points from previous meetings were reviewed in subsequent meetings and discussions held on the extent to which actions had been completed." (p6, O'Connor 2019)

Redressing power imbalances: not described

Training/support: Based on their performance during initial training, community leaders and Child Survival Project staff together selected 106 Peer Supervisors from the CHWs. Peer Supervisors received further training and were assigned 8-12 CHWs to supervise. At least one Health Management and Ward Development Committee members from same zone as Peer Supervisor provided oversight and assistance.

Table 3. Description of interventions *(Continued)*

vival Project staff and the Western Area District Health Management Teams. CHWs were assigned 25 households to visit monthly and disseminate health messages, check for danger signs of illness and collect vital event and morbidity data using Ministry of Health and Sanitation registers.

Wu 2019

Partnership intervention

aim: to "enhance the capacity of both Community Based Organisation (CBO) staff and frontline hospital workers to address client needs by strengthening the bidirectional flow of information about health and social services and building networks that span both entities." (p e32, Wu 2019)

Partnership intervention:

In the Baltimore CONNECT meetings, consumers and providers jointly undertook a needs assessment and co-developed an intervention (Healthify) to address clients' needs by enhancing the health service (JHHS) and social service (CBO) coordination.

Comparator: usual practice- no other description

Co-interventions: Johns Hopkins Community Health Partnership (J-CHiP) (not described)

Partnership format and location: face-to-face meetings, 1.5 to 2 hours in duration; location rotated among the intervention CBOs (plus email and phone calls).

Frequency and duration: monthly meetings over the 6 month co-development period and the 12 month trial period

Fidelity: Some contamination effects possible, as intervention and control CBOs may have shared some clients and provided services to the J-CHiP cohort of patients. Healthify also listed both intervention and control CBOs.

Tailored/modified: reverse innovation of the ACE framework by adapting the ACE approach to partner with intervention CBO leaders to co-develop and implement a set of interventions, or toolkit.

Decision-making activity: "To begin, iCBO leaders completed a needs assessment to identify commonly faced challenges. The most salient issues identified were: referring clients to organisations for support, developing a stronger relationship with other CBOs to better serve clients, and interfacing with JHHS. The results of the needs assessment were directly linked to formation of strategies to enhance coordination of health and social services." (p 302, Wu 2018)

Redressing power imbalances: not described

Training/support: no training described; each intervention site was assigned a student research assistant

Table 4. Comparison 1 data

Health service alterations data (changes to services resulting from partnership decisions)								
Study	Measure (Timing of assessment)	Intervention group			Control group			Notes
		Events (n)	Total (N)		Events (n)	Total (N)		
Pers-son 2013	Problems identified and actions taken to address these	-	-		-	-		Intervention group data only
Degree to which health service alterations reflect health service user (trial participant) priorities (demand responsiveness).								
No studies assessed these outcomes								
Health service user (trial participant) health service performance ratings (local accountability)								
No studies assessed these outcomes								
Health service user (trial participant) health service utilisation patterns								
No studies assessed these outcomes								
Health service provider (trial participant) reported outcomes								
Study	Measure (Timing of assessment)	Intervention group			Control group			Notes
		Mean	95% CI	N	Mean	95% CI	N	
Jha 2015	Overall attitudes in Attitudes to Patient Safety Questionnaire (26-items measuring self-reported opinion towards the causes, reporting and management of errors; overall range: 26-182; higher scores better) (3-6 weeks post-training)	134.16	131.01, 137.32	37	135.21	132.58, 137.84	53	Mean of 1.05 lower in intervention group (4.20 lower, to 2.11 higher)
Pers-son 2013	Healthcare staff knowledge on perinatal care, availability of equipment and drugs at health facilities	-	-	-	-	-	-	No data reported
Adverse events								

Table 4. Comparison 1 data (Continued)

No study reported data that related adverse events for those who received partnership compared to usual practice

Resource Use (Cost (time, money)) associated with decision-making process or with implementing new/changes in service

