

PEER REVIEW HISTORY

BMJ Open publishes all reviews undertaken for accepted manuscripts. Reviewers are asked to complete a checklist review form and are provided with free text boxes to elaborate on their assessment. These free text comments are reproduced below.

ARTICLE DETAILS

Title (Provisional)

An Exploration of Trust in Participatory Health Research Partnerships Across Two Timepoints – A Network Approach

Authors

Gilfoyle, Meghan; Salsberg, Jon; Macfarlane, Anne; McCarthy, Miriam; MacCarron, Padraig

VERSION 1 - REVIEW

Reviewer	1
Name	Jones, Nicole
Affiliation	Michigan State University College of Human Medicine, Charles Stewart Mott Department of Public Health
Date	31-Jul-2024
COI	None

The development and maintenance of trust is of critical importance to the success of participatory health research. The authors present a unique study by using both longitudinal data and a network analysis of trust dimensions. The main limitation of the work is the sample size and the contextual nature of trust both of which are acknowledged by the authors.

The measures are well described and the repetition of descriptions throughout the text is helpful to the reader. This paper is a helpful tool to health researcher who want to look at dimensions of trust within their networks.

I recommend emphasizing this is a case study (due to the limitations of generalizing the results from this small network more broadly) in the text of the paper.

Reviewer	2
Name	Lucero, Julie
Affiliation	

Date 06-Oct-2024

COI none

Bmjopen-2024-088355

Page 11, consider stating the seven dimensions in this paragraph instead of asking the reader to view the supplementary materials.

Page 15, line 345, and page 24 line 504 have rogue parenthesis

Double-check references, some citations are citing first names instead of surnames.

Since repeated interactions impact trust, would the authors provide communication context of 1) national partners (e.g. regular meetings with local sites), and 2) new names that emerged through SNA (e.g. staff turnover, or new employees).

Reviewer 3

Name Barker, Mary

Affiliation Unit University of Southampton, MRC Lifecourse Epidemiology

Date 02-Jan-2025

COI I declare no competing interests.

Thank you for sending me this paper to review. It adds to a seriously limited literature on the significance of trust in the practice of public partnerships that exist to support medical and health research. As the authors rightly say, the success or failure of research engagement with public contributors and other stakeholders is contingent upon a level of trust between them, but we have little understanding of how we create this trust or how trust evolves over time. I particularly like the analysis of trust along different dimensions. This is helpful in extending our understanding of a complex phenomenon. Whilst there are many good things about this manuscript there are a couple of issues that the authors might like to consider:

1. The paper describes a social network analysis. This is great but very complex and the language used to explain this complexity is itself complex. I, like many of the readers of this paper, am new to social network analysis. I note that they authors include a summary of their findings at the end of the Results section and appreciate the efforts that the authors have made to explain the terms and the implications of their findings but it doesn't always go far enough. It might be helpful for them to have a colleague who doesn't use SNA to read the manuscript and point out where it is difficult to follow. I have made some specific suggestions in my minor comments below.

2. There are several mentions of the study measures reflecting changes 'over time' and use of the word 'longitudinal' and the expression 'across a year' in the text. I'm not sure whether this study is really 'over time'. I think it is more about comparison of cross-sectional measurements at two time points which is subtly different to the implications of use of the phrase 'over time'. The latter implies a longitudinal evolution and probably more than two sets of measurements. The authors might want to consider amending their text throughout to reflect this.

3. There are quite a number of typographical errors in the manuscript that need to be corrected through a careful reading.

Minor comments:

1. SNA needs to appear in full in the abstract.
2. Line 125 – would be helpful to define more closely what is meant by 'partnership synergy'. This is not currently clear.
3. Line 133 – I think the words 'in the study of' are missing from this line, coming immediately before 'trust'.
4. Lines 158-160 – It needs to be clear from the start of the sentence that reference 53 is a scoping review for the second sentence to make sense.
5. Line 184 – the inclusion of the national level in the second research question needs to be justified in the text above. The text references only the local level.
6. Line 222 – it would improve clarity if there were a comma following the word 'confirming'.
7. Line 249 – insert 'and' following the word 'trust'.
8. Line 253 – I don't understand what this actually means 'to more concretely elucidate the conceptual and operational linkages of trust across and within the PHR and social network literature.'
9. Line 274 – you will need to define a node for those, like me, who don't have experience of social network analysis.
10. Lines 283-284 – this is difficult stuff and I think naïve readers are going to need more help understanding why the analysis of triads allows us to identify if a certain group is sharing trust throughout the network.
11. Line 296 – I think 'persistent in' should actually be 'existed at'.
12. Lines 336-370 – Use of the word 'similar' needs explaining. Us naïve readers will not have a good enough understanding of the range and distribution of these kinds of network measurements to know what is a big or a small difference between two numbers.

13. Line 354-355 - This underscores important nuances that are distinguishable when trust is explored multidimensionally. This reads more like a sentence from the Discussion than from the Results.

14. Lines 458-459 – I still don't really understand what 'trust connections' actually means in this context. Is there anyway in this helpful summary it could be explained again?

15. Line 480 – should read 'consistent' rather than 'persistent'.

16. Lines 483-485 – please could the authors explain what it means in terms of the relationships between actors in the partnership for networks to be similar and different. I still don't understand the implications of this.

17. Lines 511-514 - For example, considering the finding that local partners were less central compared to national partners (i.e., had fewer incoming nominations across each dimension of trust), we could recommend immediate interventions, like creating opportunity for local partners to lead on work. I don't understand how the smaller number of 'incoming nominations' suggests that local partners should lead on work. Please could the authors make this more transparent.

