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Consumers' and health providers' views and perceptions of partnering to improve health services design, delivery and evaluation: a co-produced qualitative evidence synthesis (Review)

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[Qualitative Review]

Consumers' and health providers' views and perceptions of partnering to improve health services design, delivery and evaluation: a co-produced qualitative evidence synthesis

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ABSTRACT

Background

Partnering with consumers in the planning, delivery and evaluation of health services is an essential component of person-centred care. There are many ways to partner with consumers to improve health services, including formal group partnerships (such as committees, boards or steering groups). However, consumers' and health providers' views and experiences of formal group partnerships remain unclear.

In this qualitative evidence synthesis (QES), we focus specifically on formal group partnerships where health providers and consumers share decision-making about planning, delivering and/or evaluating health services. Formal group partnerships were selected because they are widely used throughout the world to improve person-centred care.

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For the purposes of this QES, the term 'consumer' refers to a person who is a patient, carer or community member who brings their perspective to health service partnerships. 'Health provider' refers to a person with a health policy, management, administrative or clinical role who participates in formal partnerships in an advisory or representative capacity.

This QES was co-produced with a Stakeholder Panel of consumers and health providers. The QES was undertaken concurrently with a Cochrane intervention review entitled *Effects of consumers and health providers working in partnership on health services planning, delivery and evaluation.*

Objectives

1. To synthesise the views and experiences of consumers and health providers of formal partnership approaches that aimed to improve planning, delivery or evaluation of health services.

2. To identify best practice principles for formal partnership approaches in health services by understanding consumers' and health providers' views and experiences.

Search methods

We searched MEDLINE, Embase, PsycINFO and CINAHL for studies published between January 2000 and October 2018. We also searched grey literature sources including websites of relevant research and policy organisations involved in promoting person-centred care.

Selection criteria

We included qualitative studies that explored consumers' and health providers' perceptions and experiences of partnering in formal group formats to improve the planning, delivery or evaluation of health services.

Data collection and analysis

Following completion of abstract and full-text screening, we used purposive sampling to select a sample of eligible studies that covered a range of pre-defined criteria, including rich data, range of countries and country income level, settings, participants, and types of partnership activities. A Framework Synthesis approach was used to synthesise the findings of the sample. We appraised the quality of each study using the CASP (Critical Appraisal Skill Program) tool. We assessed our confidence in the findings using the GRADE-CERQual (Confidence in the Evidence from Reviews of Qualitative research) approach.

The Stakeholder Panel was involved in each stage of the review from development of the protocol to development of the best practice principles.

Main results

We found 182 studies that were eligible for inclusion. From this group, we selected 33 studies to include in the final synthesis. These studies came from a wide range of countries including 28 from high-income countries and five from low- or middle-income countries (LMICs).

Each of the studies included the experiences and views of consumers and/or health providers of partnering in formal group formats. The results were divided into the following categories.

Contextual factors influencing partnerships: government policy, policy implementation processes and funding, as well as the organisational context of the health service, could facilitate or impede partnering (moderate level of confidence).

Consumer recruitment: consumer recruitment occurred in different ways and consumers managed the recruitment process in a minority of studies only (high level of confidence). Recruiting a range of consumers who were reflective of the clinic's demographic population was considered desirable, particularly by health providers (high level of confidence). Some health providers perceived that individual consumers' experiences were not generalisable to the broader population whereas consumers perceived it could be problematic to aim to represent a broad range of community views (high level of confidence).

Partnership dynamics and processes: positive interpersonal dynamics between health providers and consumers facilitated partnerships (high level of confidence). However, formal meeting formats and lack of clarity about the consumer role could constrain consumers' involvement (high level of confidence). Health providers' professional status, technical knowledge and use of jargon were intimidating for some consumers (high level of confidence) and consumers could feel their experiential knowledge was not valued (moderate level of confidence). Consumers could also become frustrated when health providers dominated the meeting agenda (moderate level of confidence) and when they experienced token involvement, such as a lack of decision-making power (high level of confidence)

Perceived impacts on partnership participants: partnering could affect health provider and consumer participants in both positive and negative ways (high level of confidence).

Perceived impacts on health service planning, delivery and evaluation: partnering was perceived to improve the person-centredness of health service culture (high level of confidence), improve the built environment of the health service (high level of confidence), improve health service design and delivery e.g. facilitate 'out of hours' services or treatment closer to home (high level of confidence), enhance

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community ownership of health services, particularly in LMICs (moderate level of confidence), and improve consumer involvement in strategic decision-making, under certain conditions (moderate level of confidence). There was limited evidence suggesting partnering may improve health service evaluation (very low level of confidence).

Best practice principles for formal partnering to promote person-centred care were developed from these findings. The principles were developed collaboratively with the Stakeholder Panel and included leadership and health service culture; diversity; equity; mutual respect; shared vision and regular communication; shared agendas and decision-making; influence and sustainability.

Authors' conclusions

Successful formal group partnerships with consumers require health providers to continually reflect and address power imbalances that may constrain consumers' participation. Such imbalances may be particularly acute in recruitment procedures, meeting structure and content and decision-making processes. Formal group partnerships were perceived to improve the physical environment of health services, the person-centredness of health service culture and health service design and delivery. Implementing the best practice principles may help to address power imbalances, strengthen formal partnering, improve the experiences of consumers and health providers and positively affect partnership outcomes.

PLAIN LANGUAGE SUMMARY

What are consumers and health providers' views and experiences of working in formal partnerships to plan, deliver and evaluate health services?

Key messages

-Power imbalances between health providers and consumers can limit consumer participation in health service planning, delivery and evaluation.

-Power imbalances in the partnership may happen because of the ways consumers are recruited, how meetings are run, and how decisions are made.

-To have successful partnerships with consumers, health providers need to address these power imbalances.

-Some consumers and health providers believed that partnerships improved the culture and environment of the health service, as well as how health services were planned and developed.

Why is it important that consumers and health providers work together to plan, deliver and evaluate health services?

In the past, health providers decided how health services were planned, delivered and evaluated. More recently there has been a focus on designing services to better meet the needs, preferences and values of consumers. This has led to consumers partnering with health providers to design, deliver and evaluate health services. Often partnerships between consumers and health providers happen in formal group formats, such as committees, hospital boards or working groups.

What did we want to find out?

We wanted to explore the views and experiences of consumers and health providers working in partnership to plan, deliver and evaluate health services. We also wanted to identify best practice principles for partnering in formal group formats.

What did we do?

We conducted a qualitative evidence synthesis (QES) to understand the views and experiences of health providers and consumers working in partnership. A QES brings together and analyses the results from individual qualitative studies. Qualitative studies use data that are collected through interviews, focus groups, questionnaires and observations.

The QES was conducted with a Stakeholder Panel of consumers and health providers. The Panel worked with the research team to decide which questions to answer, what studies should be included, whether the analysis was comprehensive and to develop the best practice principles.

We searched databases for qualitative studies that explored consumers' and health providers' views and experiences of partnering in formal group formats. We searched for studies published from January 2000 to October 2018. We also searched websites of organisations involved in person-centred care, and asked experts to share relevant studies.

From these searches we selected 33 studies for in-depth analysis. The studies were from different countries and settings (e.g. hospital or community clinics) and involved different people (including under-represented patients) and different types of formal group partnerships (e.g. committees or steering groups).

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We combined the results of the studies and looked for common themes. These themes became our findings. We rated our confidence in each of the findings based on the relevance, quality and quantity of the data. We grouped the findings into categories.

What did we find?

Our analysis identified 19 findings, which we grouped into the following five categories.

Contextual factors influencing partnerships: government policy, processes, funding, and the organisational context of the health service influenced partnering.

Consumer recruitment:consumer recruitment occurred in various ways. In a few studies consumers managed the recruitment process. Some people (particularly health providers) felt consumers should reflect the range of people who used the health service. Some health providers thought that the experience of some consumers did not reflect the broader population. Consumers sometimes found it difficult to represent a broad range of community views.

Partnership dynamics and processes:positive relationships between health providers and consumers improved partnerships. Formal meetings and being unclear about the consumer role could limit consumers' involvement. Health providers' professional status, technical knowledge, and use of jargon could be intimidating for consumers. Consumers sometimes felt their knowledge was not valued. Consumers could become frustrated when they lacked decision-making power, and when health providers dominated the meeting agenda.

Perceived impacts on partnership participants:formal partnerships could affect health providers and consumers in both positive and negative ways.

Perceived impacts on health service planning, delivery and evaluation:people perceivedformal partnerships may improve health service culture and the physical environment of the health service. They also felt partnerships may improve health service design and delivery.

How can these findings be put into practice?

Best practice principles for partnering in formal group formats were developed from the findings. Principles included leadership and health service culture; diversity; equity; mutual respect; shared vision and regular communication; shared agendas and decision-making; influence and sustainability.

What are the limitations of the evidence?

Most of the findings in this review are rated as "high" or "moderate" confidence, which means the evidence for the findings is strong. However, one finding that showed people perceived formal partnerships improved health service evaluation, was rated as "very low" confidence because it was based on weaker evidence.

How up to date is this evidence?

This evidence is up to date to October 2018. The review took longer than usual to complete because co-produced research takes time, and the review was completed during the COVID-19 pandemic. Because most of the findings are rated "high" or "moderate" confidence, we believe an updated search may not substantially change the results.

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BACKGROUND

Introduction

This qualitative evidence synthesis (a summary and synthesis of qualitative research, or QES) focuses on how consumers and health providers work in partnership to improve the planning, delivery, and evaluation of health services. In this review, the term 'consumer' refers to a person who is a patient, carer or community member who brings their perspective to health service partnerships. The term also includes consultants who are employed by the health service to represent the patient or carer perspective. The term 'health provider' refers to a person who provides a health policy, management, administrative or clinical perspective.

For the purposes of this review, partnership approaches included formal meeting formats involving both consumers and health providers (such as committees, councils, boards, health facility committees, and steering groups). These partnerships are related to a specific part of a health service (e.g. redesigning a mental health unit), the whole health service (e.g. decision-making on a hospital quality and safety committee), or a policy or programme of care affecting multiple health services (e.g. co-design of a region's maternal and child health services policy).

This QES is linked to a Cochrane intervention review (a summary and synthesis of trials) titled *Effects of consumers and health providers working in partnership on health services planning, delivery and evaluation* (Lowe 2021). The intervention review included five trials and concluded that there was not enough evidence to determine if formal partnerships had any effects on a wide range of outcomes for consumers, providers or health services, compared to usual practice, or compared with other non-partnership approaches. This QES and the published intervention review were conducted concurrently and the QES findings supplement the findings of the latter. Specifically, in this QES, we sought to understand consumers' and health providers' views and experiences of formal partnership approaches, including how they worked across a range of settings and the barriers and facilitators to optimal partnerships. By examining the features that may facilitate or impede the effectiveness of formal group partnerships, this QES helps to better understand why the different partnerships examined by randomised trials analysed by the intervention review did not work.

Person-centred health services and formal partnership approaches

The global move towards person-centred care in health services is a major, and relatively recent, phenomenon. Historically, medical dominance, in which health providers made decisions on behalf of, and without necessarily involving, patients dominated the planning and delivery of health care (Bleakley 2014; Coulter 1999; Richards 2013). Although there is no universally agreed definition, the Institute for Patient- and Family-Centered Care defines *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). This definition, like many others, emphasises that partnerships with consumers underpin person-centred care.

Partnering with consumers across all levels of a health service is a key facilitator in the delivery of person-centred care. A report from the Australian Commission on Safety and Quality in Health Care identified partnering with consumers as one of seven attributes of high performing person-centred healthcare organisations (ACSQHC 2018). Similarly, a qualitative study by Luxford 2011, which explored the facilitators and barriers to person-centred care in healthcare institutions in the United States, found that a key facilitator to achieving person-centred care was the involvement of consumers throughout a health service. In this QES, we focused on the involvement of consumers in partnerships relating to the planning, delivery and evaluation of healthcare services, rather than their involvement in their own individual health care.

Description of the phenomenon of interest

We explored how consumers and health providers worked in formal group partnerships (such as committees, councils, boards or steering groups) to improve the planning, delivery and evaluation of health services). Examples of consumer/health provider partnerships we aimed to include were health policy committees, hospital advisory boards, experience-based co-design working groups on a ward or partnerships to co-produce health information or evaluate aspects of a health service. Formal group partnerships are part of a range of methods used by health services to involve consumers in collective decision-making. Other methods, which are beyond the scope of this review, include collecting individual patient feedback about services, creating a stand-alone committee of consumers to provide advice on different topics, conducting one-off focus groups or consultations with consumers and engaging with consumers via social media (ACSQHC 2021; Walsh 2021; WHO 2016).

How the QES was co-produced

This QES was co-produced by researchers working with a group of Australian stakeholders in health (herein called the Stakeholder Panel) using new Cochrane co-production methods (Merner 2021; Merner 2019New Reference; Pollock 2015; Pollock 2017). The Stakeholder Panel consisted of 18 people who had a wide range of expertise: six were consumer representatives with experience in service improvement, research or policy; six were health providers with expertise in clinical governance; and six were involved in researching, developing or implementing healthcare quality and safety policy and standards. The Stakeholder Panel has been involved since the beginning of the review. Recruitment of panel members, involvement in topic selection, development and publication of the protocol are described elsewhere (Merner 2018; Merner 2019New Reference).

Following publication of the protocol, on 23 November 2018, we convened a one-day, face-to-face meeting of the Stakeholder Panel in Melbourne to contribute to study selection for the review. We began the meeting with an explanation of full-text screening methods, and how they fit within the overall QES process. We then formed small groups (comprising researchers plus stakeholders) and applied the inclusion criteria to 20 full-text qualitative research articles. Decisions about inclusion for each article were made via consensus. Following the meeting, four stakeholders (CW, NR, AM, RC) contributed to full-text screening of further articles (which were dual-screened by a member of the research team (BM, DL, LW, LS)). Further detail of the full-text screening workshop is provided elsewhere (Merner 2019a; Merner 2019b).

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On 7 December 2021, after the preliminary data analysis had occurred and the findings were drafted, we held a Zoom Stakeholder Panel meeting to discuss the findings of the review and to further develop and refine the best practice principles. Stakeholder Panel members who had been involved in the review process were invited to be co-authors and provided feedback on drafts as well as final approval to publish.

Why it was important to conduct this QES

Cochrane's evidence base explicitly regarding approaches to improve person-centred care, including improving person-centred healthcare services, is limited. We sought to add to the evidence by exploring how consumers and health providers working together in formal group partnerships improved person-centred healthcare by contributing to planning, delivering and evaluating health services. Governments and health authorities are increasingly encouraging or requiring health services to demonstrate how they have included consumers in decision-making about the health service (see for example ACSQHC 2021a; AHRQ 2017; Health Canada 2019; Monitor 2014) This is a burgeoning area in healthcare policy, and health services are seeking guidance informed by evidence, as the input from the Stakeholder Panel demonstrated.

The findings of the QES contribute to understanding the findings of Lowe 2021 which investigated the effectiveness of partnerships between consumers and health providers. The results of the QES were integrated with the studies in Lowe 2021 using a matrix approach to describe the barriers and facilitators of partnership-working within each of the trials.

Additionally, as the review has been co-produced with a Stakeholder Panel, it provides a valuable resource for other systematic review authors (both within and outside Cochrane) who are seeking to include consumers, health providers and policymakers in reviews.

OBJECTIVES

Overall aims

- To synthesise the views and experiences of consumers and health providers of formal partnership approaches that aimed to improve planning, delivery or evaluation of health services.
- To identify best practice principles for formal partnership approaches in health services by understanding consumers' and health providers' views and experiences.

Objectives

- To analyse the ways consumers and health providers worked in formal group partnerships (including recruitment processes, how agendas were structured and meetings were led).
- To understand consumers' and health providers' views and experiences of working in formal partnership formats.
- To investigate the barriers and facilitators to formal partnering and how these promoted or impeded person-centred planning, delivery or evaluation of health services.

METHODS

Criteria for considering studies for this review

Types of phenomena of interest

We included qualitative studies that focused on working in formal group partnerships to improve planning, delivery or evaluation of health services. Partnering is defined as "healthcare organisations, healthcare providers and policymakers actively working with people who use the healthcare system to ensure that health information and services meet people's needs" (ACSQHC 2018). For the purposes of this review, formal group partnerships were operationalised as consumers and health providers meeting jointly and regularly in formal group formats (e.g. committees, councils, working groups) to share decision-making for the purpose of planning, delivery or evaluation in one or more health service(s).

Studies meeting the following criteria were eligible for inclusion.

- Consumers and health providers were engaged in formal group formats, such as committees, councils, boards or steering groups.
- The group involved at least one consumer and at least one health provider.
- The group met jointly, more than once via face-to-face or electronic modes.
- The group was either ongoing or time-limited (for example, groups formed for a specific project).
- The group made joint decisions for planning and/or delivery and/or evaluation of health services.

We excluded studies that involved partnering with consumers for decision-making about an individual's care or treatment, and studies focused on 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 governance). We included studies which involved partnering with consumers for health provider education, but only when these partnerships included formal group formats (e.g. a training committee or delivering joint training).

Types of studies

This review included primary, empirical qualitative studies that included a description of the sampling strategy, data collection procedures and the type of data analysis undertaken (Hannes 2011). We also included the qualitative component of mixed methods studies. We excluded opinion pieces, vignettes and editorials.

Types of settings

The setting for outcomes of the partnering approaches was health services. For the purposes of this review, *health services* were defined as healthcare organisations that provided direct care to patients in primary settings (e.g. community health centre, general practitioner practice), secondary settings (e.g. specialist outpatient clinics), or tertiary settings (e.g. hospitals). We also included home and residential services but only when the primary focus was on providing health or nursing care (e.g. home-based nursing services, nursing homes, residential rehabilitation services or hospices). Studies from rural and urban settings were eligible for inclusion,

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as well as those from high-income and low- and middle-income countries.

Types of participants

For the purposes of the QES, the terms 'consumer' and 'health provider' were defined as follows.

- 'Consumer' referred to a person who was a patient, carer or community member who brought their perspective to health service partnerships. The term also included consultants who were employed by the health service to represent the patient or carer perspective.
- 'Health provider' referred to a person who had a health policy, management, administrative, or clinical role and who participated in formal partnerships in an advisory or representative capacity. A health provider did not include a person whose primary role was a health researcher.

We excluded health provider participants who assumed the role of consumers in a partnership, as their primary role was to represent providers rather than consumers.

We analysed data from consumer and health provider participants separately, when possible. We included the findings of studies when the views of consumers or health providers were combined, as long as the findings addressed the objectives of this review. We also included data where consumer or health provider views were combined with other types of participants (e.g. community development officers). However, when analysed separately, we did not include the views of other types of participants.

Search methods for identification of studies

Electronic searches

We searched the following databases on 3 October 2018:

- MEDLINE (OvidSP) (1946 to 2 October 2018).
- Embase (OvidSP) (1947 to 2 October 2018).
- PsycINFO (OvidSP) (1806 to 2 October 2018).
- CINAHL (EBSCO) (1937 to 2 October 2018).

Consistent with a qualitative paradigm, a purposive sampling approach was used to develop the search strategy, rather than an exhaustive and comprehensive approach (Noyes 2022). Informal scoping searches of our topic in MEDLINE showed a proliferation of studies about partnering with consumers published after 2000. Our search results were therefore limited by publication date and we considered studies published from January 2000. We also restricted the search to English language studies only due to the challenges associated with translating qualitative research articles, and a lack of translating expertise within the author team (i.e. no two members of the research team spoke the same language other than English). This decision was informed by the language restrictions used in a previous Cochrane QES (see Ames 2017). There were no geographic restrictions.

We present the search strategies in Appendix 1 to Appendix 2. The strategies were developed by the Information Specialist for Cochrane Consumers and Communication and were informed by searching guidelines from the Cochrane Qualitative and Implementation Methods Group (Harris 2018). After a review of preliminary search results, we applied the McMaster University Health Information Research Unit qualitative filter (Wong 2004) to increase specificity (consistent with our purposive sampling approach). On testing, this filter has been shown to have 61% sensitivity, 99% specificity, 37% precision and 99% accuracy.

Searching other databases

We searched the ProQuest Theses and Dissertations database. In March 2019, using keywords, we also searched the websites of key national and international organisations involved in promoting person-centred care, including The King's Fund (https://www.kingsfund.org.uk/), The Health Foundation (https://www.health.org.uk), National Institute for Health and Care Excellence (https://www.nice.org.uk), Planetree (https://www.planetree.org), Picker Institute Europe (https://www.picker.org), Institute for Health Improvement (www.ihi.org), World Health Organization (https://www.who.int), Australian Commission on Safety and Quality in Health Care (https://www.safetyandquality.gov.au/), and the Agency for Healthcare Research and Quality (https://www.ahrq.gov).

We also searched reference lists of sampled studies and relevant systematic reviews. This resulted in the identification of a further 127 studies that were not in the databases above.

Additionally, we searched the included studies in the linked intervention review by Lowe 2021 for eligible qualitative trial sibling studies.

Data collection and analysis

Selection of studies

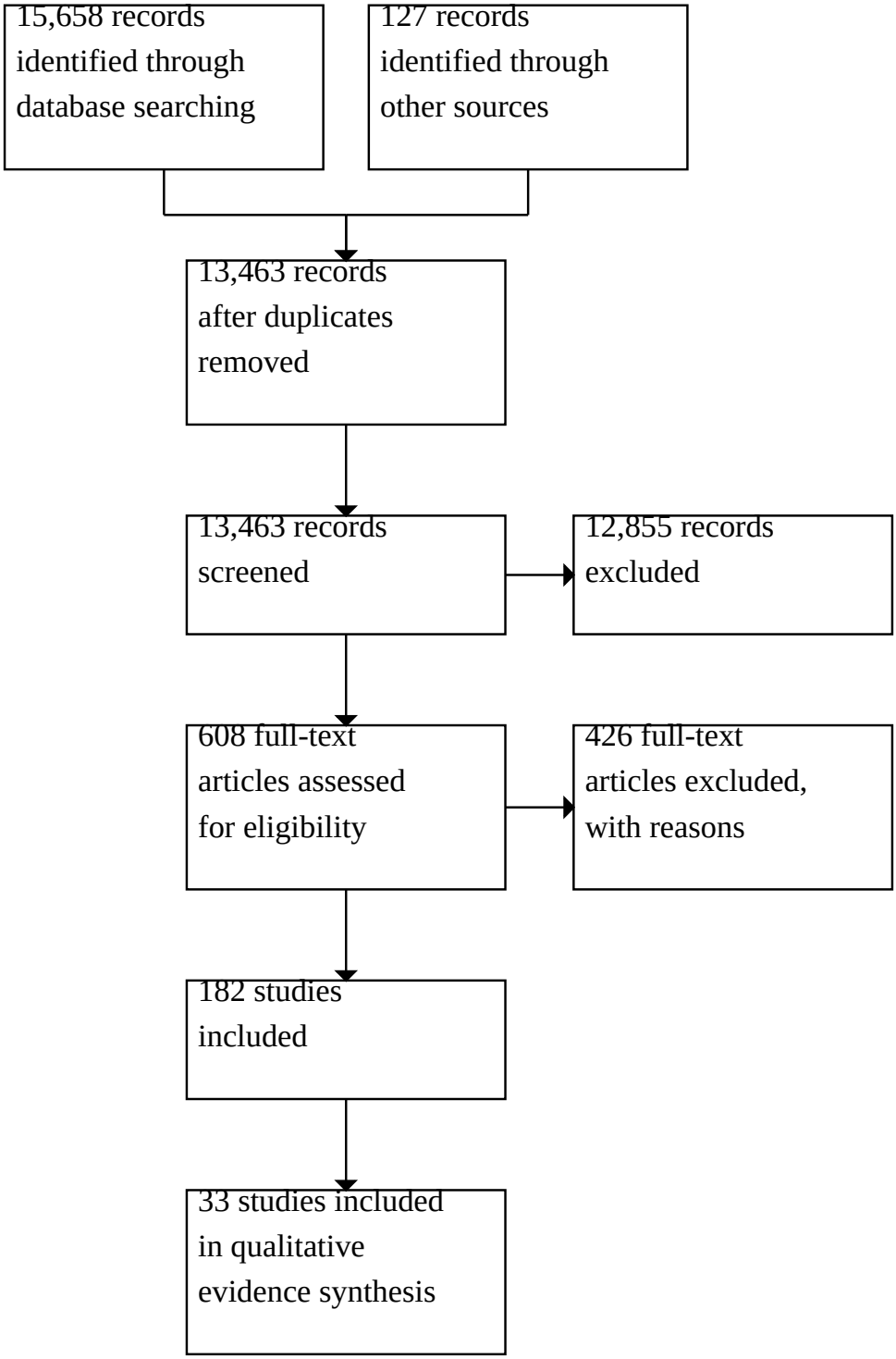
Data extraction and management

All titles and abstracts were screened independently by at least two review authors (BM, LS, DL, LW, LGW, CC, CG). Using Covidence software, each author classified each title and abstract as either irrelevant ('no'), relevant (yes') or potentially relevant ('maybe'). Studies were classified as 'irrelevant' if two review authors graded as 'no'. Where there was a combination of yes/no or maybe/no, then the conflict was resolved either through discussion or consulting a third review author. Studies that were graded yes/yes or maybe/yes or maybe/maybe progressed to full-text review.

Each full-text article was screened for inclusion or exclusion by at least two people independently. This included screening by Stakeholder Panel members (CW, NR, DM, FM, RC, MG, AM, PB, SB) and at least one member of the research team (BM, LS, DL, LW, CC, SH). Discrepancies were resolved by discussion or by consulting a third review author. We listed all potentially relevant papers excluded from the review at this stage as excluded studies, with reasons provided in the 'Characteristics of excluded studies' table. We reported the screening and selection process in an adapted PRISMA flow chart shown in Figure 1 (Liberati 2009). We identified 182 studies that met our inclusion criteria.

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Figure 1. PRISMA flow diagram



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Sampling of included studies

Given the high number of included studies and large volume of data, synthesising all of the studies would have threatened the quality of the synthesis (Cochrane EPOC 2017). Therefore, we used purposive sampling to reduce the number of included studies to a manageable amount. Our sampling frame involved these three steps.

1. All eligible studies were initially rated by one review author (BM, LS or SH) using the 5-point data richness scale developed by Ames 2019. The scale ranks data richness from 1 (very little qualitative data related to the synthesis objective) to 5 (a large amount and depth of qualitative data that relate in depth to the synthesis objective). A second review author (BM, SH or LS) checked the ratings and disagreements were resolved by consensus or consulting a third review author. Any studies rated 4 of 5 by at least one author progressed to the next step.

2. One review author (SH) sampled to achieve balance across the following criteria.

- Country and income region (e.g. low- and middle-income countries, high-income countries)
- Jurisdictional and geographical setting (e.g. provincial or state, rural or metropolitan)
- Service type (e.g. tertiary or primary health service)
- Service provision purpose (e.g. cancer, mental health, emergency department, all areas)
- Purpose of partnering (e.g. quality improvement, health service governance, evaluation)
- Breadth of services covered (e.g. partnering across a range of services compared to studies focusing on a single service)
- Populations (e.g. consumers, carers, health professionals, managers, policymakers, under-represented populations)

This process was checked by a second review author (BM) and any disagreements were resolved by consensus.

3. Any gaps remaining in the sampling frame were examined and studies with data richness of 3 that would fill the gaps were sought.

At the end of this sampling process, 33/182 studies were selected for inclusion in the final synthesis.

One review author (LS or BM) then extracted data from each study using a form adapted from Cochrane Consumers and Communication's Data Extraction Template (available at: cccrg.cochrane.org/author-resources) and the NICE 2012 Examples of Evidence Tables for Qualitative Studies. We extracted the following data: details of the study (methodology, data collection and analysis methods, setting, geographic location), details of the participants (number and description of participants, methods of recruitment, sampling and inclusion criteria), details of the partnering approach (type of partnering, participants in the partnering approach). All extracted data were checked for accuracy against the data extraction sheets by a second review author (AV).

Data were entered into NVivo 2018 which is software used for analysing qualitative data. One review author entered the data initially (LS) and it was checked for accuracy by a second review author (BM).

Appraisal of study quality

We appraised the quality of each included study using the Critical Appraisal Skills Programme (CASP) tool (CASP 2018). We chose the CASP because it provided for the assessment of the following domains of methodological strengths and limitations: clear aims and research question, congruence between the aims and the research design, rigour of sampling and data collection to address the question, and appropriate application of the method (Noyes 2018). Five members of the author team with qualitative methods experience (BM, SH, VX, LGW, DL) each assessed the quality of three studies and then a consensus meeting was held to agree on the ratings and determine how the CASP would be applied to the remaining studies.

The CASP tool was then applied to each sampled study by one review author (BM, VX, LGW, DL, LS). A second review author, also with qualitative methods experience, checked each appraisal for discrepancies. Any disagreements were resolved through discussion or consultation with a third review author. We did not exclude any studies on the basis of quality because this may have resulted in the loss of valuable insights (Hannes 2011). However, the appraisal formed part of the review authors' judgements when conducting the GRADE-CERQual assessment (Lewin 2018; described below), which determined how much confidence we had in each finding of the synthesis.

