

# BMJ Open Conceptualising, operationalising and measuring trust in participatory health research networks: a scoping review protocol

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## ABSTRACT

**Introduction** A participatory approach to co-creating new knowledge in health research has gained significant momentum in recent decades. This is founded on the described benefits of community-based participatory research (CBPR), such as increased relevance of research for those who must act on its findings. This has prompted researchers to better understand how CBPR functions to achieve these benefits through building sustainable research partnerships. Several studies have identified ‘trust’ as a key mechanism to achieve sustainable partnerships, which themselves constitute social networks. Although existing literature discuss trust and CBPR, or trust and social networks, preliminary searches reveal that none link all three concepts of trust, CBPR and social networks. Thus, we present our scoping review protocol to systematically review and synthesise the literature exploring how trust is conceptualised, operationalised and measured in CBPR and social networks.

**Methods and analysis** This protocol follows guidelines from Levac *et al* (Scoping studies: advancing the methodology. *Implement Sci* 2010;5:69), which follow the methodological framework of Arksey and O’Malley. This scoping review explores several electronic databases including Scopus, Medline, PubMed, Web of Science, CINAHL, Cochrane Library, Google Scholar and PsychINFO. Grey literature such as theses/dissertations and reports will be included. A search strategy was identified and agreed on by the team in conjunction with a research librarian. Two independent reviewers will screen articles by title and abstract, then by full text based on pre-determined exclusion/inclusion criteria. A third reviewer will arbitrate discrepancies regarding inclusions/exclusions. We plan to incorporate a thematic analysis.

**Ethics and dissemination** Ethics is not required for this review specifically. It is a component of a larger study that received ethical approval from the University of Limerick research ethics committee (#2018\_05\_12\_EHS). Translation of results to key domains is integrated through active collaboration of stakeholders from community, health services and academic sectors. Findings will be disseminated through academic conferences, and peer review publications targeting public and patient involvement in health research.

## Strengths and limitations of this study

- Scoping review is embedded in an established health research partnership and involvement of multi-sector stakeholders as co-researchers in the analysis and interpretation stages adds contextual expertise to this scoping review.
- Inclusion of multiple reviewers for all phases of identification and selection.
- The protocol adheres to Levac *et al*'s advanced methodological guidelines built on Arksey and O’Malley’s original framework as well as the methods manual from the Joanna Briggs Institute.
- For feasibility purposes, our scoping review will be limited to English rather than non-English articles or translations of non-English articles.
- Due to a lack of conceptual agreement surrounding trust, we anticipate that some included studies may rely on authors’ self-report accounts of how trust is defined and measured.

## INTRODUCTION

### Background

Participatory research (PR) is ‘systematic inquiry, with the collaboration of those affected by the issue being studied, for the purposes of education and taking action or effecting change’.<sup>1</sup> Taking a participatory approach to the co-creation and translation of new knowledge into action in health research has been gaining significant momentum in western democracies in recent decades.<sup>2,3</sup> This momentum is largely due to the recognition that PR helps to maximise the relevancy of research and usability of its products, while simultaneously building capacity and addressing issues of social justice and self-determination among end-user communities.<sup>2,3</sup> PR serves as an umbrella term for a variety of approaches, all of which strive to bridge this gap between knowledge and practice by harnessing inclusivity and recognising the importance of actively and meaningfully

engaging those who the research serves to benefit in the research process.<sup>3</sup>

One of the more widely recognised bodies of literature within PR falls under the heading of community-based participatory research (CBPR), with core philosophy and values grounded in social and environmental justice and self-determination to address inequities, particularly in regards to health.<sup>3</sup> Similarly, the W.K. Kellogg Foundation's Community Health Scholars Program<sup>4</sup> defines CBPR as:

A collaborative approach to research that equitably involves all partners in the research process and recognises the unique strengths that each brings. CBPR begins with a research topic of importance to the community with the aim of combining knowledge and action for social change to improve community health and eliminate health disparities.<sup>4</sup> (p. 2)

The use of CBPR in this protocol encompasses a broad range of terms used (eg, public and patient involvement, participatory health research, participatory action research), which embrace shared core philosophies and values.