No studies reported outcomes such as resource use associated with decision-making process (e.g. cost of organising and running meetings, training (providers/consumers), remuneration, coordination, or meeting space) or resource use associated with implementing new or changed services

Consumer (partnership participant) reported behaviours/attitudes outcomes

Study	Measure (Timing of assessment)	Intervention group		Control group		Notes
		Events	Total	Events	Total	
Pers-son 2013	Consumer partner attendance at meetings	-	-	-	-	Intervention group data only

Provider (partnership participant) reported behaviours/attitudes outcomes

Study	Measure (Timing of assessment)	Intervention Group		Control group		Notes
		Events	Total	Events	Total	
Pers-son 2013	Provider partner attendance at meetings	-	-	-	-	Intervention group data only

Measures of partnership among provider and consumer partnership participants

No trial reported these outcomes

Table 5. Comparison 2 data

Health service alterations data (changes to services resulting from partnership decisions)

Study	Measure (Timing of assessment)	Intervention group		Control group		Notes
		Events	Total	Events	Total	

Table 5. Comparison 2 data (Continued)

O'Connor 2019	Number of mothers who have ever had a community health worker (CHW) visit (21 Months)	257	379	271	413	2.2% increase in intervention group; p=0.954
O'Connor 2019	Number of mothers who had a CHW home health visit in the last year in which the CHW performed all roles (21 months)	79	379	87	413	0.3% decrease in intervention group; p=1.000
Wu 2019	Community based organisation (CBO) staff report of receiving 1+ referral from healthcare staff (12 months)	13	38	12	32	3.3% decrease in intervention group; p=0.48 (observed events calculated from % data)

Degree to which health service alterations reflect health service user (trial participant) priorities (demand responsiveness).

No studies assessed these outcomes

Health service user (trial participant) health service performance ratings (local accountability)

Study	Measure (Timing of assessment)	Intervention group			Control group			Notes
		Events	Total		Events	Total		
O'Connor 2019	Number of mothers who had a CHW visit in the past year who found visit helpful or somewhat helpful (21 months)	257	379		296	413		3.9% decrease in intervention group; p=0.246

Study	Measure (Timing of assessment)	Intervention Group			Control group			Notes
		Mean	SD	N	Mean	SD	N	

Table 5. Comparison 2 data (Continued)

Greco 2006	Overall client satisfaction with general practice (scale: 0-5, higher scores better) (12 Months)	4.17	0.19	14 sites (5000 respondents)	4.23	0.19	12 sites (3967 respondents)	Mean of 0.06 lower in intervention group (no CIs reported)
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Health service user (trial participant) health service utilisation patterns

Study	Measure (Timing of assessment)	Intervention group		Control group		Notes
		Events	Total	Events	Total	
Wu 2019	Referred from the healthcare system to a CBO (client report) (12 months)	31	198	22	186	3.9% increase in intervention group; p=0.57 (observed events calculated from % data)

Health service provider (trial participant) reported outcomes

Study	Measure (Timing of assessment)	Intervention group		Control group		Notes
		Events	Total	Events	Total	
Wu 2019	Provider barriers to referring patients to CBOs, capacity for CBOs and healthcare organizations to work together, confidence in knowledge about community resources, confidence in the capacity of CBOs to meet their clients' needs, and number of referrals to CBOs (12 months)	-	-	-	-	Pre-post data for inpatient and outpatient staff separately (but not comparatively for intervention and control group)

Adverse events

Study	Measure (Timing of assessment)	Intervention group		Control group		Notes
		Events	Total	Events	Total	
Wu 2019	Harms (12 months)	-	-	-	-	No harms observed in either group

Resource Use (Cost (time, money)) associated with decision-making process or with implementing new/ changes in service

Table 5. Comparison 2 data (Continued)

No studies reported outcomes such as resources use associated with decision-making process (e.g. cost of organising and running meetings, training (providers and consumers), remuneration, coordination, or meeting space) or with implementing new or changes in services