Data synthesis

As per the protocol, we originally intended to conduct a 'Thematic synthesis' of the data (Thomas 2008). We began by selecting the five articles in the sample considered most relevant to the synthesis objective (Croft 2016; Johns 2014; MacDonald 2015; Nathan 2014; Sharma 2016). Each of these articles was then coded line-by-line by at least two review authors independently (BM, DL, LGW, VX). After discussing the line-by-line coding process, review authors (BM, DL, LGW, VX) decided to change the synthesis method to 'Framework synthesis' (Oliver 2008) for two reasons. Firstly, we reflected that many of the studies in our QES directly addressed the review objectives and therefore a synthesis method that allowed explicit consideration of the objectives as part of a coding framework would be preferable (Dixon-Woods 2011). Secondly, we considered the time required for line-by-coding of the remaining 28 studies was not feasible within the time available for the project (Booth 2018). Following the change to Framework Synthesis, BM developed a draft framework based on the review objectives, with the most common codes from the line-by-line coding already completed, being categorised under the relevant objective. This draft framework was discussed by BM, DL, LGW and VX, who made further revisions and additions.

Once the framework was finalised, the sampled articles were uploaded into NVivo 2018. Data in the articles were then indexed against the framework by two review authors (BM, LS). To ensure the authors were coding similarly, BM and LS compared their indexing on five articles. Any differences in coding were discussed and resolved by consensus. Once the review authors established they were applying the framework similarly, only one review author (BM or LS) indexed the remaining articles.

Once all articles were indexed, two review authors (BM, LS) began constructing a picture of the data "as a whole" by charting emerging themes and sub-themes occurring across the data set. These themes were then tested and refined, by comparing and contrasting

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data both within and across themes. The final themes were then discussed at a meeting with members of the research team (BM, DL, CC, VX, LGW, SH) as well as a Stakeholder Panel member (CW). Further refinements were then made. The finalised themes became our 'findings' for the purposes of this review. The 19 findings were then grouped into five overarching categories to provide a structured narrative for the Findings section (Ames 2019a).

Assessment of confidence in the review findings

We used the GRADE-CERQual approach to assess confidence in the review findings (Lewin 2018). GRADE-CERQual assesses the extent to which the findings of the review are representative of the phenomenon being explored (Lewin 2018). The assessment is based on four components: the methodological limitations of the studies contributing to the finding; the relevance to the review question of the studies contributing to the review finding; the adequacy of the data supporting the review finding; and the coherence of the review finding (Lewin 2015). After making judgements about these four components, we gave each finding an overall rating of confidence as high, moderate, low or very low. We applied the GRADE-CERQual assessment to each review finding through discussion by two review authors working collaboratively (BM, AV). We have presented a 'CERQual evidence profile' for each finding. This includes the assessment for each CERQual component, the overall CERQual assessment, and the studies contributing to each finding. The 'Summary of Qualitative Findings' tables also included the overall confidence assessment for each finding, and the justification of the confidence assessment.

Using the synthesised qualitative findings to supplement a published Cochrane effectiveness review

We used a matrix approach to integrate the findings of the QES with the findings of the concurrent Lowe 2021 intervention effects review (Harden 2018). This approach has been used previously by Cochrane authors (see, for example, Ames 2019a). As the sampled qualitative articles mainly came from studies unrelated to the trials, the review authors adapted the QES findings into key questions to ask about the design of the interventions. These questions were listed along one side of a matrix with each of the included trials in Lowe 2021 plotted against them. When a question had been addressed in the design of the trial, this was marked as "y" for "yes". When the question had not been addressed, this was marked as "n". This helped to identify which questions were routinely addressed in trials, and the gaps that should be considered when designing future trials.

Developing the best practice principles

To provide an initial framework for the development of the best practice principles, the key questions used in the matrix approach, which reflected the findings of the review, were adapted into draft statements of best practice. The statements were then considered at a teleconference of the Stakeholder Panel. Members of the panel discussed the principles and formulated key recommendations for changes to the draft principles. Recommendations included the following: that the principles did not sufficiently address the power imbalances in formal partnerships and diversity needed in formal partnerships; that the principles needed to be broader, but supported with additional practical examples from the findings to enhance applicability; that the language of some of the draft principles needed to be strengthened. The draft principles were then revised by BM and SH and further feedback was sought from the Stakeholder Panel via email. Further minor changes were made on the basis of the feedback and the final draft was approved by the review authors and Stakeholder Panel members.

Author reflexivity

Regular meetings of the author team and stakeholder panel enhanced the authors' awareness of their own role in the research process. For example, stakeholder meetings helped the review authors to identify underlying biases in applying the selection criteria to full-text studies. During the data analysis phase, only review authors with qualitative methods experience or training (BM, LS, SH, LGW, VX, LW, DL) were directly involved in coding and quality appraisal of the included studies. These review authors met regularly to uncover underlying assumptions that may have influenced the initial coding and quality appraisal ratings, such as their own interactions with the health system, their professional backgrounds and experiences of consumer involvement in health services and research. These review authors all shared a perspective that consumer involvement in health service design, delivery and evaluation could be improved.

The Stakeholder Panel also met to discuss the draft findings. At the meeting, stakeholders were asked for their perceptions of the findings, including any potential gaps in the analysis or unexpected findings. At this stage, some stakeholders expressed surprise that training of health providers was not identified in the findings. Following the meeting, this led to re-checking the primary data with "health provider training" as a sensitising concept and realising there was a small, but sufficient, amount of data overlooked in the initial analysis, which suggested that training of health providers about consumer involvement could be useful. Thus, the draft findings were updated with these new data. However, other suggestions for potential missing findings from the stakeholder panel, for example, "characteristics of effective consumer representatives", was not found when the data were re-checked and therefore were not included. This process ensured that risk to rigour from competing personal biases was acknowledged and minimised.

Relevance to consumers

We have outlined in the Background how a multidisciplinary Stakeholder Panel was involved in the development of this QES. The Stakeholder Panel involved six consumers who all participated in various aspects of the co-production process, hence ensuring increased relevance of review content and implications for consumers. Consumer panel members were also key in the development of the best practice principles for partnering developed in this review. The implementation of the best practice principles will be highly relevant for consumers as they aim to increase consumer participation in health service partnerships.

RESULTS

Included studies

We screened 13,463 abstracts and assessed 608 full-text articles. We excluded 426 studies (Characteristics of excluded studies) and 182 studies met our inclusion criteria. From these 182 studies, we sampled 33 studies for analysis (Characteristics of included studies). Our study flow is illustrated in Figure 1. The 149 studies that met the inclusion criteria but were not sampled into the

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synthesis can be found in Table 1 (as well as the reason they were not sampled).

All 33 sampled studies were published between January 2000 and October 2018 and were published in English. Of these, 28 were from high-income countries/regions including the USA (6), England (5), Australia (5), Canada (4), Belgium (1), the Netherlands (1), New Zealand (1), Norway (1), Scotland (1), Northern Ireland (1), Wales (1), Republic of Ireland (1). Five studies were from the following low- or middle-income countries (LMICs): Nepal (1), Kenya, Tanzania and Zambia (combined) (1), Kenya (1), Zambia (1), and Uganda (1).

The range of settings included regional health authorities and commissioning organisations, hospital and primary healthcare in both metropolitan and rural areas. The sample included both generalist and specialist health services. Specialist services included adult and paediatric mental health, cancer, palliative care, paediatrics and chronic diseases.

Consumer populations were predominantly service users and community representatives. Health provider populations included health professionals, healthcare managers and policymakers.

Data collection methods mainly involved interviews, but observations, document analysis and focus groups were also included. Transcriptions were thematically analysed in the majority of studies.

Methodological limitations of the included qualitative studies

There was poor reporting of researcher reflexivity in many of the included studies, which limited the transparency regarding the role of the researcher. Due to this lack of reporting, it is unclear whether the researcher/s may have influenced participants' responses or the analysis of these responses. All studies gave some description of the context, participants, sampling, data collection and analysis methods. A few studies did not have formal ethics approval and this was noted during the CASP assessment.

Confidence in the findings

Based on our CERQual assessments, we had high confidence in 12 findings and moderate confidence in six findings, indicating they were good representations of the phenomenon of interest. We rated one finding as very low confidence indicating a weaker fit with the phenomenon of interest. Our main concerns with the very low confidence finding were data relevance, adequacy and coherence. Concerns about relevance were related to the finding only including studies from two countries and settings (compared to other findings which included a wide range of countries and settings). Concerns about adequacy related to only two studies contributing to this finding (other findings typically comprised more than 10, up to 30, studies). We were also concerned about the coherence because some of the data supporting the finding were conflicting. Overall, the methodological quality of the included studies was high.

The GRADE-CERQual evidence profile tables supporting the assessment of confidence in each finding can be found in Appendix 3 We start each section of the findings with a link to the 'CERQual summary of qualitative findings' table where a summary assessment from that section is presented.

Findings identified

The 19 findings are divided into the following five categories: (1) contextual factors influencing partnerships; (2) consumer recruitment; (3) partnership dynamics and processes; (4) perceived impacts on consumers and health providers; and (5) perceived impacts on health service delivery, planning and evaluation.

Category 1: Contextual factors influencing partnerships

There are **two** findings under this category (Findings 1 and 2). The 'Summary of qualitative findings' table for this category is shown in Table 2.

Finding 1: Government policy, policy implementation processes and funding influenced working in partnership in health services. Supportive government policies that were poorly translated into practice could hinder partnerships. Inadequate funding could also constrain partnerships (moderate level of confidence).

Evidence from several studies suggested that supportive government policies facilitated partnerships between health providers and consumers (Abelson 2004; Attree 2011; Byskov 2014; Jivanjee 2007; Johns 2014; Wiig 2013). These included policies that emphasised the importance of consumer involvement in service planning and delivery (Attree 2011; Byskov 2014; Jivanjee 2007), that created new structures for consumer involvement in healthcare governance (Abelson 2004), and policymakers collaborating with consumers to meet shared goals (Johns 2014). Three of these studies suggested such policies needed to be supported with resources to make a positive difference to partnerships (Abelson 2004; Attree 2011; Jivanjee 2007). However, a Norwegian study concluded the effectiveness of policy levers on working in partnership at the hospital level was unclear:

"At the hospital (meso) level, we do not know which national policy levers (policy expectations, statutory law/regulation, sanctions, guidance, publication of information, etc.) work best to improve the hospitals' patient involvement and use of patient experience in QI, meaning that this is a relatively evidence-light zone in which to make policy decisions." (Wiig 2013, p.10).

Ten studies from a range of geographic areas and healthcare settings demonstrated that supportive government policies that were poorly integrated into practice could have a neutral or negative impact on partnerships (Attree 2011; Croft 2016; Gurung 2017; Heenan 2004; Jivanjee 2007; Kidd 2007; MacDonald 2015; Potter 2016; Scholz 2018; Wiig 2013). Reasons for poor implementation included insufficient direction or resources about how to integrate policies into practice (Croft 2016; Heenan 2004; Jivanjee 2007; Kidd 2007; MacDonald 2015; Potter 2016; Wiig 2013) and policymakers not enacting their own policies into practice (Gurung 2017). Evidence suggests a lack of clarity about translating policies into practice could lead to barriers in consumers' participation in partnerships (Attree 2011; Croft 2016; Gurung 2017; Heenan 2004; Jivanjee 2007; Kidd 2007; MacDonald 2015; Wiig 2013). For example, Croft 2016 (p. 127) stated:

"On the one hand, organisational managers were aware of the need to engage in [patient involvement] in line with national policy. However, their interpretation of policy led them to engage in rational ideologies of control, which constrained the PI group, only allowing

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them to contribute through formally determined, and managerially led, discussions."

In a further example, Kidd 2007 (p. 217) stated:

"Having no agreed-upon definition meant that the development of processes to support the implementation of consumer participation was lacking. This lack of clear process appeared to contribute to the reluctance of clinicians to embrace the concept of consumer participation fully. Julie (clinician) identified the usefulness of a clear process and the dangers inherent if the process was not formalized"

'In a formal way, a process in place would give it some respectability or credibility rather than just 'should we have some more?' just because that's what you should do. . . and then not listen. The thing is, they are just a consumer that's the feeling and it's disrespectful, it's rude and it's a waste of time.'".

Three studies, including two from low- and middle-income countries, found that government policies that restricted local decision-making undermined the effectiveness of partnerships (Byskov 2014; Heenan 2004; Schaaf 2017). Restriction of local decision-making included central government policies interfering with local priority-setting processes (Byskov 2014), late payments from central government affecting a partnership's ability to deliver on its mandate (Schaaf 2017), and government's inability to delegate decision-making power to community members due to its statutory obligations (Heenan 2004).

Evidence from six studies suggested that inadequate funding constrained partnerships (Attree 2011; Goodman 2011; Heenan 2004; Jivanjee 2007; Kidd 2007; Schaaf 2017). Insufficient funding constrained partnerships by restricting implementation of consumer participation activities (Kidd 2007; Heenan 2004), restricting the partnership's autonomous and longer-term decision-making (Attree 2011; Goodman 2011), payment of consumer members and travel time (Jivanjee 2007; Schaaf 2017).

Finding 2: The organisational context of the health service, including management, culture and policies, could function as a facilitator or barrier to working in partnership. Attitudes of senior leaders and managers of the health service could influence partnership-working (moderate level of confidence).

Eight studies from high-income countries suggested organisational management, culture and policies can facilitate or constrain partnerships (Boivin 2014; Croft 2016; IPFCC 2018; Jivanjee 2007; Potter 2016; Restall 2013; Scholz 2018; Sitzia 2006). Partnership working could be limited in organisations where management and policies were rigid, controlled by health providers or lacking institutional commitment (Croft 2016; Jivanjee 2007; Sitzia 2006). In contrast, organisations with supportive cultures and policies facilitated partnership development (Croft 2016; IPFCC 2018; Malfait 2018; Potter 2016; Restall 2013; Scholz 2018; Sitzia 2006; Wiig 2013). Organisations that embedded partnerships across all levels and valued consumers as equal partners could facilitate partnerships (IPFCC 2018; Malfait 2018; Potter 2016; Scholz 2018; Sitzia 2006; Wiig 2013).

The attitudes and buy-in of senior leaders and managers was also an important barrier or facilitator to partnership development in high-, middle- and low-income countries (Boivin 2014; Byskov 2014; Croft 2016; Heenan 2004; IPFCC 2018; Johns 2014; Sitzia 2006; Wiig 2013). Leaders or managers could use their positions of power to influence the level of support for partnership-working (Boivin 2014; Byskov 2014; Wiig 2013), to determine how consumers were involved in partnerships (Croft 2016), as well as to sustain and build capacity in partnership working (IPFCC 2018; Johns 2014). A lack of commitment from leadership could result in perceptions of token involvement (Heenan 2004; Sitzia 2006) as demonstrated in this quotation:

"both service users and NHS staff said that they did not believe that a genuine commitment to [patient and public involvement] existed among senior NHS managers and clinicians in Trusts, as exemplified by this hospital lead cancer nurse:'there are so many interests within an organisation, that the service user interests are low down on the spectrum, there's lip service paid to it, in reality.'" (Interview 46) (Sitzia 2006, p. 68).

Category 2: Consumer recruitment

The category of consumer recruitment includes **three** findings (Findings 3 to 5). The 'Summary of qualitative findings' table for the findings in this category is shown in Table 3.

Finding 3: Consumers were recruited to partnerships in different ways. They were often selected according to specific criteria, including social and demographic characteristics and communication skills; however these could be competing priorities. Consumers managed the recruitment of other consumer members in a minority of studies (high level of confidence).

Nine studies reported consumers were recruited according to specific criteria (Abelson 2004; Boivin 2014; Byskov 2014; Gurung 2017; Jivanjee 2007; Johns 2014; Maher 2017; Scholz 2018; Sharma 2016). Of these studies, five studies included selecting consumers to balance relevant social or demographic characteristics (Boivin 2014; Byskov 2014; Gurung 2017; Johns 2014; Maher 2017). Two studies reported consumers' communication skills were also an important factor in their recruitment (Maher 2017; Sharma 2016). However, both emphasised that recruiting for balance and communication skills could be competing priorities. As Sharma 2016 stated:

"Identifying patients with excellent communication skills as well as recruiting membership reflective of the patient population served emerged as dual and possibly competing priorities. By specifically recruiting excellent communicators, patients who may be more comfortable in facilitated meeting settings may be more likely to be nominated. These findings suggest that more time and resources are needed to recruit and support patients from hard-to-reach groups served by the clinic." (p. 781).

In five studies, consumers managed the recruitment of other consumer members, or members were chosen via a popular vote (Croft 2016; Durey 2016; Goodman 2011; Johns 2014; Rutebemberwa 2009). Consumers choosing their own members could be empowering, for example, in a study where health providers partnered with Australian Aboriginal communities:

"Many participants discussed the value of increasing the capacity of [District Aboriginal Health Action Groups] by encouraging members to choose their representatives, which placed authority in the hands of the Aboriginal community. Participants talked about how this process shifted the decision making about community health issues

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to Aboriginal people rather than a top-down approach with health providers identifying the health issues. This approach led to health service providers changing practice and that was viewed as positive at the community level.
'Aboriginal people say they are the most consulted people in the world, so I think we can definitely say, 'Yes, we have been consulted, but we have got an outcome from it and people will want to be consulted now because there has been action from it' (HPAS 4)" (Durey 2016, p. 9).

However, one study in a low-income country suggested health providers could find it challenging when consumers chose their own representatives. For example, health providers could be frustrated when the people voted in by the community did not have the skills they considered necessary to perform committee tasks (Goodman 2011).

Finding 4: Recruiting a broad range of consumers who reflected the health services' demographic populations was considered desirable, particularly by health providers. Strategies to increase recruitment of consumers from underserved groups could include practical supports, flexible meeting times, payment and reimbursement (high level of confidence).

In 12 studies, recruiting a broad range of consumer members whose demographic characteristics reflected the health service's population were sought, particularly by health providers (Attree 2011; Boivin 2014; Croft 2016; Goodman 2011; Greene 2018; IPFCC 2018; Maher 2017; Nathan 2014; Newberry 2005; Scholz 2018; Sharma 2016; Sitzia 2006). When consumer members were not considered "representative", their legitimacy could be questioned (Boivin 2014; Greene 2018; Nathan 2014; Newberry 2005; Scholz 2018).

Recruiting consumers from under-served populations may be facilitated through providing practical support and flexibility (DeCamp 2015; Kidd 2007; Maher 2017; McDaid 2009; Newberry 2005; Scholz 2018; Sharma 2016; Sitzia 2006). Practical supports included convenient meeting times (such as outside work hours), childcare, food, interpreters, accessible venues, support for people with communication disabilities and transport (DeCamp 2015; Kidd 2007; McDaid 2009; Newberry 2005; Scholz 2018; Sitzia 2006). One study reported consumers also wanted flexible meeting arrangements, including breaks within meetings, and being able to pause their involvement with the committee as needed (Sharma 2016).

Payment and reimbursement of expenses (particularly transport) could also be helpful in encouraging consumer participation (Byskov 2014; DeCamp 2015; Goodman 2011; Haarsma 2015; Jivanjee 2007; Maher 2017; McDaid 2009; Schaaf 2017; Scholz 2018). However, in one study, a clinician expressed the view that paying consumers would have a negative effect on achieving a "true consumer perspective" (Kidd 2007).

Finding 5: Some health providers perceived that individual consumers' experiences were not generalisable to the broader population. Consumers perceived it could be problematic to represent a broad range of views within the community, although peer networks and access to external data could assist consumers to access a wider range of views (high level of confidence).

Several studies suggested that some health providers did not perceive individual consumers' personal experiences as being relevant to broader consumer experiences and viewpoints (Boivin 2014; Greco 2006; Greene 2018; Lewis 2014; Rutebemberwa 2009; Sitzia 2006; Wiig 2013). For example, a health provider in one study stated:

"It is important to integrate users in all types of projects. But it is difficult to find user representatives who are contributing to the project with constructive input. Our experience is that users are preoccupied with their own tragedy or their own patient history. They need the comprehensive perspective, and the user representatives with the capacity to apply a holistic perspective are really good. But our experience is that the user representatives often have a hidden agenda. I think we are asking for the professional user representative". (Wiig 2013, p. 9)

However, in one study, a health provider expressed that consumers' personal experiences motivated their involvement in health services, and therefore, should be viewed positively (Scholz 2018).

Some consumers perceived it was difficult to represent the broad range of views within the community (Gurung 2017; MacDonald 2015; Newberry 2005; Potter 2016; Sharma 2016; Sitzia 2006). Two studies reported that consumers who had access to peer networks or external data (such as consumer feedback surveys) found these resources useful in informing their contributions (Newberry 2005; Sharma 2016).

Category 3: Partnership dynamics and processes

The category of partnership dynamics and processes includes **seven** findings (Findings 6 to 12). The 'Summary of qualitative findings' table for the findings in this category is shown in Table 4.

Finding 6: Positive interpersonal dynamics between health providers and consumers facilitated partnerships. Mutual respect, commitment, two-way dialogue and information exchange were helpful. Trust, accountability, regular group communication and strong relationships with decision-makers were also facilitators. Partnerships that were equitable with shared values, a shared vision and shared decision-making powers were preferable. Skilled facilitators, moderators and consumer coordinators could help to facilitate positive interpersonal dynamics (high level of confidence).

There was a range of interpersonal and group features that facilitated partnerships. Firstly, partnerships that were supportive and included mutual respect, commitment, two-way dialogue and information exchange were positively regarded (Abelson 2004; Attree 2011; Boivin 2014; Byskov 2014; Croft 2016; DeCamp 2015; Durey 2016; Greene 2018; Haarsma 2015; Heenan 2004; Johns 2014; Maher 2017; Malfait 2018; Newberry 2005; Restall 2013; Schaaf 2017; Scholz 2018; Sitzia 2006). Secondly, trust, accountability, regular group communication and developing strong relationships with decision-makers also enhanced group-working (Abelson 2004; Croft 2016; DeCamp 2015; Durey 2016; Goodman 2011; Johns 2014; Kidd 2007; Maher 2017; MacDonald 2015; Restall 2013; Schaaf 2017). Schaaf 2017 (p. 855) described mechanisms used in a Zambian partnership for information exchange and accountability:

"... [The Citizen Voice and Action social accountability program] entailed interface meetings that promoted bi-directional information sharing. Community and government representatives from all three

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sites emphasized the mutually constitutive nature of the interface meetings, where community members aired their grievances ... and asked questions. At the same time, government officials noted that the meetings provided an important space for them to be able to explain government policy, respond to community concerns, and describe the challenges they faced in trying to strengthen health services."

Thirdly, partnerships that were equitable with shared values, vision and decision-making powers were preferable (Byskov 2014; Durey 2016; Goodman 2011; IPFCC 2018; Johns 2014; Restall 2013; Rutebemberwa 2009; Schaaf 2017; Scholz 2018; Sharma 2016; Sitzia 2006). In contrast, differing expectations or values among group members could impede the partnership (Boivin 2014; Goodman 2011; Heenan 2004; Jivanjee 2007; Kidd 2007; Lewis 2014; Sharma 2016).

Nine studies reported that certain characteristics of the leader or chairperson could facilitate partnerships (Byskov 2014; Croft 2016; Durey 2016; Haarsma 2015; Johns 2014; MacDonald 2015; Malfait 2018; Newberry 2005; Sitzia 2006). These characteristics included being impartial and equitable (Byskov 2014; Croft 2016; MacDonald 2015; Malfait 2018; Newberry 2005), helping people feel valued (Johns 2014) ,and developing a shared vision for the partnership (Johns 2014). Two studies suggested a consumer chairperson helped to facilitate equality in the partnership (Durey 2016; Sitzia 2006).

Evidence from six studies showed that skilled facilitators, moderators and consumer coordinators were helpful in ensuring equal participation in partnerships (Abelson 2004; Boivin 2014; Greco 2006; Nathan 2014; Sharma 2016; Sitzia 2006). Skilled facilitators and moderators could manage group processes to ensure consumers' views were actively sought during discussions and shaped into tangible projects (Boivin 2014; Sharma 2016; Sitzia 2006). As Boivin 2014 (pp. 336-7) explained:

"We hired an expert in communication as our lead moderator, who was assisted by 2 comoderators with formal training in health care (employees of the regional health authority). We observed that the lead moderator had less content expertise and was more focused on effective group processes, paying close attention to the setting and enforcing ground rules, supporting a relaxed atmosphere conducive to deliberation and compromise, and asking for frequent clarifications when technical language was used."

One study also reported that a consumer coordinator, employed by the health provider, helped consumers to get 'buy-in' for their ideas among health service decision-makers (Nathan 2014).

Finding 7: Lack of clarity about the consumer role constrained consumers' involvement in partnerships. Consumers could become frustrated and confused when their role was unclear. Some health providers were unsure about the consumer role and so providing training in consumer engagement may help (high level of confidence).

Consumers' own lack of clarity about their role and unmet expectations could be a barrier in participating in partnerships (Croft 2016; DeCamp 2015; Goodman 2011; Haarsma 2015; Jivanjee 2007; Kidd 2007; Lewis 2014; MacDonald 2015; Newberry 2005; Sharma 2016). Lack of clarity could lead to confusion, frustration and uncertainty for consumers (Croft 2016; DeCamp 2015; Haarsma 2015; Kidd 2007; Lewis 2014; MacDonald 2015; Newberry 2005). As Croft 2016 (pp. 126-7) stated:

"The group was asked by the lay chair to identify what they feel their contribution to the [Clinical Commissioning Group] should represent. There was a lot of confusion amongst members about their potential contribution … The chair had difficulty keeping the group on point … Two general managers attended the meeting, and they were responsible for setting the agenda. By the end of the meeting the managers had taken over the running of the session to ensure all the agenda items were discussed in a more structured manner (Field Notes: 11/04/2014)".

Similarly, health providers' lack of clarity about the role of consumers could also be a barrier (Croft 2016; Greene 2018; Haarsma 2015; Kidd 2007; Maher 2017; Newberry 2005; Scholz 2018; Sharma 2016). Some health providers faced challenges in defining a "consumer" (Kidd 2007; Scholz 2018), understanding what consumers could offer (Greene 2018; Kidd 2007), and knowing what to ask of consumers (Maher 2017).

Lack of clarity about the consumer role could also lead to dissonance and conflict between consumer and health provider members of the partnership (Goodman 2011; Jivanjee 2007; Sharma 2016).

Training health providers about engaging with consumers may assist health providers to work with consumers (Greene 2018; IPFCC 2018; Restall 2013).

Finding 8: Formal meeting formats constrained the participation of some consumers in partnerships. Health providers could facilitate consumer involvement through providing training, less formal meeting structures and consumer-only spaces (high level of confidence).

Formal meetings with explicit and implicit rules of participation could be intimidating for consumers (Lewis 2014; Malfait 2018; McDaid 2009; MacDonald 2015; Newberry 2005; Sitzia 2006). Formal meeting structures were more familiar to those from large organisational workplaces (MacDonald 2015; Lewis 2014). Lewis 2014 stated that such structures could be disproportionately marginalising for women, people with low socio-economic status and young people:

"... the beginning stages of board membership can be quite intimidating. This intimidation stems in no small part from the formality of the board process, which most often entails very specific rules of order - making motions, seconding, voting, and understanding the various roles and titular responsibilities of the members. A failure to understand basic governance and how to participate can only serve to compound additional nervousness of joining the board and performing alongside other experienced board members, many of whom have professional expertise." (p. 107)

In contrast, one study found that formal meeting procedures were important for the partnership's effectiveness (Johns 2014).

Training consumers often facilitated their participation in partnerships (Attree 2011; Boivin 2014; Byskov 2014; Durey 2016; Goodman 2011; Greene 2018; Gurung 2017; Heenan 2004; IPFCC 2018; Jivanjee 2007; Johns 2014; Malfait 2018; McDaid 2009; Newberry 2005; Restall 2013; Schaaf 2017; Scholz 2018; Sharma 2016; Wiig 2013). Training purposes mainly included building

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technical expertise as well as understanding committee processes and governance (Attree 2011; Boivin 2014; Byskov 2014; Durey 2016; Goodman 2011; Greene 2018; Gurung 2017; Johns 2014; McDaid 2009; Newberry 2005; Restall 2013; Sharma 2016). Less formal, smaller meetings, sub-committees and consumer-only meetings also promoted consumers' participation (Boivin 2014; MacDonald 2015; Newberry 2005; Restall 2013).

Finding 9: Health providers' professional status, technical knowledge and use of jargon were intimidating for some consumers. Increasing the proportion of consumers in the partnership could help address feelings of intimidation (high level of confidence).

Eight studies identified that health providers' professional status and technical knowledge resulted in some consumers feeling inferior, frustrated, less confident and/or anxious about contributing to discussions (Gurung 2017; Jivanjee 2007; Lewis 2014; Malfait 2018; McDaid 2009; Newberry 2005; Rutebemberwa 2009; Scholz 2018). As Scholz 2018 (p. 926) stated:

"A consumer recounted her experience of being on a committee by saying "I was really intimidated by the people, like the [medical specialist] who was there was very matter of fact that he was the boss. It was very much a tier, and I was at the bottom (P4)."