Recognising the importance of CBPR, a conceptual model was developed<sup>5</sup> and adapted<sup>2</sup> which provides a concrete framework for understanding how the CBPR process is influenced by contextual and process-related aspects that can affect the ability to achieve both intermediate impacts (eg, stronger partnerships) and long-term outcomes (eg, improved health, community transformation and health equity).<sup>6</sup> Due to the model's comprehensiveness and focus on the relationship between context, process dynamics and research outcomes, the CBPR conceptual model was deemed appropriate for addressing key gaps in the literature.<sup>7</sup> Such gaps include theoretically and empirically explaining 'how contexts, partnership practices and research/intervention engagement factors contribute to broad-based CBPR and health outcomes'.<sup>7</sup> Oetzel *et al*<sup>7</sup> empirically tested variables of the CBPR model, with the aim 'to better understand the mechanisms for impact on achieving' intermediate and long-term health outcomes, such as community transformation. Findings from this study found that the model was suitable for explaining important relational (eg, interactive) and structural (eg, team composition and nature) processes<sup>2</sup> and pathways for impact on intermediate and long-term outcomes.<sup>7</sup>

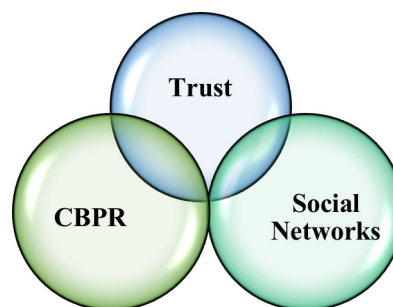
Focusing on the relational aspect of the CBPR model, a realist systematic review by Jagosh *et al*<sup>8</sup> identified partnership synergy as a universal feature of the collaborative process necessary for building and sustaining partnerships that create resilience, sustain health-related goals and extend programme infrastructure, while creating new and unexpected ideas and outcomes. Literature from the community perspective includes various accounts of community problems of engagement and trust. For example, Jagosh *et al*<sup>9</sup> identify instances where contextual factors such as history of oppression or research abuse

have triggered mistrust in the community, impacting positive outcomes, such as partnership synergy. Building on these findings, Jagosh *et al*<sup>9</sup> further explored what supports partnership synergy in successful long-term CBPR partnerships. This pointed to the building and maintenance of trust as a key mechanism in this process. However, Jagosh *et al*<sup>9</sup> treated trust as a 'black box' concept and did not attempt to unpack its internal dimensions and processes.

As we seek to explore how trust is conceptualised, operationalised and measured in CBPR partnerships, we must adopt a methodology that supports the analysis of trust as well as its contextual and relational dynamics in CBPR partnerships.

If trust is a key mechanism of how partnerships function,<sup>8,9</sup> and is an identified component of the CBPR conceptual model,<sup>7</sup> then it is important to find a way to describe and measure trust among and between research partners within CBPR. A CBPR stakeholder partnership can be seen as a social network. A social network describes the relationships among people, organisations or other social actors.<sup>10</sup> Social network analysis (SNA) is a methodology for describing and measuring contextual and relational dynamics among and between social actors.<sup>11</sup> Therefore, SNA could provide useful tools for investigating the development and maintenance of trust and trustworthiness and their effects on the relationships in a CBPR network, including partnership functioning within social networks.<sup>12</sup> As a CBPR project unfolds, the ability to measure trust using tools from SNA could allow for the design of structural interventions (eg, adding or removing planned working meetings) to improve partnership function by targeting context or social structures within the partnership.<sup>8,9</sup>

Social networks have been used to explore trust in diverse fields, such as in health<sup>13</sup> or education.<sup>14</sup> They have also been used to explore dynamics within CBPR.<sup>15,16</sup> However, social networks have never been used to explore the dynamics of trust within CBPR. Given that trust has been explored in both social networks and CBPR contexts, and both involve relational dimensions, we expect the two concepts may complement each other well. Therefore, CBPR, social networks and trust (figure 1) constitute a conceptual triad that may allow us



**Figure 1** Trust, CBPR and social networks as a conceptual triad. CBPR, community-based participatory research.

**Table 1** Boundaries and definitions for the conceptualising, operationalising and measurement of trust in our scoping review

Dimension of our research question	The definition we attached to this dimension of our research question	The boundary for data extraction to inform understanding of the research question dimension
Conceptualisation	Assigning meaning to something	Definition of trust
Operationalisation	Selecting observable phenomenon to represent abstract concepts How will we go about empirically testing the concept?	Dimensions and indicators of trust What are the operationalisation issues with the concept? ► Based on our indicators, what questions were asked to represent trust, what observations were made, what specific attributes will exist for the measure used?
Measurement	Process of observing and recording the observations, or assigning numbers to a phenomenon	Level of measurement such as nominal, ordinal, interval or ratio and type of measures such as survey, scaling, qualitative, unobtrusive used for trust

to better understand how partnership function leads to better research outcomes.