Consumer (partnership participant) reported behaviours/attitudes outcomes

Study	Measure (Timing of assessment)	Intervention group		Control group		Notes
		Events	Total	Events	Total	
O'Connor 2019	Number of peer supervisors reporting/peer supervisors trained (21 months)	39	49	42	57	5.9% increase in intervention group
Wu 2019	CBO staff ratings of working together with health service moderately or extremely well (12 months)	22	38	14	32	14% increase in intervention group; p=0.24 (observed events calculated from % data)

Provider (partnership participant) reported behaviours/attitudes outcomes

Study	Measure (Timing of assessment)	Intervention group		Control group		Notes
		Events	Total	Events	Total	
O'Connor 2019	Health management committee (HMC) use of health information in planning (21 months)	40	75	38	75	2.7% increase in intervention group

Measures of partnership among provider and consumer partnership participants

Study	Measure (Timing of assessment)	Intervention group		Control group		Notes
		Events	Total	Events	Total	
O'Connor 2019	HMC reviewed and contributed to CHW activity plans (21 months)	31	75	35	75	5.3% decrease in intervention group
Wu 2019	iCBO partner satisfaction with the partnership self-assessment tool (12 months)	-	-	-	-	Intervention group data only

CBO: COmmunity Based Organisations; **CFG:** Critical Friends Group; **CHDR:** Community Health Data Review; **CHW:** Community Health Workers; **f2f:** face-to-face; **HMC:** Health Management Committee; **IPQ:** Improving Practice Questionnaire; **J-CHiP:** Johns Hopkins Community Health Partnership; **JHHS:** Johns Hopkins Health Service; **MNHG:** Maternal and Newborn Health Groups.

APPENDICES

Appendix 1. Glossary of key terms

Consumer partnership participant(s): refers to people who are fulfilling an advisory or representative role within the partnership. These roles might include a consumer or patient representative; consumer consultant; consumer with acute or chronic condition(s), their carer, or family member; community members, general public, or citizens; representatives, consultants, or members of consumer organisations.

Facilitated partnership: assistance is provided (e.g. by researchers, consumer advocates, or others) to help partnership participants to work in partnership (e.g. provide training or support before, or moderate or advocate during meetings).

Formal group format: refers to an organised group, such as a committee, council, board, or steering group.

Health services: defined as public or privately funded services that provide direct care to consumers in primary (e.g. community health centres, general practitioner practices, private practices, dispensaries), secondary (e.g. specialist outpatient clinics), or tertiary settings (e.g. hospitals). We will include home and residential services only when they primarily provide health or nursing care (e.g. home-based nursing services, nursing homes, residential rehabilitation services, or hospices).

Health service performance information: (as an added intervention): data are collected about the performance of health service beyond that experienced by partnership participants (i.e. could be information about a measure of service quality at baseline, or performance in relation to other services), and provided to partnership participants for consideration during decision-making. Alternatively, consumer and provider partnership participants independently generate health service performance indicator ratings before meeting as a group.

Health service user or provider (demand or supply side) information (as an added intervention): data are collected about the needs, preferences, experiences, or priorities of the people who use (demand side), or who provide (supply side) the health service, beyond those who are partnership participants (i.e. additional information is gathered systematically from health service users and providers as part of the trial), and provided to partnership participants for consideration during decision-making.

Intervention effects review: in a systematic review of intervention effects, the researchers aim to locate, assess the risk of bias, and synthesise all of the available evidence related to a specific research question about the effects of an intervention. In this case, the question is 'what are the effects of consumers and providers working in partnership to promote person-centred health services'?

Partnership at health service level (i.e. upstream, at a higher level than the point of care): consumer and health providers jointly plan, develop, and monitor health services at the national, state, or regional policy or organisational governance level.

Partnership at point of care: refers the clinical consultation (or encounter) level during which individual health practitioner(s) interact with individual patient(s) to jointly plan and manage their own health care, sometimes called the direct care level (can include more than one consumer and provider interacting in self-management groups). Partnerships at the point of care level are excluded from this review.