In a study conducted in Nepal, consumers who were less educated, more socio-economically disadvantaged and from rural areas, could feel particularly intimidated by health providers. However, even those consumers who were educated still felt a sense of inferiority because they lacked technical knowledge (Gurung 2017).

In a Belgian study about partnerships in general hospitals and psychiatric hospitals, Malfait 2018 (p. 386) found power imbalances in committees related to health providers' professional status and knowledge:

"the identified conditions for actual involvement seem strategies mainly aimed at overcoming imbalances of power in the stakeholder committee. Concerning power imbalances, such imbalances do exist and are perhaps consciously installed, possibly reflected by the small group of patients and the public in the stakeholder committees. As pointed out before, interaction between professionals and patients starts from an inherent power imbalance ashealthcare professionals have a strong professional dominance over patients due to a comprehensive knowledge on practices and professional expertise and knowledge"

Jargon and technical language was also a barrier for some consumers (Greene 2018; Maher 2017; McDaid 2009; Newberry 2005; Potter 2016; Scholz 2018). As Greene 2018 stated:

"The patient partner role is new to the patient volunteers, particularly in the beginning when many patient partners feel intimidated by the new vocabulary, as well as by the people with whom they are interacting."

Power imbalances in formal meeting formats could be reduced through increasing the number of consumers in the partnership (Boivin 2014; Durey 2016; Lewis 2014; McDaid 2009; Newberry 2005; Schaaf 2017; Scholz 2018). As Lewis 2014 (page number not given) recounted:

"Service user participants also came up with a number of other practical suggestions for progressing user involvement. These included an equal representation of service users and providers at committee meetings in order to achieve a 'fairer balance of power' and using voting instead of consensus-working for decision-making".

Suggestions of proportions of consumer members in partnerships varied across studies from one-third membership (Newberry 2005) to equal or majority membership (Lewis 2014; Durey 2016; McDaid 2009; Scholz 2018).

Finding 10: When health providers dominated the meeting agenda, consumers could become frustrated. Some consumers wanted more opportunities to shape their role, contribute their priorities and lead or share the agenda (moderate level of confidence).

Eleven studies reported that health providers dominated the agenda in partnerships (Croft 2016; Goodman 2011; Greene 2018; Heenan 2004; Lewis 2014; Malfait 2018; McDaid 2009; MacDonald 2015; Nathan 2014; Scholz 2018; Wiig 2013). Health provider dominance ranged from pre-determining the agenda without consumer input (McDaid 2009; Nathan 2014; Wiig 2013), not accommodating contributions perceived to be outside health providers' priorities (Croft 2016; Greene 2018; Lewis 2014), allowing but not encouraging consumer contributions to the agenda (MacDonald 2015), only allowing consumer issues to be raised as "any other business" (MacDonald 2015) and/or assuming consumers would not want to be involved in particular agenda items (Scholz 2018).

Six studies reported consumers felt frustrated and constrained when health providers controlled the agenda (Abelson 2004; Croft 2016; Lewis 2014; McDaid 2009; MacDonald 2015; Newberry 2005). Some consumers felt health provider control led to token consumer contributions (Abelson 2004; Croft 2016; Lewis 2014). Three studies found that consumers wanted opportunities to shape their own role, contribute their own priorities and provide feedback about services without adverse consequences (Croft 2016; DeCamp 2015; Lewis 2014). Consumer-led or shared agendas may facilitate consumer participation (Croft 2016; Jha 2018; Johns 2014; Schaaf 2017; Sitzia 2006).

Finding 11: Consumers could feel their experiential knowledge was not valued by health providers, leading to feelings of being dismissed or overridden. Some health providers perceived consumers' contributions were not as valuable in the partnership. Mutual respect for knowledge and expertise facilitated partnerships (moderate level of confidence).

Five studies suggested consumers perceived their experiential knowledge was not valued by health providers (Attree 2011; Gurung 2017; Haarsma 2015; McDaid 2009; Newberry 2005). This could lead to feelings of being dismissed or overridden (McDaid 2009; Newberry 2005), ignored (Newberry 2005) or not being taken seriously, as Haarsma 2015 (p. 3196) found:

"Professionals' recognition of experiential knowledge was very important to patient representatives, but they complained that they were not being taken seriously by the professionals of the [palliative care networks]. Several patient representatives talked in terms of volunteers vs. professionals, and how big a gap there can be between the two.

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'I might be putting it too bluntly, but I just think the management team is an entirely different group. They're professionals; we can't compare ourselves to them. (Patient representative B5)'".

Three studies suggested health providers perceived consumers' knowledge as less valuable (Croft 2016; Haarsma 2015; Newberry 2005). Reasons for this included perceiving consumers lacked the knowledge and experience to contribute in a meaningful way (Croft 2016), lacked analytical skills (Haarsma 2015) and could only contribute to decisions where their experience was directly relevant (Newberry 2005). Additionally, three studies suggested some health providers experienced discomfort listening to consumers' personal experiences and grievances (Lewis 2014; McDaid 2009; Sitzia 2006). In contrast, mutual respect for knowledge and expertise was shown to facilitate partnerships in six studies (Kidd 2007; Newberry 2005; Potter 2016; Restall 2013; Scholz 2018; Sitzia 2006). As Sitzia 2006 (p. 71) stated:

"[National Health Service] staff were acknowledged as having specialist knowledge of the local NHS environment, particularly with regard to policy constraints, funding mechanisms, local history and influential actors. Service users, notably, were acknowledged as having specialist knowledge and insights about the patients' experience. These knowledges seemed to be regarded as complementary, both types as useful and relevant to the group's work, and their delimitation one of the unwritten ''ground rules''."

Finding 12: Consumers could experience token involvement in partnerships, including a lack of decision-making power, being left out of key discussions and being unable to contribute ideas outside health providers' priorities. Token involvement resulted in consumers feeling frustrated. Consumers valued contributing to tangible changes in health policy and services (high level of confidence).

Eighteen studies included examples of token involvement of consumers in partnerships (Abelson 2004; Attree 2011; Boivin 2014; Croft 2016; Goodman 2011; Gurung 2017; Haarsma 2015; Heenan 2004; Kidd 2007; Lewis 2014; McDaid 2009; Nathan 2014; Newberry 2005; MacDonald 2015; Restall 2013; Scholz 2018; Sitzia 2006; Wiig 2013). Token involvement included having no power over decision-making processes (Attree 2011; Boivin 2014; Croft 2016; Goodman 2011; Gurung 2017; Heenan 2004; Sitzia 2006; Wiig 2013), "rubber-stamping" decisions already made (Abelson 2004; Attree 2011; Lewis 2014; MacDonald 2015; Restall 2013), being unable to contribute outside managerially-determined priorities (Croft 2016; Lewis 2014), not being included in key discussions (Gurung 2017; Scholz 2018), lack of staff engagement with operationalising consumer participation policies (Kidd 2007), including consumers because it was "the proper thing to do" (McDaid 2009) and not listening to consumers' suggestions (Haarsma 2015; Nathan 2014; Newberry 2005). Many consumers felt frustrated and dissatisfied with token involvement (Abelson 2004; Gurung 2017; Haarsma 2015; Heenan 2004; Lewis 2014; Sitzia 2006; Wiig 2013). Consumers valued seeing tangible changes to health policy and services as a result of their contributions (Abelson 2004; Attree 2011; DeCamp 2015; Durey 2016; Greene 2018; Haarsma 2015; Heenan 2004; IPFCC 2018; Maher 2017; Malfait 2018; Nathan 2014; Schaaf 2017; Sitzia 2006).

Category 4: Perceived impacts on partnership participants

The category of perceived impacts on partnership participants includes **one** finding (Finding 13). The 'Summary of qualitative findings' table for finding 13 is shown in Table 5.

Finding 13: Working in partnership could affect health provider and consumer participants in both positive and negative ways. Health providers perceived consumers provided a unique perspective that could improve services, but they were concerned about the time pressures and unmet expectations that could accompany their involvement in partnerships. Consumers perceived there were benefits of working in partnership, including empowerment, increased confidence, knowledge and skills. However, they reported that participating in partnerships could be physically and/or emotionally demanding (high level of confidence).

Many health providers perceived consumers provided a unique perspective that could improve services (Attree 2011; Boivin 2014; Byskov 2014; Croft 2016; Goodman 2011; Greene 2018; Jivanjee 2007; Maher 2017; Nathan 2014; Potter 2016; Restall 2013; Scholz 2018; Sitzia 2006). However, in six studies, some health providers perceived negative impacts from working in partnership. These impacts included not having enough time to participate in the partnership (Goodman 2011; Greco 2006; Schaaf 2017; Sitzia 2006; Wiig 2013), and setting up expectations they could not meet (Greco 2006; Restall 2013). In one study from a low income country, health providers perceived the consumers had too much power:

"Several health workers complained that since the committees had been told the facility was theirs, they had started acting like "watchdogs", trying to supervise everything the health workers were doing and undermining them" (Goodman 2011, page number not given).

Consumers perceived the personal benefits of working in partnership were empowerment, as well as increased confidence, knowledge and skills (Croft 2016; DeCamp 2015; Durey 2016; Greco 2006; Greene 2018; Newberry 2005; Potter 2016; Restall 2013; Schaaf 2017; Sitzia 2006). However, consumers could also find partnerships physically and/or emotionally demanding (Attree 2011; Heenan 2004; Jivanjee 2007; Kidd 2007; McDaid 2009; Newberry 2005; Schaaf 2017; Sitzia 2006). Demands included sustaining participation over long periods (Attree 2011; Heenan 2004; Schaaf 2017), becoming emotionally affected by the role (Jivanjee 2007; Sitzia 2006), participating while experiencing chronic or acute illness (Attree 2011; Kidd 2007; McDaid 2009; Newberry 2005; Restall 2013) and while trying to meet basic needs, such as housing and food (Restall 2013).

Category 5: Perceived impacts on health service planning, delivery and evaluation

The category of 'perceived impacts on health service planning, delivery and evaluation' includes **six** findings (Findings 14 to 19). The 'Summary of qualitative findings' table for the findings in this category is shown in Table 6.

Finding 14: Working in partnership was perceived to improve consumer involvement in strategic decision-making, under certain conditions (moderate level of confidence).

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Studies reported varied perceptions about whether partnership-working improved consumer involvement in strategic decision-making processes (Attree 2011; Byskov 2014; Croft 2016; Durey 2016; Haarsma 2015; Restall 2013; Schaaf 2017). Two studies conducted in low-income countries reported partnership-working increased community input into priority-setting (Byskov 2014; Schaaf 2017). Success in these two studies was related to supportive policies, leadership capacity and commitment of stakeholders. Durey 2016's study reported community involvement in decision-making in local health issues increased. The authors related this to the two-way dialogue between partners and shared learning. Croft 2016 reported consumer involvement in strategic issues occurred when partnerships were more collaborative, and consumers were encouraged to contribute outside of their formal, managerially-determined roles. Restall 2013 found that creative strategic solutions resulted when health providers valued the diversity of consumers' perspectives on different policy issues.

Two studies found consumers' ability to influence strategic level changes (such as commissioning decisions or macro-level policy) was limited (Attree 2011; Haarsma 2015). This related to the partnership's primary focus being on operational rather than strategic issues.

Finding 15: Working in partnership was perceived to enhance community ownership of health services, particularly in low- and middle-income countries (moderate level of confidence).

Evidence from six studies - three in low- and middle-income countries - suggested working in partnership improved community ownership of health services (Byskov 2014; Croft 2016; Durey 2016; Goodman 2011; Johns 2014; Schaaf 2017). Byskov 2014 found that encouraging community involvement in key decisions helped to foster a sense of ownership of the health service. In Schaaf 2017's study conducted in Zambia, regular meetings with community members were recognised by the community as a new channel for aggregating a collective community voice. Goodman 2011 found that providing additional funds for the partnership to manage, including to plan and implement more activities, helped with community ownership of the health service.

In two Australian studies, the authors also found community ownership of health services increased (Durey 2016; Johns 2014). Durey 2016's study found a key factor in increasing ownership was encouraging Aboriginal community members to choose their own representatives:

"Participants talked about how this process shifted the decision-making about community health issues to Aboriginal people rather than a top-down approach with health providers identifying the health issues" (no page number given).

Finding 16: Working in partnership was perceived to lead to improvements in the person-centredness of health service culture (high level of confidence).

Eight studies showed that working in partnership led to a greater willingness from health providers to collaborate with consumers (Attree 2011; Byskov 2014; Durey 2016; Greco 2006; Goodman 2011; Jha 2018; Sharma 2016; Wiig 2013). Working in partnership could also lead to strengthened relationships between consumers and health providers (Attree 2011; Croft 2016; Durey 2016; Restall 2013; Schaaf 2017). Five studies reported health providers experienced increased focus and understanding of the patient's needs and experiences in their decision-making processes (DeCamp 2015; Greene 2018; IPFCC 2018; Schaaf 2017; Sharma 2016).

Finding 17: Working in partnership was perceived to lead to improvements in the built environment of the health service (high level of confidence).

Improvements in the built environment of health services were reported in 10 studies (Attree 2011; DeCamp 2015; Greene 2018; Haarsma 2015; Johns 2014; Nathan 2014; Schaaf 2017; Scholz 2018; Sharma 2016; Sitzia 2006). Improvements included successful funding applications for new buildings (Johns 2014), planning the layout of new buildings or services (Attree 2011; Scholz 2018; Sitzia 2006), improving the physical space of existing facilities (DeCamp 2015; Greene 2018; Nathan 2014; Sharma 2016), and improved access for people with a disability (Haarsma 2015).

Finding 18: Working in partnership was perceived to lead to improvements in health service design and delivery (high level of confidence)

Some health providers and partnership groups perceived partnering contributed to improvements in health service design and delivery (Attree 2011; Durey 2016; DeCamp 2015; Greene 2018; Johns 2014; Nathan 2014; Restall 2013). Specific examples of improvements included increased awareness of health services (Johns 2014), providing medical treatment closer to home (Attree 2011), establishing 'out of hours' care (Attree 2011) and developing culturally-sensitive services (Durey 2016).

Both health providers and consumers perceived that partnerships improved communication with patients and patient information (Attree 2011; DeCamp 2015; Greene 2018; Maher 2017; Nathan 2014; Schaaf 2017; Sitzia 2006). Examples included the development of new written resources for patients (including web-based information) (Attree 2011; DeCamp 2015; Greene 2018), drafting of scripts to help clinicians explain the rationale for goal-setting (Greene 2018), improving the telephone system menu (Greene 2018), development of new forms for patients (Greene 2018), and the development of standards for breaking bad news to patients (Sitzia 2006).

However, in three studies, some partnerships experienced no improvements in service design and delivery. Heenan 2004 and Nathan 2014 both found that consumers had tried to communicate their ideas, but health providers had not taken action to implement them. Also, Lewis 2014 argued that consumers' views were controlled and constrained by health providers to maintain the status quo.

Finding 19: Working in partnership may lead to improvements in health service evaluation (very low level of confidence).

Two studies showed working in partnership led to improvements in health service evaluation (Croft 2016; Jivanjee 2007). Jivanjee 2007 (p. 378) reported the involvement of consumers on an evaluation team *"contributed to increased accuracy of the data because of their experiences and their local knowledge"*.

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Supplementing the Cochrane intervention review with synthesised qualitative findings - matrix results

The Cochrane intervention review found there was insufficient robust evidence to determine the effects of consumers and providers working in partnership to plan, deliver and evaluate health services (Lowe 2021). The results of the intervention review were impacted by the small number of trials included (n = 5). The included trials had myriad differences in terms of setting, population, context, outcomes and partnership purposes which hampered comparisons between them. In addition, many of the included trials also did not measure, at least directly, outcomes related to health services planning, delivery and evaluation leading to uncertain judgements of effectiveness of partnership approaches on these outcomes. Given this, the review concluded "... qualitative research methods may be particularly suited to better understanding elements of successful partnerships, and so to inform development of effective approaches" (Lowe 2021, p.26).

Despite the uncertain evidence of effectiveness, we developed a matrix approach to ascertain whether key aspects of successful partnering, as shown by our QES, were incorporated in the trials. The matrix consisted of 12 questions derived from our findings that we applied to the primary studies in the intervention review (see Appendix 4, and a list of all the studies included in the analysis is shown in Appendix 5).

Based on the findings of the QES, we explored whether the trialists had described the following aspects of working in partnership.

1. Was the partnership conducted in a supportive government policy context?
2. Was the partnership conducted in a supportive organisational context?
3. Were consumers involved in the recruitment process?
4. Were resources in place to recruit and support members from groups who are underserved?
5. If expected to represent other consumers, were consumers facilitated to do this (e.g. with external data, peer networks etc)?
6. Were strategies used to facilitate positive interpersonal dynamics in the partnership?
7. Were consumers offered training and practical support to facilitate their participation in the partnership?
8. Were consumers and health providers both clear about the expectations of the consumer role, and were consumers involved in shaping their role?
9. Were strategies used to decrease the potential for consumers to feel intimidated a) in a formal group formats and b) working with health providers?
10. Were strategies used to ensure consumers could contribute meaningfully to the agenda, including leading the meeting and/or contributing their own priorities?
11. Were consumers involved meaningfully in decision-making in the partnership?
12. Were strategies used to reduce negative effects of partnerships on both health providers and consumers?

The matrix table shown in Appendix 4 demonstrates that most of the trials did not describe the government or organisational context in which the trial was taking place. Three of the five trials also did not include consumers in recruiting consumer members for the partnership. In most of the trials, the consumer members were paid for their time and/or reimbursed for their expenses, had access to peer networks or external data to inform their contributions and received training. External facilitators were also used in most trials. Several of the trials used strategies that may have lessened consumers' feelings of intimidation during meetings, including having an equal number of consumers as health providers, having consumers co-facilitate sessions and having access to consumer-only meetings prior to participating in the partnership with health providers. However, many studies did not provide opportunities for consumers to develop their own role, or contribute their own priorities in discussions. In addition, the decision-making processes were not well-described, so it was difficult to determine whether consumers had been involved meaningfully in decision-making. Finally, consideration of the positive and negative impacts of partnerships on consumer and health provider members was generally not addressed. These impacts may affect the sustainability of partnerships over the longer-term e.g. consumer fatigue, lack of time for health providers.

Best practice principles of working in partnership

The principles below are based on the findings of the review and were developed in collaboration with the Stakeholder Panel.

Leadership and health service culture

Formal partnering is supported and endorsed by government stakeholders and health service leadership.

Examples of best practice

- Government policies and standards endorse the importance of formal partnering in service planning, delivery and evaluation.
- Governments support the implementation of policies and standards of formal partnering into health services through guidance documents, funding and structures that support formal partnership decision-making.
- Health service leaders are committed to building capacity in formal partnering. Formal partnering is embedded across all levels of the health service.

Diversity

Formal partnering opportunities are accessible to a diverse range of consumers.

Examples of best practice

- Time and resources are dedicated to recruiting consumers from underserved populations, such as Indigenous populations, culturally and linguistically diverse groups, LGBTIQA+ communities (including people who identify as lesbian, gay, bisexual, transgender, intersex, queer, asexual, agender, aromantic or have other diverse sexual orientations or gender identities), people from low socio-economic groups and people with disabilities.
- Any recruitment criteria and processes for consumer representatives balance the need for specific skills with the need to promote diversity (e.g. previous committee experience may privilege people from professional backgrounds).
- Meeting times are accessible for a broad range of consumers (e.g. meeting outside work hours or on weekends may be preferable).

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- Meeting arrangements are flexible (e.g. breaks are provided in meetings, consumers can pause their involvement for a period of time in a formal partnership when needed).
- Other resources are provided during meetings to support a diverse range of consumers to participate (e.g. childcare, food, accessible venues, support for people with communication disabilities and access to interpreters).
- Remunerating consumers for their time and/or expenses (such as transport to meetings) may improve access to a more diverse range of consumers.

Equity

Consumers have access to the support they need, to contribute equitably in formal partnerships with health providers. Power imbalances between health providers and consumers in formal partnerships are identified and addressed.

Examples of best practice

- Consumers are involved in recruiting new consumers for formal partnerships (e.g. consumers choose their own representatives and/or are involved in the recruitment strategy).
- The proportion of consumers to health providers in a formal partnership is equitable (e.g. consumers could comprise one third, one half or majority membership of a formal partnership).
- Less formal, smaller meetings or sub-committees may be more accessible for some consumers than large, formal meeting structures.
- Consumers have access to consumer-only meetings to help support their involvement in formal partnerships.
- Consumers have access to peer networks or data (such as consumer feedback surveys) to inform their contributions.
- Remunerating consumers for their time and/or expenses (such as transport to meetings) may help to reduce power imbalances.
- Consumers are offered ongoing training about the health service, formal partnerships and conducting their role.

Mutual respect, shared vision, and regular communication

Consumers and health providers are respected for their knowledge and expertise. The consumer role is clear to both consumers and health providers. They share a common vision for the formal partnership, and foster commitment and trust. Consumers and health providers communicate regularly, exchange information and have strong relationships with senior decision-makers in the health service.

Examples of best practice

- The chairperson is impartial, helps all partners feel valued and facilitates the development of a shared vision for the formal partnership.
- Consumers are involved in shaping their role and/or are clear about the expectations of the role.
- Training is provided to health providers to reflect on potential assumptions about the role of consumers and the value of their contributions, and how to partner with consumers.
- When needed, skilled facilitators and moderators may help to ensure consumers' views are actively sought and integrated into decisions.
- Employment of a consumer coordinator may help to facilitate buy-in of consumers' ideas with senior leadership.

Shared agendas and decision-making

Consumers and health providers share agenda setting and decision-making in formal partnerships.

Examples of best practice

- Consumers may lead or co-lead a formal partnership.
- Consumers are actively involved in agenda-setting. Token involvement in agenda-setting is avoided, including health providers pre-determining the agenda without consumer input, health providers not accommodating contributions perceived to be outside the health service's priorities, health providers only allowing consumer issues to be raised as "any other business" and health providers assuming consumers do not want to be involved in particular agenda items.
- Consumers understand the decisions to be made and are involved in the decision-making process. Token involvement in decision-making is avoided, including consumers having no power over decision-making processes, consumers being asked to "rubber-stamp" decisions already made and consumers not being included in key discussions.
- When the formal partnership is tasked with providing advice or options, rather than final decisions, consumers' suggestions and ideas are listened to and followed up.

Influence

By working in formal partnerships, consumers have influence by contributing to tangible improvements in health policy and services, i.e. in the promotion of and delivery of more person-centred care. These improvements can occur in strategic decision-making and community ownership of health services, health service culture and the built environment, health service design, delivery and evaluation.

Sustainability

Consumers and health providers involved in formal partnerships may experience both positive and negative impacts of their involvement over time. Negative impacts should be addressed to avoid undermining the sustainability of the formal partnership.

Examples of impacts for consumers

- Positive impacts: increased confidence, knowledge and skills.
- Negative impacts: difficulty sustaining participation over long periods, becoming emotionally affected by the role and managing the impact of a chronic or acute illness while participating in formal partnerships.

Examples of impacts for health providers

- Positive impacts: benefit from the unique perspective provided by consumers.
- Negative impacts: not having sufficient time to participate in formal partnerships, perceiving they are setting up consumer expectations they cannot meet.

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DISCUSSION

Summary of key findings

Partnering underpins person-centred care. As stated by the IPFCC, person-centred care is the "planning, delivery, and evaluation of health care that is grounded in mutually beneficial partnerships among healthcare providers, patients, and families" (IPFCC 2012). Overall, the findings of the QES suggest that, in formal partnerships at least, mutually beneficial partnerships remain elusive. The influences on, and power imbalances in, formal group partnerships are symptomatic of broader patterns of inequality between health providers and consumers in health services that impact on the provision of person-centred care.

The QES showed that formal group partnerships were shaped by government, via government policies and funding as well as the culture and leadership of the health service. This finding is supported by previous literature (Gilson 2003). Consistent with earlier research, health providers' own attitudes towards consumers were strongly influenced by their managers and broader organisational management practices (Gilson 2003).

The findings also showed that formal partnerships were influenced by the nature and process of recruitment practices. Although health services often desired consumers who represented the demographics of their clinic population, sometimes their selection criteria (e.g. wanting excellent communication skills) could undermine this. The findings showed that recruiting a diverse range of consumers required tailored supports, such as flexible meeting times, remuneration and practical supports (such as interpreters). Previous literature has shown that approaches to increasing the diversity of the consumers involved in decision-making processes, including in formal group formats, should recognise that some groups have more constraints on their participation than others (Gilson 2003). Excluding these groups from decision-making processes may also further exacerbate their disadvantage (Gilson 2003).

The findings demonstrated that partnerships were facilitated by positive interpersonal dynamics between health providers and consumers. The importance of positive interpersonal dynamics in partnerships is supported by Gilson 2003 (p. 1461) who stated:

"if undertaken freely and openly, the process of communication and dialogue with others requires us to confront the mismatches between our own beliefs and those of others, enabling self-reflection and learning. Such discourse can not only encourage mutual respect, but also generate the mechanisms, such as shared understandings, persuasion, promises, that align self-interest with the collective interest and so build trust".

Consumers could also perceive that health providers did not value their experiential knowledge, and this was supported by the perceptions of some health providers that consumers' knowledge was less valuable. Health providers' perceptions of their knowledge as superior has been studied previously. Grimen 2009 argues that enhanced technical health knowledge is essential to being a health professional, in a similar way that enhanced technical legal knowledge is vital for being a lawyer. They suggest that rather than seeking to equalise knowledge between consumers and health providers, the solution may be to encourage more self-reflection from health providers (including during their professional education) about the power such knowledge bestows on their relationship with consumers (Grimen 2009). Sensitive use of health providers' discretionary power to create optimal conditions for collaboration is supported by other literature (Østergaard 2015).

The findings also showed that some consumers could find formal group formats intimidating. This finding highlights that formal group formats are only one tool from among many in a toolbox for health services to engage with consumers to improve person-centred care (AHRQ 2018). Improving formal partnerships to become more equitable may also be a way of nudging a broader cultural shift in health services whereby consumers invite health providers to design services, rather than the other way around. Another finding of the QES was that some consumers and health providers experienced a lack of clarity about consumers' roles. Health providers' lack of clarity about the consumer role was an interesting finding and suggests that efforts to centre health services around consumers is still an aspiration rather than a reality.

We also found that health providers often controlled the agenda of meetings, and the decision-making process. Previous research has shown that agenda-setting is an institutional form that allows the exercise of considerable power by health providers. Firstly, because quote: "it concerns what is up for grabs in an interaction and what is not, and who decides" (Grimen 2009, p. 27), and also allows them to define the participants' world view e.g. by defining what illness is versus what normal is. Such institutional forms can significantly impact on how power is used, and transformational change may occur when they are openly discussed and critiqued, including with participation from health providers (Grimen 2009).

Over time, the findings demonstrated that formal partnering could have mixed impacts on consumers and health providers. Consumers could feel empowered and benefit from increased knowledge and skills. However, they could also find formal partnering physically and/or emotionally demanding. Health providers perceived that consumers had a unique perspective on health services, but health providers also felt pressured for time and perceived they were unable to meet consumers' expectations.

In the companion intervention review, Lowe 2021 concluded there was not enough evidence to determine if formal partnerships had any effects compared to usual practice, or compared with other non-partnership approaches. Interestingly though, our findings showed that health providers and consumers perceived positive impacts of formal partnering on person-centred culture, built environment, design and delivery of services. There may be a couple of reasons for this discrepancy. Firstly, measuring outcomes related to health service culture, built environment, design and delivery of services using quantitative data is challenging. Secondly, to demonstrate there were improvements in outcomes such as health service culture, design and delivery, measurements would need to be taken from the broader patient population rather than solely from the partnership members. However, some of the included studies in the companion review did not collect data from this broader patient population.

Finally, implementation of the best practice principles for partnering developed in this review may be complex. Whilst partnering with consumers is core to person-centred care, the findings of this review suggest that in practice, partnering is still perceived as an "optional extra" for many health services. Further

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alignment of health services with the goals of person-centred care may assist in facilitating the system-wide changes needed to foster successful partnerships (Byrne 2020). This might happen, for example, by ensuring health providers are supported with the time and resources critical to building strong, trusting and accountable partnerships with consumers.

Overall completeness and applicability of evidence

This QES was co-produced with an Australian Stakeholder Panel of consumers, health providers and policymakers. The contributions of the Stakeholder Panel, at various stages across the QES process, were a strength and enhanced the applicability of this review to health services. The best practice principles, for example, could not have been developed without their input. However, a limitation of the Stakeholder Panel was that it included only Australian representatives. While adhering to principles of scientific research, and basing any suggested changes or additions to the review within that context, the lens of the stakeholders was the Australian health system. Whilst the best practice principles are based on the QES findings, it is possible that they are more applicable to the Australian context given the consumers, practitioners and policymakers shaping their formation were all based in Australia.