### Purpose of conducting the scoping review

Although existing literature discuss trust and CBPR,<sup>17</sup> or trust and social networks,<sup>18</sup> preliminary searches have revealed that none of the literature explores all three concepts of trust, CBPR and social networks (One review involved social networks, CBPR and social trust, but as a feature of social capital<sup>19</sup>). Furthermore, preliminary searches revealed a lack of consensus regarding how trust is conceptualised, operationalised and measured. With this in mind, the objectives of this scoping review are to:

- Identify the literature on trust in CBPR and social networks.
- Clarify how trust is conceptualised, operationalised and measured in CBPR and social networks.
- Identify where these dimensions of trust may intersect across both CBPR and social networks.

Table 1 presents the definitions and boundaries that guide how we will conceptualise, operationalise and measure trust in our scoping review.

### METHODS/DESIGN

Due to the broad nature of our research question and objectives, going beyond effectiveness of treatments and interventions,<sup>20</sup> we want to capture a vast breadth of literature, that is, more inclusive in terms of what is included/excluded.<sup>21 22</sup> With that in mind, a scoping review was identified as the most suitable methodology to help understand the extent of the literature and clarify key concepts, in a systematic way that can be replicable in the future.<sup>22</sup> This scoping review was undertaken between March and October 2020. To ensure rigour in our approach, the methodology for this scoping review followed the guidelines and stages set out by Levac *et al*,<sup>23</sup> which consists of a further developed methodological framework from that of the widely cited Arksey and O'Malley.<sup>24</sup> This extended framework from Levac *et al*<sup>23</sup> incorporates six stages: (1) identifying the research question; (2) identifying relevant studies; (3) study selection; (4) charting the data; (5) collating, summarising and reporting results and (6)

consultation with knowledge users. This scoping review will outline how we will address each of the six stages.

### Stage 1: identifying the research question

In order to clearly identify our research question guiding the scope of the review, we iteratively searched and revised our search terms to capture the most appropriate body of literature. When forming the research question, we identified our main concept of trust and two principal contextual settings for which the concept will be explored: CBPR and social networks. The broad nature of these concepts is important in capturing a breadth of literature.<sup>25</sup> This is followed by addressing our target population, being all human studies. Finally, our outcome of interest is to use the literature to see how social network research and CBPR intersect in their conceptualisation, operationalisation and methods of measurement for trust. This led to the formulation of our research question:

How does the literature conceptualise, operationalise and measure trust within the context of community-based participatory health research and social networks?

### Stage 2: identifying relevant studies

Recognising that comprehensiveness is a key strength of a scoping review, we want to ensure data sources are heterogenous, while not compromising feasibility. With that in mind, we will explore several electronic databases including Scopus, Medline, PubMed, Web of Science, CINAHL, Cochrane Library, Google Scholar and PsychINFO. We will also include grey literature such as theses/dissertations and reports from Google Scholar and Open Grey. Deliberation among two additional members of the research team regarding exclusion and inclusion criteria at the outset of the scoping review process will occur. Table 2 provides an overview of the eligibility criteria for this scoping review.

### Stage 3: search strategy and study selection

As discussed by Arksey and O'Malley,<sup>24</sup> it is important for us to clearly define the terminology we intend to use when conducting the literature search as it ensures the

**Table 2** Eligibility criteria

Criterion	Inclusion	Exclusion	Justification
Population and sample	Humans	Any study population other than humans, that is, animal studies	▶ Referring to CBPR partnerships between humans.
Language	Written in English	Any other language that is not in English	▶ Reviewers only speak English.
Time period	1995–2020	Outside this time period	▶ Still able to capture a wide breadth of literature within the time when CBPR research became more prominent and defined by the pioneers in the field. ▶ Our definition of CBPR is consistent with that defined by Green and colleagues <sup>1</sup>
Study focus	(1) Articles that discuss participatory health research and trust OR (2) Articles that discuss social networks and trust	(1) Must be participatory health research, not other forms of participatory research outside of the health context OR (2) Social networks across a variety of disciplines, excluding those with a sole focus on online social networks using platforms such as Facebook, Instagram and Twitter, with no reference to conceptualising (operationalising or measuring) trust in a relational context	▶ One key reason participatory research was developed, historically, was to address inequities related to health. ▶ Ensuring continuity in conceptualisations from the literature to inform the formation of a conceptual framework for participatory health research. In our study context, and the context of CBPR more generally, interactions and partnership building are usually about interpersonal face-to-face contact and communication, which is not adequately reflected in social media networks, such as Facebook and Twitter. ▶ Online social network platforms (like those above) are looking at social phenomenon unrelated to the type of interactions we are interested in uncovering (such as, creating online trust communities, where people share thoughts and opinions with others they may not know, or have had a face-to-face interaction with). <sup>32</sup>
Type of article	Peer reviewed journal articles or reviews and grey literature. Specifically, grey literature will include theses/dissertations, reports, conference proceedings, editorials and chapters in a textbook.	Any other literature that is not listed in the inclusion criteria, such as websites.	▶ Scoping reviews aim to capture more than peer reviewed and published literature in order to expansively explore a broad research question. ▶ Preliminary searches of grey literature generally revealed those listed in our inclusion criteria. ▶ Acknowledging feasibility and time constraints, we felt the literature criteria listed would be sufficient in capturing the necessary literature to inform our review and ultimately, a conceptual framework.
Geographic location	Any location—an international context.	None	▶ Participatory research has applications globally.