Provider partnership participant(s): refers to people who are fulfilling an advisory or representative role within the partnership. These roles might include, for example: a clinician (such as a doctor, nurse, allied health, or community health worker from any discipline), health service manager, supervisor, or administrator (including quality co-ordinators, chief executives, etc.), health policy maker, or consumer liaison officer. Health provider participants do not include people who are primarily health researchers or academics.

Qualitative evidence synthesis: in a systematic review of qualitative evidence, the researchers aim to locate, assess the methodological quality, and synthesise evidence related to a specific research question about the experience of a phenomenon. When combined with an intervention effects review, the qualitative evidence synthesis aims to help understand how the intervention works, for whom, and in what context, and how best to implement it (Flemming 2019). In this case, the question is 'what are the barriers, facilitators, and experiences of consumers and providers working in partnership to promote person-centred health services'?

Working in partnership (as an intervention): defined as a joint meeting of at least one consumer and health provider, which occurs more than once, in a formal group format, to make decisions together, with the aim of promoting person-centred care in one or more areas of a health service or services. The group is to meet face-to-face or virtually (i.e. meet in real-time, on an ongoing or time-limited basis).

Appendix 2. MEDLINE search strategy

1. exp Community Participation/
2. Stakeholder Participation/
3. Decision making/
4. exp Patient-Centered Care/
5. ((patient* or communit* or consumer* or user* or carer* or caregiver* or client* or famil* or lay*) adj3 (decid* or decision* or engag* or involv* or participat*)).ti,ab,kf.
6. or/1-5

7. "Health Priorities"/
8. exp Patient Care Team/
9. exp Ambulatory Care Facilities/
- 10.*"Mental Health Services"/
- 11.*"Community Health Services"/
- 12.*"Health Services Administration"/
- 13."Quality Improvement"/
- 14.*"Hospitals, Public"/
- 15."Quality of Health Care"/
- 16."Delivery of Health Care"/
- 17."Delivery of Health Care, Integrated"/
- 18.or/7-17
- 19."Community-Institutional Relations"/
- 20."Advisory Committees"/og
- 21.(partner* or participat* or consult* or decision* or deliberation* or co#design* or involv* or contribut* or role* or empower* or engag* or collab* or advoca* or organi#ation* or respons*).ti,ab,kf.
- 22.(experience based adj2 design).ti,ab,kf.
- 23.or/19-22
- 24.randomized controlled trial.pt.
- 25.controlled clinical trial.pt.
- 26.randomized.ab.
- 27.placebo.ab.
- 28.drug therapy.fs.
- 29.randomly.ab.
- 30.trial.ab.
- 31.groups.ab.
- 32.or/24-31
- 33.Non-Randomized Controlled Trials as Topic/
- 34.((cluster or quasi) adj3 trial*).tw.
- 35.or/33-34
- 36.exp animals/ not humans.sh.
- 37.32 not 36
- 38.35 not 36
- 39.limit 37 to (english language and yr="2000 -Current")
- 40.limit 38 to (english language and yr="2000 -Current")
- 41.and/6,18,23,39
- 42.and/6,18,23,40
- 43.or/41-42

Appendix 3. Cochrane Library search strategy

#1 MeSH descriptor: [Community Participation] explode all trees

#2 MeSH descriptor: [Stakeholder Engagement] this term only

#3 MeSH descriptor: [Decision Making] this term only

#4 MeSH descriptor: [Patient-Centered Care] explode all trees

#5 (((patient* or communit* or consumer* or user* or carer* or caregiver* or client* or famil* or lay*) NEAR (decid* or decision* or engag* or involv* or participat*)):ti,ab,kw (Word variations have been searched)