A limitation of this review was that the database searches were conducted in October 2018. The lapse in time between the search date and review completion incorporates the additional time needed for co-production, including during a pandemic. We believe that findings in this QES are not greatly sensitive to change as there is already a large body of contributing evidence from a wide range of settings and participants. Adding more studies to an already large body of evidence is unlikely to change our confidence in most of the review findings. The only finding rated as very low confidence was *Finding 19 Working in partnership could lead to improvements in health service evaluation.* Our confidence in this finding was rated down primarily due to relevance and adequacy, as findings were based on only two studies in two countries and settings.This finding would therefore be strengthened by additional studies from a range of countries in a range of different healthcare settings.

There were other limitations in the data set. Firstly, whilst we included studies from a range of countries (including low- and middle-income countries), there were some gaps in the consumer populations sampled. In particular, we were unable to find any studies fitting the eligibility criteria that included consumers who had an intellectual disablity or cognitive impairment (such as dementia). Secondly, we only included studies in English, due to a lack of translating capacity in the author team. Finally, we defined the term 'health provider' broadly, to ensure we included studies from health policy as well as health service planning, delivery and evaluation. However, a narrower definition of health provider (e.g. limiting the definition to health practitioners) may have yielded results more tailored to specific health provider roles.

Agreements and disagreements with other studies or reviews

The findings of our QES resonate strongly with the results of other recent systematic and scoping reviews about partnering with consumers in health services (Biddle 2021; Bombard 2018; Brett 2014; Liang 2018). Bombard 2018's systematic review of consumer engagement in the design, delivery, and evaluation of health services included 48 studies. They included a wider range of involvement approaches than our review (including one-off consultations with consumers) but found many similar facilitators including institutional commitment, involving consumers in recruitment, striving for a wide representation of consumers, creating flexible environments, offering stipends or reimbursement for participation, using external facilitators and including a higher proportion of consumers than providers. Given our QES included studies from more low- and middle income countries than Bombard 2018 (where over 50 per cent of studies originated in the UK), this suggests these facilitators have relevance in a broader range of geographical settings.

Biddle 2021 also captured a broader range of consumer involvement approaches than our QES, and a broader range of settings (including research facilities as well as health services). They also restricted their search to European public and private facilities (excluding the UK). Their results supported several of our key findings including that consumer involvement could be tokenistic and lacking in influence, that health providers' professional knowledge was privileged over consumers' experiential knowledge and that consumer involvement was negatively affected by a policy/practice gap. The broader scope of Biddle 2021 suggests that some findings of our review may be applicable to a wider range of consumer involvement approaches, as well as different settings (including research facility-consumer partnerships).

In a scoping review of consumer involvement in hospital health services (including 10 studies), Liang 2018 also found barriers and facilitators similar to our review. These included that barriers occurred mainly at the provider level, involved negative beliefs about patient roles and input, and that challenges existed in resolving differences in management and patient priorities. Facilitators similar to our QES included formalising patient roles, facilitating informal interactions and active solicitation of patient input. The similarity of our findings to a scoping review in a more narrow context (hospitals rather than health services more generally) indicates our findings are also applicable to more specific healthcare settings.

Finally, Brett 2014 conducted a systematic review of the impacts of consumer involvement in the UK National Health Service. Similar to our review, the authors found that working with consumers contributed to changing health provider attitudes about the value of user involvement.

Summary of integrating the qualitative findings with a Cochrane intervention effects review

We integrated the results of the QES with the corresponding Cochrane intervention effects review (Lowe 2021) using a matrix approach. The results showed that facilitators of formal partnering used in the trials included remuneration for consumers, consumers' access to peer networks or data to inform their contributions and use of external facilitators. The trials also often included strategies to lessen consumers' feelings of intimidation, including having an equal number of consumers as health providers, having consumers co-facilitate sessions and having access to consumer-only meetings prior to participating in the partnership with health providers. Barriers to formal partnering within the trials included lack of opportunities for consumers to develop their own role, or contribute their own priorities in discussions. Vague descriptions of decision-making processes

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often made it difficult to determine whether consumers had been involved meaningfully in decision-making. Consideration of the government and organisational context, as well as the positive and negative impacts of partnerships on consumer and health provider members were also often neglected.

The results suggest that future randomised controlled trials of partnering in formal group formats could be improved by designing the partnership intervention to optimise partnership facilitators, as found in this QES. The findings also suggest that future trials could include additional outcome measures such as consumer involvement in shaping the consumer role, consumers' ability to contribute their own priorities and consumers' satisfaction with decision-making processes.

AUTHORS' CONCLUSIONS

Successful partnerships with consumers require health providers to continually reflect on and address power imbalances that may constrain consumers' participation. Such imbalances may be particularly acute in recruitment procedures, meeting structure and content, and decision-making processes. Formal partnerships can have both positive and negative impacts on consumers and health providers.

The findings of the QES were developed into best practice principles for formal partnering to promote person-centred health services. These principles focused on the facilitators of positive partnership formation and process, and practical strategies to support implementing the principles into practice. The following were the best practice principles.

Leadership and health service culture

Formal partnering is supported and endorsed by government stakeholders and health service leadership.

Examples of best practice

- Government policies and standards endorse the importance of formal partnering in service planning, delivery and evaluation.
- Governments support the implementation of policies and standards of formal partnering into health services through guidance documents, funding, and structures that support formal partnership decision-making.
- Health service leaders are committed to building capacity in formal partnering. Formal partnering is embedded across all levels of the health service.

Diversity

Formal partnering opportunities are accessible to a diverse range of consumers.

Examples of best practice

- Time and resources are dedicated to recruiting consumers from underserved populations, such as Indigenous populations, culturally and linguistically diverse groups, LGBTIQA+ communities, people from low socio-economic groups, and people with disabilities.
- Any recruitment criteria and processes for consumer representatives balance the need for specific skills with the need to promote diversity (e.g. previous committee experience may privilege people from professional backgrounds).
- Meeting times are accessible for a broader range of consumers (e.g. meeting outside work hours or on weekends may be preferable)
- Meeting arrangements are flexible (e.g. breaks are provided in meetings, and consumers can pause their involvement for a period of time in a formal partnership when needed).
- Other resources are provided during meetings to support a diverse range of consumers to participate (e.g. childcare, food, accessible venues, support for people with communication disabilities, and access to interpreters).
- Remunerating consumers for their time and/or expenses (such as transport to meetings) may improve access to a more diverse range of consumers.

Equity

Consumers have access to the support they need, to contribute equally equitably in formal partnerships with health providers. Power imbalances between health providers and consumers in formal partnerships are identified and addressed.

Examples of best practice

- Consumers are involved in recruiting new consumers for formal partnerships (e.g. consumers choose their own representatives and/or are involved in the recruitment strategy).
- The proportion of consumers to health providers in a formal partnership is equitable (e.g. consumers could comprise one third, one half or majority membership of a formal partnership).
- Less formal, smaller meetings or sub-committees may be more accessible than large, formal meeting structures.
- Consumers have access to consumer-only meetings to help support their involvement in formal partnerships.
- Consumers have access to peer networks or data (such as consumer feedback surveys) to inform their contributions.
- Remunerating consumers for their time and/or expenses (such as transport to meetings) may improve equity.
- Consumers are offered ongoing training about the health service, formal partnerships and conducting their role.

Mutual respect, shared vision, and regular communication

Consumers and health providers are respected for their knowledge and expertise. The consumer role is clear to both consumers and health providers. They share a common vision for the formal partnership, and foster commitment and trust. Consumers and health providers communicate regularly, exchange information, and have strong relationships with senior decision-makers in the health service.

Examples of best practice

- The chairperson is impartial, helps all partners feel valued, and facilitates the development of a shared vision for the formal partnership.
- Consumers are involved in shaping their role and/or are clear about the expectations of the role.

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- Training is provided to health providers to reflect on potential assumptions about the role of consumers and the value of their contributions, and how to partner with consumers.
- When needed, skilled facilitators and moderators may help to ensure consumers' views are actively sought and integrated into decisions.
- Employment of a consumer coordinator may help to facilitate buy-in of consumers' ideas with senior leadership.

Shared agendas and decision-making

Consumers and health providers share agenda-setting and decision-making in formal partnerships.

Examples of best practice

- Consumers may lead or co-lead a formal partnership.
- Consumers are actively involved in agenda-setting. Token involvement in agenda-setting is avoided, including health providers pre-determining the agenda without consumer input, health providers not accommodating contributions perceived to be outside the health service's priorities, health providers only allowing consumer issues to be raised as "any other business" and health providers assuming consumers do not want to be involved in particular agenda items.
- Consumers understand the decisions to be made and are involved in the decision-making process. Token involvement in decision-making is avoided, including consumers having no power over decision-making processes, consumers being asked to "rubber-stamp" decisions already made and consumers not being included in key discussions.
- When the formal partnership is tasked with providing advice or options, rather than final decisions, consumers' suggestions and ideas are listened to and followed up.

Influence

By working in formal partnerships, consumers contribute to tangible improvements in health policy and services, i.e., in the promotion of and delivery of more person-centred care. These improvements can occur in strategic decision-making and community ownership of health services, health service culture and the built environment, health service design, delivery and evaluation.

Sustainability

Consumers and health providers involved in formal partnerships may experience both positive and negative impacts of their involvement over time. Negative impacts should be addressed to avoid undermining the sustainability of the formal partnership.

Examples of impacts for consumers

- Positive impacts: increased confidence, knowledge and skills.
- Negative impacts: difficulty sustaining participation over long periods, becoming emotionally affected by the role and managing the impact of a chronic or acute illness while participating in formal partnerships.

Examples of impacts for health providers

- Positive impacts: benefit from the unique perspective provided by consumers.
- Negative impacts: not having sufficient time to participate in formal partnerships, perceiving they are setting up consumer expectations they cannot meet.

Implications for research

Randomised controlled trials that incorporate the best practice principles of formal partnership approaches are required. Ideally, these trials should also examine how formal partnering approaches in health services planning, delivery and evaluation impact on patients' day-to-day clinical care. Qualitative research focusing on the barriers and facilitators to implementing the best practice principles would also contribute to our understanding of whether, and how the principles work in practice.

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* Indicates the major publication for the study

CHARACTERISTICS OF STUDIES

Characteristics of included studies *[ordered by study ID]*

Abelson 2004

Study characteristics	
Country	Canada
Setting	Health Authorities

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Abelson 2004 *(Continued)*

Specific clinical area	Range
Partnership participants	Citizens (members of community-based volunteer organisation), and health decision-makers
Partnership format	Public deliberation processes
Purpose of partnership	Health policy decision making (priority-setting, resource allocation and health planning) for public participation in the health sector
Data collection method	Focus groups
Notes	No conflicts of interest declared
Notes	Funding source: the Canadian Health Services Research Foudation, which is now called Healthcare Excellence Canada.

Attree 2011

Study characteristics	
Country	England
Setting	Health and social care/ cancer; Macmillan regions
Specific clinical area	Cancer services
Partnership participants	Health professionals, service user representatives (cancer patients)
Partnership format	Committee Network Partnership Groups
Purpose of partnership	Improvement of the quality of cancer care through service user involvement.
Data collection method	Interviews, documentary analysis
Notes	No conflicts of interest declared
Notes	Funding source: Macmillan Cancer Support

Boivin 2014

Study characteristics	
Country	Canada
Setting	Health and Social Services Centers
Specific clinical area	Chronic diseases
Partnership participants	Patients, public representatives and professionals
Partnership format	Meetings

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Boivin 2014 *(Continued)*

Purpose of partnership	Development and implementation of an effective public involvement intervention
Data collection method	Analysis of video transcripts; structured notes; observations
Notes	Article does not include a conflict of interest statement. Attempts to contact lead author were unsuccessful.
Notes	Funding source: the Canadian Foundation for Healthcare Improvement and the Agence de la Sant´e et des Services Sociaux de l'Abitibi-T´emiscamingue. Antoine Boivin was supported by a Clinician-Scientist Award from the Canadian Institutes of Health Research, and Pascale Lehoux held the Canada Research Chair on Innovation in Health.

Byskov 2014

Study characteristics	
Country	Africa; Tanzania, Kenya, Zambia
Setting	Health sector decision-making at district, hospital, and first line facility level
Specific clinical area	Range
Partnership participants	District/Council Healthcare Management Team plus community stakeholders
Partnership format	Committees
Purpose of partnership	Priority-setting for district health services, especially HIV/AIDS, malaria, emergency obstetric care and general care
Data collection method	Document analysis and observations, in-depth interviews
Notes	No conflicts of interest declared
Notes	Funding source: European Union Sixth Framework Programme (INCO-2003-A.1.2, contract PL517709) for the Specific Targeted Research and Innovation Project REACT – REsponse to ACcountable priority setting for Trust in health systems.

Croft 2016

Study characteristics	
Country	England
Setting	Commissioning organisations
Specific clinical area	Range
Partnership participants	Managers, clinicians, patient involvement representatives
Partnership format	Committee and governing board
Purpose of partnership	Enhance decision

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Croft 2016 *(Continued)*

	making processes for commissioning organisations
Data collection method	Semi-structured interviews and observations
Notes	Article does not include a conflict of interest statement. Attempts to contact lead author were unsuccessful.
Notes	Funding source: the NIHR HS&DR funding stream Grant number 12/5002/01, Graeme Currie & Sophie Staniszewska were funded by NIHR CLAHRC West Midlands.

DeCamp 2015

Study characteristics	
Country	USA
Setting	Hospital-based primary care practice; ambulatory care
Specific clinical area	Paediatrics
Partnership participants	Latina mothers/ consumer representatives, clinic staff
Partnership format	Advisory board
Purpose of partnership	Quality improvement of health services by understanding the experiences of Spanish-speaking parents on a family advisory board
Data collection method	Semi-structured interviews
Notes	Article does not include a conflict of interest statement. Attempts to contact lead author were unsuccessful.
Notes	Funding source: the Thomas Wilson Sanitarium for the Children of Baltimore City, the Aaron and Lillie Straus Foundation, and Johns Hopkins Bayview Medical Center.

Durey 2016

Study characteristics	
Country	Australia
Setting	District / local health care services; Hospitals
Specific clinical area	Range
Partnership participants	Health service users (some part of the Health Action Group and local community members), health provider of Aboriginal services, plus mainstream health service providers, Aboriginal and non-Aboriginal professionals
Partnership format	Committee (District Aboriginal Health Action Groups)
Purpose of partnership	Quality improvement of the community engagement strategy targeting Indigenous Australians

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Durey 2016 *(Continued)*

Data collection method	Interviews, yarning circle (culturally appropriate group discussion)
Notes	No conflicts of interest declared
Notes	Funding source: the Government of Western Australia, Department of Health to Curtin University in Perth

Goodman 2011

Study characteristics	
Country	Kenya
Setting	Health centres and dispensaries
Specific clinical area	Range
Partnership participants	Health worker in-charge of the health facility, district (rural) managers, health workers, health facility committee members, and community members (patients)
Partnership format	Health facility committees
Purpose of partnership	To explore the nature and depth of the engagement of Health Facility Committees by management and how this contributed to community accountability
Data collection method	Interviews
Notes	No conflicts of interest declared
Notes	Funding source: the Consortium for Research on Equitable Health Systems (CREHS) which is supported by the United Kingdom's Department for International Development (DFID). CG, AO and SM were members of the KEMRI-Wellcome Trust Research Programme in Kenya (core grant #077092). SM was also supported by a fellowship from the Wellcome Trust (WT 085418).

Greco 2006

Study characteristics	
Country	Devon, England, UK
Setting	North and East Devon localities, GPs, Primary Care
Specific clinical area	Primary Healthcare
Partnership participants	General practitioners, Nurses, patients, Health professionals
Partnership format	Patient – staff partnership groups (critical friend group)
Purpose of partnership	To discuss the issues raised via systematic patient feedback and progress the patient involvement agenda in line with the new British general practice (GP) contract.

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Greco 2006 *(Continued)*

Data collection method	Qual component of mixed methods: Interviews
Notes	Article does not include a conflict of interest statement. Attempts to contact lead author were unsuccessful.
Notes	Funding source: the NHS Modernisation Agency and the former North and East Devon Regional Health Authority

Greene 2018

Study characteristics	
Country	USA
Setting	Primary care, specialist, paediatric clinic; ambulatory care
Specific clinical area	Range
Partnership participants	Patient partners and health providers
Partnership format	Quality improvement team meetings
Purpose of partnership	To identify the ways patient partners influence quality improvement teams and to document the extent of the impact on the quality of medical care
Data collection method	Interviews and focus groups
Notes	No conflicts of interest declared
Notes	Funding source: the Robert Wood Johnson Foundation

Gurung 2017

Study characteristics	
Country	Nepal
Setting	Mental health organisations
Specific clinical area	Mental health
Partnership participants	Mental health service users and caregivers in policy making, service planning, monitoring and research
Partnership format	National health system processes, caregivers.
Purpose of partnership	Improve mental health outcomes through exploring service user and caregiver involvement and barriers to involvement in a low- and middle-income country
Data collection method	Semi-structured interviews
Notes	No conflicts of interest declared

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Gurung 2017 *(Continued)*

Notes	Funding source: the European Union within the 7th Framework Program (Grant Agreement Number305968)

Haarsma 2015

Study characteristics	
Country	the Netherlands
Setting	Palliative care networks
Specific clinical area	Palliative care
Partnership participants	Patient representatives and professional staff
Partnership format	Sounding board group and management team meetings
Purpose of partnership	Examine in depth the current practice of public involvement in palliative care to increase the quality of care
Data collection method	Interviews (including fictional critical incidents technique) and focus groups; field notes
Notes	No conflicts of interest declared
Notes	Funding source: The Netherlands Organisation for Health Research and Development

Heenan 2004

Study characteristics	
Country	Northern Ireland
Setting	Community health project
Specific clinical area	Range (health promotion)
Partnership participants	Health and social service professionals, and community and voluntary workers
Partnership format	Working group
Purpose of partnership	Identify key issues that emerged during the establishment of partnership between statutory health providers and the community and voluntary sectors and to assess how they could inform future initiatives, to increase the effectiveness of health promotion planning and delivery.
Data collection method	Interviews
Notes	No conflicts of interest declared
Notes	Funding source: the author reported no funding was provided.

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IPFCC 2018

Study characteristics	
Country	USA
Setting	Hospitals
Specific clinical area	Range
Partnership participants	Patients and families, health care professionals / hospitals
Partnership format	Patient and Family Advisory Councils (PFACs)/ and PFACs in hospitals (NYC)
Purpose of partnership	Improving healthcare policies and practices by understanding the prevalence and functioning of Patient and Family Advisory Councils and Patient and Family Advisors
Data collection method	Survey, interviews, follow-up interviews, site visits
Notes	No conflicts of interest declared
Notes	Funding source: the New York State Health Foundation (NYSHealth).

Jha 2018

Study characteristics	
Country	England, UK
Setting	Training school/ two hospitals
Specific clinical area	Range
Partnership participants	Patients with personal experience of harm or error during medical diagnosis, treatment, care either to themselves or relatives and trainee doctors.
Partnership format	Patient involvement in patient-led safety initiatives in collaboration with trainee doctors.
Purpose of partnership	To test an educational patient-led intervention to increase patient safety
Data collection method	Qual component of mixed methods: workshops, culminating in an Intervention (sharing of narrative, discussion, follow-up interviews, evaluations)
Notes	No conflicts of interest declared
Notes	Funding source: the National Institute of Health Research

Jivanjee 2007

Study characteristics	
Country	USA
Setting	Children's mental health services; ambulatory care

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Jivanjee 2007 *(Continued)*

Specific clinical area	Mental health
Partnership participants	Mental health professional and other service providers and community representatives/family members
Partnership format	Advisory groups
Purpose of partnership	To evaluate 'systems of care' by examining the partnership between evaluators and family members
Data collection method	Unstructured or semi-structured Interviews
Notes	No conflicts of interest declared
Notes	Funding source: the Substance Abuse and Mental Health Services Administration (SAMHSA) Center for Mental Health Services' Comprehensive Community Mental Health Services for Children and Their Families program

Johns 2014

Study characteristics	
Country	Australia
Setting	Community setting- rural health service; Council, and hospital
Specific clinical area	Health and aged care
Partnership participants	Local rural community members, community representatives,health professionals, staff members from health centres, such as GP
Partnership format	Committee
Purpose of partnership	Promote and improve community health and well-being in rural areas
Data collection method	Individual and group interviews, written documentation, and observation
Notes	No conflicts of interest declared
Notes	Funding source: authors contacted about funding source but no response received

Kidd 2007

Study characteristics	
Country	Australia
Setting	Rural mental health service
Specific clinical area	Mental health
Partnership participants	Consumer representatives and health providers

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Kidd 2007 *(Continued)*

Partnership format	Steering committee
Purpose of partnership	To explore the perceptions of consumer advocates and clinicians and understand how consumer participation policy initiatives are enacted at a service delivery level
Data collection method	Semi-structured interviews
Notes	Article does not include a conflict of interest statement. Attempts to contact lead author were unsuccessful.
Notes	Funding source: authors contacted about funding source but no response received

Lewis 2014

Study characteristics	
Country	Scotland
Setting	Statutory sector and community groups
Specific clinical area	Mental health
Partnership participants	Service users, healthcare staff/managers
Partnership format	Policy and planning committee
Purpose of partnership	To advise policy to improve service user involvement in mental health services
Data collection method	Participant observation at service user/community and policy group meetings, interviews, informal interactions
Notes	Article does not include a conflict of interest statement. Attempts to contact lead author were unsuccessful.
Notes	Funding source: the UK Medical Research Council

MacDonald 2015

Study characteristics	
Country	United Kingdom
Setting	Mental health Service foundation trusts in rural/ urban areas
Specific clinical area	Mental health
Partnership participants	Elected and appointed governors, and public and patient governor
Partnership format	Council of Governors in three foundation trusts
Purpose of partnership	To explore the experience of service user governors in foundation trusts and their capacity to hold boards to account

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MacDonald 2015 *(Continued)*

Data collection method	Survey of staff and users/ topic, service-based forums, via user input to recruitment and staff training, interviews, case studies of user groups, focus groups, document analysis, observations
Notes	No conflicts of interest declared
Notes	Funding source: the National Institute for Health Research Service Delivery and Organisation Programme, NIHR Service Delivery and Organisation programme

Maher 2017

Study characteristics	
Country	New Zealand
Setting	Innovation and improvement centre
Specific clinical area	Range
Partnership participants	Healthcare professionals and patients
Partnership format	Experience-based co-design programme commissioned by the Health Quality and Safety Commission New Zealand
Purpose of partnership	Quality improvement and to support and enable patient engagement and participation across the health and disability sector
Data collection method	Analysis of Workbooks and semi-structured interviews
Notes	No conflicts of interest declared
Notes	Funding source: author contacted and reported that there was no specific grants or funds attached to this project. Ko Awatea organisation funded the project through the authors' wages.

Malfait 2018

Study characteristics	
Country	Belgium
Setting	General and mental health hospitals
Specific clinical area	Range
Partnership participants	Internal stakeholders (e.g. hospital employees and members of the board), and professional external stakeholders (e.g. insurance companies or primary healthcare workers), patients, their family members, and patient representatives, president and secretaries
Partnership format	Stakeholder committees
Purpose of partnership	To identify conditions that contribute to the involvement of patients and public in the decision making processes of hospital policy through a stakeholder committee

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Malfait 2018 *(Continued)*

Data collection method	Qual component of mixed methods: questionnaires, observation, focus groups
Notes	No conflicts of interest declared
Notes	Funding sources: the ICURO, the Flemish federation of public hospitals, and The King Baudouin Foundation [Koning Boudewijn Stichting]

McDaid 2009

Study characteristics	
Country	Ireland
Setting	National mental health non-governmental organisation
Specific clinical area	Mental health
Partnership participants	Mental health professionals and consumers
Partnership format	Advisory committee; mental health service users experience on an AC
Purpose of partnership	To identify barriers to equal participation of service users in advisory committees and strategic decision-making
Data collection method	Semi-structured interviews
Notes	No conflicts of interest declared
Notes	Funding source: part funded by the National Disability Authority

Nathan 2014

Study characteristics	
Country	Australia
Setting	Health region hospitals
Specific clinical area	Range
Partnership participants	Staff and consumer representatives
Partnership format	Committee (community representatives)
Purpose of partnership	Improve effectiveness of community representatives in health services
Data collection method	Interviews, observations, field notes
Notes	Article does not include a conflict of interest statement. Attempts to contact lead author were unsuccessful.

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Nathan 2014 *(Continued)*

Notes	Funding source: Authors noted that quote: "This research received no specific grant from any funding agency in the public, commercial or not-for profit sectors."

Newberry 2005

Study characteristics	
Country	Canada
Setting	21 Ontario branches of the Canadian Mental Health Association
Specific clinical area	Mental health
Partnership participants	Executive directors, professionals, and consumers
Partnership format	Hybrid, management and policy boards ;consumers on mental health boards of health agencies
Purpose of partnership	To improve meaningful participation of consumers of health services on the governing boards of mental health agencies
Data collection method	Interviews
Notes	Article does not include a conflict of interest statement. Lead author reported no conflicts of interest.
Notes	Funding source: author reported that the research was self-funded

Potter 2016

Study characteristics	
Country	USA
Setting	Community-based services; children mental health programs
Specific clinical area	Children's mental health
Partnership participants	Family members (primarily parents) and health professionals
Partnership format	Committee (Community Collaboratives)
Purpose of partnership	To explore the motives of lay participants in community collaborations for children's mental health
Data collection method	Observations and interviews
Notes	No conflicts of interest declared
Notes	Funding source: An Alumni Dissertation Grant from the Heller School at Brandeis University paid for professional transcription of half of the interviews. Funding through a subcontract to Human Services Research Institute (Cambridge, MA) and from the children's mental health department in the state in which the study was conducted supported the staff time of the author during the first few months of data collection.

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Restall 2013

Study characteristics	
Country	Canada
Setting	Mental health and social policy making context
Specific clinical area	Mental health
Partnership participants	Consumers and health providers
Partnership format	Policy debates via formal group formats
Purpose of partnership	To explore how the social and personal outcomes of citizen-user involvement in mental health policy-making were understood by policy actors and to guide and develop citizen-user involvement
Data collection method	Semi-structured Interviews, document review, field notes
Notes	No conflicts of interest declared
Notes	Funding source: the Canadian Institutes of Health Research Fellowship and the Canadian Association of Occupational Therapists Doctoral Scholarship

Rutebemberwa 2009

Study characteristics	
Country	Uganda
Setting	Hospitals
Specific clinical area	Range
Partnership participants	Hospital staff and service user (community) representatives
Partnership format	Committees
Purpose of partnership	To explore how communities that live around hospitals pass on their views to and receive feedback from the hospitals' management and administration
Data collection method	Interviews and focus groups
Notes	No conflicts of interest declared
Notes	Funding source: the UK Department for International Development (DfID).

Schaaf 2017

Study characteristics	
Country	Zambia

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Schaaf 2017 *(Continued)*

Setting	Primary care; local level
Specific clinical area	Range
Partnership participants	Citizens, health providers and locally-elected officials
Partnership format	Citizen voice and action group (world vision)
Purpose of partnership	Inform program implementers, donors and other stakeholders about aspects of context, mechanisms and outcomes that might be considered in the application of a social accountability program theory to improve quality of health services in low- and middle-income countries
Data collection method	Interviews and focus groups
Notes	No conflicts of interest declared
Notes	Funding source: the Danish Ministry of Foreign Affairs and World Vision International

Scholz 2018

Study characteristics	
Country	Australia
Setting	Tertiary referral Hospital
Specific clinical area	Range
Partnership participants	Managers, clinicians, consumers
Partnership format	Consumers and health professionals engaged in systemic partnerships
Purpose of partnership	Improve the quality of health services by understanding how to overcome power imbalances in partnerships between consumers and health professionals
Data collection method	Semi-structured interviews
Notes	No conflicts of interest declared
Notes	Funding source: University of Canberra Health Research Institute Funding Grant.

Sharma 2016

Study characteristics	
Country	USA
Setting	Primary care clinics
Specific clinical area	Range

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Sharma 2016 *(Continued)*

Partnership participants	Patients, family members, caregivers, clinic staff members, leaders and principal regional stakeholders in patient engagement
Partnership format	Participant Advisory Council
Purpose of partnership	Practice improvement by understanding how patient advisory councils are organised and the common challenges and benefits of high functioning PACs
Data collection method	Semi-structured interviews
Notes	Conflict of interest: AES has received travel reimbursement for dissemination of research findings at the Western Clinicians Network (WCN) Region IX Annual Meeting in June 2015, and served as a consultant for WCN to develop a toolkit based on research findings. The Center for Excellence in Primary Care received payment for a training and keynote address about patient engagement delivered by Rachel Willard-Grace in 2014. AW, OZ, KD, CP, and MBP have no conflicts to disclose.
Notes	Funding Source: the National Center for Advancing Translational Sciences, National Institutes of Health (NIH), through UCSF-CTSI Grant Number UL1 TR000004. AES was supported by National Research Service Award T32HP19025.

