

BMJ Open

BMJ Open is committed to open peer review. As part of this commitment we make the peer review history of every article we publish publicly available.

When an article is published we post the peer reviewers' comments and the authors' responses online. We also post the versions of the paper that were used during peer review. These are the versions that the peer review comments apply to.

The versions of the paper that follow are the versions that were submitted during the peer review process. They are not the versions of record or the final published versions. They should not be cited or distributed as the published version of this manuscript.

BMJ Open is an open access journal and the full, final, typeset and author-corrected version of record of the manuscript is available on our site with no access controls, subscription charges or pay-per-view fees (<http://bmjopen.bmj.com>).

If you have any questions on BMJ Open's open peer review process please email info.bmjopen@bmj.com

BMJ Open

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

Journal:	<i>BMJ Open</i>
Manuscript ID	bmjopen-2020-038840
Article Type:	Protocol
Date Submitted by the Author:	25-Mar-2020
Complete List of Authors:	Gilfoyle, Meghan; University of Limerick, Public and Patient Involvement Research Unit, Graduate Entry Medical School and Health Research Institute Macfarlane, Anne; University of Limerick, Public and Patient Involvement Research Unit, Graduate Entry Medical School and Health Research Institute Salsberg, Jon; University of Limerick, Public and Patient Involvement Research Unit, Graduate Entry Medical School and Health Research Institute
Keywords:	PUBLIC HEALTH, QUALITATIVE RESEARCH, PRIMARY CARE

SCHOLARONE™
Manuscripts



I, the Submitting Author has the right to grant and does grant on behalf of all authors of the Work (as defined in the below author licence), an exclusive licence and/or a non-exclusive licence for contributions from authors who are: i) UK Crown employees; ii) where BMJ has agreed a CC-BY licence shall apply, and/or iii) in accordance with the terms applicable for US Federal Government officers or employees acting as part of their official duties; on a worldwide, perpetual, irrevocable, royalty-free basis to BMJ Publishing Group Ltd ("BMJ") its licensees and where the relevant Journal is co-owned by BMJ to the co-owners of the Journal, to publish the Work in this journal and any other BMJ products and to exploit all rights, as set out in our [licence](#).

The Submitting Author accepts and understands that any supply made under these terms is made by BMJ to the Submitting Author unless you are acting as an employee on behalf of your employer or a postgraduate student of an affiliated institution which is paying any applicable article publishing charge ("APC") for Open Access articles. Where the Submitting Author wishes to make the Work available on an Open Access basis (and intends to pay the relevant APC), the terms of reuse of such Open Access shall be governed by a Creative Commons licence – details of these licences and which [Creative Commons](#) licence will apply to this Work are set out in our licence referred to above.

Other than as permitted in any relevant BMJ Author's Self Archiving Policies, I confirm this Work has not been accepted for publication elsewhere, is not being considered for publication elsewhere and does not duplicate material already published. I confirm all authors consent to publication of this Work and authorise the granting of this licence.

1
2
3 **TITLE: Conceptualising, operationalising, and measuring trust in participatory health**
4 **research networks: a scoping review protocol**
5

6 **Lead Author:**
7

8 Meghan Gilfoyle
9 Public & Patient Involvement Research Unit, Graduate Entry Medical School and Health
10 Research Institute (HRI)
11 University of Limerick
12 Limerick, Ireland
13 V94 T9PX
14 meghan.gilfoyle@ul.ie
15 +353 85 233 7972
16

17
18 **Co-Authors:**
19

20 Prof Anne MacFarlane
21 Public & Patient Involvement Research Unit, Graduate Entry Medical School and Health
22 Research Institute (HRI)
23 University of Limerick
24 Limerick, Ireland
25 V94 T9PX
26 Anne.MacFarlane@ul.ie
27

28 Dr Jon Salsberg (**Corresponding Author**)
29 Public & Patient Involvement Research Unit, Graduate Entry Medical School and Health
30 Research Institute (HRI)
31 University of Limerick
32 Limerick, Ireland
33 V94 T9PX
34 Jon.Salsberg@ul.ie
35
36

37
38 **Word Count:** 2,509
39

40 **Key Words:** Primary Care, Public Health, Qualitative Research
41
42
43
44
45
46
47
48
49
50
51
52
53
54
55
56
57
58
59
60

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 synthesize the literature that explores how trust is conceptualised, operationalised, and measured in CBPR and social networks.

Methods and analysis

This protocol follows guidelines set out by Levac *et al*, which in turn follow the methodological framework of Arksey and O'Malley. This scoping review begins by exploring several electronic databases including Scopus, Medline, PubMed, Web of Science, CINAHL, Cochrane Library, Google Scholar, and PsychINFO. A search strategy was identified and agreed upon by the team in conjunction with a research librarian. Two independent reviewers will screen the articles by title and abstract, then by full-text based on pre-determined exclusion/inclusion criteria. A third reviewer will arbitrate discrepancy regarding inclusion/exclusion.

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

STRENGTHS AND LIMITATIONS

- 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*²³ advanced methodological guidelines built on Arksey and O'Malley's²⁴ original framework as well as the methods manual from the Joanna Briggs Institute.²²
- For feasibility purposes, our scoping review will be limited to English
- 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”.¹ 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.^{2,3} 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.^{2,3} Participatory research 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 recognizing the importance of actively and meaningfully engaging those who the research serves to benefit in the research process.³

One of the more widely recognized 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.³ Similarly, the W.K. Kellogg Foundation’s Community Health Scholars Program⁴ defines CBPR as:

A collaborative approach to research that equitably involves all partners in the research process and recognizes 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.^{4(p.2)}

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

Recognizing the importance of CBPR, a conceptual model was developed⁵ and adapted² 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 (e.g. stronger partnerships) and long-term outcomes (e.g. improved health, community transformation and health equity).⁶ 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.⁷ Such gaps include theoretically and empirically explaining “how contexts, partnership practices, and research/intervention engagement factors contribute to broad-based CBPR and health outcomes”.⁷ Oetzel *et al*⁷ 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* (e.g. interactive) and *structural* (e.g. team composition and nature) processes² and pathways for impact on intermediate and long-term outcomes.⁷

Focusing on the relational aspect of the CBPR model, a realist systematic review by Jagosh *et al*⁸ 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 program infrastructure, while creating new and unexpected ideas and

1
2
3 outcomes. Building on these findings, Jagosh *et al*⁹ further explored what supports partnership
4 synergy in successful long-term CBPR partnerships. This pointed to the building and maintenance
5 of *trust* as a key mechanism in this process. However, Jagosh *et al*⁹ treated trust as a 'black box'
6 concept and did not attempt to unpack its internal dimensions and processes.
7

8 As we seek to explore how trust is conceptualised, operationalised and measured in
9 CBPR partnerships, we must adopt a methodology that supports the analysis of trust as well as
10 its contextual and relational dynamics in CBPR partnerships.
11

12 If trust is a key mechanism of how partnerships function,^{8,9} and is an identified component
13 of the CBPR conceptual model,⁷ then it is important to find a way to describe and measure trust
14 among and between research partners within CBPR. A CBPR stakeholder partnership can be
15 seen as a *social network*, which is defined as connections among people, organisations or other
16 social actors.¹⁰ Social network analysis (SNA) is a methodology for describing and measuring
17 contextual and relational dynamics among and between social actors.¹¹ SNA provides useful tools
18 for investigating the development and maintenance of trust and trustworthiness and their effects
19 on partnership functioning within social networks.¹² As a CBPR project unfolds, the ability to
20 measure trust can allow for the design of structural interventions (e.g. adding or removing planned
21 working meetings) to improve partnership function by targeting context or social structures within
22 the partnership.^{8,9}
23
24

25 Social networks have been used to explore trust in diverse fields, such as in health¹³ or
26 education.¹⁴ They have also been used to explore dynamics within CBPR.^{15,16} However, social
27 networks have never been used to explore the dynamics of trust *within* CBPR. Therefore, CBPR,
28 social networks and trust (figure 1) constitute a conceptual triad that may allow us to better
29 understand how partnership function leads to better research outcomes.
30

31 *Figure 1 Trust, CBPR, and social networks as a conceptual triad*
32

33 **Purpose of conducting the literature review**

34
35 Although existing literature discuss *trust and CBPR*,¹⁷ or *trust and social networks*,¹⁸
36 preliminary searches have revealed that none of the literature explores all three concepts of *trust*,
37 *CBPR and social networks*. Furthermore, preliminary searches revealed a lack of consensus
38 regarding how trust is conceptualised, operationalised and measured. With this in mind, the
39 objectives of this scoping review are to:
40
41

- 42 1. Identify the literature on trust in CBPR and social networks
- 43 2. Clarify how trust is conceptualised, operationalised, and measured in CBPR and social
44 networks
- 45 3. Identify where these dimensions of trust may intersect across both CBPR and social
46 networks
47

48 Specific questions within the context of CBPR and social networks include:
49

- 50 1. What meaning do researchers and other stakeholders attach to the concept of trust?
- 51 2. What dimensions and indicators will be used to measure trust?
- 52 3. What research methods lead to empirical observations of trust?
53
54
55

56 ** One review involved social networks, CBPR and social trust, but as a feature of social capital¹⁹
57
58
59

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

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 will attach 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? <ul style="list-style-type: none"> 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

METHODS/DESIGN

Due to the broad nature of our research question and objectives, going beyond effectiveness of treatments and interventions,²⁰ we want to capture a vast breadth of literature, that is more inclusive in terms of what is included/excluded.^{21,22} 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.²² To ensure rigour in our approach, the protocol for this scoping review followed the guidelines and stages set out by Levac *et al*,²³ which consists of a further developed methodological framework from that of the widely cited Arksey and O'Malley.²⁴ This extended framework from Levac *et al*²³ incorporates six stages: 1) Identifying the research question; 2) Identifying relevant studies; 3) Study selection; 4) Charting the data; 5) Collating, summarizing, and reporting results; and 6) Consultation with knowledge users. This protocol 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 are iteratively searching and revising 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.²⁵ 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

Recognizing 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. 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.