#6 {OR #1-#5}

#7 MeSH descriptor: [Health Priorities] this term only

#8 MeSH descriptor: [Patient Care Team] explode all trees

#9 MeSH descriptor: [Ambulatory Care Facilities] explode all trees

#10 MeSH descriptor: [Mental Health Services] this term only

#11 MeSH descriptor: [Community Health Services] this term only

#12 MeSH descriptor: [Health Services Administration] this term only

#13 MeSH descriptor: [Quality Improvement] this term only

#14 MeSH descriptor: [Hospitals, Public] this term only

#15 MeSH descriptor: [Quality of Health Care] this term only

#16 MeSH descriptor: [Delivery of Health Care] this term only

#17 MeSH descriptor: [Delivery of Health Care, Integrated] this term only

#18 {OR #7-#17}

#19 MeSH descriptor: [Community-Institutional Relations] this term only

#20 MeSH descriptor: [Advisory Committees] this term only and with qualifier(s): [organization & administration - OG]

#21 ((partner* or participat* or consult* or decision* or deliberation* or co#design* or involv* or contribut* or role* or empower* or engag* or collab* or advoca* or organi#ation* or respons*)):ti,ab,kw (Word variations have been searched)

#22 ((experience based NEAR design)):ti,ab,kw (Word variations have been searched)

#23 {OR #19-#22}

#24 #6 AND #18 AND #23

Appendix 4. CINAHL search strategy

S31	S20 AND S30
S30	S21 or S22 or S23 or S24 or S25 or S26 or S27 or S28 or S29
S29	TI (singl* or doubl* or tripl* or trebl*) and TI (blind* or mask*)
S28	AB (singl* or doubl* or tripl* or trebl*) and AB (blind* or mask*)
S27	AB (random* or trial or placebo*) or TI (random* or trial or placebo*)
S26	MH Quantitative Studies
S25	MH Placebos
S24	MH Random Assignment
S23	MH Clinical Trials+
S22	PT Clinical Trial
S21	"randomi?ed controlled trial" or PT randomized controlled trial
S20	S4 AND S8 AND S17
S19	S4 AND S8 AND S17

(Continued)

S18	S4 AND S8 AND S17
S17	S9 OR S10 OR S11 OR S12 OR S13 OR S14 OR S15 OR S16
S16	MH "Program Evaluation" OR (AB (health service*))
S15	MH "Program Implementation"
S14	MM "Quality Improvement"
S13	MH "Decision Making"
S12	MM "Community Mental Health Services"
S11	MM "Decision Making, Patient"
S10	MH "Community Health Services"
S9	MM "Health Care Delivery"
S8	S5 OR S6 OR S7
S7	TX (partner* or participat* or consult* or decision* or deliberation* or (co design*) or involv* or contribut* or role* or empower* or engag* or collab* or advoca* or organisation* or organization* or respons*)
S6	TX (experience based N2 design)
S5	(MH "Patient Centered Care")
S4	S1 OR S2 OR S3
S3	MH "Professional-Patient Relations"
S2	(MH "Consumer Participation") OR (TI (consumer N2 particip* OR client* N2 engage* OR stakeholder* N2 engage* OR communit* N2 particip* or patient* N2 particip* or client* N2 particip* or citizen* N2 particip* or consumer N2 involve* or patient* N2 involve* or client* N2 involve* or citizen* N2 involve*) or AB (consumer N2 particip* OR communit* N2 particip* or client* N2 engage* OR stakeholder* N2 engage* OR patient* N2 particip* or client* N2 particip* or citizen* N2 particip*)
S1	(MH "Patient Care Conferences") OR (MH "Consumer Attitudes") OR (stakeholder* N2 (participat* or engag* or involv* or satisf*)) OR (patient* N2 (participat* or engag* or involv* or satisf*))

Appendix 5. EMBASE search strategy

1. advisory committee/
2. ((patient* or communit* or consumer* or user* or carer* or caregiver* or client* or famil* or lay*) adj3 (partner* or consult* or decision* or deliberation* or contribut* or role* or empower* or collab* or advoca* or organi#ation* or respons*)).ti,ab,kw.
3. (co#design* or (experience based adj2 design)).ti,ab,kw.
4. (citizen\$ adj (council? or jury or juries or panel?)).ti,ab,kw.
5. (public adj (meeting? or forum?)).ti,ab,kw.
6. participatory intervention?.ti,ab,kw.