Sitzia 2006

Study characteristics	
Country	England
Setting	Local cancer services/ networks
Specific clinical area	Cancer
Partnership participants	National health service staff and consumers
Partnership format	Partnership Groups
Purpose of partnership	Cancer service improvement by understanding the nature and outcomes of the partnership between staff and service users
Data collection method	Semi-structured interviews
Notes	No conflicts of interest to declare
Notes	Funding source: the Macmillan Cancer Relief and the Department of Health

Wiig 2013

Study characteristics	
Country	Norway
Setting	Hospitals, including micro and meso analysis at Maternal and Oncology services
Specific clinical area	Maternity and oncology

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Wiig 2013 *(Continued)*

Partnership participants	Patients, representatives, ombudsmen, hospital managers and clinical staff
Partnership format	Quality committee, patient safety committee, user panel, management meetings
Purpose of partnership	Quality improvement by understanding expectations and how patient involvement and experiences are used by hospitals
Data collection method	Interviews, non-participant observation, document analysis
Notes	No conflicts of interest to declare
Notes	Funding source: the European Community's Seventh Framework Programme

PACs: Patient advisory councils

Characteristics of excluded studies *[ordered by study ID]*

Study	Reason for exclusion
Aantjes 2014	Wrong on two or more criteria
Abayneh 2017	Wrong on two or more criteria
Abayneh 2018	Wrong study design
Abbott 2005	Wrong on two or more criteria
Aboumatar 2015	Wrong intervention
Abushousheh 2012	Wrong study design
Ackermann 2010	Wrong participants
Acri 2013	Wrong participants
Adams 2014	Wrong population
Adams 2015	Wrong on two or more criteria
Adongo 2013	Wrong on two or more criteria
Agbanu 2010	Wrong on two or more criteria
Agrawal 2016	Wrong population
Ahluwalia 2003	Wrong on two or more criteria
Ahmad 2012	Wrong participants
Ahmad 2017	Wrong on two or more criteria
Aiken 2013	Wrong on two or more criteria
Ajayi 2013	Wrong partnership format

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Study	Reason for exclusion
Alcock 2009	Wrong on two or more criteria
Alfandari 2017	Not related to person-centred care
Alghanim 2018	No shared decision-making
Allen 2005	Wrong on two or more criteria
Almeida 2016	Wrong on two or more criteria
Alvidrez 2010	Wrong on two or more criteria
Amann 2017	Wrong on two or more criteria
Anazodo 2016	Wrong on two or more criteria
Anders 2006	Wrong on two or more criteria
Anderson 2009	Wrong study design
Anderson 2011	Wrong on two or more criteria
Anderson-Lewis 2012	Wrong phenomenon
Andersson 2004	Wrong on two or more criteria
Andersson 2012	Wrong on two or more criteria
Andrews 2013	Wrong on two or more criteria
Anghel 2009	Wrong on two or more criteria
Anie 2016	Wrong on two or more criteria
Antonacci 2018	Wrong on two or more criteria
Ardila-Gomez 2018	Wrong on two or more criteria
Arem 2011	Wrong on two or more criteria
Arevian 2018	Not related to person-centred care
Argaw 2007	Wrong on two or more criteria
Armstrong 2017	Wrong on two or more criteria
Asad 2016	Wrong on two or more criteria
Atkinson 2011	Wrong study design
Attree 2004	Wrong on two or more criteria
Babu 2006	Wrong phenomenon
Bailey 2005	Wrong on two or more criteria

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Study	Reason for exclusion
Baines 2018	Wrong study design
Balbale 2016	Wrong on two or more criteria
Bandesha 2005	Wrong on two or more criteria
Baptiste 2005	Wrong on two or more criteria
Baquet 2012	Wrong on two or more criteria
Baraitser 2003	No shared decision making
Barbato 2014a	Wrong phenomenon
Barker 2016	Wrong partnership format
Barnes 2004	Wrong study design
Barnes 2006	Wrong on two or more criteria
Barnes 2009	Wrong study design
Barnett 2009	Wrong on two or more criteria
Baron-Epel 2003	Wrong study design
Barr 2015	Wrong on two or more criteria
Barson 2017	Wrong on two or more criteria
Battams 2009	Wrong on two or more criteria
Batten 2011	Not related to person-centred care
Bedford 2017	Wrong on two or more criteria
BeLue 2012	Wrong on two or more criteria
Benbow 2011	Not related to person-centred care
Bergman 2016	Wrong participants
Berkowitz 2001	Wrong study design
Bernardes 2015	Wrong on two or more criteria
Berry 2011	Wrong on two or more criteria
Bertrand 2018	Wrong phenomenon
Bess 2011	Wrong on two or more criteria
Bethell 2017	Wrong phenomenon
Bettger 2016	Wrong phenomenon

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Study	Reason for exclusion
Blackwell 2000	Wrong on two or more criteria
Blackwell 2017	Wrong on two or more criteria
Blank 2004	Wrong on two or more criteria
Blickem 2013	Wrong on two or more criteria
Bodolica 2016	Wrong study design
Boelsma 2014	Wrong on two or more criteria
Boivin 2009	Wrong on two or more criteria
Boivin 2010	Not related to person-centered care
Bokhour 2018	Wrong on two or more criteria
Bollard 2012	Wrong on two or more criteria
Bolton 2016	Wrong on two or more criteria
Borg 2009	Wrong study design
Bors 2012	Wrong on two or more criteria
Bortoletto 2017	Wrong on two or more criteria
Bossen 2012	Wrong on two or more criteria
Bouch 2011	Wrong on two or more criteria
Boudioni 2012	Wrong on two or more criteria
Bovaird 2007	Wrong study design
Boyd 2012	Wrong on two or more criteria
Bradshaw 2008	Wrong study design
Braithwaite 2017	Wrong on two or more criteria
Breslau 2015	Wrong on two or more criteria
Brown 2001	Wrong on two or more criteria
Brown 2008	Wrong study design
Brown 2010	Wrong on two or more criteria
Brown 2013	No shared decision-making
Bruni 2007	Wrong on two or more criteria
Brussoni 2012	Wrong on two or more criteria

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Study	Reason for exclusion
Buck 2004	Wrong intervention
Butterfoss 2001	Wrong study design
Butterfoss 2006	Wrong study design
Bynum 2014	Wrong on two or more criteria
Cabassa 2015	Wrong on two or more criteria
Campbell 2013	Wrong on two or more criteria
Campbell 2017	Wrong study design
Carlson 2006	Not related to person-centred care
Carlsson 2006	No shared decision-making
Carpenter 2018	Wrong on two or more criteria
Carroll 2015	Wrong participants
Carter 2013	Wrong on two or more criteria
Carter 2015	Wrong study design
Cashin 2008	Wrong on two or more criteria
Castro 2018	Wrong study design
Cavet 2004	Wrong study design
Challenor 2010	Wrong on two or more criteria
Chamberlin 2005	Wrong study design
Chan 2013	Wrong participants
Chantler 2017	Wrong phenomenon
Chaoniyom 2005	Wrong on two or more criteria
Chilaka 2005	Wrong on two or more criteria
Chreim 2012	Wrong on two or more criteria
Christianson 2016	Wrong on two or more criteria
Chung 2010	Wrong on two or more criteria
Clarke 2017	Wrong study design
Cleary 2006	Wrong study design
Coad 2008	Wrong on two or more criteria

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Study	Reason for exclusion
Coker 2014	Wrong phenomenon
Cook 2002	Wrong on two or more criteria
Cornish 2006	Wrong on two or more criteria
Cowan 2011	Wrong phenomenon
Coyne 2011	Wrong on two or more criteria
Craddock 2002	Wrong on two or more criteria
Cramm 2013	Wrong study design
Crawford 2001	Wrong study design
Curry 2012	Wrong on two or more criteria
D'Avanzo 2018	Wrong study design
Daudelin 2011	Wrong intervention
Davies 2014	Wrong on two or more criteria
Daykin 2004	Wrong phenomenon
De Rouck 2008	Wrong on two or more criteria
Delnoij 2010	Wrong phenomenon
Demetrakopoulos 2012	No shared decision-making
Denis 2017	Wrong on two or more criteria
Dent 2006	Wrong study design
Dent 2013	Wrong study design
Devlin 2003	Wrong study design
Diaz 2011	Wrong on two or more criteria
Doherty 2006	Wrong on two or more criteria
Donetto 2015	Wrong study design
Dongre 2009	Wrong on two or more criteria
Downe 2007	Wrong on two or more criteria
Dye 2005	Wrong phenomenon
Earle-Richardson 2009	Wrong on two or more criteria
Early 2014	Wrong on two or more criteria

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Study	Reason for exclusion
Edelenbos 2006	Not related to person-centred care
Eftekhari 2013	Wrong on two or more criteria
Eisinger 2001	Not related to person-centred care
El 2002	Wrong phenomenon
Elder 2017	Wrong on two or more criteria
Eldh 2006	Wrong on two or more criteria
Ellinis 2011	Wrong on two or more criteria
Ennis 2014	Wrong phenomenon
Enriquez 2010	Wrong participants
Enzinger 2017	Wrong on two or more criteria
Erwin 2017	Not related to person-centred care
Escaron 2016	Wrong on two or more criteria
Evans 2003	Wrong phenomenon
Eyre 2003	Wrong phenomenon
Faber 2003	Wrong participants
Factor 2002	Wrong on two or more criteria
Falahat 2013	Wrong on two or more criteria
Farmer 2018a	Wrong on two or more criteria
Fawcett 2013	Wrong phenomenon
Feldman 2015	Wrong on two or more criteria
Fitzgerald 2011	Wrong on two or more criteria
Fleet 2017	Wrong on two or more criteria
Forbat 2009	Wrong on two or more criteria
Forrest 2000	Wrong on two or more criteria
Forrest 2004a	Not related to person-centred care
Forster 2008	Wrong study design
Fotaki 2011	Wrong study design
Fraser 2017	Wrong partnership format

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Study	Reason for exclusion
Frazier 2007	Not related to person-centred care
Fredelius 2002	Wrong on two or more criteria
Fuertes 2012	Wrong phenomenon
Garcia 2014	Wrong on two or more criteria
Gibson 2005	Wrong on two or more criteria
Gil 2014	Wrong on two or more criteria
Gill 2011	Wrong on two or more criteria
Gill 2011a	Wrong on two or more criteria
Given 2011	Wrong participants
Glase 2015	Wrong on two or more criteria
Glynos 2012	Wrong phenomenon
Godfrey 2013	Wrong on two or more criteria
Goodridge 2018	No shared decision-making
Gordon 2005	Wrong study design
Goto 2009	Not related to person-centred care
Grant 2007	Wrong study design
Grant 2018	Wrong study design
Greene 2007	Wrong on two or more criteria
Griswold 2013	Wrong study design
Groene 2014	Wrong study design
Groene 2015	Wrong study design
Groenen 2017	Wrong on two or more criteria
Grogan 2012	Wrong on two or more criteria
Grundy 2017	Wrong phenomenon
Gustavsson 2016	Wrong partnership format
Gutteridge 2010	Wrong on two or more criteria
Hagensen 2016	Wrong intervention
Haigh 2008	Wrong study design

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Study	Reason for exclusion
Hall 2006	Wrong study design
Hall 2011	Wrong partnership format
Hameen-Anttila 2015	Wrong on two or more criteria
Happell 2002	Wrong on two or more criteria
Happell 2006	Wrong on two or more criteria
Happell 2015	Wrong on two or more criteria
Happell 2016	Wrong phenomenon
Happell 2017	Wrong on two or more criteria
Harris 2015b	Wrong study design
Hashem 2018	Wrong on two or more criteria
Henwood 2013	Wrong on two or more criteria
Hibbard 2003	Wrong study design
Higgins 2017	Wrong on two or more criteria
Hinchcliff 2016	No shared decision-making
Hogg 2001	Wrong study design
Hsieh 2005	Wrong on two or more criteria
Hsu 2010	Wrong on two or more criteria
Hunter 2016	Wrong study design
Hutt 2018	No shared decision-making
Hyman 2018	Wrong phenomenon
Isaacson 2018	Wrong phenomenon
Jacobson 2007	Wrong on two or more criteria
Jakobsen 2006	Wrong on two or more criteria
Jenkinson 2014	Wrong on two or more criteria
Johnson 2016	Wrong on two or more criteria
Jones 2008	Wrong phenomenon
Jones 2010	Wrong on two or more criteria
Jones 2011	Wrong on two or more criteria

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Study	Reason for exclusion
Jones 2017	Wrong phenomenon
Jones 2018	Wrong on two or more criteria
Jones 2018a	Wrong on two or more criteria
Kapiriri 2003	Wrong on two or more criteria
Kaplan 2006	Wrong participants
Katahoire 2015	Wrong partnership format
Kerrissey 2017	Wrong on two or more criteria
Kettles 2008	Wrong on two or more criteria
Khodyakov 2017	Wrong on two or more criteria
Kidd 2015	Wrong on two or more criteria
Kilewo 2015	Wrong population
Kiley 2000	Wrong on two or more criteria
Kim 2016	Wrong on two or more criteria
Kitson 2013	Wrong study design
Klammer 2015	Wrong on two or more criteria
Kleintjes 2013	Wrong on two or more criteria
Knightbridge 2006	Wrong phenomenon
Koutantji 2005	Wrong on two or more criteria
Kvarnström 2013	Wrong partnership format
Kyne 2009	Wrong on two or more criteria
Ladikos 2016	Wrong intervention
Larkin 2015	Wrong intervention
Lempp 2018	Wrong intervention
Liang 2018	Wrong study design
Litva 2002	Wrong phenomenon
Locock 2014	Wrong intervention
Lodenstein 2017	Wrong study design
Lwembe 2017	Wrong phenomenon

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Study	Reason for exclusion
Maar 2009	Wrong participants
Martin 2009	Wrong study design
Massoi 2009	Not related to person-centred care
Masters 2002	Wrong participants
Maxwell 2003	Wrong on two or more criteria
Mayer 2017	Wrong partnership format
McCabe 2012	Wrong on two or more criteria
McHugh 2012	Wrong on two or more criteria
McKay 2011	Wrong on two or more criteria
McKeown 2012	Wrong participants
Meehan 2007	Wrong on two or more criteria
Mende 2013	Wrong study design
Mentes 2005	Wrong participants
Mitton 2003	Wrong on two or more criteria
Mkoka 2014	Wrong phenomenon
Mohapatra 2018	Wrong partnership format
Montesanti 2017	Wrong intervention
Montgomery 2014	Wrong study design
Montoya 2011	Wrong on two or more criteria
Moreira 2015	Wrong on two or more criteria
Mosquera 2001	Wrong partnership format
Motley 2013	Wrong on two or more criteria
Muhlbacher 2014	Wrong phenomenon
Mullins 2012	Wrong participants
Murray 2015	Wrong study design
Namatovu 2014	Wrong intervention
Nathan 2011	Wrong study design
Neech 2018	Wrong on two or more criteria

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Study	Reason for exclusion
Nelson 2006	Not related to person-centred care
Nelson 2016	Wrong study design
Neuwelt 2005	Wrong on two or more criteria
Nimegeer 2016	Wrong on two or more criteria
Nunn 2015	Wrong on two or more criteria
Nyonator 2005	Wrong on two or more criteria
O'Connor 2007	Wrong on two or more criteria
O'Gorman 2012	Wrong partnership format
Oldenhof 2018	Wrong on two or more criteria
Ottmann 2008	Wrong participants
Owens 2011	Wrong phenomenon
Padgett 2004	Not related to person-centred care
Pagatpatan 2017	Wrong study design
Pals 2018	Wrong on two or more criteria
Papoulias 2018	Wrong on two or more criteria
Parker 2003	not related to person-centred care
Paterson 2014	Wrong on two or more criteria
Patten 2005	Wrong on two or more criteria
Patterson 2010	Wrong phenomenon
Payan 2017	Wrong on two or more criteria
Pelletier 2011	Not related to person-centred care
Petersen 2012	Wrong on two or more criteria
Ponte 2003	Wrong study design
Preston 2010	Wrong study design
Pursell 2013	Not related to person-centred care
Quennell 2001	Not person-centred care
Radermacher 2011	Wrong participants
Rai 2018	Not related to person-centred care

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Study	Reason for exclusion
Rance 2015	Wrong participants
Rapport 2008	Wrong phenomenon
Rasmus 2014	Wrong on two or more criteria
Ratcliffe 2017	Wrong on two or more criteria
Rathod 2016	Wrong phenomenon
Reath 2008	Wrong phenomenon
Reay 2017	Wrong participants
Reeve 2002	Wrong on two or more criteria
Reeve 2007	Wrong on two or more criteria
Renfrew 2008	Wrong phenomenon
Repper 2007	Wrong study design
Restall 2008	Wrong phenomenon
Restall 2011	Wrong on two or more criteria
Rhodes 2013	Wrong phenomenon
Rios 2007	Wrong phenomenon
Rise 2011	Wrong study design
Rise 2016	Wrong on two or more criteria
Ritchie 2001	Wrong on two or more criteria
Robert 2015	Wrong phenomenon
Roberts 2012	Wrong on two or more critera
Robinson 2014	Wrong on two or more criteria
Rose 2003	Wrong on two or more criteria
Ross 2014	Wrong on two or more criteria
Rowe 2002	Wrong phenomenon
Roy 2002	Wrong phenomenon
Rozmovits 2018	Not related to person-centred care
Rubenstein 2014	Wrong on two or more criteria
Ryan-Nicholls 2007	Wrong study design

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Study	Reason for exclusion
Sadler 2017	Wrong phenomenon
Salerno 2015	Wrong participants
Sano 2016	Wrong on two or more criteria
Savage 2006	Not related to person-centred care
Scammell 2016	Wrong study design
Scanlon 2012	Wrong phenomenon
Scholz 2017	Wrong on two or more criteria
Schulte 2007	Wrong phenomenon
Scott 2016	Wrong on two or more criteria
Sennun 2006	Wrong on two or more criteria
Shah 2006	Wrong study design
Sharma 2017	Wrong study design
Sharma 2017a	Wrong study design
Shikako-Thomas 2016	Wrong on two or more criteria
Sibbald 2009	Wrong phenomenon
Slack 2001	Wrong on two or more criteria
Slutsky 2016	Wrong phenomenon
Snijder 2015	Wrong study design
Snow 2018	Wrong on two or more criteria
Soffe 2004	Wrong on two or more criteria
Soper 2013	Wrong on two or more criteria
Sorrentino 2017	Wrong phenomenon
Speer 2005	Wrong on two or more criteria
Steffens 2015	Wrong on two or more criteria
Steffens 2016	Wrong on two or more criteria
Storm 2011	Wrong study design
Sullivan 2014	Wrong on two or more criteria
Tantchou 2017	Wrong study design

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Study	Reason for exclusion
Tataw 2012	Wrong phenomenon
Tataw 2017	Wrong on two or more criteria
Taylor 2018	Wrong on two or more criteria
Tempfer 2011	Wrong study design
Theodorou 2010	Wrong on two or more criteria
Thomas 2016	Wrong phenomenon
Thomas 2017	Wrong on two or more criteria
Thomson 2013	Wrong on two or more criteria
Thomson 2015	Wrong on two or more criteria
Thorarinsdottir 2014	Wrong study design
Thornton 2003	Wrong on two or more criteria
Timor-Shlevin 2016	Wrong on two or more criteria
Toledo 2007	Wrong on two or more criteria
Tollyfield 2014	Wrong study design
Tooke 2013	Wrong participants
Torrance 2010	Wrong study design
Towle 2003	Wrong on two or more criteria
Tritter 2003	Wrong phenomenon
Tritter 2011	Wrong study design
Tritter 2011a	Wrong study design
Truman 2002	Wrong on two or more criteria
van C, 2015	Wrong study design
van Deventer 2012	Wrong study design
van Deventer 2016	Wrong phenomenon
van Draanen 2013	Wrong on two or more criteria
van Wersch 2011	Not person-centred care related
Wait 2006	Wrong study design
Walker 2007	Wrong participants

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Study	Reason for exclusion
Walker 2015	Wrong on two or more criteria
Wallerstein 2010	Wrong on two or more criteria
Walsh 2005	Wrong phenomenon
Weinstein 2006	Wrong on two or more criteria
Whiting 2016	Wrong on two or more criteria
Wilkie 2016	Wrong study design
Willard-Grace 2015	Wrong study design
Willis 2000	Wrong on two or more criteria
Winter 2010	Wrong on two or more criteria;
Wong 2017	Wrong on two or more criteria
Worswick 2015	Wrong on two or more criteria
Wright 2006	Not related to person-centred care
Wright 2012	Wrong study design
Young 2017	Wrong on two or more criteria
Zandee 2015	Wrong on two or more criteria
Zeitz 2011	No shared decision-making

ADDITIONAL TABLES

Table 1. Studies that met the eligibility criteria but were not included in the final synthesis

Study ID	Reason not included in the final synthesis
Abelson 2001	Data richness of 3 or below
Abimbola 2015	Data richness of 3 or below
Al-Iryani 2011	Data richness of 3 or below
Allen 2008	Data richness of 3 or below
Allen 2012	Sufficient studies from the UK
Anderson 2006	Sufficient studies from the UK
Armstrong 2013	Sufficient studies from the UK

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Table 1. Studies that met the eligibility criteria but were not included in the final synthesis *(Continued)*

Austin 2011	Data richness of 3 or below
Baatiema 2013	Data richness of 3 or below
Barbato 2014	Data richness of 3 or below
Barnes 2000	Data richness of 3 or below
Bennetts 2011	Data richness of 3 or below
Bess 2009	Sufficient studies already from the USA, sufficient studies on service planning and delivery already included
Boaz 2016	Sufficient studies already included from UK, sufficient studies in the speciality of cancer
Bowen 2013	Sufficient studies already from this geographic location, older population already included
Brooks 2008	Sufficient studies already from this geographic location and in the acute setting
Campbell 2004	Data richness of 3 or below
Carr 2012	Data richness of 3 or below
Chiarella 2010	Data richness of 3 or below
Clarke 2014	Data richness of 3 or below
Coleman 2009	Data richness of 3 or below
Cotterell 2011	Data richness of 3 or below
Crawford 2003	Data richness of 3 or below
Davis 2016	Data richness of 3 or below
Daykin 2002	Data richness of 3 or below
de Freitas 2015	Data richness of 3 or below
de Souza 2017	Data richness of 3 or below
Diamond 2003	Data richness of 3 or below
Dickens 2006	Sufficient studies already included from UK, sufficient studies in the speciality of mental health
Donaldson 2007	Sufficient studies already included from UK, sufficient studies in the speciality of cancer
El Enany 2013	Sufficient studies already included from UK, sufficient studies in the speciality of mental health
Elstad 2009	Data richness of 3 or below
Evans 2015	Sufficient studies already included from UK, sufficient studies in healthcare governance
Faria 2017	Data richness of 3 or below
Farmer 2015	Data richness of 3 or below

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Table 1. Studies that met the eligibility criteria but were not included in the final synthesis *(Continued)*

Farmer 2018	Data richness of 3 or below
Flower 2000	Data richness of 3 or below
Forrest 2004	Data richness of 3 or below
Freeman 2016	Data richness of 3 or below
Frumence 2014	Data richness of 3 or below
Fudge 2008	Data richness of 3 or below
Gold 2005	Sufficient studies already included from Canada, sufficient studies in the speciality of cancer
Greene 2016	Data richness of 3 or below
Greer 2016	Data richness of 3 or below
Haines 2018	Data richness of 3 or below
Hamil 2018	Data richness of 3 or below
Harding 2010	Sufficient studies already included from UK, sufficient studies in the speciality of mental health
Harpham 2002	Data richness of 3 or below
Harris 2015	Data richness of 3 or below
Harrison 2018	Data richness of 3 or below
Heaslip 2018	Data richness of 3 or below
Herald 2012	Data richness of 3 or below
Hodge 2005	Sufficient studies already included from UK, sufficient studies in the speciality of mental health
Horrocks 2010	Data richness of 3 or below
Iedema 2010	Data richness of 3 or below
Iyanda 2017	Data richness of 3 or below
Jackson 2012	Data richness of 3 or below
Jacobs 2003	Data richness of 3 or below
Jernigan 2010	Data richness of 3 or below
Joy 2012	Data richness of 3 or below
Jun 2018	Data richness of 3 or below
Kamuzora 2013	Data richness of 3 or below
Karki 2016	Another study from Nepal already included

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Table 1. Studies that met the eligibility criteria but were not included in the final synthesis *(Continued)*

Kavcic 2015	Data richness of 3 or below
Kelaher 2014	Data richness of 3 or below
Kenyon 2016	Data richness of 3 or below
Kohler 2017	Data richness of 3 or below
Lammers 2004	Data richness of 3 or below
Lathlean 2002	Data richness of 3 or below
Lavoie-Tremblay 2014	Sufficient studies already included from Canada
Lavoie-Tremblay 2016	Sufficient studies already included from Canada
Lewis 2008	Data richness of 3 or below
Lewis 2012	Sufficient studies already included from UK, sufficient studies in the speciality of mental health
Lichon 2015	Data richness of 3 or below
Lightfoot 2006	Data richness of 3 or below
Linhorst 2001	Data richness of 3 or below
Linhorst 2005	Data richness of 3 or below
Litva 2009	Data richness of 3 or below
Livingston 2013	Data richness of 3 or below
Loignon 2018	Data richness of 3 or below
Luxford 2011	Data richness of 3 or below
Macdonell 2013	Data richness of 3 or below
Macha 2011	Data richness of 3 or below
MacNeill 2009	Sufficient studies already included from the UK
Malfait 2017	Data richness of 3 or below
Marin 2007	Data richness of 3 or below
Martin 2008	Sufficient studies already included from the UK
Martin 2009a	Data richness of 3 or below
Martin 2011	Sufficient studies already included from the UK
Martin 2011a	Sufficient studies already included from the UK
Martin 2018	Sufficient studies already included from the UK

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Table 1. Studies that met the eligibility criteria but were not included in the final synthesis *(Continued)*

Mathers 2014	Data richness of 3 or below
Middleton 2004	Data richness of 3 or below
Milewa 2003	Data richness of 3 or below
Miller 2013	Data richness of 3 or below
Minkler 2001	Data richness of 3 or below
Mubyazi 2007	Data richness of 3 or below
Munoz 2013	Sufficient studies already included from the UK
Murphy 2015	Data richness of 3 or below
Nathan 2013	Data richness of 3 or below
Neuwelt 2012	Data richness of 3 or below
Ocloo 2013	Data richness of 3 or below
Omeni 2014	Data richness of 3 or below
Patterson 2009	Data richness of 3 or below
Patterson 2009a	Data richness of 3 or below
Pavolini 2015	Data richness of 3 or below
Pickard 2002	Data richness of 3 or below
Piper 2012	Data richness of 3 or below
Pohontsch 2015	Data richness of 3 or below
Poland 2005	Data richness of 3 or below
Pollard 2014	Data richness of 3 or below
Potter 2010	A more recent study by this author team on a similar topic has already been included
Eftekhari 2014	Data richness of 3 or below
Rawlinson 2016	Data richness of 3 or below
Renedo 2015	Sufficient studies already included from the UK
Revenas 2015	Data richness of 3 or below
Richardson 2005	Data richness of 3 or below
Rise 2014	Data richness of 3 or below
Robert 2003	Sufficient studies already included from UK, sufficient studies in the speciality of mental health

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Table 1. Studies that met the eligibility criteria but were not included in the final synthesis *(Continued)*

Rojatz 2017	Data richness of 3 or below
Rosales 2010	Data richness of 3 or below
Rose 2016	Data richness of 3 or below
Rosstad 2013	Data richness of 3 or below
Rowland 2017	Data richness of 3 or below
Rutter 2004	Data richness of 3 or below
Rise 2013	Data richness of 3 or below
Samorinha 2015	Data richness of 3 or below
Samudre 2016	Data richness of 3 or below
Sanna 2010	Data richness of 3 or below
Scholz 2018b	Sufficient studies from Australia already included
Serapioni 2014	Data richness of 3 or below
Sideras 2016	Data richness of 3 or below
Summers 2003	Data richness of 3 or below
Taylor 2010	Data richness of 3 or below
Taylor 2015	Data richness of 3 or below
Tobin 2002	Data richness of 3 or below
Treloar 2011	Data richness of 3 or below
Tsianakas 2012	Data richness of 3 or below
Uzochukwu 2004	Data richness of 3 or below
van der Ham 2014	Data richness of 3 or below
Vennik 2016	Data richness of 3 or below
Veronesi 2013	Data richness of 3 or below
von dem Knesebeck 2002	Data richness of 3 or below
Wakefield 2011	Data richness of 3 or below
Waweru 2013	Data richness of 3 or below
Wolstenholme 2017	Data richness of 3 or below
Zeh 2013	Data richness of 3 or below

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Table 1. Studies that met the eligibility criteria but were not included in the final synthesis *(Continued)*

Zeh 2014	Data richness of 3 or below
Solbjor 2011	Data richness of 3 or below

Table 2. 'Summary of qualitative findings' table for findings 1 and 2 (contextual factors influencing partnerships)