Table 2 Eligibility criteria

Criterion	Inclusion	Exclusion	Justification
Population and Sample	Humans	Any study population other than humans, i.e. animal studies	<ul style="list-style-type: none"> Referring to CBPR partnerships between humans
Language	Written in English	Any other language that is not in English	<ul style="list-style-type: none"> Reviewers only speak English
Time Period	1995 - 2020	Outside this time period	<ul style="list-style-type: none"> 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 Lawrence W. Green and colleagues¹ in the 1995 text “Study of participatory research in health promotion: review and recommendations for development of participatory research in health promotion in Canada”
Study Focus	1) Articles that discuss participatory <u>health</u> research and trust OR	1) Must be participatory <u>health</u> research, not other forms of participatory research outside of the health context	1) <ul style="list-style-type: none"> 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

	2) Articles that discuss social networks and trust	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	formation of a conceptual framework for participatory <u>health research</u> 2) <ul style="list-style-type: none"> 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)²⁶
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.	<ul style="list-style-type: none"> 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	<ul style="list-style-type: none"> Participatory research has applications globally

Stage 3: Search strategy and study selection

As discussed by Arksey and O'Malley,²⁴ it is important for us to clearly define the terminology we intend to use when conducting the literature search as it ensures the 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*,²³ is a team approach. In alignment with the guidelines from the JBI Reviewer's Manual²² 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. Secondly, 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. A complete search strategy from one of the major databases used is outlined in Appendix A. The search strategy was conducted in CINAHL and was based on the concepts of trust, community-based participatory research (CBPR) in health, and social networks.

Study selection

Once the appropriate search strategy has been identified and agreed upon 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. 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 Appendix B for the PRISMA²⁷ flow diagram template from 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 organized in Excel (see Table 3), following guidelines from the JBI Reviewer's Manual,²² 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*.²⁸ 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 measured in these contexts. This additional information is important to note for the next stage of the review process; collating, summarizing, and reporting the results (identifying themes). Data charting will be an iterative process as new data is presented in the examination stages, leading to continual charting updates.

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

Charting Elements	Associated Questions
Publication details	
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)
General study details	
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?
Methods	What specific methods were use in this study?
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?
Key findings that relate specifically to the concept of trust	
What is the context of trust?	Is the study/document conceptualising or operationalising trust in social networks and/or measuring trust using social network analysis?
<ul style="list-style-type: none"> • Social networks • CBPR • Both CBPR and social networks 	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? <ul style="list-style-type: none"> • 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 extraction²² and Nittas et al.²⁸

Stage 5: Collating, summarizing and reporting the results

As suggested by the JBI Reviewer's Manual,²² 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*,²³ using qualitative description.²⁹ Findings will therefore 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.

Stage 6: Consultation with knowledge users

As suggested by Levac *et al*,²³ 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).³⁰ 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*.

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

Public and Patient Involvement

1
2
3 This scoping review is part of a larger study governed by a PPI partnership. The PPI partners
4 review and approve all components of the larger study. Stakeholder involvements in this current
5 aspect of the study (the scoping review) will take place in later stages of the review, specifically
6 in the analysis, interpretation and dissemination of the results.
7

8 **Acknowledgements**

9 We acknowledge the collaborating partners from the PPI Ignite@UL team for their contributions
10 to the overall direction of this review. We would also like to acknowledge the Education and Health
11 Sciences Faculty Librarian at the University of Limerick for helping to set-up the search strategy
12 for this scoping review.
13

14 **Author Statement**

15 All authors have made substantive intellectual contributions to the development of this protocol.
16 MG conceptualized the review approach and drafted the protocol. JS and AM secured funding
17 and contributed to the conceptualisation, writing and editing of the protocol.
18
19

20 **Funding**

21 This work was supported by the GEMS-10 scholarship from the University of Limerick (Ireland),
22 and a scholarship from the Integrated Knowledge Translation Research Network (Canada: CIHR
23 Foundation Grant; FDN #143237). The parent study 'PPI Ignite@UL' is funded by the Irish Health
24 Research Board (HRB PPI-2017-009).
25

26 **Competing interests**

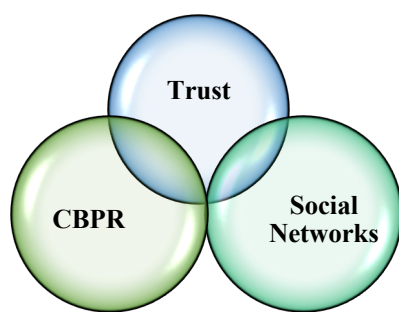
27 None to declare.
28
29
30
31
32
33
34
35
36
37
38
39
40
41
42
43
44
45
46
47
48
49
50
51
52
53
54
55
56
57
58
59
60

REFERENCES

1. Green LW, Canada RSo, Research BCfHP, editors. Study of participatory research in health promotion: Review and recommendations for the development of participatory research in health promotion in Canada 1995: Royal Society of Canada.
2. Wallerstein N, Duran B, Oetzel JG, Minkler M, editors. Community-based participatory research for health: Advancing social and health equity. San Francisco, CA: Jossey-Bass 2017:3-13.
3. Cargo M, Mercer SL. The value and challenges of participatory research: strengthening its practice. *Annu Rev Public Health* 2008;29:325-50.
4. W. K. Kellogg Foundation Community Health Scholars Program. Stories of impact [brochure]. Ann Arbor: University of Michigan, School of Public Health, Community Health Scholars Program, National Program Office; 2001.
5. Wallerstein N, Oetzel J, Duran B, Belone L, Tafoya G, Rae R. CBPR: what predicts outcomes? In 'Community-Based Participatory Research for Health: From Process to Outcomes, 2nd edn'. (Eds M Minkler, N Wallerstein). San Francisco, CA: Jossey-Bass 2008:371-92.
6. Wallerstein N, Duran B. Community-based participatory research contributions to intervention research: the intersection of science and practice to improve health equity. *Am J Public Health* 2010;100(S1):S40-S6.
7. Oetzel JG, Wallerstein N, Duran B, Sanchez-Youngman S, Nguyen T, Woo K, et al. Impact of participatory health research: A test of the community-based participatory research conceptual model. *BioMed Res Int* 2018;2018.
8. Jagosh J, Macaulay AC, Pluye P, Salsberg J, Bush PL, Henderson J, et al. Uncovering the benefits of participatory research: implications of a realist review for health research and practice. *Milbank Q* 2012;90(2):311-46.
9. Jagosh J, Bush PL, Salsberg J, Macaulay AC, Greenhalgh T, Wong G, et al. A realist evaluation of community-based participatory research: partnership synergy, trust building and related ripple effects. *BMC public health* 2015;15(1):725.
10. Valente TW. Social networks and health: Models, methods, and applications. New York, NY: Oxford University Press 2010:3-5.
11. Scott J. Social Network Analysis. 4ed. London, England: SAGE Publications Ltd 2017:2-6.
12. Lyon F, Møllering G, Saunders MN, editors. Handbook of research methods on trust. Edward Elgar Publishing; 2015 Aug 28.
13. Luque JS, Tyson DM, Bynum SA, Noel-Thomas S, Wells KJ, Vadaparampil ST, et al. A social network analysis approach to understand changes in a cancer disparities community partnership network. *Ann Anthropol Pract* 2011;35(2):112-35.
14. Giandini RS, Kuz A, editors. Social Network Analysis: a practical measurement and evaluation of Trust in a classroom environment. XVIII Congreso Argentino de Ciencias de la Computación; 2012.

15. Salsberg J, Macridis S, Garcia Bengoechea E, Macaulay AC, Moore S, Committee KSTP. The shifting dynamics of social roles and project ownership over the lifecycle of a community-based participatory research project. *Fam Pract* 2017;34(3):305-12.
16. Valente TW, Fujimoto K, Palmer P, Tanjasiri SP. A network assessment of community-based participatory research: linking communities and universities to reduce cancer disparities. *Am J Public Health* 2010;100(7):1319-25.
17. Sherriff SL, Miller H, Tong A, Williamson A, Muthayya S, Redman S, et al. Building trust and sharing power for co-creation in Aboriginal health research: a stakeholder interview study. *Evid Policy* 2019;15(3):371-92.
18. Levula A, Harré M. Social networks and mental health: an egocentric perspective. *Mental Health Review Journal* 2016.
19. Jones L, Lu MC, Lucas-Wright A, Dillon-Brown N, Broussard M, Wright K, et al. One hundred intentional acts of kindness toward a pregnant woman: Building reproductive social capital in Los Angeles. *Ethn Dis*. 2010;20(102):S2.
20. Temple University. Systematic & Other Review Types [Internet]. Temple University, 2019 [2020 February 28; 2019 December 01]. Available from <https://guides.temple.edu/c.php?g=78618&p=415660720> (Accessed 20 Nov 2019)
21. Peters MD, Godfrey CM, Khalil H, McInerney P, Parker D, Soares CB. Guidance for conducting systematic scoping reviews. *Int J Evid Based Healthc* 2015;13(3):141-6.
22. Peters, M.D.J., Godfrey, C., McInerney, P., Baldini, Soares, C., Khalil, H., Parker, D. Chapter 11: Scoping Reviews. In: Aromataris E, Munn Z (Editors). *Joanna Briggs Institute Reviewer's Manual*. The Joanna Briggs Institute, 2017. Available from <https://reviewersmanual.joannabriggs.org/> (Accessed 20 Nov 2019)
23. Levac D, Colquhoun H, O'Brien KK. Scoping studies: advancing the methodology. *Implement Sci* 2010 Dec 1;5(1):69.
24. Arksey H, O'Malley L. Scoping studies: towards a methodological framework. *Int J Soc Res Methodol* 2005;8(1):19-32.
25. Kenny A, Hyett N, Sawtell J, Dickson-Swift V, Farmer J, O'Meara P. Community participation in rural health: a scoping review. *BMC Health Serv Res* 2013;13(1):64.
26. Sherchan W, Nepal S, Paris C. A survey of trust in social networks. *ACM Comput Surv* 2013 Aug 30;45(4):1-33.
27. Moher D, Liberati A, Tetzlaff J, Altman DG. Preferred reporting items for systematic reviews and meta-analyses: the PRISMA statement. *Ann Intern Med* 2009 Aug 18;151(4):264-9.
28. Nittas V, Mütsch M, Ehrler F, Puhan MA. Electronic patient-generated health data to facilitate prevention and health promotion: a scoping review protocol. *BMJ open* 2018;8(8):e021245.