7. community participation/
8. stakeholder engagement/
9. patient participation/
10. Patient-Centered Care/
11. ((patient* or communit* or consumer* or user* or carer* or caregiver* or client* or famil* or lay*) adj3 (engag* or involv* or participat*)).ti,ab,kw.
12. or/7-11
13. health care planning/
14. exp patient care/
15. *outpatient department/
16. *mental health service/
17. exp *"community care"/
18. exp *"health service"/
19. total quality management/
20. *"public hospital"/
21. exp health care quality/
22. exp health care delivery/
23. integrated health care system/
24. or/13-23
25. public relations/
26. advisory committee/
27. ((patient* or communit* or consumer* or user* or carer* or caregiver* or client* or famil* or lay*) adj3 (partner* or consult* or decision* or deliberation* or contribut* or role* or empower* or collab* or advoca* or organi#ation* or respons* or author*)).ti,ab,kw.
28. (experience based adj2 design).ti,ab,kw.
29. (co-design or codesign).ti,ab,kw.
30. (citizen\$ adj (council? or jury or juries or panel?)).ti,ab,kw.
31. (public adj (meeting? or forum?)).ti,ab,kw.
32. participatory intervention?.ti,ab,kw.
33. governance.ti,ab,kw.
34. or/25-33
35. randomized controlled trial/
36. controlled clinical trial/
37. single blind procedure/ or double blind procedure/
38. crossover procedure/
39. random*.tw.
40. placebo*.tw.

41. ((singl* or doubl*) adj (blind* or mask*)).tw.
42. (crossover or cross over or factorial* or latin square).tw.
43. (assign* or allocat* or volunteer*).tw.
44. or/35-43
45. quasi experimental study/
46. ((cluster or quasi) adj3 trial*).tw.
47. or/45-46
48. nonhuman/
49. 44 not 48
50. 47 not 48
51. and/12,24,34,49
52. and/12,24,34,50
53. limit 51 to (english language and yr="2000 -Current")
54. limit 52 to (english language and yr="2000 -Current")
55. or/53-54

Appendix 6. PsycINFO search strategy

1. exp community involvement/
2. participation/ or client participation/ or involvement/
3. advocacy/
4. empowerment/
5. cooperation/ or collaboration/
6. or/1-5
7. stakeholder/
8. clients/
9. patients/
10. or/7-9
11. and/6,10
12. ((patient* or communit* or consumer* or user* or carer* or caregiver* or client* or famil* or lay*) adj3 (decid* or decision* or engag* or involv* or participat*)).ti,ab.
13. or/11-12
14. exp Health Care Services/ or exp Health Care Delivery/
15. exp community involvement/
16. (partner* or participat* or consult* or decision* or deliberation* or co#design* or involv* or contribut* or role* or empower* or engag* or collab* or advoca* or organi#ation* or respons*).ti,ab.
17. (experience based adj2 design).ti,ab.
18. or/15-17

19. and/13-14,18
20. limit 19 to (english language and yr="2000 -Current")
21. random*.ti,ab,hw,id.
22. intervention.ti,ab,hw,id.
23. trial.ti,ab,hw,id.
24. placebo*.ti,ab,hw,id.
25. groups.ab.
26. ((singl* or doubl* or trebl* or tripl*) and (blind* or mask*)).ti,ab,hw,id.
27. (cross over or crossover).ti,ab,hw,id.
28. latin square.ti,ab,hw,id.
29. (assign* or allocat* or volunteer*).ti,ab,hw,id.
30. (control or controlled).ti,ab,hw,id.
31. treatment effectiveness evaluation/
32. mental health program evaluation/
33. exp experimental design/
34. "2100".md.
35. or/21-34
36. animal.po.
37. 35 not 36
38. 20 and 37