Finding		Overall CERQual assessment	Explanation for assessment	Contributing studies
1	Government policy, policy implementation processes and funding influenced working in partnership in health services. Supportive government policies that were poorly translated into practice could hinder partnerships. Inadequate funding could also constrain partnerships.	Moderate level of confidence	Due to moderate concerns regarding relevance of studies; and minor concerns regarding methodological limitations	Abelson 2004; Attree 2011; Byskov 2014; Croft 2016; Goodman 2011; Gurung 2017; Heenan 2004; Jivanjee 2007; Johns 2014; Kidd 2007; MacDonald 2015; Potter 2016; Scholz 2018; Schaaf 2017; Wiig 2013
2	The organisational context of the health service, including management, culture and policies, could function as a facilitator or barrier to working in partnership. Attitudes of senior leaders and managers of the health service could influence partnership-working.	Moderate level of confidence	Due to moderate concerns regarding relevance of studies; and minor concerns regarding methodological limitations and adequacy	Boivin 2014; Byskov 2014; Croft 2016; Heenan 2004; IPFCC 2018; Jivanjee 2007; Johns 2014; Malfait 2018; Potter 2016; Restall 2013; Scholz 2018; Sitzia 2006; Wiig 2013

Table 3. 'Summary of qualitative findings' table for findings 3 to 5 (consumer recruitment)

Finding		Overall CERQual assessment	Explanation for assessment	Contributing studies
3	Consumers were recruited to partnerships in different ways. They were often selected according to specific criteria, including social and demographic characteristics and communication skills; however these could be competing priorities. Consumers managed the recruitment of other consumer members in a minority of studies.	High level of confidence	Due to minor concerns regarding coherence, relevance and adequacy	Abelson 2004; Boivin 2014; Byskov 2014; Croft 2016; Durey 2016; Goodman 2011; Gurung 2017; Jivanjee 2007; Johns 2014; Maher 2017; Rutebemberwa 2009; Scholz 2018; Sharma 2016
4	Recruiting a range of consumers who were reflective of the clinic's demographic population was considered desirable, particularly by health providers. Strategies to increase recruitment of consumers from under-represented groups included practical supports, flexible meeting times, payment and reimbursement.	High level of confidence	Due to minor concerns regarding methodological limitations and relevance	Attree 2011; Boivin 2014; Byskov 2014 Croft 2016; DeCamp 2015; Goodman 2011; Greene 2018; Haarsma 2015; IPFCC 2018; Jivanjee 2007; Kidd 2007; Maher 2017; McDaid 2009; MacDonald 2015; Nathan 2014; Newberry 2005; Schaaf 2017; Scholz 2018; Sharma 2016; Sitzia 2006

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Table 3. 'Summary of qualitative findings' table for findings 3 to 5 (consumer recruitment) *(Continued)*

5	Some health providers perceived that individual consumers' experiences were not generalisable to the broader population. Consumers perceived it could be problematic to represent a broad range of views within the community, although being linked to peer networks and being able to access external data could assist.	High level of confidence	Due to minor concerns regarding coherence, relevance and adequacy	Boivin 2014; Greco 2006; Gurung 2017; Lewis 2014; Malfait 2018; Newberry 2005; Potter 2016;Rutebemberwa 2009; Sharma 2016; Sitzia 2006; Wiig 2013

Table 4. 'Summary of qualitative findings' table for findings 6 to 12 (partnership dynamics and processes)

Finding		Overall CERQual assessment	Explanation for assessment	Contributing studies
6	Positive interpersonal dynamics between health providers and consumers that facilitated partnerships. Mutual respect, commitment, two way dialogue and information exchange were helpful. Trust, accountability, regular group communication and strong relationships with decision-makers were also facilitators. Partnerships that were equitable with shared values, a shared vision and shared decision-making powers were preferable. Skilled facilitators, moderators and consumer coordinators could help to facilitate positive interpersonal dynamics.	High level of confidence	Due to minor concerns regarding coherence and relevance	Abelson 2004; Attree 2011; Boivin 2014; Byskov 2014; Croft 2016; DeCamp 2015; Durey 2016; Goodman 2011; Greco 2006; Greene 2018; Haarsma 2015; Heenan 2004; IPFCC 2018; Jivanjee 2007; Johns 2014; Kidd 2007; Lewis 2014; Maher 2017; Malfait 2018; MacDonald 2015; Nathan 2014; Newberry 2005; Restall 2013; Rutebemberwa 2009; Schaaf 2017; Scholz 2018; Sharma 2016; Sitzia 2006
7	Lack of clarity about the consumer role constrained consumers' involvement in partnerships. Consumers could become frustrated and confused when their role was unclear. Some health providers were unsure about the consumer role.	High level of confidence	Due to minor concerns regarding coherence, relevance and adequacy	Croft 2016; DeCamp 2015; Goodman 2011; Greene 2018; Haarsma 2015; Jivanjee 2007; Kidd 2007; Lewis 2014; Maher 2017; MacDonald 2015; Newberry 2005; Restall 2013; Scholz 2018; Sharma 2016
8	Formal meeting formats constrained the participation of some consumers in partnerships. Health providers could facilitate consumer involvement though providing training, less formal meeting structures and consumer-only spaces.	High level of confidence	Due to minor concerns regarding methodological limitations, coherence and relevance	Attree 2011; Boivin 2014; Byskov 2014; Durey 2016; Goodman 2011; Greene 2018; Gurung 2017; Heenan 2004; IPFCC 2018; Jivanjee 2007; Johns 2014; Lewis 2014; Malfait 2018; McDaid 2009; MacDonald 2015; Newberry 2005; Restall 2013; Scholz 2018; Schaaf 2017; Sharma 2016; Sitzia 2006; Wiig 2013
9	Health providers' professional status, technical knowledge and use of jargon were intimidating for some consumers. Health providers could increase the number of consumers in	High level of confidence	Due to minor concerns regarding coherence, relevance and adequacy	Boivin 2014; Durey 2016; Greene 2018; Gurung 2017; Jivanjee 2007; Lewis 2014; Maher 2017; Malfait 2018; McDaid 2009; Newberry 2005; Potter

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Table 4. 'Summary of qualitative findings' table for findings 6 to 12 (partnership dynamics and processes) *(Continued)*

	the partnership to lessen intimidation.			2016; Rutebemberwa 2009; Scholz 2018; Schaaf 2017
10	When health providers dominated the meeting agenda, consumers became frustrated. Some consumers want more opportunities to shape their role, contribute their priorities and lead or share the agenda.	Moderate level of confidence	Due to moderate concerns regarding methodological limitations and coherence; and minor concerns regarding relevance	Abelson 2004; Croft 2016; DeCamp 2015; Goodman 2011; Greene 2018; Heenan 2004; Jha 2018; Johns 2014; Lewis 2014; MacDonald 2015; Malfait 2018; McDaid 2009; MacDonald 2015; Nathan 2014; Newberry 2005; Schaaf 2017; Scholz 2018; Sitzia 2006; Wiig 2013
11	Consumers could feel their experiential knowledge was not valued by health providers, leading to feelings of being dismissed or overridden. Some health providers perceived consumers' contributions were not as valuable in the partnership. Mutual respect for knowledge and expertise facilitated partnerships.	Moderate level of confidence	Due to moderate concerns regarding coherence; and minor concerns regarding methodological limitations, relevance and adequacy	Attree 2011; Croft 2016; Gurung 2017; Haarsma 2015; Kidd 2007; Lewis 2014; McDaid 2009; Newberry 2005; Potter 2016; Restall 2013; Scholz 2018; Sitzia 2006
12	Consumers could experience token involvement in partnerships, including a lack of decision-making power, being left out of key discussions and being unable to contribute ideas outside health providers' priorities. Token involvement resulted in consumers' feeling frustrated. Consumers valued contributing to tangible changes in health policy and services.	High level of confidence	Due to minor concerns regarding methodological limitations, coherence and relevance	Abelson 2004; Attree 2011; Boivin 2014; Croft 2016; DeCamp 2015; Durey 2016; Goodman 2011; Greene 2018; Gurung 2017; Haarsma 2015; Heenan 2004; IPFCC 2018; Kidd 2007; Lewis 2014; Maher 2017; Malfait 2018; McDaid 2009; MacDonald 2015; Nathan 2014; Newberry 2005; Restall 2013; Schaaf 2017; Scholz 2018; Sitzia 2006; Wiig 2013

Table 5. 'Summary of qualitative findings' table for finding 13 (perceived impacts on partnership participants)

Finding		Overall CERQual assessment	Explanation for assessment	Contributing studies
13	Working in partnership could affect health provider and consumer participants in both positive and negative ways. Health providers perceived consumers provided a unique perspective that could improve services, but they were concerned about the time pressures and unmet expectations that could accompany their involvement in partnerships. Consumers perceived there were benefits of working in partnership, including empowerment, increased confidence, knowledge and skills. However, they reported that participating in partnerships could be physically and/or emotionally demanding.	High level of confidence	Due to minor concerns regarding coherence and relevance	Attree 2011; Boivin 2014; Byskov 2014; Croft 2016; DeCamp 2015; Durey 2016; Goodman 2011; Greco 2006; Greene 2018; Heenan 2004 Jivanjee 2007; Kidd 2007; Maher 2017; McDaid 2009; Nathan 2014; Newberry 2005; Potter 2016; Restall 2013; Schaaf 2017; Scholz 2018; Sitzia 2006; Wiig 2013

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Table 6. 'Summary of qualitative findings' table for findings 14 to 19 (perceived impacts on health service planning, delivery and evaluation)

Finding		Overall CERQual assessment	Explanation for assessment	Contributing studies
14	Working in partnership was perceived to improve consumer involvement in strategic decision-making	Moderate level of confidence	Due to moderate concerns regarding adequacy and coherence; and minor concerns regarding relevance	Attree 2011; Byskov 2014; Croft 2016; Durey 2016; Haarsma 2015; Restall 2013; Schaaf 2017
15	Working in partnership could improve community ownership of health services, particularly in LMICs	Moderate level of confidence	Due to moderate concerns regarding relevance and adequacy; and minor concerns regarding coherence	Byskov 2014; Croft 2016; Durey 2016; Goodman 2011; Johns 2014; Schaaf 2017
16	Working in partnership was perceived to lead to improvements in the person-centredness of health service culture	High level of confidence	Due to minor concerns regarding adequacy and relevance	Attree 2011; Byskov 2014; Croft 2016; DeCamp 2015; Durey 2016; Goodman 2011; Greco 2006; Greene 2018; IPFCC 2018; Jha 2018; Restall 2013; Schaaf 2017; Sharma 2016; Sitzia 2006; Wiig 2013
17	Working in partnership was perceived to lead to improvements in the built environment of the health service	High level of confidence	Due to minor concerns regarding methodological limitations, coherence, relevance and adequacy	Attree 2011; DeCamp 2015; Greene 2018; Haarsma 2015; Johns 2014; Nathan 2014; Schaaf 2017; Scholz 2018; Sharma 2016; Sitzia 2006
18	Working in partnership was perceived to lead to improvements in health service design and delivery.	High level of confidence	Due to minor concerns regarding coherence, relevance and adequacy	Attree 2011; DeCamp 2015; Durey 2016; Greene 2018; Heenan 2004; Johns 2014; Lewis 2014; Maher 2017; Nathan 2014; Restall 2013; Schaaf 2017; Sitzia 2006
19	Working in partnership could lead to improvements in health service evaluation.	Very low level of confidence	Due to serious concerns regarding relevance and adequacy; and moderate concerns regarding coherence	Croft 2016; Jivanjee 2007

APPENDICES

Appendix 1. MEDLINE search strategy

1. exp Community Participation/

2. Stakeholder Participation/

3. Decision Making/

4. exp Patient-Centered Care/

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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. qualitative.tw.

25. themes.tw.

26. or/24-25

27. and/6,18,23,26

28. limit 27 to yr="2000 -Current"

29. limit 28 to english language

Appendix 2. 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/

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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. themes.tw.

21. qualitative.tw.

22. or/20-21

23. and/19,22

24. limit 23 to (english language and yr="2000 -Current")

Appendix 3. CERQual evidence profiles

Finding 1. Government policy, policy implementation processes and funding influenced working in partnership in health services. Supportive government policies that were poorly translated into practice could hinder partnerships. Inadequate funding could also constrain partnerships.	
Assessment of each CERQual component	
Methodological limitations	Minor concerns regarding methodological limitations due to a limited number of studies not reporting to have engaged in researcher reflexivity.
Coherence	No or very minor concerns regarding coherence.
Relevance	Moderate concerns regarding relevance due to a fair number of studies where interventions were only partially relevant to the review question. However, data comprised a broad range of countries (including LMICs), settings and partnership purposes.
Adequacy	No or very minor concerns.
Overall CERQual assessment	
Moderate level of confidence	Due to moderate concerns regarding relevance of studies; and minor concerns regarding methodological limitations.
Contributing studies	
Study	**Context**

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(Continued)

Abelson 2004	Canada; health authorities; citizens and health decision makers; focus groups; working with a range or regional health authority decision making processes.
Attree 2011	UK; health and social care/ cancer; Macmillian region; interviews with health professionals, in partnership with service user representatives (cancer patients) in the Committtee Network Partnership Groups.
Byskov 2014	Africa; document analysis and observational interviews; in partnership with District Council, Healthcare Management Team plus community stakeholders.
Croft 2016	UK; Commissioning organisations; Interviews and observations; in partnership with managers, clinicians and patient representatives.
Goodman 2011	Kenya; health centres and dispensaries; interviews; in partnership with Health worker in-charge of the health facility, district (rural) managers, health workers, health facility committee members, and community members (patients).
Gurung 2017	Nepal; mental health organisations; interviews to involve mental health service users and care givers in policy making, service planning, monitoring and research.
Heenan 2004	Northern Ireland; community health project; interviews with health service professionals, and community and voluntary workers.
Jivanjee 2007	USA; Children's mental health and ambulatory care; unstructured or semi-structured interviews with mental health professionals, other service providers and community representatives, including family members.
Johns 2014	Tasmania Australia; community and rural health service, council and hospital; individual and group interviews with local rural community members and representatives, health professionals, staff members from centres, such as GPs, through a committee.
Kidd 2007	Australia; rural mental health service; semi-structured interviews with consumer representatives and health providers; steering committee.
MacDonald 2015	UK; mental health service foundation trust in rural and urban areas; survey and interviews, focus groups, document analysis and observations; working in partnership with elected and appointed governors and pubic and patient governors in three foundation trusts.
Potter 2016	USA; community-based services and children mental health; observations and interviews; in partnership with family members, health professionals in the community collaboratives committee.
Scholz 2018	Australia; tertiary referral hospital; semi-structured interviews; partnership with managers, clinicians and consumers.
Schaaf 2017	Zambia; primary care at the local level; interviews and focus groups; in partnership with citizens, health providers and locally elected officials through the citizen voice and action group (world vision).
Wiig 2013	Norway; hospitals including micro and meso analysis at maternal and oncology services; interviews and non-participant observations, document analysis; working with patients, representative ombudsmen, hospital managers and clinical staff through committees and meetings.

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Finding 2. The organisational context of the health service, including management, culture and policies, could function as a facilitator or barrier to working in partnership. Attitudes of senior leaders and managers of the health service could influence partnership-working.

Assessment of each CERQual component	
Methodological limitations	Minor concerns regarding methodological limitations due to a limited number of studies not reporting to have engaged in researcher reflexivity and one study without formal ethics approval.
Coherence	No or very minor concerns regarding coherence
Relevance	Moderate concerns regarding relevance due to a fair number of studies where interventions were only partially relevant to the review question. However, data comprised a broad range of countries (including LMICs), settings and partnership purposes.
Adequacy	Minor concerns regarding adequacy due to less than 15 studies comprising the finding
Overall CERQual assessment	
Moderate level of confidence	Due to moderate concerns regarding relevance of studies; and minor concerns regarding methodological limitations and adequacy
Contributing studies	
Study	**Context**
Boivin 2014	Canada; health and social services centres; analysis of video transcripts, structured notes and observations; through meetings with public representatives, patients and professionals.
Byskov 2014	Africa; health sector; document analysis and observational interviews; in partnership with District Council, Healthcare Management Team plus stakeholders through committees.
Croft 2016	UK; Commissioning organisations; Interviews and observations; in partnership with managers, clinicians and patient representatives through committee and a governing board.
Heenan 2004	Northern Ireland; community health project; in partnership with the working group of health service professionals, and community and voluntary workers.
IPFCC 2018	USA; hospitals; survey interviews, follow-up interviews, site visits, working with patients and families, health care professionals and hospitals, also referred to as the Patient and Family Advisory Councils in hospitals.
Jivanjee 2007	USA; Children's mental health and ambulatory care; unstructured or semi-structured interviews with mental health professionals, other service providers and community representatives, including family members through advisory groups.
Johns 2014	Tasmania Australia; community and rural health service, council and hospital; individual and group interviews with local rural community members and representatives, health professionals, staff members from centres, such as GPs, through a committee.
Malfait 2018	Belgium; general and mental health hospitals; questionnaires, observations, focus groups, working with internal stakeholders and external stakeholders, patients, family members, patient representatives and president and secretaries of a stakeholder committee.
Potter 2016	USA; community-based services and children mental health; observations and interviews; in partnership with family members, health professionals through community collaboratives committee.

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Restall 2013	Canada; mental health and social policy making context; semi-structured interviews, document review and field notes; in partnership with consumers and health providers through policy debates conducted in formal group formats.
Scholz 2018	Australia; tertiary referral hospital; semi-structured interviews; partnership with managers, clinicians and consumers.
Sitzia 2006	UK England; local cancer services; semi-structured interviews; working with NHS staff and consumers in partnership groups.
Wiig 2013	Norway; hospitals including micro and meso analysis at maternal and oncology services; interviews and non-participant observations, document analysis; working with patients, representative ombudsmen, hospital managers and clinical staff through committees and meetings.

Finding 3. Consumers were recruited to partnerships in different ways. They were often selected according to specific criteria, including social and demographic characteristics and communication skills, however these could be competing priorities. Consumers managed the recruitment of other consumer members in a minority of studies.

Assessment of each CERQual component	
Methodological limitations	No or very minor concerns regarding methodological limitations.
Coherence	Minor concerns for coherence as one sub-finding is slightly less well-supported than the other sub-finding.
Relevance	Minor concerns regarding relevance due to a limited number of studies being partially rather than fully relevant.
Adequacy	Minor concerns regarding adequacy due to less than 15 studies comprising the finding.
Overall CERQual assessment	
High level of confidence	Due to minor concerns regarding coherence, relevance and adequacy.
Contributing studies	
Study	**Context**
Abelson 2004	Canada; health authorities; citizens and health decision makers; focus groups; working with a range or regional health authority decision making processes.
Boivin 2014	Canada; health and social services centres; analysis of video transcripts, structured notes and observations; through meetings with public representatives, patients and professionals.
Byskov 2014	Africa; health sector; document analysis and observational interviews; in partnership with District Council, Healthcare Management Team plus stakeholders through committees.
Croft 2016	UK; Commissioning organisations; Interviews and observations; in partnership with managers, clinicians and patient representatives through committee and a governing board.
Durey 2016	Australia; district/ local health care services including hospitals; interviews, yarning circles (culturally appropriate for Indigenous Australians); working with Aboriginal community members on the

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	committee; health service users, health providers of Aboriginal health services, plus mainstream health service providers and Aboriginal and non-Aboriginal professionals.
Goodman 2011	Kenya; health centres and dispensaries; interviews; in partnership with Health worker in-charge of the health facility, district (rural) managers, health workers, health facility committee members, and community members (patients).
Gurung 2017	Nepal; mental health organisations; interviews to involve mental health service users and care givers in policy making, service planning, monitoring and research.
Jivanjee 2007	USA; Children's mental health and ambulatory care; unstructured or semi-structured interviews with mental health professionals, other service providers and community representatives, including family members through advisory groups.
Johns 2014	Tasmania Australia; community and rural health service, council and hospital; individual and group interviews with local rural community members and representatives, health professionals, staff members from centres, such as GPs, through a committee.
Maher 2017	New Zealand; Innovation and improvement centre; analysis of workbooks and semi-structured interviews; working with health professionals and patients through an experience based co-design program.
Rutebemberwa 2009	Uganda; hospitals; interviews and focus groups, working with hospital staff and service user representatives in the community through committees.
Scholz 2018	Australia; tertiary referral hospital; semi-structured interviews; partnership with managers, clinicians and consumers.
Sharma 2016	USA; primary care clinics; semi-structured interviews; working with patient, family members, caregivers, clinic staff members, leaders and principle regional stakeholders in patient engagement through the Participant Advisory Council.

Finding 4. Recruiting a range of consumers who were reflective of the clinic's demographic population was considered desirable, particularly by health providers. Strategies to increase recruitment of consumers from under-represented groups included practical supports, flexible meeting times, payment and reimbursement.

Assessment of each CERQual component	
Methodological limitations	Minor concerns for methodological limitations due to a limited number of studies not reporting researcher reflexivity and a few not reporting formal ethical approval.
Coherence	No or very minor concerns for coherence.
Relevance	Minor concerns regarding relevance due to a limited number of studies that were partially rather than fully relevant. However, data comprised a broad range of countries (including LMICs), settings and partnership purposes.
Adequacy	No or very minor concerns regarding adequacy.
Overall CERQual assessment	
High level of confidence	Due to minor concerns regarding relevance and methodological limitations.
Contributing studies	

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Study	Context
Attree 2011	UK; health and social care/ cancer; Macmillian region; interviews with health professionals, in partnership with service user representatives (cancer patients) in the Committtee Network Partnership Groups.
Boivin 2014	Canada; health and social services centres; analysis of video transcripts, structured notes and observations; in partnership with public representatives, patients and professionals.
Byskov 2014	Africa; health sector; document analysis and observational interviews; in partnership with District Council, Healthcare Management Team plus stakeholders through committees.
Croft 2016	UK; Commissioning organisations; Interviews and observations; in partnership with managers, clinicians and patient representatives through committee and a governing board.
DeCamp 2015	USA; hospital based primary care practice and ambulatory care; interviews; working with mothers, consumer representatives and clinical staff on the advisory board.
Goodman 2011	Kenya; health centres and dispensaries; interviews; in partnership with Health worker in-charge of the health facility, district (rural) managers, health workers, health facility committee members, and community members (patients).
Greene 2018	USA; primary care specialist, paediatric clinic, ambulatory care; interviews and focus groups; in partnership with patient partners and health providers through quality improvement team meetings.
Haarsma 2015	Netherlands; Palliative care networks; interviews, focus groups and field notes; working with patient representatives and professional staff through sounding board group and management team meetings.
IPFCC 2018	USA; hospitals; survey interviews, follow-up interviews, site visits, working with patients and families, health care professionals and hospitals, also referred to as the Patient and Family Advisory Councils in hospitals.
Jivanjee 2007	USA; Children's mental health and ambulatory care; unstructured or semi-structured interviews with mental health professionals, other service providers and community representatives, including family members through advisory groups.
Kidd 2007	Australia; rural mental health service; semi-structured interviews with consumer representatives and health providers; steering committee.
Maher 2017	New Zealand; Innovation and improvement centre; analysis of workbooks and semi-structured interviews; working with health professionals and patients through an experience based co-design program.
McDaid 2009	Ireland; National mental health non-government organisations; semi-structured interviews; in partnership with mental health professionals and consumers through advisory committee.
MacDonald 2015	UK; mental health service foundation trust in rural and urban areas; survey and interviews, focus groups, document analysis and observations; working in partnership with elected and appointed governors and pubic and patient governors in three foundation trusts.
Nathan 2014	Australia; health region hospitals; interviews, observations, field notes; working with staff and consumers representatives through committees.
Newberry 2005	Canada; Ontario branches of the Canadian Mental Health Association; interviews; in partnership with executive directors, professionals and consumers through management, policy boards and mental health boards of health agencies.

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Schaaf 2017	Zambia; Primary care at the local level; Interviews and focus groups; working with citizens, health providers and locally-elected officials through a citizen voice and action group (world vision).
Scholz 2018	Australia; tertiary referral hospital; semi-structured interviews; partnership with managers, clinicians and consumers.
Sharma 2016	USA; primary care clinics; semi-structured interviews; working with patient, family members, caregivers, clinic staff members, leaders and principle regional stakeholders in patient engagement through the Participant Advisory Council.
Sitzia 2006	UK England; local cancer services; semi-structured interviews; working with NHS staff and consumers in partnership groups.

Finding 5. Some health providers perceived that individual consumers' experiences were not generalisable to the broader population. Consumers perceived it could be problematic to represent a broad range of views within the community, although being linked to peer networks and being able to access external data could assist.

Assessment of each CERQual component	
Methodological limitations	No or very minor concerns for methodological limitations
Coherence	Minor concerns for coherence due to a limited amount of contradictory data.
Relevance	Minor concerns regarding relevance due to a limited number of studies that were partially rather than fully relevant.
Adequacy	Minor concerns regarding adequacy as less than 15 studies contributed to this finding.
Overall CERQual assessment	
High level of confidence	Due to minor concerns regarding coherence, relevance and adequacy
Contributing studies	
Study	**Context**
Boivin 2014	Canada; health and social services centres; analysis of video transcripts, structured notes and observations; in partnership with public representatives, patients and professionals.
Greco 2006	UK England; North and East Devon localities GPs and primary care; qualitative component of mixed methods and interviews; in partnership with GPs, nurses, patients, health professionals through patient and staff partnership groups (critical friend groups).
Gurung 2017	Nepal; mental health organisations; interviews to involve mental health service users and care givers in policy making, service planning, monitoring and research.
Lewis 2014	Scotland; statutory sector and community groups; in partnership with service users, healthcare, staff and managers through the policy planning committee.
Malfait 2018	Belgium; general and mental health hospitals; questionnaires, observations, focus groups, working with internal stakeholders and external stakeholders, patients, family members, patient representatives and president and secretaries of a stakeholder committee.

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Newberry 2005	Canada; Ontario branches of the Canadian Mental Health Association; interviews; in partnership with executive directors, professionals and consumers through management, policy boards and mental health boards of health agencies.
Potter 2016	USA; community-based services and children mental health; observations and interviews; in partnership with family members, health professionals through community collaboratives committee.
Rutebemberwa 2009	Uganda; hospitals; interviews and focus groups, working with hospital staff and service user representatives in the community through committees.
Sharma 2016	USA; primary care clinics; semi-structured interviews; working with patient, family members, caregivers, clinic staff members, leaders and principle regional stakeholders in patient engagement through the Participant Advisory Council.
Sitzia 2006	UK England; local cancer services; semi-structured interviews; working with NHS staff and consumers in partnership groups.
Wiig 2013	Norway; hospitals including micro and meso analysis at maternal and oncology services; interviews and non-participant observations, document analysis; working with patients, representative ombudsmen, hospital managers and clinical staff through committees and meetings.

Finding 6. Positive interpersonal dynamics between health providers and consumers that facilitated partnerships. Mutual respect, commitment, two way dialogue and information exchange were helpful. Trust, accountability, regular group communication and strong relationships with decision-makers were also facilitators. Partnerships that were equitable with shared values, a shared vision and shared decision-making powers were preferable. Skilled facilitators, moderators and consumer coordinators could help to facilitate positive interpersonal dynamics.

Assessment of each CERQual component	
Methodological limitations	No or very minor concerns for methodological limitations.
Coherence	Minor concerns regarding coherence as some subfindings are more well-supported than others.
Relevance	Minor concerns regarding relevance due to a limited number of studies being partially rather than fully relevant.
Adequacy	No or very minor concerns regarding adequacy
Overall CERQual assessment	
High level of confidence	Due to minor concerns regarding coherence and relevance
Contributing studies	
Study	**Context**
Abelson 2004	Canada; health authorities; citizens and health decision makers; focus groups; working with a range or regional health authority decision making processes.
Attree 2011	UK; health and social care/ cancer; Macmillian region; interviews with health professionals, in partnership with service user representatives (cancer patients) in the Committtee Network Partnership Groups.

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(Continued)

Boivin 2014	Canada; health and social services centres; analysis of video transcripts, structured notes and observations; in partnership with public representatives, patients and professionals.
Byskov 2014	Africa; health sector; document analysis and observational interviews; in partnership with District Council, Healthcare Management Team plus stakeholders through committees.
Croft 2016	UK; Commissioning organisations; Interviews and observations; in partnership with managers, clinicians and patient representatives through committee and a governing board.
DeCamp 2015	USA; hospital based primary care practice and ambulatory care; interviews; working with mothers, consumer representatives and clinical staff on the advisory board.
Durey 2016	Australia; district/ local health care services including hospitals; interviews, yarning circles (culturally appropriate for Indigenous Australians); working with Aboriginal community members on the committee; health service users, health providers of Aboriginal health services, plus mainstream health service providers and Aboriginal and non-Aboriginal professionals.
Goodman 2011	Kenya; health centres and dispensaries; interviews; in partnership with Health worker in-charge of the health facility, district (rural) managers, health workers, health facility committee members, and community members (patients).
Greco 2006	UK England; North and East Devon localities GPs and primary care; qualitative component of mixed methods and interviews; in partnership with GPs, nurses, patients, health professionals through patient and staff partnership groups (critical friend groups).
Greene 2018	USA; primary care specialist, paediatric clinic, ambulatory care; interviews and focus groups; in partnership with patient partners and health providers through quality improvement team meetings.
Haarsma 2015	Netherlands; Palliative care networks; interviews, focus groups and field notes; working with patient representatives and professional staff through sounding board group and management team meetings.
Heenan 2004	Northern Ireland; community health project; interviews with health service professionals, and community and voluntary workers.
IPFCC 2018	USA; hospitals; survey interviews, follow-up interviews, site visits, working with patients and families, health care professionals and hospitals, also referred to as the Patient and Family Advisory Councils in hospitals.
Jivanjee 2007	USA; Children's mental health and ambulatory care; unstructured or semi-structured interviews with mental health professionals, other service providers and community representatives, including family members through advisory groups.
Johns 2014	Tasmania Australia; community and rural health service, council and hospital; individual and group interviews with local rural community members and representatives, health professionals, staff members from centres, such as GPs, through a committee.
Kidd 2007	Australia; rural mental health service; semi-structured interviews with consumer representatives and health providers; steering committee.
Lewis 2014	Scotland; statutory sector and community groups; in partnership with service users, healthcare, staff and managers through the policy planning committee.
Maher 2017	New Zealand; Innovation and improvement centre; analysis of workbooks and semi-structured interviews; working with health professionals and patients through an experience based co-design program.