- 1
2
3 29. Sandelowski M. Whatever happened to qualitative description? *Res Nurs Health*
4 2000;23(4):334-40.
5
6 30. de Brún T, O'Reilly-de Brún M, van Weel-Baumgarten E, Burns N, Dowrick C, Lionis C,
7 O'Donnell C, Mair FS, Papadakaki M, Saridaki A, Spiegel W. Using Participatory Learning &
8 Action (PLA) research techniques for inter-stakeholder dialogue in primary healthcare: an
9 analysis of stakeholders' experiences. *Res Involv Engagem* 2017 Dec;3(1):28.
10
11
12
13
14
15
16
17
18
19
20
21
22
23
24
25
26
27
28
29
30
31
32
33
34
35
36
37
38
39
40
41
42
43
44
45
46
47
48
49
50
51
52
53
54
55
56
57
58
59
60



For peer review only

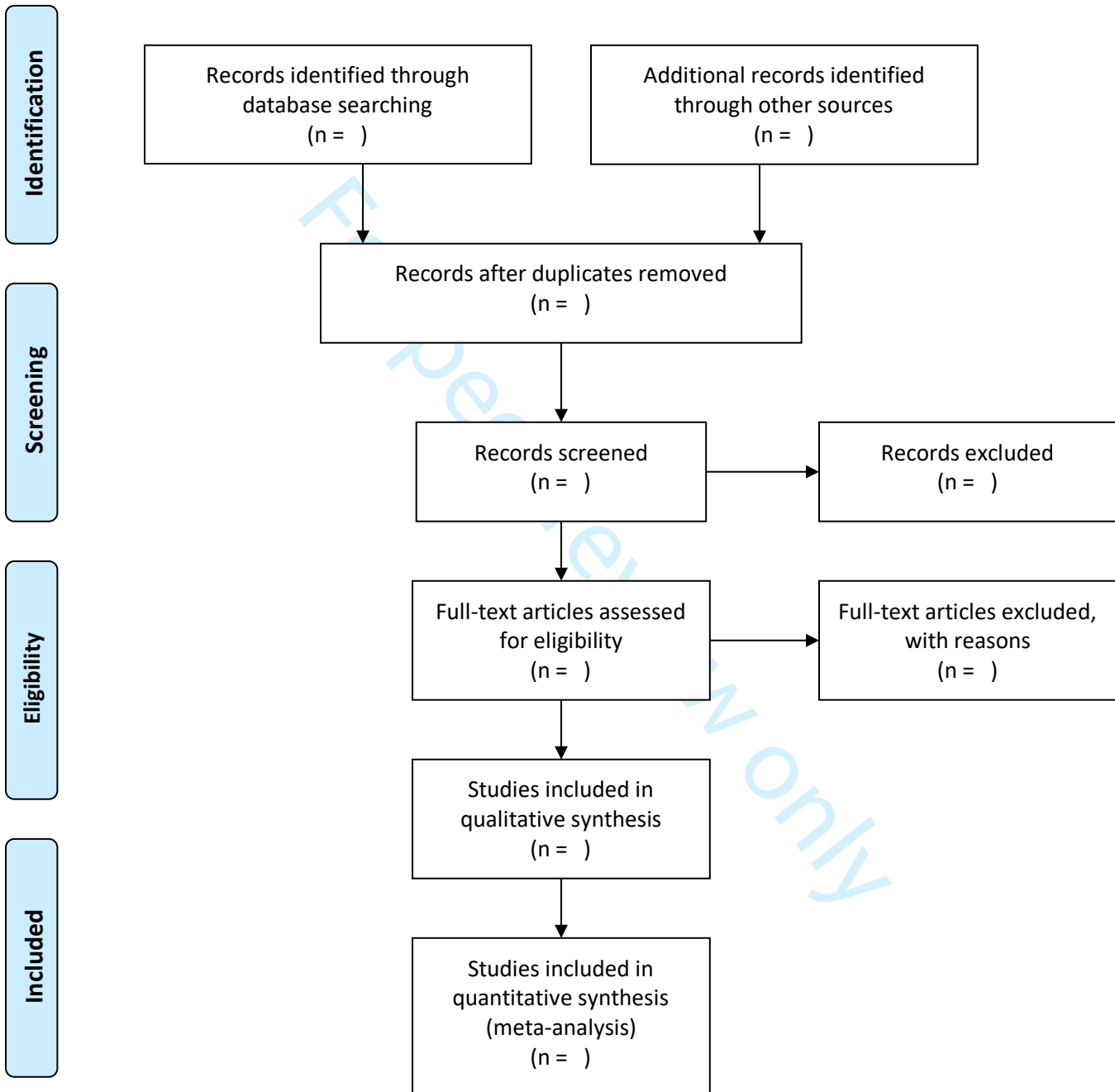
Appendix A

Search strategy in CINAHL

Database	Concept 1 "Participatory Health Research"	Concept 2 "Trust"	Concept 3 "Social Networks"	Notes
CINAHL	(MM "Action Research") OR TI (action research OR community-based participatory research OR public and patient involvement OR participatory health research) OR AB (action research OR community-based participatory research OR public and patient involvement OR participatory health research)	(MM "Trust") OR TI (trust or trusting or trustworthiness or trustworthy) OR AB (trust or trusting or trustworthiness or trustworthy)	(MM "Social Networks") OR TI (social networks OR social network) OR AB (social networks OR social network)	<p>A variety of search combinations were used to see which variations were necessary to retrieve key articles.</p> <p>Trust on its own wasn't sufficient at capturing all relevant articles</p> <p>Adding social network analysis did not change search output</p>
Results when combined with Concept 2 search	354		341	Results when all concepts are combined in one search: 5

Appendix B

Prisma Flow Diagram 2009



51 From: Moher D, Liberati A, Tetzlaff J, Altman DG, The PRISMA Group (2009). Preferred Reporting Items for Systematic
52 Reviews and Meta-Analyses: The PRISMA Statement. PLoS Med 6(7): e1000097. doi:10.1371/journal.pmed1000097
53

54 For more information, visit www.prisma-statement.org.

BMJ Open

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

Journal:	<i>BMJ Open</i>
Manuscript ID	bmjopen-2020-038840.R1
Article Type:	Protocol
Date Submitted by the Author:	09-Aug-2020
Complete List of Authors:	Gilfoyle, Meghan; University of Limerick, Public and Patient Involvement Research Unit, Graduate Entry Medical School and Health Research Institute Macfarlane, Anne; University of Limerick, Public and Patient Involvement Research Unit, Graduate Entry Medical School and Health Research Institute Salsberg, Jon; University of Limerick, Public and Patient Involvement Research Unit, Graduate Entry Medical School and Health Research Institute
Primary Subject Heading:	Public health
Secondary Subject Heading:	Qualitative research
Keywords:	PUBLIC HEALTH, QUALITATIVE RESEARCH, PRIMARY CARE

SCHOLARONE™
Manuscripts



I, the Submitting Author has the right to grant and does grant on behalf of all authors of the Work (as defined in the below author licence), an exclusive licence and/or a non-exclusive licence for contributions from authors who are: i) UK Crown employees; ii) where BMJ has agreed a CC-BY licence shall apply, and/or iii) in accordance with the terms applicable for US Federal Government officers or employees acting as part of their official duties; on a worldwide, perpetual, irrevocable, royalty-free basis to BMJ Publishing Group Ltd ("BMJ") its licensees and where the relevant Journal is co-owned by BMJ to the co-owners of the Journal, to publish the Work in this journal and any other BMJ products and to exploit all rights, as set out in our [licence](#).

The Submitting Author accepts and understands that any supply made under these terms is made by BMJ to the Submitting Author unless you are acting as an employee on behalf of your employer or a postgraduate student of an affiliated institution which is paying any applicable article publishing charge ("APC") for Open Access articles. Where the Submitting Author wishes to make the Work available on an Open Access basis (and intends to pay the relevant APC), the terms of reuse of such Open Access shall be governed by a Creative Commons licence – details of these licences and which [Creative Commons](#) licence will apply to this Work are set out in our licence referred to above.

Other than as permitted in any relevant BMJ Author's Self Archiving Policies, I confirm this Work has not been accepted for publication elsewhere, is not being considered for publication elsewhere and does not duplicate material already published. I confirm all authors consent to publication of this Work and authorise the granting of this licence.

1
2
3 **TITLE: Conceptualising, operationalising, and measuring trust in participatory health**
4 **research networks: a scoping review protocol**
5

6 **Lead Author:**
7

8 Meghan Gilfoyle
9 Public & Patient Involvement Research Unit, Graduate Entry Medical School and Health
10 Research Institute (HRI)
11 University of Limerick
12 Limerick, Ireland
13 V94 T9PX
14 meghan.gilfoyle@ul.ie
15 +353 85 233 7972
16

17
18 **Co-Authors:**
19

20 Prof Anne MacFarlane
21 Public & Patient Involvement Research Unit, Graduate Entry Medical School and Health
22 Research Institute (HRI)
23 University of Limerick
24 Limerick, Ireland
25 V94 T9PX
26 Anne.MacFarlane@ul.ie
27

28 Dr Jon Salsberg (**Corresponding Author**)
29 Public & Patient Involvement Research Unit, Graduate Entry Medical School and Health
30 Research Institute (HRI)
31 University of Limerick
32 Limerick, Ireland
33 V94 T9PX
34 Jon.Salsberg@ul.ie
35

36
37
38 **Word Count:** 2,756
39

40 **Key Words:** Primary Care, Public Health, Qualitative Research
41
42
43
44
45
46
47
48
49
50
51
52
53
54
55
56
57
58
59
60

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 synthesize 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*, 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 upon 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.

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

- 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*²³ advanced methodological guidelines built on Arksey and O'Malley's²⁴ original framework as well as the methods manual from the Joanna Briggs Institute²²
- 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”.¹ 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.^{2,3} 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.^{2,3} Participatory research 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 recognizing the importance of actively and meaningfully engaging those who the research serves to benefit in the research process.³

One of the more widely recognized 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.³ Similarly, the W.K. Kellogg Foundation’s Community Health Scholars Program⁴ defines CBPR as:

A collaborative approach to research that equitably involves all partners in the research process and recognizes 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.^{4(p.2)}

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

Recognizing the importance of CBPR, a conceptual model was developed⁵ and adapted² 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 (e.g. stronger partnerships) and long-term outcomes (e.g. improved health, community transformation and health equity).⁶ 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.⁷ Such gaps include theoretically and empirically explaining “how contexts, partnership practices, and research/intervention engagement factors contribute to broad-based CBPR and health outcomes”.⁷ Oetzel *et al*⁷ 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* (e.g. interactive) and *structural* (e.g. team composition and nature) processes² and pathways for impact on intermediate and long-term outcomes.⁷

Focusing on the relational aspect of the CBPR model, a realist systematic review by Jagosh *et al*⁸ 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 program 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*⁹ 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*⁹ 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*⁹ 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,^{8,9} and is an identified component of the CBPR conceptual model,⁷ 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.¹⁰ Social network analysis (SNA) is a methodology for describing and measuring contextual and relational dynamics among and between social actors.¹¹ 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.¹² As a CBPR project unfolds, the ability to measure trust using tools from SNA could allow for the design of structural interventions (e.g. adding or removing planned working meetings) to improve partnership function by targeting context or social structures within the partnership.^{8,9}

Social networks have been used to explore trust in diverse fields, such as in health¹³ or education.¹⁴ They have also been used to explore dynamics within CBPR.^{15,16} 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 to better understand how partnership function leads to better research outcomes.