Appendix 7. PROQUEST search strategy

PROQUEST Lowe_2021

noft(((health OR medical OR clinical) AND (service* OR hospital* OR care))) AND (noft((experience based design)) OR noft((partner* OR participat* OR consult* OR decision* OR deliberation* OR co#design* OR involv* OR contribut* OR role* OR empower* OR engag* OR collab* OR advoca* OR organi#ation* OR respons*))) AND noft(((patient* OR communit* OR consumer* OR user* OR carer* OR caregiver* OR client* OR famil* OR lay*) AND (decid* OR decision* OR engag* OR involv* OR participat*))) AND (noft(random*) OR noft(trial*))

Appendix 8. Clinical trials search strategy

CT GOV scanned from

citizen participation

citizen involvement

citizen engagement

Appendix 9. Web of Science search strategy

STUDY author	TITLE	WoS references
Bjorkman	POWER TO THE PEOPLE	215

(Continued)

Boivin	What Are the Key Ingredients for Effective Public Involvement	
Boivin	Target for improvement	8
Boivin	Involving patients in setting priorities for healthcare improvement: a cluster randomized trial	64
English	A Community Engagement Method to Design Patient Engagement Materials	4
Greco	Impact of patient involvement	1
Gullo	Creating spaces for dialogue	0
Gullo	Effects of a social accountability approach, CARE's Community Score Card	0
Hanson	Expanded Quality Management Using Information Power	2
Nyqvist	Experimental Evidence on the Long-Run Impact of Community-Based Monitoring	6
Ong	A Community-Partnered, Participatory, Cluster-Randomized	1
Palmer	The CORE study protocol: a stepped wedge cluster randomised controlled trial	15
Palmer	Balancing opposing forces - a nested process evaluation study protocol for a stepped wedge designed cluster randomized controlled	0
Waiswa	Community and District Empowerment for Scale-up	6

HISTORY

Protocol first published: Issue 7, 2019

CONTRIBUTIONS OF AUTHORS

DL: conceptual development of the protocol and review, screening titles, abstracts and full-text articles for inclusion and exclusions, extracting data for included trials and undertaking risk of bias and GRADE assessments, drafting of the protocol and review, organising and participating in the Stakeholder Panel workshop

RR: conceptual development of the review, providing consensus decisions on eligibility of articles, extracting data for included trials and undertaking risk of bias and GRADE assessments, drafting of the review, screening updated search output

LS: screening titles, abstracts and full-text articles for inclusion and exclusions, cross-checking data entered in RevMan with data extracted; providing feedback on drafts

BM: conceptual development of the protocol, screening titles, abstracts and full-text articles for inclusion and exclusions, providing feedback on drafts, organising and participating in Stakeholder Panel meetings and the workshop

LW: conceptual development of the protocol, providing consensus decisions on eligibility of articles, providing feedback on drafts, organising and participating in the Stakeholder Panel workshop, screening updated search output

LGW: conceptual development of the protocol, screening full-text articles for inclusion and exclusions, providing feedback on drafts

SH: conceptual development of the protocol and review, providing consensus decisions on eligibility of articles, drafting of the protocol and review, organising and participating in Stakeholder Panel meetings and the workshop

DECLARATIONS OF INTEREST

DL is the Technical Editor for the Cochrane Consumers and Communication Group.

RR is the Joint Co-ordinating Editor of the Cochrane Consumers and Communication Group.

LS: none known.

BM is the Joint Managing Editor of the Cochrane Consumers and Communication Group.

LW is the Joint Managing Editor of the Cochrane Consumers and Communication Group, and is a facilitator for the Australian Collaborative Pairs program, funded by the Consumers Health Forum of Australia. The Collaborative Pairs program aims to bring health service providers together with consumers to develop and strengthen their capacity to work together to transform the health system; participated in a podcast interview about the importance of consumer advocacy and involving consumers in the planning of health services; worked as a physiotherapist at Monash University.

LGW: none known.

SH is the Joint Co-ordinating Editor of the Cochrane Consumers and Communication Group.

The work of the Cochrane Group is situated within the Centre for Health Communication and Participation, La Trobe University, and is supported, in part, by grants from Safer Care Victoria and the National Health and Medical Research Council Australia. SH, BM, DL, and LW were not involved in the editorial processes for this review. RR was the contact editor for the protocol but was not involved in editorial processes after protocol publication.