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Malfait 2018	Belgium; general and mental health hospitals; questionnaires, observations, focus groups, working with internal stakeholders and external stakeholders, patients, family members, patient representatives and president and secretaries of a stakeholder committee.
MacDonald 2015	UK; mental health service foundation trust in rural and urban areas; survey and interviews, focus groups, document analysis and observations; working in partnership with elected and appointed governors and pubic and patient governors in three foundation trusts.
Nathan 2014	Australia; health region hospitals; interviews, observations, field notes; working with staff and consumers representatives through committees.
Newberry 2005	Canada; Ontario branches of the Canadian Mental Health Association; interviews; in partnership with executive directors, professionals and consumers through management, policy boards and mental health boards of health agencies.
Restall 2013	Canada; mental health and social policy making context; semi-structured interviews, document review and field notes; in partnership with consumers and health providers through policy debates conducted in formal group formats.
Rutebemberwa 2009	Uganda; hospitals; interviews and focus groups, working with hospital staff and service user representatives in the community through committees.
Schaaf 2017	Zambia; Primary care at the local level; Interviews and focus groups; working with citizens, health providers and locally-elected officials through a citizen voice and action group (world vision).
Scholz 2018	Australia; tertiary referral hospital; semi-structured interviews; partnership with managers, clinicians and consumers.
Sharma 2016	USA; primary care clinics; semi-structured interviews; working with patient, family members, caregivers, clinic staff members, leaders and principle regional stakeholders in patient engagement through the Participant Advisory Council.
Sitzia 2006	UK England; local cancer services; semi-structured interviews; working with NHS staff and consumers in partnership groups.

Finding 7. Lack of clarity about the consumer role constrained consumers' involvement in partnerships. Consumers could become frustrated and confused when their role was unclear. Some health providers were unsure about the consumer role and so providing training in consumer engagement may help.

Assessment of each CERQual component	
Methodological limitations	No or very minor concerns regarding methodological limitations.
Coherence	Minor concerns regarding coherence due to some subfindings being more well-supported than others.
Relevance	Minor concerns regarding relevance due to a limited number of studies being partially, rather than fully relevant.However, data comprised a broad range of countries (including LMICs), settings and partnership purposes.
Adequacy	Minor concerns regarding adequacy as less than 15 studies comprise this finding.
Overall CERQual assessment	

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(Continued)

High level of confidence	Due to minor concerns regarding coherence, relevance and adequacy.

Contributing studies

Study	Context
Croft 2016	UK; Commissioning organisations; Interviews and observations; in partnership with managers, clinicians and patient representatives through committee and a governing board.
DeCamp 2015	USA; hospital based primary care practice and ambulatory care; interviews; working with mothers, consumer representatives and clinical staff on the advisory board.
Goodman 2011	Kenya; health centres and dispensaries; interviews; in partnership with Health worker in-charge of the health facility, district (rural) managers, health workers, health facility committee members, and community members (patients).
Greene 2018	USA; primary care specialist, paediatric clinic, ambulatory care; interviews and focus groups; in partnership with patient partners and health providers through quality improvement team meetings.
Haarsma 2015	Netherlands; Palliative care networks; interviews, focus groups and field notes; working with patient representatives and professional staff through sounding board group and management team meetings.
Jivanjee 2007	USA; Children's mental health and ambulatory care; unstructured or semi-structured interviews with mental health professionals, other service providers and community representatives, including family members through advisory groups.
Kidd 2007	Australia; rural mental health service; semi-structured interviews with consumer representatives and health providers; steering committee.
Lewis 2014	Scotland; statutory sector and community groups; in partnership with service users, healthcare, staff and managers through the policy planning committee.
Maher 2017	New Zealand; Innovation and improvement centre; analysis of workbooks and semi-structured interviews; working with health professionals and patients through an experience based co-design program.
MacDonald 2015	UK; mental health service foundation trust in rural and urban areas; survey and interviews, focus groups, document analysis and observations; working in partnership with elected and appointed governors and pubic and patient governors in three foundation trusts.
Newberry 2005	Canada; Ontario branches of the Canadian Mental Health Association; interviews; in partnership with executive directors, professionals and consumers through management, policy boards and mental health boards of health agencies.
Restall 2013	Canada; mental health and social policy making context; semi-structured interviews, document review and field notes; in partnership with consumers and health providers through policy debates conducted in formal group formats.
Scholz 2018	Australia; tertiary referral hospital; semi-structured interviews; partnership with managers, clinicians and consumers.
Sharma 2016	USA; primary care clinics; semi-structured interviews; working with patient, family members, caregivers, clinic staff members, leaders and principle regional stakeholders in patient engagement through the Participant Advisory Council.

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Finding 8. Formal meeting formats constrained the participation of some consumers in partnerships. Health providers could facilitate consumer involvement through providing training, less formal meeting structures and consumer-only spaces.	
Assessment of each CERQual component	
Methodological limitations	Minor concerns for methodological limitations due to a limited number of studies not reporting researcher reflexivity and two studies not having formal ethics approval.
Coherence	Minor concerns regarding coherence as some subfindings were more well-supported than others.
Relevance	Minor concerns regarding relevance as a limited number of studies were partially rather than fully relevant.
Adequacy	No or very minor concerns regarding adequacy
Overall CERQual assessment	
High level of confidence	Due to minor concerns regarding methodological limitations, coherence and relevance
Contributing studies	
Study	**Context**
Attree 2011	UK; health and social care/ cancer; Macmillian region; interviews with health professionals, in partnership with service user representatives (cancer patients) in the Committtee Network Partnership Groups.
Boivin 2014	Canada; health and social services centres; analysis of video transcripts, structured notes and observations; in partnership with public representatives, patients and professionals.
Byskov 2014	Africa; health sector; document analysis and observational interviews; in partnership with District Council, Healthcare Management Team plus stakeholders through committees.
Durey 2016	Australia; district/ local health care services including hospitals; interviews, yarning circles (culturally appropriate for Indigenous Australians); working with Aboriginal community members on the committee; health service users, health providers of Aboriginal health services, plus mainstream health service providers and Aboriginal and non-Aboriginal professionals.
Goodman 2011	Kenya; health centres and dispensaries; interviews; in partnership with Health worker in-charge of the health facility, district (rural) managers, health workers, health facility committee members, and community members (patients).
Greene 2018	USA; primary care specialist, paediatric clinic, ambulatory care; interviews and focus groups; in partnership with patient partners and health providers through quality improvement team meetings.
Gurung 2017	Nepal; mental health organisations; interviews to involve mental health service users and care givers in policy making, service planning, monitoring and research.
Heenan 2004	Northern Ireland; community health project; interviews with health service professionals, and community and voluntary workers.
IPFCC 2018	USA; hospitals; survey interviews, follow-up interviews, site visits, working with patients and families, health care professionals and hospitals, also referred to as the Patient and Family Advisory Councils in hospitals.

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Jivanjee 2007	USA; Children's mental health and ambulatory care; unstructured or semi-structured interviews with mental health professionals, other service providers and community representatives, including family members through advisory groups.
Johns 2014	Tasmania Australia; community and rural health service, council and hospital; individual and group interviews with local rural community members and representatives, health professionals, staff members from centres, such as GPs, through a committee.
Lewis 2014	Scotland; statutory sector and community groups; in partnership with service users, healthcare, staff and managers through the policy planning committee.
Malfait 2018	Belgium; general and mental health hospitals; questionnaires, observations, focus groups, working with internal stakeholders and external stakeholders, patients, family members, patient representatives and president and secretaries of a stakeholder committee.
McDaid 2009	Ireland; National mental health non-government organisations; semi-structured interviews; in partnership with mental health professionals and consumers through advisory committee.
MacDonald 2015	UK; mental health service foundation trust in rural and urban areas; survey and interviews, focus groups, document analysis and observations; working in partnership with elected and appointed governors and pubic and patient governors in three foundation trusts.
Newberry 2005	Canada; Ontario branches of the Canadian Mental Health Association; interviews; in partnership with executive directors, professionals and consumers through management, policy boards and mental health boards of health agencies.
Restall 2013	Canada; mental health and social policy making context; semi-structured interviews, document review and field notes; in partnership with consumers and health providers through policy debates conducted in formal group formats.
Schaaf 2017	Zambia; Primary care at the local level; Interviews and focus groups; working with citizens, health providers and locally-elected officials through a citizen voice and action group (world vision).
Scholz 2018	Australia; tertiary referral hospital; semi-structured interviews; partnership with managers, clinicians and consumers.
Sharma 2016	USA; primary care clinics; semi-structured interviews; working with patient, family members, caregivers, clinic staff members, leaders and principle regional stakeholders in patient engagement through the Participant Advisory Council.
Sitzia 2006	UK England; local cancer services; semi-structured interviews; working with NHS staff and consumers in partnership groups.
Wiig 2013	Norway; hospitals including micro and meso analysis at maternal and oncology services; interviews and non-participant observations, document analysis; working with patients, representative ombudsmen, hospital managers and clinical staff through committees and meetings.

Finding 9. Health providers' professional status, technical knowledge and use of jargon were intimidating for some consumers. Health providers could increase the number of consumers in the partnership to lessen intimidation.

Assessment of each CERQual component	
Methodological limitations	No or very minor concerns for methodological limitations

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Coherence	Minor concerns regarding coherence due to some sub-findings being slightly less well-supported than others.
Relevance	Minor concerns regarding relevance due to a limited number of studies being partially rather than fully relevant.
Adequacy	Minor concerns regarding adequacy due to less than 15 studies comprising the finding.
Overall CERQual assessment	
High level of confidence	Due to minor concerns regarding coherence, relevance and adequacy.
Contributing studies	

Study	**Context**
Boivin 2014	Canada; health and social services centres; analysis of video transcripts, structured notes and observations; in partnership with public representatives, patients and professionals.
Durey 2016	Australia; district/ local health care services including hospitals; interviews, yarning circles (culturally appropriate for Indigenous Australians); working with Aboriginal community members on the committee; health service users, health providers of Aboriginal health services, plus mainstream health service providers and Aboriginal and non-Aboriginal professionals.
Greene 2018	USA; primary care specialist, paediatric clinic, ambulatory care; interviews and focus groups; in partnership with patient partners and health providers through quality improvement team meetings.
Gurung 2017	Nepal; mental health organisations; interviews to involve mental health service users and care givers in policy making, service planning, monitoring and research.
Jivanjee 2007	USA; Children's mental health and ambulatory care; unstructured or semi-structured interviews with mental health professionals, other service providers and community representatives, including family members through advisory groups.
Lewis 2014	Scotland; statutory sector and community groups; in partnership with service users, healthcare, staff and managers through the policy planning committee.
Maher 2017	New Zealand; Innovation and improvement centre; analysis of workbooks and semi-structured interviews; working with health professionals and patients through an experience based co-design program.
Malfait 2018	Belgium; general and mental health hospitals; questionnaires, observations, focus groups, working with internal stakeholders and external stakeholders, patients, family membrers, patient representatives and president and secretaries of a stakeholder committee.
McDaid 2009	Ireland; National mental health non-government organisations; semi-structured interviews; in partnership with mental health professionals and consumers through advisory committee.
Newberry 2005	Canada; Ontario branches of the Canadian Mental Health Association; interviews; in partnership with executive directors, professionals and consumers through management, policy boards and mental health boards of health agencies.
Potter 2016	USA; community-based services and children mental health; observations and interviews; in partnership with family members, health professionals through community collaboratives committee.

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Rutebemberwa 2009	Uganda; hospitals; interviews and focus groups, working with hospital staff and service user representatives in the community through committees.
Schaaf 2017	Zambia; Primary care at the local level; Interviews and focus groups; working with citizens, health providers and locally-elected officials through a citizen voice and action group (world vision).
Scholz 2018	Australia; tertiary referral hospital; semi-structured interviews; partnership with managers, clinicians and consumers.

Finding 10. Health providers can dominate meeting agendas leading to frustration for consumers. Providing consumers with more opportunities to shape their role, contribute their priorities and share or co-lead the agenda may facilitate their involvement.

Assessment of each CERQual component	
Methodological limitations	Moderate concerns for methodological limitations due to a fair number of studies not reporting researcher reflexivity.
Coherence	Moderate concerns regarding coherence as there was a fair difference in how well-supported some subfindings were compared to others and some studies only contributed to one sub-finding rather than multiple sub-findings.
Relevance	Minor concerns regarding relevance due to a limited number of studies being partially rather than fully relevant.
Adequacy	No or very minor concerns regarding adequacy.
Overall CERQual assessment	
Moderate level of confidence	Due to moderate concerns regarding methodological limitations and coherence; and minor concerns regarding relevance.
Contributing studies	
Study	**Context**
Abelson 2004	Canada; health authorities; citizens and health decision makers; focus groups; working with a range or regional health authority decision making processes.
Croft 2016	UK; Commissioning organisations; Interviews and observations; in partnership with managers, clinicians and patient representatives through committee and a governing board.
DeCamp 2015	USA; hospital based primary care practice and ambulatory care; interviews; working with mothers, consumer representatives and clinical staff on the advisory board.
Goodman 2011	Kenya; health centres and dispensaries; interviews; in partnership with Health worker in-charge of the health facility, district (rural) managers, health workers, health facility committee members, and community members (patients).
Greene 2018	USA; primary care specialist, paediatric clinic, ambulatory care; interviews and focus groups; in partnership with patient partners and health providers through quality improvement team meetings.

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Heenan 2004	Northern Ireland; community health project; interviews with health service professionals, and community and voluntary workers.
Jha 2018	UK England; Training school and two hospitals; Qualitative component of mixed methods, workshops and patient safety intervention aimed at trainee doctors; working with patients with personal experience of harm or error during medical diagnosis, treatment, care either to themselves or relatives and trainee doctors.
Johns 2014	Tasmania Australia; community and rural health service, council and hospital; individual and group interviews with local rural community members and representatives, health professionals, staff members from centres, such as GPs, through a committee.
Lewis 2014	Scotland; statutory sector and community groups; in partnership with service users, healthcare, staff and managers through the policy planning committee.
MacDonald 2015	UK; mental health service foundation trust in rural and urban areas; survey and interviews, focus groups, document analysis and observations; working in partnership with elected and appointed governors and pubic and patient governors in three foundation trusts.
Malfait 2018	Belgium; general and mental health hospitals; questionnaires, observations, focus groups, working with internal stakeholders and external stakeholders, patients, family members, patient representatives and president and secretaries of stakeholder committee.
McDaid 2009	Ireland; National mental health non-government organisations; semi-structured interviews; in partnership with mental health professionals and consumers through advisory committee.
Nathan 2014	Australia; health region hospitals; interviews, observations, field notes; working with staff and consumers representatives through committees.
Newberry 2005	Canada; Ontario branches of the Canadian Mental Health Association; interviews; in partnership with executive directors, professionals and consumers through management, policy boards and mental health boards of health agencies.
Schaaf 2017	Zambia; Primary care at the local level; Interviews and focus groups; working with citizens, health providers and locally-elected officials through a citizen voice and action group (world vision).
Scholz 2018	Australia; tertiary referral hospital; semi-structured interviews; partnership with managers, clinicians and consumers.
Sitzia 2006	UK England; local cancer services; semi-structured interviews; working with NHS staff and consumers in partnership groups.
Wiig 2013	Norway; hospitals including micro and meso analysis at maternal and oncology services; interviews and non-participant observations, document analysis; working with patients, representative ombudsmen, hospital managers and clinical staff through committees and meetings.

Finding 11. Consumers could feel their experiential knowledge was not valued by health providers, leading to feelings of being dismissed or overridden. Some health providers perceived consumers' contributions were not as valuable in the partnership. Mutual respect for knowledge and expertise facilitated partnerships.

Assessment of each CERQual component	
Methodological limitations	Minor concerns related to a limited number of studies not reporting researcher reflexivity.

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Coherence	Moderate concerns regarding coherence as there was a fair difference in how well-supported some subfindings were supported compared to others and some studies only contributed to one sub-finding rather than multiple sub-findings.
Relevance	Minor concerns regarding relevance due to a limited number of studies being partially rather than fully relevant.
Adequacy	Minor concerns regarding adequacy due to less than 15 studies comprising this finding.
Overall CERQual assessment	
Moderate level of confidence	Due to moderate concerns regarding coherence; and minor concerns regarding methodological limitations, relevance and adequacy.
Contributing studies	

Study	Context
Attree 2011	UK; health and social care/ cancer; Macmillian region; interviews with health professionals, in partnership with service user representatives (cancer patients) in the Committtee Network Partnership Groups.
Croft 2016	UK; Commissioning organisations; Interviews and observations; in partnership with managers, clinicians and patient representatives through committee and a governing board.
Gurung 2017	Nepal; mental health organisations; interviews to involve mental health service users and care givers in policy making, service planning, monitoring and research.
Haarsma 2015	Netherlands; Palliative care networks; interviews, focus groups and field notes; working with patient representatives and professional staff through sounding board group and management team meetings.
Kidd 2007	Australia; rural mental health service; semi-structured interviews with consumer representatives and health providers; steering committee.
Lewis 2014	Scotland; statutory sector and community groups; in partnership with service users, healthcare, staff and managers through the policy planning committee.
McDaid 2009	Ireland; National mental health non-government organisations; semi-structured interviews; in partnership with mental health professionals and consumers through advisory committee.
Newberry 2005	Canada; Ontario branches of the Canadian Mental Health Association; interviews; in partnership with executive directors, professionals and consumers through management, policy boards and mental health boards of health agencies.
Restall 2013	Canada; mental health and social policy making context; semi-structured interviews, document review and field notes; in partnership with consumers and health providers through policy debates conducted in formal group formats.
Potter 2016	USA; community-based services and children mental health; observations and interviews; in partnership with family members, health professionals through community collaboratives committee.
Scholz 2018	Australia; tertiary referral hospital; semi-structured interviews; partnership with managers, clinicians and consumers.
Sitzia 2006	UK England; local cancer services; semi-structured interviews; working with NHS staff and consumers in partnership groups.

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Finding 12. Consumers could experience token involvement in partnerships, including a lack of decision-making power, being left out of key discussions and being unable to contribute ideas outside health providers' priorities. Token involvement resulted in consumers' feeling frustrated. Consumers valued contributing to tangible changes in health policy and services.

Assessment of each CERQual component	
Methodological limitations	Minor concerns for methodological limitations due to a limited number of studies not reporting researcher reflexivity.
Coherence	Minor concerns regarding coherence due to some sub-findings being slightly less well-supported than others.
Relevance	Minor concerns regarding relevance due to a limited number of studies being partially rather than fully relevant.
Adequacy	No or very minor concerns regarding adequacy
Overall CERQual assessment	
High level of confidence	Due to minor concerns regarding methodological limitations, coherence and relevance.
Contributing studies	
Study	**Context**
Abelson 2004	Canada; health authorities; citizens and health decision makers; focus groups; working with a range or regional health authority decision making processes.
Attree 2011	UK; health and social care/ cancer; Macmillian region; interviews with health professionals, in partnership with service user representatives (cancer patients) in the Committtee Network Partnership Groups.
Boivin 2014	Canada; health and social services centres; analysis of video transcripts, structured notes and observations; in partnership with public representatives, patients and professionals.
Croft 2016	UK; Commissioning organisations; Interviews and observations; in partnership with managers, clinicians and patient representatives through committee and a governing board.
DeCamp 2015	USA; hospital based primary care practice and ambulatory care; interviews; working with mothers, consumer representatives and clinical staff on the advisory board.
Durey 2016	Australia; district/ local health care services including hospitals; interviews, yarning circles (culturally appropriate for Indigenous Australians); working with Aboriginal community members on the committee; health service users, health providers of Aboriginal health services, plus mainstream health service providers and Aboriginal and non-Aboriginal professionals.
Goodman 2011	Kenya; health centres and dispensaries; interviews; in partnership with Health worker in-charge of the health facility, district (rural) managers, health workers, health facility committee members, and community members (patients).
Greene 2018	USA; primary care specialist, paediatric clinic, ambulatory care; interviews and focus groups; in partnership with patient partners and health providers through quality improvement team meetings.

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Gurung 2017	Nepal; mental health organisations; interviews to involve mental health service users and care givers in policy making, service planning, monitoring and research.
Haarsma 2015	Netherlands; Palliative care networks; interviews, focus groups and field notes; working with patient representatives and professional staff through sounding board group and management team meetings.
Heenan 2004	Northern Ireland; community health project; interviews with health service professionals, and community and voluntary workers.
IPFCC 2018	USA; hospitals; survey interviews, follow-up interviews, site visits, working with patients and families, health care professionals and hospitals, also referred to as the Patient and Family Advisory Councils in hospitals.
Kidd 2007	Australia; rural mental health service; semi-structured interviews with consumer representatives and health providers; steering committee.
Lewis 2014	Scotland; statutory sector and community groups; in partnership with service users, healthcare, staff and managers through the policy planning committee.
Maher 2017	New Zealand; Innovation and improvement centre; analysis of workbooks and semi-structured interviews; working with health professionals and patients through an experience based co-design program.
Malfait 2018	Belgium; general and mental health hospitals; questionnaires, observations, focus groups, working with internal stakeholders and external stakeholders, patients, family members, patient representatives and president and secretaries of a stakeholder committee.
McDaid 2009	Ireland; National mental health non-government organisations; semi-structured interviews; in partnership with mental health professionals and consumers through advisory committee.
MacDonald 2015	UK; mental health service foundation trust in rural and urban areas; survey and interviews, focus groups, document analysis and observations; working in partnership with elected and appointed governors and pubic and patient governors in three foundation trusts.
Nathan 2014	Australia; health region hospitals; interviews, observations, field notes; working with staff and consumers representatives through committees.
Newberry 2005	Canada; Ontario brancehs of the Canadian Mental Health Association; interviews; in partnership with executive directors, professionals and consumers through management, policy boards and mental health boards of health agencies.
Restall 2013	Canada; mental health and social policy making context; semi-structured interviews, document review and field notes; in partnership with consumers and health providers through policy debates conducted in formal group formats.
Schaaf 2017	Zambia; Primary care at the local level; Interviews and focus groups; working with citizens, health providers and locally-elected officials through a citizen voice and action group (world vision).
Scholz 2018	Australia; tertiary referral hospital; semi-structured interviews; partnership with managers, clinicians and consumers.
Sitzia 2006	UK England; local cancer services; semi-structured interviews; working with NHS staff and consumers in partnership groups.
Wiig 2013	Norway; hospitals including micro and meso analysis at maternal and oncology services; interviews and non-participant observations, document analysis; working with patients, representative ombudsmen, hospital managers and clinical staff through committees and meetings.

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Finding 13. Working in partnership could affect health providers and consumer participants in both positive and negative ways. Health providers perceived consumers provided a unique perspective that could improve services, but they were concerned about the time pressures and unmet expectations that could accompany their involvement in partnerships. Consumers perceived there were benefits of working in partnership, including empowerment, increased confidence, knowledge and skills. However, they reported that participating in partnerships could be physically and/or emotionally demanding.

Assessment of each CERQual component	
Methodological limitations	No or very minor concerns for methodological limitations.
Coherence	Minor concerns regarding coherence due to some sub-findings being slightly less well-supported than others.
Relevance	Minor concerns regarding relevance due to a limited number of studies being partially rather than fully relevant.
Adequacy	No to very minor concerns regarding adequacy.
Overall CERQual assessment	
High level of confidence	Due to minor concerns regarding relevance and coherence.
Contributing studies	
Study	**Context**
Attree 2011	UK; health and social care/ cancer; Macmillian region; interviews with health professionals, in partnership with service user representatives (cancer patients) in the Committtee Network Partnership Groups.
Boivin 2014	Canada; health and social services centres; analysis of video transcripts, structured notes and observations; in partnership with public representatives, patients and professionals.
Byskov 2014	Africa; health sector; document analysis and observational interviews; in partnership with District Council, Healthcare Management Team plus stakeholders through committees.
Croft 2016	UK; Commissioning organisations; Interviews and observations; in partnership with managers, clinicians and patient representatives through committee and a governing board.
DeCamp 2015	USA; hospital based primary care practice and ambulatory care; interviews; working with mothers, consumer representatives and clinical staff on the advisory board.
Durey 2016	Australia; district/ local health care services including hospitals; interviews, yarning circles (culturally appropriate for Indigenous Australians); working with Aboriginal community members on the committee; health service users, health providers of Aboriginal health services, plus mainstream health service providers and Aboriginal and non-Aboriginal professionals.
Goodman 2011	Kenya; health centres and dispensaries; interviews; in partnership with Health worker in-charge of the health facility, district (rural) managers, health workers, health facility committee members, and community members (patients).
Greco 2006	UK England; North and East Devon localities GPs and primary care; qualitative component of mixed methods and interviews; in partnership with GPs, nurses, patients, health professionals through patient and staff partnership groups (critical friend groups).

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Greene 2018	USA; primary care specialist, paediatric clinic, ambulatory care; interviews and focus groups; in partnership with patient partners and health providers through quality improvement team meetings.
Heenan 2004	Northern Ireland; community health project; interviews with health service professionals, and community and voluntary workers.
Jivanjee 2007	USA; Children's mental health and ambulatory care; unstructured or semi-structured interviews with mental health professionals, other service providers and community representatives, including family members through advisory groups.
Kidd 2007	Australia; rural mental health service; semi-structured interviews with consumer representatives and health providers; steering committee.
Maher 2017	New Zealand; Innovation and improvement centre; analysis of workbooks and semi-structured interviews; working with health professionals and patients through an experience based co-design program.
McDaid 2009	Ireland; National mental health non-government organisations; semi-structured interviews; in partnership with mental health professionals and consumers through advisory committee.
Nathan 2014	Australia; health region hospitals; interviews, observations, field notes; working with staff and consumers representatives through committees.
Newberry 2005	Canada; Ontario branches of the Canadian Mental Health Association; interviews; in partnership with executive directors, professionals and consumers through management, policy boards and mental health boards of health agencies.
Potter 2016	USA; community-based services and children mental health; observations and interviews; in partnership with family members, health professionals through community collaboratives committee.
Restall 2013	Canada; mental health and social policy making context; semi-structured interviews, document review and field notes; in partnership with consumers and health providers through policy debates conducted in formal group formats.
Schaaf 2017	Zambia; Primary care at the local level; Interviews and focus groups; working with citizens, health providers and locally-elected officials through a citizen voice and action group (world vision).
Scholz 2018	Australia; tertiary referral hospital; semi-structured interviews; partnership with managers, clinicians and consumers.
Sitzia 2006	UK England; local cancer services; semi-structured interviews; working with NHS staff and consumers in partnership groups.
Wiig 2013	Norway; hospitals including micro and meso analysis at maternal and oncology services; interviews and non-participant observations, document anslysis; working with patients, representative ombudsmen, hospital managers and clinical staff through committees and meetings.

Finding 14. Working in partnership was perceived to improve consumer involvement in strategic decision-making.

Assessment of each CERQual component	
Methodological limitations	No or very minor concerns for methodological limitations

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Coherence	Moderate concerns regarding coherence as this finding has some contradictory findings.
Relevance	Minor concerns regarding relevance due to a limited number of studies that are partially rather than fully relevant. However, data comprised a broad range of countries (including LMICs), settings and partnership purposes.
Adequacy	Moderate concerns regarding adequacy due to less than 10 studies contributing to this finding.
Overall CERQual assessment	
Moderate level of confidence	Due to moderate concerns regarding coherence and adequacy; and minor concerns regarding relevance.
Contributing studies	
Study	**Context**
Attree 2011	UK; health and social care/ cancer; Macmillian region; interviews with health professionals, in partnership with service user representatives (cancer patients) in the Committtee Network Partnership Groups.
Byskov 2014	Africa; health sector; document analysis and observational interviews; in partnership with District Council, Healthcare Management Team plus stakeholders through committees.
Croft 2016	UK; Commissioning organisations; Interviews and observations; in partnership with managers, clinicians and patient representatives through committee and a governing board.
Durey 2016	Australia; district/ local health care services including hospitals; interviews, yarning circles (culturally appropriate for Indigenous Australians); working with Aboriginal community members on the committee; health service users, health providers of Aboriginal health services, plus mainstream health service providers and Aboriginal and non-Aboriginal professionals.
Haarsma 2015	Netherlands; Palliative care networks; interviews, focus groups and field notes; working with patient representatives and professional staff through sounding board group and management team meetings.
Restall 2013	Canada; mental health and social policy making context; semi-structured interviews, document review and field notes; in partnership with consumers and health providers through policy debates conducted in formal group formats.
Schaaf 2017	Zambia; Primary care at the local level; Interviews and focus groups; working with citizens, health providers and locally-elected officials through a citizen voice and action group (world vision).