CBPR, community-based participatory research.

syntax used is appropriately capturing the literature that best reflects our research question. Identifying our search strategy has been an iterative process that, as suggested by Levac *et al*,<sup>23</sup> is a team approach. In alignment with the guidelines from the Joanna Briggs Institute (JBI) Reviewer's Manual,<sup>22</sup> a three-step process is underway to identify the search strategy. First, we are conducting a preliminary search in CINAHL and Medline searching article titles, abstracts, keywords and subject headings to guide the development our second search strategy. Second, we are including the identified keywords and subject headings in the search strategy across all databases being used. Finally, we are looking at the reference lists from articles selected

for the review. A faculty librarian has also provided suggestions and verifications regarding the appropriate syntax and the adaptation of search strategies across databases. A complete search strategy from one of the major databases used is outlined in online supplemental appendix 1. The search strategy was conducted in CINAHL and was based on the concepts of trust, CBPR in health and social networks.

### Study selection

Once the appropriate search strategy has been identified and agreed on by the team, two independent reviewers will screen the articles by title and abstract and then at



full text based on our pre-determined exclusion/inclusion criteria. If it is unclear whether or not to include an article based on the first stage of the reviewing process, at title and abstract, then the study will be included for full-text review to ensure it is not being excluded without full consideration. The pair of reviewers will meet at multiple stages throughout the reviewing process to discuss any discrepancies that may have emerged. Inter-rater agreement will be calculated using the Kappa statistic. If there are any discrepancies regarding which articles to include or exclude and/or why, a third reviewer will be consulted to make the final decision. See online supplemental appendix 2 for the Preferred Reporting Items for Systematic Reviews and Meta-Analyses<sup>26</sup> flow diagram template

form that will be completed, including all numbers finalised, by the end of the scoping review.

#### Stage 4: preliminary charting elements and associated questions

To ensure the most suitable information is extracted, a tabular chart organised in Excel (see [table 3](#)), following guidelines from the JBI Reviewer's Manual,<sup>22</sup> will be incorporated and adapted to include an additional column pertaining to associated questions guiding the charting elements, as illustrated in the protocol by Nittas *et al.*<sup>27</sup> Furthermore, additional rows will be added that discuss in which context the article is addressing trust, as well as how trust is conceptualised, operationalised and

**Table 3** Preliminary table of charting elements and associated questions for data

Charting elements	Associated questions
<b>Publication details</b>	
Author(s)	Who wrote the study/document?
Year of publication	What year was the study/document published?
Origin/country of origin	Where was the study/document conducted and/or published?
Publication type	What type of publication is this? (empirical study or grey literature)
<b>General study details</b>	
Aims/purpose	What were the aims of the study/document?
Methodological design	What methodological design was used for this study?
Study population and sample size (if applicable)	Who is the target population of the study and how many (n) were included in the study?
<b>Methods</b>	
Intervention type, (if applicable)	Was an intervention used in this study?
Comparator and duration of the intervention (if applicable)	If yes to the intervention type, what was the comparator and duration of the intervention?
Outcomes and details of these (if applicable)	What was the study outcome?
<b>Key findings that relate specifically to the concept of trust</b>	
What is the context of trust? ▶ Social networks ▶ CBPR ▶ Both CBPR and social networks	Is the study/document conceptualising or operationalising trust in social networks and/or measuring trust using social network analysis? Is the study/document conceptualising, operationalising or measuring trust in CBPR? Is the study/document conceptualising, operationalising or measuring trust in social networks as well as within the context of CBPR?
How trust is conceptualised	How does the study define trust?
How trust is operationalised	What are the dimensions and indicators used for trust? What operationalisation issues exist? ▶ Based on our indicators, what questions were asked to represent trust? What observations were made? What specific attributes will exist for the measure used?
How trust is measured	What level of measurement was used (nominal, ordinal, interval, ratio) to measure trust? What type of measures was (survey, scaling, qualitative, unobtrusive) used for trust?
Limitations/quality issues	Were there any reported limitations or quality issues? (not a critical appraisal)