SOURCES OF SUPPORT

Internal sources

- La Trobe University, Australia

BM receives funding from La Trobe University to undertake this review.

External sources

- Safer Care Victoria and the National Health and Medical Research Centre, Australia

The work of the Cochrane Group is situated within the Centre for Health Communication and Participation, La Trobe University, and is supported, in part, by grants from Safer Care Victoria and the National Health and Medical Research Council.

DIFFERENCES BETWEEN PROTOCOL AND REVIEW

We modified the review title from 'The effects of consumers and health providers working in partnership as an intervention for the promotion of person-centred health services' based on peer referee feedback.

We added Networked Digital Library of Theses and Dissertations (during search update) and Web of Science (during original search) (both not identified in the protocol) to the search strategy so as to minimise potential for missed studies.

We used the RCT Classifier to sort the database search output into records likely to be RCTs and records unlikely to be RCTs. The title and abstract records that were identified as unlikely to be RCTs were screened by one review author in Covidence. Those identified as potentially relevant were then obtained in full-text and screened by two review authors, with a process of resolving disagreements by consensus with a third review author. In addition to the records that were classified as unlikely to be RCT, only one author screened the Clinical Trials registries search outputs and conducted grey literature searching, snowballing and screening of review and included studies citations. Again all records identified as potentially relevant were screened in full-text by two review authors with a process of achieving consensus by consulting a third review author. The remainder of the search output (those records identified as likely to be RCTs by the RCT Classifier and the Cochrane Library search outputs) were screened by two authors at title and abstract stage, however instead of retrieving in full text any papers identified as potentially relevant by at least one review author, records identified by two review authors as potentially relevant were obtained in full-text; again where there was disagreement amongst review authors, a third review author independently provided a consensus decision. These screening decisions were made independently in Covidence. All references that were retrieved in full-text were screened by two review authors, with a third review author providing a consensus decision.

Instead of two review authors independently extracting data and undertaking Risk of Bias assessments, one review author extracted all data and conducted all Risk of Bias assessments, the second review author independently cross-checked all extracted data and assessments against the publications, consensus was reached by resolving any disagreements through discussion.

We could not conduct meta-analyses, sensitivity analyses, subgroup analyses or investigate heterogeneity as planned due to an insufficient number of studies identified within each comparison and each outcome, instead results are synthesised descriptively by comparison and outcome, with data from the longest-term time point. We planned the following sensitivity analyses to explore the impact of assumptions, imputed data, and the inclusion of studies at high risk of bias by:

- comparing the results of studies at higher and lower risk of bias (remove from the analysis studies with a high or unclear rating on the sequence generation item of the 'Risk of bias' tool and see how robust the results are when based only on studies with low risk of bias);
- comparing the results based on imputed data, e.g. when ICC values have been taken from external sources for cluster-RCTs.

We planned subgroup analyses to examine trials that explicitly attempt to address intrinsic power imbalances in preparation for partnerships (e.g. provision of salary or financial reimbursement, orientation, training, coaching, or support (e.g. via an advocate, facilitator, moderator, mentor, or consumer liaison officer) versus trials that did not); the ratio of consumers to providers (consumer majority versus provider majority); and the partnership duration (e.g. ongoing versus time-limited), but there were too few trials to do so.

As there were too few studies measuring similar outcomes to undertake statistical analyses, where a study did report multiple outcome measures for the same outcome, we extracted all, and review authors met to discuss and identify the outcome measure most relevant to person-centred health care. Additionally, we did not use GRADEpro software to present the results of the meta-analysis as the findings were limited to descriptive synthesis for each major comparisons of the review.

NOTES

This review is based on standard text and guidance provided by Cochrane Consumers and Communication ([Ryan 2016](#)).

INDEX TERMS

Medical Subject Headings (MeSH)

*Delivery of Health Care; Family; *Health Services; Infant Mortality; Patient Safety

MeSH check words

Humans; Infant, Newborn