Finding 15. Working in partnership was perceived to enhance community ownership of health services .	
Assessment of each CERQual component	
Methodological limitations	No or very minor concerns for methodological limitations
Coherence	Minor concerns related to coherence due to a limited amount of conflicting data.
Relevance	Moderate concerns regarding relevance as there is a reduced range of countries and contexts included.

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Adequacy	Moderate concerns regarding adequacy as this finding includes less than 10 studies.
Overall CERQual assessment	
Moderate level of confidence	Due to moderate concerns regarding relevance and adequacy.
Contributing studies	

Study	Context
Byskov 2014	Africa; health sector; document analysis and observational interviews; in partnership with District Council, Healthcare Management Team plus stakeholders through committees.
Croft 2016	UK; Commissioning organisations; Interviews and observations; in partnership with managers, clinicians and patient representatives through committee and a governing board.
Durey 2016	Australia; district/ local health care services including hospitals; interviews, yarning circles (culturally appropriate for Indigenous Australians); working with Aboriginal community members on the committee; health service users, health providers of Aboriginal health services, plus mainstream health service providers and Aboriginal and non-Aboriginal professionals.
Goodman 2011	Kenya; health centres and dispensaries; interviews; in partnership with Health worker in-charge of the health facility, district (rural) managers, health workers, health facility committee members, and community members (patients).
Johns 2014	Tasmania Australia; community and rural health service, council and hospital; individual and group interviews with local rural community members and representatives, health professionals, staff members from centres, such as GPs, through a committee.
Schaaf 2017	Zambia; Primary care at the local level; Interviews and focus groups; working with citizens, health providers and locally-elected officials through a citizen voice and action group (world vision).

Finding 16. Working in partnership was perceived to lead to improvements in the person-centredness of health service culture.	
Assessment of each CERQual component	
Methodological limitations	No or very minor concerns regarding methodological limitations.
Coherence	No or very minor concerns regarding coherence.
Relevance	Minor concerns regarding relevance due to a limited number of studies being partially rather than fully relevant.
Adequacy	No or very minor concerns regarding adequacy.
Overall CERQual assessment	
High level of confidence	Due to minor concerns regarding relevance.
Contributing studies	

Study	Context

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Attree 2011	UK; health and social care/ cancer; Macmillian region; interviews with health professionals, in partnership with service user representatives (cancer patients) in the Committtee Network Partnership Groups.
Byskov 2014	Africa; health sector; document analysis and observational interviews; in partnership with District Council, Healthcare Management Team plus stakeholders through committees.
Croft 2016	UK; Commissioning organisations; Interviews and observations; in partnership with managers, clinicians and patient representatives through committee and a governing board.
DeCamp 2015	USA; hospital based primary care practice and ambulatory care; interviews; working with mothers, consumer representatives and clinical staff on the advisory board.
Durey 2016	Australia; district/ local health care services including hospitals; interviews, yarning circles (culturally appropriate for Indigenous Australians); working with Aboriginal community members on the committee; health service users, health providers of Aboriginal health services, plus mainstream health service providers and Aboriginal and non-Aboriginal professionals.
Goodman 2011	Kenya; health centres and dispensaries; interviews; in partnership with Health worker in-charge of the health facility, district (rural) managers, health workers, health facility committee members, and community members (patients).
Greco 2006	UK England; North and East Devon localities GPs and primary care; qualitative component of mixed methods and interviews; in partnership with GPs, nurses, patients, health professionals through patient and staff partnership groups (critical friend groups).
Greene 2018	USA; primary care specialist, paediatric clinic, ambulatory care; interviews and focus groups; in partnership with patient partners and health providers through quality improvement team meetings.
IPFCC 2018	USA; hospitals; survey interviews, follow-up interviews, site visits, working with patients and families, health care professionals and hospitals, also referred to as the Patient and Family Advisory Councils in hospitals.
Jha 2018	UK England; Training school and two hospitals; Qualitative component of mixed methods, workshops and patient safety intervention aimed at trainee doctors; working with patients with personal experience of harm or error during medical diagnosis, treatment, care either to themselves or relatives and trainee doctors.
Restall 2013	Canada; mental health and social policy making context; semi-structured interviews, document review and field notes; in partnership with consumers and health providers through policy debates conducted in formal group formats.
Schaaf 2017	Zambia; Primary care at the local level; Interviews and focus groups; working with citizens, health providers and locally-elected officials through a citizen voice and action group (world vision).
Sharma 2016	USA; primary care clinics; semi-structured interviews; working with patient, family members, caregivers, clinic staff members, leaders and principle regional stakeholders in patient engagement through the Participant Advisory Council.
Sitzia 2006	UK England; local cancer services; semi-structured interviews; working with NHS staff and consumers in partnership groups.
Wiig 2013	Norway; hospitals including micro and meso analysis at maternal and oncology services; interviews and non-participant observations, document analysis; working with patients, representative ombudsmen, hospital managers and clinical staff through committees and meetings.

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Finding 17. Working in partnership was perceived to lead to improvements in the built environment of the health service.	
Assessment of each CERQual component	
Methodological limitations	Minor concerns for methodological limitations due to a limited number of studies not reporting researcher reflexivity
Coherence	Minor concerns regarding coherence as some of the data is conflicting.
Relevance	Minor concerns regarding relevance due to a limited number of studies being partially rather than fully relevant.
Adequacy	Minor concerns regarding adequacy as less than 15 studies contributed to this finding.
Overall CERQual assessment	
High level of confidence	Due to minor concerns regarding methodological limitations, coherence, relevance and adequacy
Contributing studies	
Study	**Context**
Attree 2011	UK; health and social care/ cancer; Macmillian region; interviews with health professionals, in partnership with service user representatives (cancer patients) in the Committtee Network Partnership Groups.
DeCamp 2015	USA; hospital based primary care practice and ambulatory care; interviews; working with mothers, consumer representatives and clinical staff on the advisory board.
Greene 2018	USA; primary care specialist, paediatric clinic, ambulatory care; interviews and focus groups; in partnership with patient partners and health providers through quality improvement team meetings.
Haarsma 2015	Netherlands; Palliative care networks; interviews, focus groups and field notes; working with patient representatives and professional staff through sounding board group and management team meetings.
Johns 2014	Tasmania Australia; community and rural health service, council and hospital; individual and group interviews with local rural community members and representatives, health professionals, staff members from centres, such as GPs, through a committee.
Nathan 2014	Australia; health region hospitals; interviews, observations, field notes; working with staff and consumers representatives through committees.
Schaaf 2017	Zambia; Primary care at the local level; Interviews and focus groups; working with citizens, health providers and locally-elected officials through a citizen voice and action group (world vision).
Scholz 2018	Australia; tertiary referral hospital; semi-structured interviews; partnership with managers, clinicians and consumers.
Sharma 2016	USA; primary care clinics; semi-structured interviews; working with patient, family members, caregivers, clinic staff members, leaders and principle regional stakeholders in patient engagement through the Participant Advisory Council.

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Sitzia 2006	UK England; local cancer services; semi-structured interviews; working with NHS staff and consumers in partnership groups.

Finding 18. Working in partnership was perceived to lead to improvements in health service design and delivery.	
Assessment of each CERQual component	
Methodological limitations	No or very minor concerns for methodological limitations.
Coherence	Minor concerns regarding coherence as some of the data is conflicting.
Relevance	Minor concerns regarding relevance due to a limited number of studies being partially rather than fully relevant.
Adequacy	Minor concerns regarding adequacy because the finding includes less than 15 studies.
Overall CERQual assessment	
High level of confidence	Due to minor concerns regarding coherence, relevance and adequacy
Contributing studies	
Study	**Context**
Attree 2011	UK; health and social care/ cancer; Macmillian region; interviews with health professionals, in partnership with service user representatives (cancer patients) in the Committtee Network Partnership Groups.
DeCamp 2015	USA; hospital based primary care practice and ambulatory care; interviews; working with mothers, consumer representatives and clinical staff on the advisory board.
Durey 2016	Australia; district/ local health care services including hospitals; interviews, yarning circles (culturally appropriate for Indigenous Australians); working with Aboriginal community members on the committee; health service users, health providers of Aboriginal health services, plus mainstream health service providers and Aboriginal and non-Aboriginal professionals.
Greene 2018	USA; primary care specialist, paediatric clinic, ambulatory care; interviews and focus groups; in partnership with patient partners and health providers through quality improvement team meetings.
Heenan 2004	Northern Ireland; community health project; interviews with health service professionals, and community and voluntary workers.
Johns 2014	Tasmania Australia; community and rural health service, council and hospital; individual and group interviews with local rural community members and representatives, health professionals, staff members from centres, such as GPs, through a committee.
Lewis 2014	Scotland; statutory sector and community groups; in partnership with service users, healthcare, staff and managers through the policy planning committee.
Maher 2017	New Zealand; Innovation and improvement centre; analysis of workbooks and semi-structured interviews; working with health professionals and patients through an experience based co-design program.

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(Continued)

Nathan 2014	Australia; health region hospitals; interviews, observations, field notes; working with staff and consumers representatives through committees.
Restall 2013	Canada; mental health and social policy making context; semi-structured interviews, document review and field notes; in partnership with consumers and health providers through policy debates conducted in formal group formats.
Schaaf 2017	Zambia; Primary care at the local level; Interviews and focus groups; working with citizens, health providers and locally-elected officials through a citizen voice and action group (world vision).
Sitzia 2006	UK England; local cancer services; semi-structured interviews; working with NHS staff and consumers in partnership groups.

Finding 19. Working in partnership could lead to improvements in health service evaluation.	
Assessment of each CERQual component	
Methodological limitations	No or very minor concerns for methodological limitations.
Coherence	Moderate concerns regarding coherence as this finding has some conflicting data.
Relevance	Serious concerns regarding relevance due to only study is fully relevant and there is a significant lack of diversity in settings and countries (including no LMICS) included in the finding.
Adequacy	Serious concerns regarding adequacy due to only two studies comprising this finding.
Overall CERQual assessment	
Very low level of confidence	Due to serious concerns regarding coherence, relevance and adequacy.
Contributing studies	
Study	**Context**
Croft 2016	UK; Commissioning organisations; Interviews and observations; in partnership with managers, clinicians and patient representatives through committee and a governing board.
Jivanjee 2007	USA; Children's mental health and ambulatory care; unstructured or semi-structured interviews with mental health professionals, other service providers and community representatives, including family members through advisory groups.

Appendix 4. Expanded matrix table

Based on the findings of the QES, we explored whether the trialists had described the following aspects of working in partnership:

1. Was the partnership conducted in a supportive government policy context?
2. Was the partnership conducted in a supportive organisational context?
3. Were consumers involved in the recruitment process?
4. Were resources in place to recruit and support members from groups who are underserved?
5. If expected to represent other consumers, were consumers facilitated to do this (e.g. with data, peer networks etc)?
6. Were strategies used to facilitate positive interpersonal dynamics in the partnership?

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7. Were consumers offered training and practical support to facilitate their participation in the partnership?
8. Were consumers and health providers both clear about the expectations of the consumer role, and were consumers involved in shaping their role?
9. Were strategies used to decrease the potential for consumers to feel intimidated a) in a formal group formats and b) working with health providers?
10. Were strategies used to ensure consumers could contribute meaningfully to the agenda, including leading the meeting and/or contributing their own priorities?
11. Were consumers involved meaningfully in decision-making in the partnership?
12. Were strategies used to reduce negative effects of partnerships on both health providers and consumers?

Results key:

Y = yes

N = no

U = unsure/not reported

N/A = not applicable

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Trial	Question											
	1	2	3	4	5	6	7	8	9	10	11	12
Greco 2006	U	Y	N	Y	Y	Y	Y	N	Y	N	U	N
Jha 2018	U	U	N	Y	N/A	Y	Y	Y	Y	Y	Y	Y
O'Connor 2019	Y	U	Y	U	Y	Y	Y	U	U	U	U	Y
Persson 2013	U	U	N	Y	Y	N	Y	U	Y	Y	Y	U
Wu 2019	U	U	Y	Y	Y	Y	Y	Y	Y	U	Y	U

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Appendix 5. List of all studies included in the matrix analysis

Greco 2006

- Primary reference: Greco 2006

Jha 2018

- Primary reference: Jha 2018
- Supplementary references: Jha 2015, Quinton 2018, Winterbottom 2010, Wright 2016

O'Connor 2019

- Primary reference: O'Connor 2019

Persson 2013

- Primary reference: Persson 2013
- Supplementary references: Eriksson 2016, Eriksson 2018, Målqvist 2015 , Nga 2010, Nga 2012, Wallin 2011

Wu 2019

- Primary reference: Wu 2018
- Supplementary references: Wu 2019, Dadwal 2017, John Hopkins 2014, Ibe 2018

Appendix 6. CASP ratings of studies included in the synthesis

CASP questions

1. Was there a clear statement of the aims of the research?

2. Is a qualitative methodology appropriate?

3. Was the research design appropriate to address the aims of the research?

4. Was the recruitment strategy appropriate to the aims of the research?

5. Was the data collected in a way that addressed the research issue?

6. Has the relationship between researcher and participants been adequately considered?

7. Have ethical issues been taken into consideration?

8. Was the data analysis sufficiently rigorous?

9. Is there a clear statement of findings?

10. How valuable is the research?

Y = yes

N = no

C/T = can't tell

V = valuable

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Study ID	CASP question									
	1	2	3	4	5	6	7	8	9	10
Abelson 2004	Y	Y	Y	Y	Y	C/T	Y	Y	Y	V
Attree 2011	Y	Y	Y	Y	Y	Y	Y	Y	Y	V
Boivin 2014	Y	Y	Y	Y	Y	Y	Y	Y	Y	V
Byskov 2014	Y	Y	Y	Y	Y	Y	Y	Y	Y	V
Croft 2016	Y	Y	Y	Y	Y	Y	Y	Y	Y	V
DeCamp 2015	Y	Y	Y	Y	Y	Y	Y	Y	Y	V
Durey 2016	Y	Y	Y	Y	Y	Y	Y	Y	Y	V
Goodman 2011	Y	Y	Y	Y	Y	C/T	Y	Y	Y	V
Greco 2006	Y	Y	Y	Y	Y	Y	Y	Y	Y	V
Greene 2018	Y	Y	Y	Y	Y	C/T	Y	Y	Y	V
Gurung 2017	Y	Y	Y	Y	Y	Y	Y	Y	Y	V
Haarsma 2015	Y	Y	Y	Y	Y	Y	Y	Y	Y	V
Heenan 2004	Y	Y	Y	Y	Y	C/T	Y	Y	Y	V
IPFCC 2018	Y	Y	Y	Y	Y	C/T	N	Y	Y	V
Jha 2018	Y	Y	Y	Y	Y	C/T	Y	Y	Y	V
Jivanjee 2007	Y	Y	Y	Y	Y	Y	Y	Y	Y	V
Johns 2014	Y	Y	Y	Y	Y	C/T	Y	Y	Y	V
Kidd 2007	Y	Y	Y	Y	Y	C/T	Y	Y	Y	V
Lewis 2014	Y	Y	Y	Y	Y	C/T	Y	Y	Y	V

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(Continued)

MacDonald 2015	Y	Y	Y	Y	Y	Y	Y	Y	Y	V
Maher 2017	Y	Y	Y	Y	Y	Y	N	Y	Y	V
Malfait 2018	Y	Y	Y	Y	Y	C/T	Y	Y	Y	V
McDaid 2009	Y	Y	Y	Y	Y	C/T	N	Y	Y	V
Nathan 2014	Y	Y	Y	Y	Y	C/T	Y	Y	Y	V
Newberry 2005	Y	Y	Y	Y	Y	Y	Y	Y	Y	V
Potter 2016	Y	Y	Y	Y	Y	C/T	Y	Y	Y	V
Restall 2013	Y	Y	Y	Y	Y	C/T	Y	Y	Y	V
Rutebemberwa 2009	Y	Y	Y	Y	Y	Y	Y	Y	Y	V
Schaaf 2017	Y	Y	Y	Y	Y	Y	Y	Y	Y	V
Scholz 2018	Y	Y	Y	Y	Y	C/T	Y	Y	Y	V
Sharma 2016	Y	Y	Y	Y	Y	C/T	Y	Y	Y	V
Sitzia 2006	Y	Y	Y	Y	Y	C/T	Y	Y	Y	V
Wiig 2013	Y	Y	Y	Y	Y	C/T	Y	Y	Y	V

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Appendix 7. CINAHL search strategy

Search ID#	**Search Terms**
S52	S31 AND S49
S51	S31 AND S49
S50	S31 AND S49
S49	S35 AND S39 AND S48
S48	S40 OR S41 OR S42 OR S43 OR S44 OR S45 OR S46 OR S47
S47	MH "Program Evaluation" OR (AB (health service*))
S46	MH "Program Implementation"
S45	MM "Quality Improvement"
S44	MH "Decision Making"
S43	MM "Community Mental Health Services"
S42	MM "Decision Making, Patient"
S41	MH "Community Health Services"
S40	MM "Health Care Delivery"
S39	S36 OR S37 OR S38
S38	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*)
S37	TX (experience based N2 design)
S36	(MH "Patient Centered Care")
S35	S32 OR S33 OR S34
S34	MH "Professional-Patient Relations"
S33	(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* or consumer N2 ...
S32	(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*))
S31	(MH "Qualitative Studies+")

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(Continued)

S30	S23 OR S24 OR S25 OR S26 OR S27 OR S28 OR S29
S29	TI participatory systems approach to design for safer integrated medicine management
S28	TI Implementing patient centred cancer care
S27	TI Utilizing experience based co design to improve the experience of patients accessing emergency departments in New South Wales
S26	TI Same description different values
S25	TI Investigating the role of NHS Foundation Trust governors in the governance of patient safety
S24	aiming for inclusion case study
S23	TI community representatives on health service committees
S22	S1 AND S19
S21	S1 AND S19
S20	S1 AND S19
S19	S5 AND S9 AND S18
S18	S10 OR S11 OR S12 OR S13 OR S14 OR S15 OR S16 OR S17
S17	MH "Program Evaluation" OR (AB (health service*))
S16	MH "Program Implementation"
S15	MM "Quality Improvement"
S14	MH "Decision Making"
S13	MM "Community Mental Health Services"
S12	MM "Decision Making, Patient"
S11	MH "Community Health Services"
S10	MM "Health Care Delivery"
S9	S6 OR S7 OR S8
S8	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*)
S7	TX (experience based N2 design)
S6	(MH "Patient Centered Care")
S5	S2 OR S3 OR S4
S4	MH "Professional-Patient Relations"

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(Continued)

S3	(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* or consumer N2 ...
S2	(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*))
S1	(MH "Qualitative Studies+")

Appendix 8. Embase search strategy

1. community participation/

2. stakeholder engagement/

3. patient participation/

4. 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,kw.

6. or/1-5

7. health care planning/

8. exp patient care/

9. *outpatient department/

10. *mental health service/

11. exp *"community care"/

12. exp *"health service"/

13. total quality management/

14. *"public hospital"/

15. exp health care quality/

16. exp health care delivery/

17. integrated health care system/

18. or/7-17

19. public relations/

20. advisory committee/

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.

22. (experience based adj2 design).ti,ab,kw.

23. or/19-22

24. qualitative.tw.

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25. qualitative study.tw.

26. or/24-25

27. and/6,18,23,26

28. limit 27 to (english language and yr="2000 -Current")

Appendix 9. Glossary of key terms

Consumers: for the purposes of this review, consumers were defined a patient, carer or community member who brought their perspective to health service partnerships. The term also included consultants who were employed by the health service to represent the patient or carer perspective. This definition is a simplified version of that used in the companion intervention effects review (Lowe 2021).

Formal group partnerships: for the purposes of this review, formal group partnerships were defined as consumers and health providers meeting jointly and regularly in formal group formats (e.g. committees, councils, working groups) to share decision-making for the purpose of planning, delivery or evaluation in one or more health service(s). The same definition was used in the companion intervention effects review (Lowe 2021).

Health providers: for the purposes of this review, health providers referred to a person who had a health policy, management, administrative, or clinical role and who participated in formal partnerships in an advisory or representative capacity. A health provider did not include a person whose primary role was a health researcher. This definition is a simplified version of that used in the companion intervention effects review (Lowe 2021).

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 included home and residential services only when they were primarily providing health or nursing care (e.g. home-based nursing services, nursing homes, residential rehabilitation services, or hospices). The same definition was used in the companion intervention effects review (Lowe 2021).

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. The companion intervention effects review by Lowe 2021 addressed the question ‘what are the effects of consumers and health providers working in partnership on health services planning, delivery and evaluation'?

Partnering (as an intervention): For the purposes of this review, the intervention was defined as:

- consumers and health providers engaged in formal group formats, such as committees, councils, boards or steering groups;
- the group involved at least one consumer and at least one health provider;
- the group met jointly, more than once via face-to-face or electronic modes;
- the group was either ongoing or time-limited (for example, groups formed for a specific project);
- the group made joint decisions for planning and/or delivery and/or evaluation of health services.

The same definition was used in the companion intervention effects review (Lowe 2021).

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 consumers and health providers’ views and experiences of partnering to improve health services planning, delivery and evaluation'?

WHAT'S NEW

Date	Event	Description
30 May 2023	Amended	Plain Language Summary edited to remove inadvertent underlining of all text.

HISTORY

Protocol first published: Issue 2, 2019

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Review first published: Issue 3, 2023

CONTRIBUTIONS OF AUTHORS

BM - screening, sampling, data extraction, data analysis, quality appraisal, CerQual assessments, development of matrix, development of best practice principles, drafting the review, organising and participating in stakeholder advisory panel meetings

LS - screening, sampling, data extraction, data analysis, quality appraisal, providing feedback on drafts

AV - data extraction, quality appraisal, CerQual assessments, development of matrix, development of best practice principles, participating in stakeholder advisory panel meetings, drafting the review

DL - screening, quality appraisal, data analysis, participating in stakeholder advisory panel meetings, providing feedback on drafts

LW - screening, quality appraisal, participating in stakeholder advisory panel meetings, development of best practice principles, providing feedback on drafts

CW - screening, data analysis, stakeholder advisory panel member, development of best practice principles, providing feedback on drafts

LGW - screening, quality appraisal, data analysis, providing feedback on drafts

VX - quality appraisal, data analysis, providing feedback on drafts

CC - screening, assistance with data analysis and quality appraisal, providing feedback on drafts

NR - screening, stakeholder advisory panel member, planning of stakeholder advisory panel meetings, development of best practice principles, providing feedback on drafts

PB - screening, stakeholder advisory panel member, planning of stakeholder advisory panel meetings, development of best practice principles, providing feedback on drafts

RC - screening, stakeholder advisory panel member, development of best practice principles, providing feedback on drafts

FM - screening, stakeholder advisory panel member, development of best practice principles, providing feedback on drafts

NM - screening, stakeholder advisory panel member, development of best practice principles, providing feedback on drafts

AM - screening, stakeholder advisory panel member, development of best practice principles, providing feedback on drafts

LS - stakeholder advisory panel member, development of best practice principles, providing feedback on drafts

SB - screening, stakeholder advisory panel member, providing feedback on drafts

MG - screening, stakeholder advisory panel member, providing feedback on drafts

DM - screening, stakeholder advisory panel member, providing feedback on drafts

CG - screening, providing feedback on drafts

LE - planning of stakeholder advisory panel meetings, stakeholder panel member, providing feedback on drafts

LA - stakeholder panel member. providing feedback on drafts

NP - stakeholder panel member, providing feedback on drafts

RR - providing feedback on drafts, methodological guidance throughout the review

SH - stewardship of the review, screening, sampling, quality appraisal, methodological guidance throughout review, participating in stakeholder advisory panel meetings, development of best practice principles, providing feedback on drafts

None of the authors listed above were involved in the conduct, analysis or publication of any of the included studies.

DECLARATIONS OF INTEREST

BM - no relevant interests; former Joint Managing Editor of Cochrane Consumers and Communication Group until June 2021. BM was not involved in the editorial process for this review.

LS - none known.

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AV - none known.

DL - no relevant interests; former Technical Editor of Cochrane Consumers and Communication until March 2021. DL was not involved in the editorial process for this review.

LW - no relevant interests; shared own opinions and comments on own social media regarding consumer engagement in health service design and health service research; registered physiotherapist who works in health service research and teaches subjects in physiotherapy degrees; consulting work for Consumers Health Forum of Australia (ongoing); consumer representative with ongoing consumer roles with consumers Health Forum of Australia and the Victorian Clinical Informatics Council (Department of Health); Managing Editor of Cochrane Consumers and Communication. LW was not involved in the editorial process for this review.

CW - no relevant interests; Senior Engagement Officer, Metro South Hospital and Health Service.

LGW - none known.

VX - none known.

CC - none known.

NR - none known.

PB - none known.

FM - CatholicCare Victoria (Clinical Services Practice Leader); Medibank Private (stock).

RC - no relevant interests; Director Partnerships, Clinical Education and Planning at the Royal Victorian Eye and Ear Hospital (as part of this role - mange the Patient Experience Team and also lead the work to meet the ACSQHC National Standard 2: Partnering with consumers.

NM - no relevant interests; Clinical Trials Manager, Peter MacCallum Cancer Centre, 2017-2019; Medical Scientist (Casual Position), St. Vincent's Hospital Melbourne, 2020-present; Quality Consultant (Casual Position, Hudson Institute of Medical Research, 2020-present.

AM - none known.

DM - Weenthunga Health Network (Board Member).

LS - no relevant interests; Psychologist, Department of Communities, Western Australia.

SB - none known.

MG - no relevant interests; Board Member of the Health Issues Centre (a not for profit organisation that advocates for consumer involvement in planning and delivery of health care).

CG - no relevant interests; Resident at Authority Health, Michigan State University.

LE - none known.

LA - none known.

NP - no relevant interests; Australian Commission on Safety and Quality in Health Care (government agency with position on partnering with consumers).

RR - no relevant interests; Co-ordinating Editor of Cochrane Consumers and Communication. RR was not involved in the editorial process for this review.

SH - no relevant interests; former Joint Co-ordinating Editor of Cochrane Consumers and Communication until June 2022. SH was not involved in the editorial process for this review.

SOURCES OF SUPPORT

Internal sources

- La Trobe University, Australia

  BM received funding from La Trobe University towards undertaking this review

External sources

- No sources of support provided

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DIFFERENCES BETWEEN PROTOCOL AND REVIEW

The title of this review has been changed twice. Firstly, the title was changed from *Consumers and health providers working in partnership for the promotion of person-centred health services: a co-produced qualitative evidence synthesis* to *Consumers and health providers working in partnership to improve health services' planning, delivery and evaluation: a co-produced qualitative evidence synthesis.* The title was changed to maintain consistency with the effectiveness review. The title of the effectiveness review was changed to reflect peer review feedback that the terms "working in partnership" and "person-centred care" were an oxymoron. Prior to publication, the title was changed again from *Consumers and health providers working in partnership to improve health services' planning, delivery and evaluation: a co-produced qualitative evidence synthesis* to *Consumers and health providers' views and perceptions of partnering to improve health services design, delivery and evaluation: a co-produced qualitative evidence synthesis* to align more closely with the titles of other QES published in the Cochrane Library.

The Background section of this review has been updated to focus more explicitly on formal group partnerships, and reduce focus on person-centred care, to reflect feedback on the companion effectiveness review.

The Methods section has several differences compared to the protocol:

- Inclusion criteria: following feedback from our Stakeholder Panel, we refined the inclusion criterion of "sharing responsibility for decisions" to become "making joint decisions". The Stakeholder Panel expressed that, in practice, many of the formal group partnerships between consumers and health providers did not share ultimate responsibility for decisions, because responsibility lay with hospital executives. However, they could make "joint decisions or recommendations" to higher authorities. The inclusion criteria of the companion effectiveness review was also updated consistent with this feedback.
- Data synthesis approach: the reasons for changing from Thematic Synthesis to Framework Synthesis have been reported in the 'Data synthesis' section.
- Using the synthesised qualitative findings to supplement the Cochrane effectiveness review: we used a matrix approach rather than a sequential approach to integrate the qualitative findings with the quantitative findings. This change was made after the publication of the protocol when we were determining the method for developing the best practice principles, for which the matrix method was more suited.

NOTES

This protocol includes standard text and guidance provided by Cochrane Consumers and Communication (Ryan 2016).

INDEX TERMS

Medical Subject Headings (MeSH)

Caregivers; Community Participation; *Health Personnel; *Health Services

MeSH check words

Humans

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