Figure 1 Trust, CBPR, and social networks as a conceptual triad

Purpose of conducting the literature review

Although existing literature discuss *trust and CBPR*,¹⁷ or *trust and social networks*,¹⁸ preliminary searches have revealed that none of the literature explores all three concepts of *trust, CBPR and social networks*. 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:

1. Identify the literature on trust in CBPR and social networks
2. Clarify how trust is conceptualised, operationalised, and measured in CBPR and social networks

** One review involved social networks, CBPR and social trust, but as a feature of social capital¹⁹

3. Identify where these dimensions of trust may intersect across both CBPR and social networks

Specific questions within the context of CBPR and social networks include:

1. What meaning do researchers and other stakeholders attach to the concept of trust?
2. What dimensions and indicators will be used to measure trust?
3. What research methods lead to empirical observations of trust?

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

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 will attach 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? <ul style="list-style-type: none"> • 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

METHODS/DESIGN

Due to the broad nature of our research question and objectives, going beyond effectiveness of treatments and interventions,²⁰ we want to capture a vast breadth of literature, that is more inclusive in terms of what is included/excluded.^{21,22} 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.²² This scoping review was undertaken between March and September of 2020. To ensure rigour in our approach, the protocol for this scoping review followed the guidelines and stages set out by Levac *et al*,²³ which consists of a further developed methodological framework from that of the widely cited Arksey and O'Malley.²⁴ This extended framework from Levac *et al*²³ incorporates six stages: 1) Identifying the research question; 2) Identifying relevant studies; 3) Study selection; 4) Charting the data; 5) Collating, summarizing, and reporting results; and 6) Consultation with knowledge users. This protocol 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 are iteratively searching and revising 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.²⁵ 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

Recognizing 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.

Table 2 Eligibility criteria

Criterion	Inclusion	Exclusion	Justification
Population and Sample	Humans	Any study population other than humans, i.e. animal studies	<ul style="list-style-type: none"> Referring to CBPR partnerships between humans
Language	Written in English	Any other language that is not in English	<ul style="list-style-type: none"> Reviewers only speak English
Time Period	1995 - 2020	Outside this time period	<ul style="list-style-type: none"> 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 Lawrence W. Green and colleagues¹ in the 1995 text “Study of participatory research in health promotion: review and recommendations for development of

			participatory research in health promotion in Canada”
Study Focus	<p>1) Articles that discuss participatory <u>health</u> research and trust</p> <p>OR</p> <p>2) Articles that discuss social networks and trust</p>	<p>1) Must be participatory <u>health</u> research, not other forms of participatory research outside of the health context</p> <p>OR</p> <p>2) Social networks across a variety of disciplines, excluding those with a <u>sole focus</u> 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</p>	<p>1)</p> <ul style="list-style-type: none"> 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 <u>health</u> research <p>2)</p> <ul style="list-style-type: none"> 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)²⁶

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.	<ul style="list-style-type: none"> • 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	<ul style="list-style-type: none"> • Participatory research has applications globally

Stage 3: Search strategy and study selection

As discussed by Arksey and O'Malley,²⁴ it is important for us to clearly define the terminology we intend to use when conducting the literature search as it ensures the 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*,²³ is a team approach. In alignment with the guidelines from the JBI Reviewer's Manual²² 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. Secondly, 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 Appendix A. The search strategy was conducted in CINAHL and was based on the concepts of trust, community-based participatory research (CBPR) in health, and social networks.

Study selection

Once the appropriate search strategy has been identified and agreed upon 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 Appendix B for the PRISMA²⁷

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 organized in Excel (see Table 3), following guidelines from the JBI Reviewer's Manual,²² 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.*²⁸ 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 measured in these contexts. This additional information is important to note for the next stage of the review process; collating, summarizing and reporting the results (identifying themes). Data charting will be an iterative process as new data is presented in the examination stages, leading to continual charting updates.

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

Charting Elements	Associated Questions
Publication details	
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)
General study details	
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?
Methods	What specific methods were use in this study?
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?
Key findings that relate specifically to the concept of trust	
What is the context of trust?	Is the study/document conceptualising or operationalising trust in social networks and/or measuring trust using social
<ul style="list-style-type: none"> Social networks 	

<ul style="list-style-type: none"> • CBPR • Both CBPR and social networks 	<p>network analysis?</p> <p>Is the study/document conceptualising, operationalising, or measuring trust in CBPR?</p> <p>Is the study/document conceptualising, operationalising, or measuring trust in social networks as well as within the context of CBPR?</p>
How trust is conceptualised	How does the study define trust?
How trust is operationalised	<p>What are the dimensions and indicators used for trust?</p> <p>What operationalisation issues exist?</p> <ul style="list-style-type: none"> • 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	<p>What level of measurement was used (Nominal, Ordinal, Interval, Ratio) to measure trust?</p> <p>What type of measures was (survey, scaling, qualitative, unobtrusive) used for trust?</p>
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 extraction²² and Nittas et al.²⁸

Stage 5: Collating, summarizing and reporting the results

In line with recommendations from Levac *et al.*,²³ we will extend stage 5 of Arksey and O'Malley's²⁴ framework into three distinct steps:

Step 1: Collating and summarizing the results

As suggested by the JBI Reviewer's Manual,²² 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.*,²³ using qualitative description²⁹ following the guidance of Braun and Clarke.³⁰ We understand the importance of not pre-empting the findings of the scoping review and will therefore employ strategies from Braun and Clarke^{30,31} such as "A15-point checklist of criteria for good thematic analysis"^{30,31} to ensure rigour in collating and summarizing 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

1
2
3
4 By understanding how trust is conceptualised, operationalised and measured within CBPR
5 and social networks, we expect findings from this scoping review will inform specific new research
6 questions aimed at understanding and sustaining CBPR partnerships.
7

8 **Stage 6: Consultation with knowledge users**

9

10 As suggested by Levac *et al*,²³ consultation with knowledge users adds to the
11 methodological rigour of a study and should be included as a non-optional stage in developing a
12 scoping review.
13

14 As mentioned earlier, this review is part of a larger participatory health research project.
15 This larger project consists of 11 collaborating stakeholders that are representatives from
16 community and patient organisations, as well as academic and health services entities that
17 comprise the public and patient involvement capacity building team at the University of Limerick
18 (known as 'PPI-Ignite@UL'). As they are existing co-researchers, they have been involved in the
19 design of the larger project and will be involved in later phases of analysis and interpretation of
20 the results from this scoping review. The format for structured stakeholder discussion is still being
21 considered, but will likely involve collaboration tools from participatory learning and action (PLA).³²
22 In summary, our workshop style discussion will constitute a collaborative platform for the
23 presentation of results from the scoping review, allowing for PLA dialogues between stakeholders
24 about any potential modifications regarding how the literature conceptualised, operationalised,
25 and measured trust in CBPR and social networks.
26
27

28 **ETHICS AND DISSEMINATION**

29

30 **Ethics**

31

32 Ethics is not required for this scoping review, although it is a component of a larger study
33 that received ethical approval from the University of Limerick Education and Health Sciences
34 research ethics committee (#2018_05_12_EHS).
35

36 **Dissemination**

37

38 Translation of results is integrated through the active collaboration of key stakeholders
39 from community, health services, and academic sectors in the design and implementation of this
40 study. This was highlighted above in *Stage 6: Consultation with knowledge users*.
41
42

43 In addition, findings will be disseminated through academic conferences, and peer review
44 publications targeting public and patient involvement in health research.
45

46 **Public and Patient Involvement**

47

48 This scoping review is part of a larger study governed by a PPI partnership. The PPI
49 partners review and approve all components of the larger study. Stakeholder involvements in this
50 current aspect of the study (the scoping review) will take place in later stages of the review,
51 specifically in the analysis, interpretation and dissemination of the results.
52

53 **Acknowledgements**

54

55 We acknowledge the collaborating partners from the PPI Ignite@UL team for their contributions
56 to the overall direction of this review. We would also like to acknowledge the Education and Health
57
58
59

Sciences Faculty Librarian at the University of Limerick for helping to set-up the search strategy for this scoping review.

Author Statement

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

Funding

This work was supported by the GEMS-10 scholarship from the University of Limerick (Ireland), and a scholarship from the Integrated Knowledge Translation Research Network (Canada: CIHR Foundation Grant; FDN #143237). The parent study 'PPI Ignite@UL' is funded by the Irish Health Research Board (HRB PPI-2017-009).