Edited from JBI Reviewer's Manual, 11.2.7 Data extraction<sup>22</sup> and Nittas *et al.*<sup>27</sup>  
CBPR, community-based participatory research.



measured in these contexts. This additional information is important to note for the next stage of the review process; collating, summarising and reporting the results (identifying themes). Data charting will be an iterative process as new data are presented in the examination stages, leading to continual charting updates.

### Stage 5: collating, summarising and reporting the results

In line with recommendations from Levac *et al.*<sup>23</sup>, we will extend stage 5 of Arksey and O'Malley's<sup>24</sup> framework into three distinct steps:

#### Step 1: collating and summarising the results

As suggested by the JBI Reviewer's Manual,<sup>22</sup> a narrative summary will be included to complement the tabular results, and we will directly discuss how the findings relate to the research question and objectives. In addition to this descriptive narrative summary, we will also present a thematic analysis of the literature, as suggested by Levac *et al.*,<sup>23</sup> using qualitative description<sup>28</sup> following the guidance of Braun and Clarke.<sup>29</sup> We understand the importance of not pre-empting the findings of the scoping review and will therefore employ strategies from Braun and Clarke<sup>29,30</sup> such as 'A 15-point checklist of criteria for good thematic analysis'<sup>29,30</sup> to ensure rigour in collating and summarising the results.

#### Step 2: reporting the results

Findings will be organised into thematic categories such as aims, methodological design, key findings and gaps in the literature, but also by categories that specifically highlight theoretical and operational linkages such as context, conceptual and operational features and measurements used.

#### Step 3: research implications for future research, practice and policy

By understanding how trust is conceptualised, operationalised and measured within CBPR and social networks, we expect findings from this scoping review will inform specific new research questions aimed at understanding and sustaining CBPR partnerships.

### Stage 6: consultation with knowledge users

As suggested by Levac *et al.*,<sup>23</sup> consultation with knowledge users adds to the methodological rigour of a study and should be included as a non-optional stage in developing a scoping review.

As mentioned earlier, this review is part of a larger participatory health research project. This larger project consists of 11 collaborating stakeholders that are representatives from community and patient organisations, as well as academic and health services entities that comprise the public and patient involvement capacity building team at the University of Limerick (known as 'PPI-Ignite@UL'). As they are existing co-researchers, they have been involved in the design of the larger project and will be involved in later phases of analysis and interpretation of the results from this scoping review.

The format for structured stakeholder discussion is still being considered, but will likely involve collaboration tools from participatory learning and action (PLA).<sup>31</sup> In summary, our workshop style discussion will constitute a collaborative platform for the presentation of results from the scoping review, allowing for PLA dialogues between stakeholders about any potential modifications regarding how the literature conceptualised, operationalised and measured trust in CBPR and social networks.

## ETHICS AND DISSEMINATION

### Ethics

Ethics is not required for this scoping review, although it is a component of a larger study that received ethical approval from the University of Limerick Education and Health Sciences research ethics committee (#2018\_05\_12\_EHS).

### Dissemination

Translation of results is integrated through the active collaboration of key stakeholders from community, health services and academic sectors in the design and implementation of this study. This was highlighted above in Stage 6: consultation with knowledge users section.

In addition, findings will be disseminated through academic conferences, and peer review publications targeting lay audiences and public and patient involvement in health research.

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**Contributors** All authors have made substantive intellectual contributions to the development of this protocol. MG conceptualised the review approach and drafted the protocol. JS and AM secured funding and contributed to the conceptualisation, writing and editing of the protocol.

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**Competing interests** None declared.

**Patient and public involvement statement** This scoping review is part of a larger study governed by a PPI partnership. The PPI partners review and approve all components of the larger study. Stakeholder involvements in this current aspect of the study (the scoping review) will take place in later stages of the review, specifically in the analysis, interpretation and dissemination of the results.

**Patient consent for publication** Not required.

**Provenance and peer review** Not commissioned; externally peer reviewed.

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