Competing interests

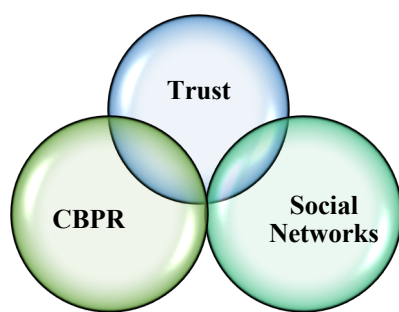
None to declare

REFERENCES

1. Green LW, Canada RSo, Research BCfHP, editors. Study of participatory research in health promotion: Review and recommendations for the development of participatory research in health promotion in Canada 1995: Royal Society of Canada.
2. Wallerstein N, Duran B, Oetzel JG, Minkler M, editors. Community-based participatory research for health: Advancing social and health equity. San Francisco, CA: Jossey-Bass 2017:3-13.
3. Cargo M, Mercer SL. The value and challenges of participatory research: strengthening its practice. *Annu Rev Public Health* 2008;29:325-50.
4. W. K. Kellogg Foundation Community Health Scholars Program. Stories of impact [brochure]. Ann Arbor: University of Michigan, School of Public Health, Community Health Scholars Program, National Program Office; 2001.
5. Wallerstein N, Oetzel J, Duran B, Belone L, Tafoya G, Rae R. CBPR: what predicts outcomes? In 'Community-Based Participatory Research for Health: From Process to Outcomes, 2nd edn'. (Eds M Minkler, N Wallerstein). San Francisco, CA: Jossey-Bass 2008:371-92.
6. Wallerstein N, Duran B. Community-based participatory research contributions to intervention research: the intersection of science and practice to improve health equity. *Am J Public Health* 2010;100(S1):S40-S6.
7. Oetzel JG, Wallerstein N, Duran B, Sanchez-Youngman S, Nguyen T, Woo K, et al. Impact of participatory health research: A test of the community-based participatory research conceptual model. *BioMed Res Int* 2018;2018.
8. Jagosh J, Macaulay AC, Pluye P, Salsberg J, Bush PL, Henderson J, et al. Uncovering the benefits of participatory research: implications of a realist review for health research and practice. *Milbank Q* 2012;90(2):311-46.

9. Jagosh J, Bush PL, Salsberg J, Macaulay AC, Greenhalgh T, Wong G, et al. A realist evaluation of community-based participatory research: partnership synergy, trust building and related ripple effects. *BMC public health* 2015;15(1):725.
10. Valente TW. *Social networks and health: Models, methods, and applications*. New York, NY: Oxford University Press 2010:3-5.
11. Scott J. *Social Network Analysis*. 4ed. London, England: SAGE Publications Ltd 2017:2-6.
12. Lyon F, Møllering G, Saunders MN, editors. *Handbook of research methods on trust*. Edward Elgar Publishing; 2015 Aug 28.
13. Luque JS, Tyson DM, Bynum SA, Noel-Thomas S, Wells KJ, Vadaparampil ST, et al. A social network analysis approach to understand changes in a cancer disparities community partnership network. *Ann Anthropol Pract* 2011;35(2):112-35.
14. Giandini RS, Kuz A, editors. *Social Network Analysis: a practical measurement and evaluation of Trust in a classroom environment*. XVIII Congreso Argentino de Ciencias de la Computación; 2012.
15. Salsberg J, Macridis S, Garcia Bengoechea E, Macaulay AC, Moore S, Committee KSTP. The shifting dynamics of social roles and project ownership over the lifecycle of a community-based participatory research project. *Fam Pract* 2017;34(3):305-12.
16. Valente TW, Fujimoto K, Palmer P, Tanjasiri SP. A network assessment of community-based participatory research: linking communities and universities to reduce cancer disparities. *Am J Public Health* 2010;100(7):1319-25.
17. Sherriff SL, Miller H, Tong A, Williamson A, Muthayya S, Redman S, et al. Building trust and sharing power for co-creation in Aboriginal health research: a stakeholder interview study. *Evid Policy* 2019;15(3):371-92.
18. Levula A, Harré M. Social networks and mental health: an egocentric perspective. *Mental Health Review Journal* 2016.
19. Jones L, Lu MC, Lucas-Wright A, Dillon-Brown N, Broussard M, Wright K, et al. One hundred intentional acts of kindness toward a pregnant woman: Building reproductive social capital in Los Angeles. *Ethn Dis*. 2010;20(102):S2.
20. Temple University. *Systematic & Other Review Types* [Internet]. Temple University, 2019 [2020 February 28; 2019 December 01]. Available from <https://guides.temple.edu/c.php?g=78618&p=415660720> (Accessed 20 Nov 2019)
21. Peters MD, Godfrey CM, Khalil H, McInerney P, Parker D, Soares CB. Guidance for conducting systematic scoping reviews. *Int J Evid Based Healthc* 2015;13(3):141-6.
22. Peters, M.D.J., Godfrey, C., McInerney, P., Baldini, Soares, C., Khalil, H., Parker, D. Chapter 11: Scoping Reviews. In: Aromataris E, Munn Z (Editors). *Joanna Briggs Institute Reviewer's Manual*. The Joanna Briggs Institute, 2017. Available from <https://reviewersmanual.joannabriggs.org/> (Accessed 20 Nov 2019)

- 1
2
3 23. Levac D, Colquhoun H, O'Brien KK. Scoping studies: advancing the methodology. *Implement Sci* 2010 Dec 1;5(1):69.
4
5
6 24. Arksey H, O'Malley L. Scoping studies: towards a methodological framework. *Int J Soc Res Methodol* 2005;8(1):19-32.
7
8
9 25. Kenny A, Hyett N, Sawtell J, Dickson-Swift V, Farmer J, O'Meara P. Community participation in rural health: a scoping review. *BMC Health Serv Res* 2013;13(1):64.
10
11
12 26. Sherchan W, Nepal S, Paris C. A survey of trust in social networks. *ACM Comput Surv* 2013 Aug 30;45(4):1-33.
13
14
15 27. Moher D, Liberati A, Tetzlaff J, Altman DG. Preferred reporting items for systematic reviews and meta-analyses: the PRISMA statement. *Ann Intern Med* 2009 Aug 18;151(4):264-9.
16
17
18 28. Nittas V, Mütsch M, Ehrler F, Puhan MA. Electronic patient-generated health data to facilitate prevention and health promotion: a scoping review protocol. *BMJ open* 2018;8(8):e021245.
19
20
21 29. Sandelowski M. Whatever happened to qualitative description? *Res Nurs Health* 2000;23(4):334-40.
22
23
24 30. Braun V, Clarke V. Successful qualitative research: A practical guide for beginners. sage; 2013 Mar 22.
25
26
27 31. Braun V, Clarke V. Using thematic analysis in psychology. *Qualitative research in psychology*. 2006 Jan 1;3(2):77-101.
28
29
30 32. de Brún T, O'Reilly-de Brún M, van Weel-Baumgarten E, Burns N, Dowrick C, Lionis C, O'Donnell C, Mair FS, Papadakaki M, Saridaki A, Spiegel W. Using Participatory Learning & Action (PLA) research techniques for inter-stakeholder dialogue in primary healthcare: an analysis of stakeholders' experiences. *Res Involv Engagem* 2017 Dec;3(1):28.
31
32
33
34
35
36
37
38
39
40
41
42
43
44
45
46
47
48
49
50
51
52
53
54
55
56
57
58
59
60



For peer review only

Appendix A

Search strategy in CINAHL

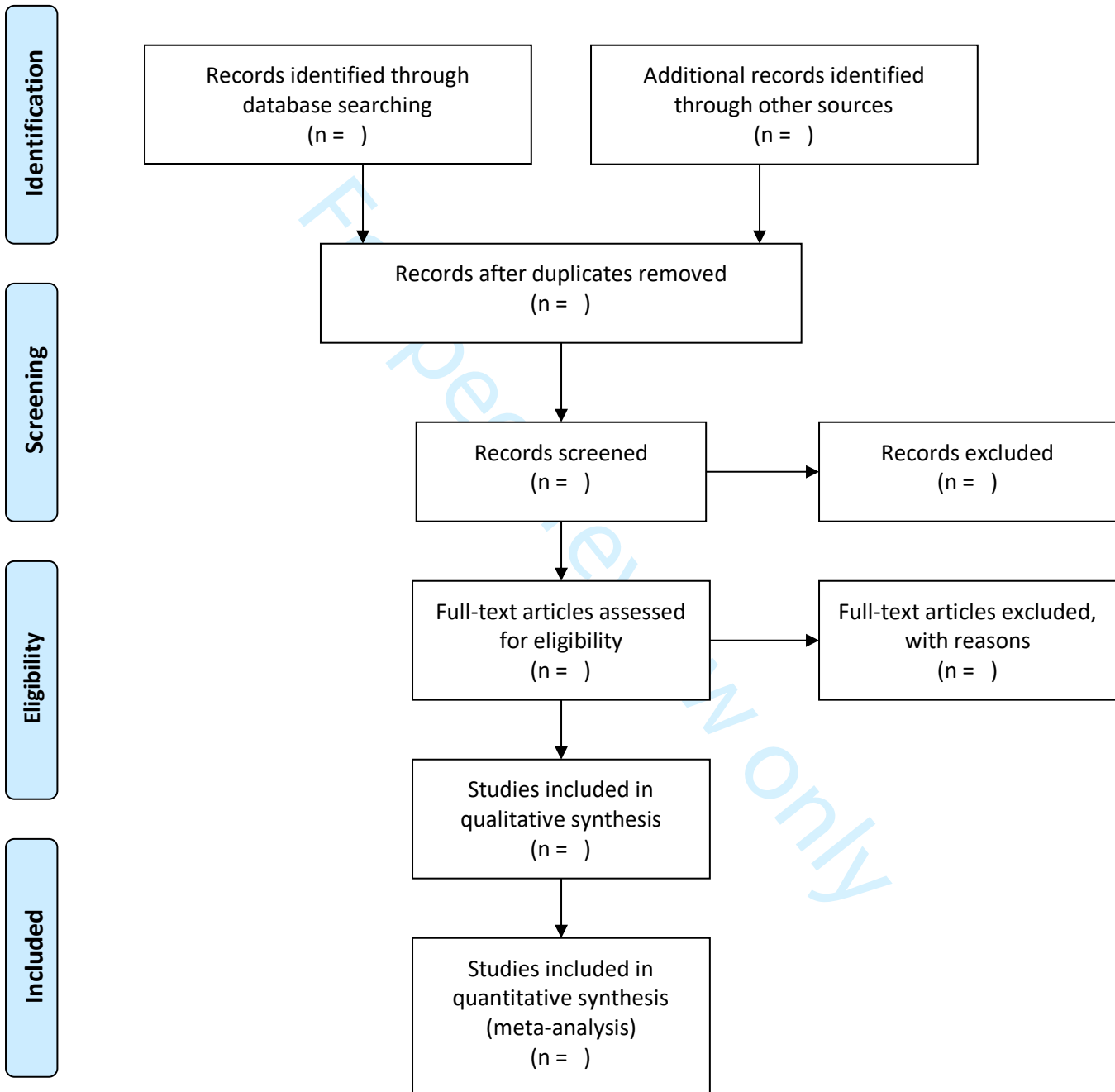
Search History/Alerts

[Print Search History](#) [Retrieve Searches](#) [Retrieve Alerts](#) [Save Searches / Alerts](#)

<input type="checkbox"/> Select / deselect all <input type="button" value="Search with AND"/> <input type="button" value="Search with OR"/> <input type="button" value="Delete Searches"/> <input type="button" value="Refresh Search Results"/>			
Search ID#	Search Terms	Search Options	Actions
<input type="checkbox"/> S6	(((MM "Social Networks") OR TI (social networks OR social network) OR AB (social networks OR social network)) AND (S2 AND S4)) AND (S1 AND S2 AND S4)	Expanders - Apply equivalent subjects Search modes - Boolean/Phrase	View Results (6) View Details Edit
<input type="checkbox"/> S5	(((MM "Social Networks") OR TI (social networks OR social network) OR AB (social networks OR social network)) AND (S2 AND S4))	Expanders - Apply equivalent subjects Search modes - Boolean/Phrase	View Results (391) View Details Edit
<input type="checkbox"/> S4	(MM "Social Networks") OR TI (social networks OR social network) OR AB (social networks OR social network)	Expanders - Apply equivalent subjects Search modes - Boolean/Phrase	View Results (13,927) View Details Edit
<input type="checkbox"/> S3	S1 AND S2	Expanders - Apply equivalent subjects Search modes - Boolean/Phrase	View Results (379) View Details Edit
<input type="checkbox"/> S2	MM "Trust" OR TI (trust or trusting or trustworthiness or trustworthy) OR AB (trust or trusting or trustworthiness or trustworthy)	Expanders - Apply equivalent subjects Search modes - Boolean/Phrase	View Results (34,194) View Details Edit
<input type="checkbox"/> S1	MM "Action Research" OR TI (action research OR community-based participatory research OR public and patient involvement OR participatory health research) OR AB (action research OR community-based participatory research OR public and patient involvement OR participatory health research)	Expanders - Apply equivalent subjects Search modes - Boolean/Phrase	View Results (8,960) View Details Edit

Appendix B

Prisma Flow Diagram 2009



51 From: Moher D, Liberati A, Tetzlaff J, Altman DG, The PRISMA Group (2009). Preferred Reporting Items for Systematic
52 Reviews and Meta-Analyses: The PRISMA Statement. PLoS Med 6(7): e1000097. doi:10.1371/journal.pmed1000097
53

54 For more information, visit www.prisma-statement.org.

BMJ Open

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

Journal:	<i>BMJ Open</i>
Manuscript ID	bmjopen-2020-038840.R2
Article Type:	Protocol
Date Submitted by the Author:	30-Sep-2020
Complete List of Authors:	Gilfoyle, Meghan; University of Limerick, Public and Patient Involvement Research Unit, Graduate Entry Medical School and Health Research Institute Macfarlane, Anne; University of Limerick, Public and Patient Involvement Research Unit, Graduate Entry Medical School and Health Research Institute Salsberg, Jon; University of Limerick, Public and Patient Involvement Research Unit, Graduate Entry Medical School and Health Research Institute
Primary Subject Heading:	Public health
Secondary Subject Heading:	Qualitative research
Keywords:	PUBLIC HEALTH, QUALITATIVE RESEARCH, PRIMARY CARE

SCHOLARONE™
Manuscripts



I, the Submitting Author has the right to grant and does grant on behalf of all authors of the Work (as defined in the below author licence), an exclusive licence and/or a non-exclusive licence for contributions from authors who are: i) UK Crown employees; ii) where BMJ has agreed a CC-BY licence shall apply, and/or iii) in accordance with the terms applicable for US Federal Government officers or employees acting as part of their official duties; on a worldwide, perpetual, irrevocable, royalty-free basis to BMJ Publishing Group Ltd ("BMJ") its licensees and where the relevant Journal is co-owned by BMJ to the co-owners of the Journal, to publish the Work in this journal and any other BMJ products and to exploit all rights, as set out in our [licence](#).

The Submitting Author accepts and understands that any supply made under these terms is made by BMJ to the Submitting Author unless you are acting as an employee on behalf of your employer or a postgraduate student of an affiliated institution which is paying any applicable article publishing charge ("APC") for Open Access articles. Where the Submitting Author wishes to make the Work available on an Open Access basis (and intends to pay the relevant APC), the terms of reuse of such Open Access shall be governed by a Creative Commons licence – details of these licences and which [Creative Commons](#) licence will apply to this Work are set out in our licence referred to above.

Other than as permitted in any relevant BMJ Author's Self Archiving Policies, I confirm this Work has not been accepted for publication elsewhere, is not being considered for publication elsewhere and does not duplicate material already published. I confirm all authors consent to publication of this Work and authorise the granting of this licence.

1
2
3 **TITLE: Conceptualising, operationalising, and measuring trust in participatory health**
4 **research networks: a scoping review protocol**
5

6 **Lead Author:**
7

8 Meghan Gilfoyle
9 Public & Patient Involvement Research Unit, Graduate Entry Medical School and Health
10 Research Institute (HRI)
11 University of Limerick
12 Limerick, Ireland
13 V94 T9PX
14 meghan.gilfoyle@ul.ie
15 +353 85 233 7972
16

17
18 **Co-Authors:**
19

20 Prof Anne MacFarlane
21 Public & Patient Involvement Research Unit, Graduate Entry Medical School and Health
22 Research Institute (HRI)
23 University of Limerick
24 Limerick, Ireland
25 V94 T9PX
26 Anne.MacFarlane@ul.ie
27

28 Dr Jon Salsberg (**Corresponding Author**)
29 Public & Patient Involvement Research Unit, Graduate Entry Medical School and Health
30 Research Institute (HRI)
31 University of Limerick
32 Limerick, Ireland
33 V94 T9PX
34 Jon.Salsberg@ul.ie
35

36
37
38 **Word Count:** 2,756
39

40 **Key Words:** Primary Care, Public Health, Qualitative Research
41
42
43
44
45
46
47
48
49
50
51
52
53
54
55
56
57
58
59
60

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 synthesize 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*, 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 upon 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

- 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*²³ advanced methodological guidelines built on Arksey and O'Malley's²⁴ original framework as well as the methods manual from the Joanna Briggs Institute²²
- 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”.¹ 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.^{2,3} 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.^{2,3} Participatory research 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 recognizing the importance of actively and meaningfully engaging those who the research serves to benefit in the research process.³

One of the more widely recognized 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.³ Similarly, the W.K. Kellogg Foundation’s Community Health Scholars Program⁴ defines CBPR as:

A collaborative approach to research that equitably involves all partners in the research process and recognizes 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.^{4(p.2)}

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

Recognizing the importance of CBPR, a conceptual model was developed⁵ and adapted² 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 (e.g. stronger partnerships) and long-term outcomes (e.g. improved health, community transformation and health equity).⁶ 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.⁷ Such gaps include theoretically and empirically explaining “how contexts, partnership practices, and research/intervention engagement factors contribute to broad-based CBPR and health outcomes”.⁷ Oetzel *et al*⁷ 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* (e.g. interactive) and *structural* (e.g. team composition and nature) processes² and pathways for impact on intermediate and long-term outcomes.⁷

Focusing on the relational aspect of the CBPR model, a realist systematic review by Jagosh *et al*⁸ identified partnership synergy as a universal feature of the collaborative process necessary for building and sustaining partnerships that create resilience, sustain health-related

1
2
3 goals, and extend program infrastructure, while creating new and unexpected ideas and
4 outcomes. Literature from the community perspective includes various accounts of community
5 problems of engagement and trust. For example, Jagosh *et al*⁹ identify instances where
6 contextual factors such as history of oppression or research abuse have triggered mistrust in the
7 community, impacting positive outcomes, such as partnership synergy. Building on these
8 findings, Jagosh *et al*⁹ further explored what supports partnership synergy in successful long-term
9 CBPR partnerships. This pointed to the building and maintenance of *trust* as a key mechanism in
10 this process. However, Jagosh *et al*⁹ treated trust as a 'black box' concept and did not attempt to
11 unpack its internal dimensions and processes.
12

13
14 As we seek to explore how trust is conceptualised, operationalised and measured in
15 CBPR partnerships, we must adopt a methodology that supports the analysis of trust as well as
16 its contextual and relational dynamics in CBPR partnerships.
17

18 If trust is a key mechanism of how partnerships function,^{8,9} and is an identified component
19 of the CBPR conceptual model,⁷ then it is important to find a way to describe and measure trust
20 among and between research partners within CBPR. A CBPR stakeholder partnership can be
21 seen as a *social network*. A social network describes the relationships among people,
22 organisations or other social actors.¹⁰ Social network analysis (SNA) is a methodology for
23 describing and measuring contextual and relational dynamics among and between social actors.¹¹
24 Therefore, SNA could provide useful tools for investigating the development and maintenance of
25 trust and trustworthiness and their effects on the relationships in a CBPR network, including
26 partnership functioning within social networks.¹² As a CBPR project unfolds, the ability to measure
27 trust using tools from SNA could allow for the design of structural interventions (e.g. adding or
28 removing planned working meetings) to improve partnership function by targeting context or social
29 structures within the partnership.^{8,9}
30

31 Social networks have been used to explore trust in diverse fields, such as in health¹³ or
32 education.¹⁴ They have also been used to explore dynamics within CBPR.^{15,16} However, social
33 networks have never been used to explore the dynamics of trust *within* CBPR. Given that trust
34 has been explored in both social networks and CBPR contexts, and both involve relational
35 dimensions, we expect the two concepts may complement each other well. Therefore, CBPR,
36 social networks and trust (figure 1) constitute a conceptual triad that may allow us to better
37 understand how partnership function leads to better research outcomes.
38
39

40 *Figure 1 Trust, CBPR, and social networks as a conceptual triad*
41

42 **Purpose of conducting the scoping review**

43

44 Although existing literature discuss *trust and CBPR*,¹⁷ or *trust and social networks*,¹⁸
45 preliminary searches have revealed that none of the literature explores all three concepts of *trust*,
46 *CBPR and social networks**. Furthermore, preliminary searches revealed a lack of consensus
47 regarding how trust is conceptualised, operationalised and measured. With this in mind, the
48 objectives of this scoping review are to:
49

- 50 1. Identify the literature on trust in CBPR and social networks
- 51 2. Clarify how trust is conceptualised, operationalised, and measured in CBPR and social
52 networks
53

54
55
56 ** One review involved social networks, CBPR and social trust, but as a feature of social capital¹⁹
57
58
59

3. 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.

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? <ul style="list-style-type: none"> 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

METHODS/DESIGN

Due to the broad nature of our research question and objectives, going beyond effectiveness of treatments and interventions,²⁰ we want to capture a vast breadth of literature, that is more inclusive in terms of what is included/excluded.^{21,22} 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.²² This scoping review was undertaken between March and October of 2020. To ensure rigour in our approach, the methodology for this scoping review followed the guidelines and stages set out by Levac *et al*,²³ which consists of a further developed methodological framework from that of the widely cited Arksey and O'Malley.²⁴ This extended framework from Levac *et al*²³ incorporates six stages: 1) Identifying the research question; 2) Identifying relevant studies; 3) Study selection; 4) Charting the data; 5) Collating, summarizing, 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.²⁵ 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

Recognizing 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.

Table 2 Eligibility criteria

Criterion	Inclusion	Exclusion	Justification
Population and Sample	Humans	Any study population other than humans, i.e. animal studies	<ul style="list-style-type: none"> Referring to CBPR partnerships between humans
Language	Written in English	Any other language that is not in English	<ul style="list-style-type: none"> Reviewers only speak English
Time Period	1995 - 2020	Outside this time period	<ul style="list-style-type: none"> 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 Lawrence W. Green and colleagues¹ in the 1995 text “Study of participatory research in health promotion: review and recommendations for development of participatory research in health promotion in Canada”
Study Focus	1) Articles that discuss participatory	1) Must be participatory <u>health</u> research, not other forms of	1) <ul style="list-style-type: none"> One key reason participatory research was developed,

	<p><u>health</u> research and trust</p> <p>OR</p> <p>2) Articles that discuss social networks and trust</p>	<p>participatory research outside of the health context</p> <p>OR</p> <p>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</p>	<p>historically, was to address inequities related to health</p> <ul style="list-style-type: none"> Ensuring continuity in conceptualisations from the literature to inform the formation of a conceptual framework for participatory <u>health</u> research <p>2)</p> <ul style="list-style-type: none"> 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)²⁶
<p>Type of article</p>	<p>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.</p>	<p>Any other literature that is not listed in the inclusion criteria, such as websites.</p>	<ul style="list-style-type: none"> 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	<ul style="list-style-type: none"> Participatory research has applications globally
----------------------------	--	------	--

Stage 3: Search strategy and study selection

As discussed by Arksey and O'Malley,²⁴ it is important for us to clearly define the terminology we intend to use when conducting the literature search as it ensures the 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*,²³ is a team approach. In alignment with the guidelines from the JBI Reviewer's Manual²² 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. Secondly, 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 Appendix A. The search strategy was conducted in CINAHL and was based on the concepts of trust, community-based participatory research (CBPR) in health, and social networks.

Study selection

Once the appropriate search strategy has been identified and agreed upon 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 Appendix B for the PRISMA²⁷ 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 organized in Excel (see Table 3), following guidelines from the JBI Reviewer's Manual,²² 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*.²⁸ 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 measured in these contexts. This additional information is important to note for the next stage of the review process; collating, summarizing and reporting the results (identifying themes). Data charting will be an iterative process as new data is presented in the examination stages, leading to continual charting updates.

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

Charting Elements	Associated Questions
Publication details	
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)
General study details	
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?
Methods	What specific methods were use in this study?
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?
Key findings that relate specifically to the concept of trust	
What is the context of trust? <ul style="list-style-type: none"> • Social networks • CBPR • Both CBPR and social networks 	<p>Is the study/document conceptualising or operationalising trust in social networks and/or measuring trust using social network analysis?</p> <p>Is the study/document conceptualising, operationalising, or measuring trust in CBPR?</p> <p>Is the study/document conceptualising, operationalising, or measuring trust in social networks as well as within the context of CBPR?</p>
How trust is conceptualised	How does the study define trust?
How trust is operationalised	<p>What are the dimensions and indicators used for trust?</p> <p>What operationalisation issues exist?</p> <ul style="list-style-type: none"> • 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 extraction²² and Nittas et al.²⁸

Stage 5: Collating, summarizing and reporting the results

In line with recommendations from Levac *et al.*,²³ we will extend stage 5 of Arksey and O'Malley's²⁴ framework into three distinct steps:

Step 1: Collating and summarizing the results

As suggested by the JBI Reviewer's Manual,²² 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.*,²³ using qualitative description²⁹ following the guidance of Braun and Clarke.³⁰ We understand the importance of not pre-empting the findings of the scoping review and will therefore employ strategies from Braun and Clarke^{30,31} such as "A15-point checklist of criteria for good thematic analysis"^{30,31} to ensure rigour in collating and summarizing 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.*,²³ 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

1
2
3 design of the larger project and will be involved in later phases of analysis and interpretation of
4 the results from this scoping review. The format for structured stakeholder discussion is still being
5 considered, but will likely involve collaboration tools from participatory learning and action (PLA).³²
6 In summary, our workshop style discussion will constitute a collaborative platform for the
7 presentation of results from the scoping review, allowing for PLA dialogues between stakeholders
8 about any potential modifications regarding how the literature conceptualised, operationalised,
9 and measured trust in CBPR and social networks.
10

11 **ETHICS AND DISSEMINATION**

13 **Ethics**

14
15
16 Ethics is not required for this scoping review, although it is a component of a larger study
17 that received ethical approval from the University of Limerick Education and Health Sciences
18 research ethics committee (#2018_05_12_EHS).
19

20 **Dissemination**

21
22 Translation of results is integrated through the active collaboration of key stakeholders
23 from community, health services, and academic sectors in the design and implementation of this
24 study. This was highlighted above in *Stage 6: Consultation with knowledge users*.
25

26 In addition, findings will be disseminated through academic conferences, and peer review
27 publications targeting lay audiences and public and patient involvement in health research.
28

29 **Public and Patient Involvement**

30
31 This scoping review is part of a larger study governed by a PPI partnership. The PPI
32 partners review and approve all components of the larger study. Stakeholder involvements in this
33 current aspect of the study (the scoping review) will take place in later stages of the review,
34 specifically in the analysis, interpretation and dissemination of the results.
35

36 **Acknowledgements**

37
38 We acknowledge the collaborating partners from the PPI Ignite@UL team for their contributions
39 to the overall direction of this review. We would also like to acknowledge the Education and Health
40 Sciences Faculty Librarian at the University of Limerick for helping to set-up the search strategy
41 for this scoping review.
42

43 **Author Statement**

44 All authors have made substantive intellectual contributions to the development of this protocol.
45 MG conceptualized the review approach and drafted the protocol. JS and AM secured funding
46 and contributed to the conceptualisation, writing and editing of the protocol.
47

48 **Funding**

49 This work was supported by the GEMS-10 scholarship from the University of Limerick (Ireland),
50 and a scholarship from the Integrated Knowledge Translation Research Network (Canada: CIHR
51 Foundation Grant; FDN #143237). The parent study 'PPI Ignite@UL' is funded by the Irish Health
52 Research Board (HRB PPI-2017-009).
53

54 **Competing interests**

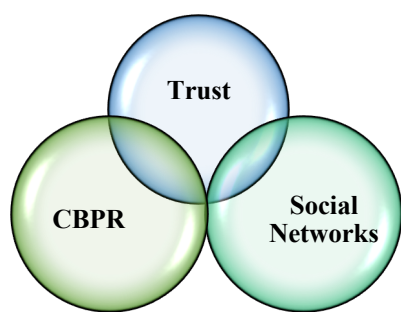
55 None to declare
56
57
58
59
60

REFERENCES

1. Green LW, Canada RSo, Research BCfHP, editors. Study of participatory research in health promotion: Review and recommendations for the development of participatory research in health promotion in Canada 1995: Royal Society of Canada.
2. Wallerstein N, Duran B, Oetzel JG, Minkler M, editors. Community-based participatory research for health: Advancing social and health equity. San Francisco, CA: Jossey-Bass 2017:3-13.
3. Cargo M, Mercer SL. The value and challenges of participatory research: strengthening its practice. *Annu Rev Public Health* 2008;29:325-50.
4. W. K. Kellogg Foundation Community Health Scholars Program. Stories of impact [brochure]. Ann Arbor: University of Michigan, School of Public Health, Community Health Scholars Program, National Program Office; 2001.
5. Wallerstein N, Oetzel J, Duran B, Belone L, Tafoya G, Rae R. CBPR: what predicts outcomes? In 'Community-Based Participatory Research for Health: From Process to Outcomes, 2nd edn'. (Eds M Minkler, N Wallerstein). San Francisco, CA: Jossey-Bass 2008:371-92.
6. Wallerstein N, Duran B. Community-based participatory research contributions to intervention research: the intersection of science and practice to improve health equity. *Am J Public Health* 2010;100(S1):S40-S6.
7. Oetzel JG, Wallerstein N, Duran B, Sanchez-Youngman S, Nguyen T, Woo K, et al. Impact of participatory health research: A test of the community-based participatory research conceptual model. *BioMed Res Int* 2018;2018.
8. Jagosh J, Macaulay AC, Pluye P, Salsberg J, Bush PL, Henderson J, et al. Uncovering the benefits of participatory research: implications of a realist review for health research and practice. *Milbank Q* 2012;90(2):311-46.
9. Jagosh J, Bush PL, Salsberg J, Macaulay AC, Greenhalgh T, Wong G, et al. A realist evaluation of community-based participatory research: partnership synergy, trust building and related ripple effects. *BMC public health* 2015;15(1):725.
10. Valente TW. Social networks and health: Models, methods, and applications. New York, NY: Oxford University Press 2010:3-5.
11. Scott J. Social Network Analysis. 4ed. London, England: SAGE Publications Ltd 2017:2-6.
12. Lyon F, Møllering G, Saunders MN, editors. Handbook of research methods on trust. Edward Elgar Publishing; 2015 Aug 28.
13. Luque JS, Tyson DM, Bynum SA, Noel-Thomas S, Wells KJ, Vadaparampil ST, et al. A social network analysis approach to understand changes in a cancer disparities community partnership network. *Ann Anthropol Pract* 2011;35(2):112-35.

14. Giandini RS, Kuz A, editors. Social Network Analysis: a practical measurement and evaluation of Trust in a classroom environment. XVIII Congreso Argentino de Ciencias de la Computación; 2012.
15. Salsberg J, Macridis S, Garcia Bengoechea E, Macaulay AC, Moore S, Committee KSTP. The shifting dynamics of social roles and project ownership over the lifecycle of a community-based participatory research project. *Fam Pract* 2017;34(3):305-12.
16. Valente TW, Fujimoto K, Palmer P, Tanjasiri SP. A network assessment of community-based participatory research: linking communities and universities to reduce cancer disparities. *Am J Public Health* 2010;100(7):1319-25.
17. Sherriff SL, Miller H, Tong A, Williamson A, Muthayya S, Redman S, et al. Building trust and sharing power for co-creation in Aboriginal health research: a stakeholder interview study. *Evid Policy* 2019;15(3):371-92.
18. Levula A, Harré M. Social networks and mental health: an egocentric perspective. *Mental Health Review Journal* 2016.
19. Jones L, Lu MC, Lucas-Wright A, Dillon-Brown N, Broussard M, Wright K, et al. One hundred intentional acts of kindness toward a pregnant woman: Building reproductive social capital in Los Angeles. *Ethn Dis.* 2010;20(102):S2.
20. Temple University. Systematic & Other Review Types [Internet]. Temple University, 2019 [2020 February 28; 2019 December 01]. Available from <https://guides.temple.edu/c.php?g=78618&p=415660720> (Accessed 20 Nov 2019)
21. Peters MD, Godfrey CM, Khalil H, McInerney P, Parker D, Soares CB. Guidance for conducting systematic scoping reviews. *Int J Evid Based Healthc* 2015;13(3):141-6.
22. Peters, M.D.J., Godfrey, C., McInerney, P., Baldini, Soares, C., Khalil, H., Parker, D. Chapter 11: Scoping Reviews. In: Aromataris E, Munn Z (Editors). *Joanna Briggs Institute Reviewer's Manual*. The Joanna Briggs Institute, 2017. Available from <https://reviewersmanual.joannabriggs.org/> (Accessed 20 Nov 2019)
23. Levac D, Colquhoun H, O'Brien KK. Scoping studies: advancing the methodology. *Implement Sci* 2010 Dec 1;5(1):69.
24. Arksey H, O'Malley L. Scoping studies: towards a methodological framework. *Int J Soc Res Methodol* 2005;8(1):19-32.
25. Kenny A, Hyett N, Sawtell J, Dickson-Swift V, Farmer J, O'Meara P. Community participation in rural health: a scoping review. *BMC Health Serv Res* 2013;13(1):64.
26. Sherchan W, Nepal S, Paris C. A survey of trust in social networks. *ACM Comput Surv* 2013 Aug 30;45(4):1-33.
27. Moher D, Liberati A, Tetzlaff J, Altman DG. Preferred reporting items for systematic reviews and meta-analyses: the PRISMA statement. *Ann Intern Med* 2009 Aug 18;151(4):264-9.

- 1
2
3 28. Nittas V, Mütsch M, Ehrler F, Puhan MA. Electronic patient-generated health data to facilitate
4 prevention and health promotion: a scoping review protocol. *BMJ open* 2018;8(8):e021245.
5
6 29. Sandelowski M. Whatever happened to qualitative description? *Res Nurs Health*
7 2000;23(4):334-40.
8
9 30. Braun V, Clarke V. Successful qualitative research: A practical guide for beginners. sage; 2013
10 Mar 22.
11
12 31. Braun V, Clarke V. Using thematic analysis in psychology. *Qualitative research in psychology*.
13 2006 Jan 1;3(2):77-101.
14
15 32. de Brún T, O'Reilly-de Brún M, van Weel-Baumgarten E, Burns N, Dowrick C, Lionis C,
16 O'Donnell C, Mair FS, Papadakaki M, Saridaki A, Spiegel W. Using Participatory Learning &
17 Action (PLA) research techniques for inter-stakeholder dialogue in primary healthcare: an
18 analysis of stakeholders' experiences. *Res Involv Engagem* 2017 Dec;3(1):28.
19
20
21
22
23
24
25
26
27
28
29
30
31
32
33
34
35
36
37
38
39
40
41
42
43
44
45
46
47
48
49
50
51
52
53
54
55
56
57
58
59
60



For peer review only

Appendix A

Search strategy in CINAHL

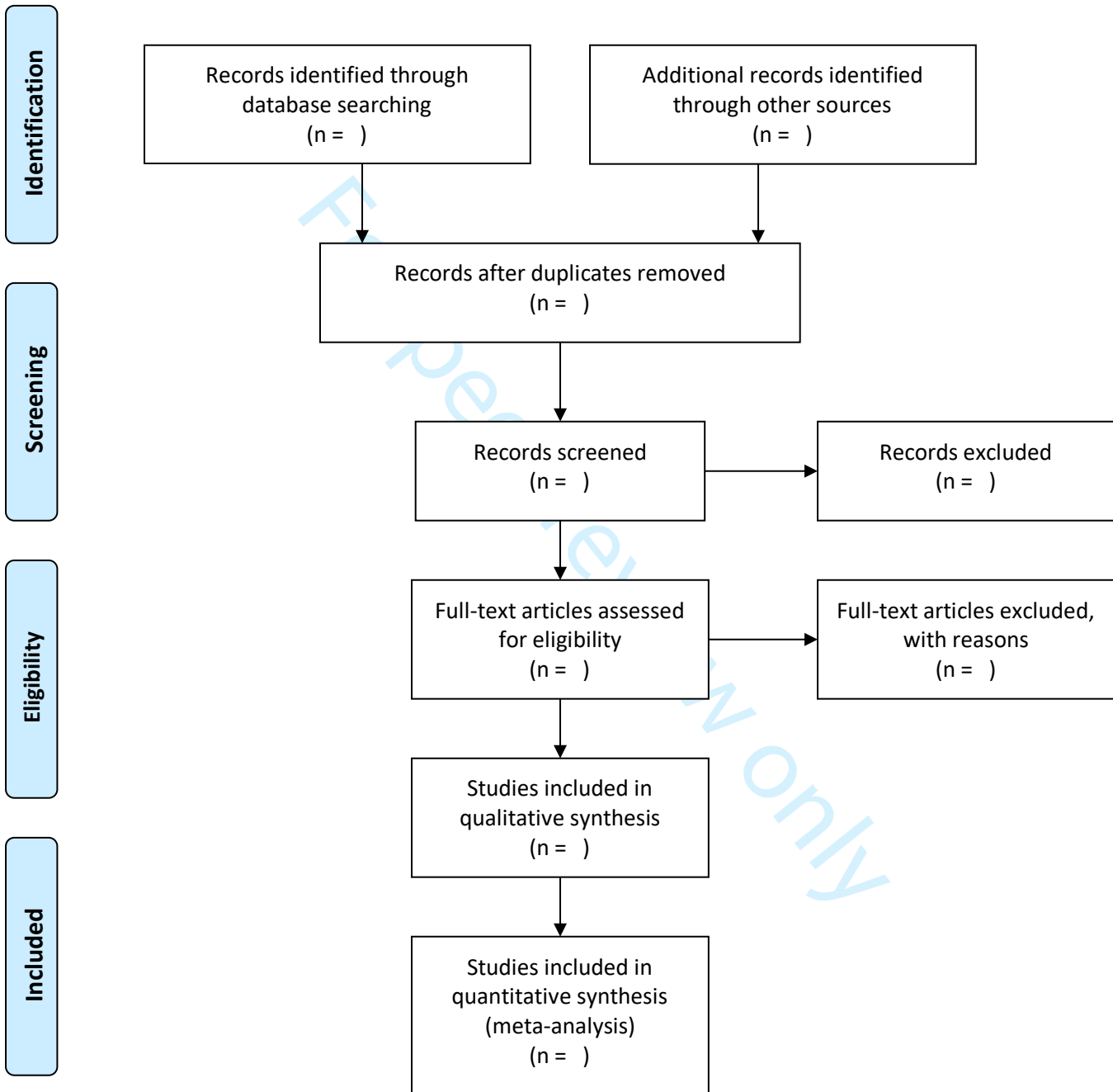
Search History/Alerts

[Print Search History](#) [Retrieve Searches](#) [Retrieve Alerts](#) [Save Searches / Alerts](#)

<input type="checkbox"/> Select / deselect all <input type="button" value="Search with AND"/> <input type="button" value="Search with OR"/> <input type="button" value="Delete Searches"/> <input type="button" value="Refresh Search Results"/>			
Search ID#	Search Terms	Search Options	Actions
<input type="checkbox"/> S6	(((MM "Social Networks") OR TI (social networks OR social network) OR AB (social networks OR social network)) AND (S2 AND S4)) AND (S1 AND S2 AND S4)	Expanders - Apply equivalent subjects Search modes - Boolean/Phrase	View Results (6) View Details Edit
<input type="checkbox"/> S5	(((MM "Social Networks") OR TI (social networks OR social network) OR AB (social networks OR social network)) AND (S2 AND S4))	Expanders - Apply equivalent subjects Search modes - Boolean/Phrase	View Results (391) View Details Edit
<input type="checkbox"/> S4	(MM "Social Networks") OR TI (social networks OR social network) OR AB (social networks OR social network)	Expanders - Apply equivalent subjects Search modes - Boolean/Phrase	View Results (13,927) View Details Edit
<input type="checkbox"/> S3	S1 AND S2	Expanders - Apply equivalent subjects Search modes - Boolean/Phrase	View Results (379) View Details Edit
<input type="checkbox"/> S2	MM "Trust" OR TI (trust or trusting or trustworthiness or trustworthy) OR AB (trust or trusting or trustworthiness or trustworthy)	Expanders - Apply equivalent subjects Search modes - Boolean/Phrase	View Results (34,194) View Details Edit
<input type="checkbox"/> S1	MM "Action Research" OR TI (action research OR community-based participatory research OR public and patient involvement OR participatory health research) OR AB (action research OR community-based participatory research OR public and patient involvement OR participatory health research)	Expanders - Apply equivalent subjects Search modes - Boolean/Phrase	View Results (8,960) View Details Edit

Appendix B

Prisma Flow Diagram 2009



51 From: Moher D, Liberati A, Tetzlaff J, Altman DG, The PRISMA Group (2009). Preferred Reporting Items for Systematic
52 Reviews and Meta-Analyses: The PRISMA Statement. PLoS Med 6(7): e1000097. doi:10.1371/journal.pmed1000097
53

54 For more information, visit www.prisma-statement.org.