18. Lines 526-530 – The Limitations section is itself too limited. It would be helpful for the reader to understand, for example, whether there are any implications for the findings of the fact that there were fewer respondents at time two than at time one.

19. Lines 532-533 - Areas of future work could include exploring whether trust conceptualised and operationalised in the PPI Ignite Network led to better partnership outcomes. This sounds like a good idea but how do the authors suggest we do this?

VERSION 1 - AUTHOR RESPONSE

Reviewer: 1

Dr. Nicole Jones, Michigan State University College of Human Medicine

Comments to the Author:

The development and maintenance of trust is of critical importance to the success of participatory health research. The authors present a unique study by using both longitudinal data and a network analysis of trust dimensions. The main limitation of the work is the sample size and the contextual nature of trust both of which are acknowledged by the authors.

The measures are well described and the repetition of descriptions throughout the text is helpful to the reader. This paper is a helpful tool to health researcher who want to look at dimensions of trust within their networks.

Thank-you for this feedback, much appreciated.

I recommend emphasizing this is a case study (due to the limitations of generalizing the results from this small network more broadly) in the text of the paper.

We agree with this comment, thank-you and have emphasized this as a case study throughout, including:

Pg 1, 8, 10, 23, 26

Reviewer: 2

Julie Lucero

Comments to the Author:

Please see attached file (added below)

Page 11, consider stating the seven dimensions in this paragraph instead of asking the reader to view the supplementary materials.

We appreciate this comment and have added the supplementary file as a Table (1) in the manuscript (see pg 12).

Page 15, line 345, and page 24 line 504 have rogue parenthesis

Pg 15 has been edited. Pg 24, the second closed bracket is because it is a citation within a parentheses (see line above)

Double-check references, some citations are citing first names instead of surnames.

Thank-you, these have been edited.

Since repeated interactions impact trust, would the authors provide communication context of 1) national partners (e.g. regular meetings with local sites), and 2) new names that emerged through SNA (e.g. staff turnover, or new employees).

Thank-you for this comment. We have added the following text to provide more context regarding communication opportunities and new names emerging within the PPI Ignite Network:

Pg 10

"All partners (i.e., National and Local) in the PPI Ignite Network interacted through multiple avenues, including, local partner meetings (i.e., site leads and their local partners), PPI Ignite Network-wide meetings (all partners), five work packages¹ each addressing a specific function central to the Network's goals (open to all partners), and the National PPI Festival² (open to all partners and external participants)."

¹ Work package 1: build capacity for PPI in community and academic settings; work package 2: develop accredited education programmes for PPI; work package 3: enhance university policies and procedures to support PPI; work package 4: develop quality improvement and impact and work package 5: create systems for national co-ordination and functioning.

² <https://ppinetwork.ie/national-ppi-festival/>

¹ *Work package 1: build capacity for PPI in community and academic settings; work package 2: develop accredited education programmes for PPI; work package 3: enhance university policies and procedures to support PPI; work package 4: develop quality improvement and impact and work package 5: create systems for national co-ordination and functioning.*

² <https://ppinetwork.ie/national-ppi-festival/>

Pg 14

“This enabled us to examine how trust evolved over time for those naming new individuals in T2 (e.g., due to staff turnover, new partnerships, or interactions driven by work package preference), compared to those who maintained their nominations from T1.”

Pg 24

“(e.g., new employees or partners given staff and partnership turnover and/or interacting with new people depending on their work package)”

Reviewer: 3

Dr. Mary Barker, University of Southampton

Comments to the Author:

Thank you for sending me this paper to review. It adds to a seriously limited literature on the significance of trust in the practice of public partnerships that exist to support medical and health research. As the authors rightly say, the success or failure of research engagement with public contributors and other stakeholders is contingent upon a level of trust between them, but we have little understanding of how we create this trust or how trust evolves over time. I particularly like the analysis of trust along different dimensions. This is helpful in extending our understanding of a complex phenomenon. Whilst there are many good things about this manuscript there are a couple of issues that the authors might like to consider:

1. The paper describes a social network analysis. This is great but very complex and the language used to explain this complexity is itself complex. I, like many of the readers of this paper, am new to social network analysis. I note that they authors include a summary of their findings at the end of the Results section and appreciate the efforts that the authors have made to explain the terms and the implications of their findings, but it doesn't always go far enough. It might be helpful for them to have a colleague who doesn't use SNA to read the manuscript and point out where it is difficult to follow. I have made some specific suggestions in my minor comments below.

Thank-you for this comment. We appreciate that SNA is a complex topic, especially for those who are not familiar with this approach. Thus, we have made several edits throughout the manuscript (evidenced via tracked changes) to clarify and reduce terminology when not essential. We hope this helps with readability of the manuscript.

2. There are several mentions of the study measures reflecting changes 'over time' and use of the word 'longitudinal' and the expression 'across a year' in the text. I'm not sure whether this study is really 'over time'. I think it is more about comparison of cross-sectional measurements at two time points which is subtly different to the implications of use of the

phrase 'over time'. The latter implies a longitudinal evolution and probably more than two sets of measurements. The authors might want to consider amending their text throughout to reflect this.

We appreciate this comment. To clarify, we have reduced the usage of terms "over time" and instead, often refer to two timepoints (e.g., title change)

3. There are quite a number of typographical errors in the manuscript that need to be corrected through a careful reading.

Thank-you. We have reviewed the manuscript thoroughly and have made numerous edits throughout (see tracked changes) to improve sentence structure, grammar etc.

Minor comments:

1. SNA needs to appear in full in the abstract.

This has been added.

2. Line 125 – would be helpful to define more closely what is meant by 'partnership synergy'. This is not currently clear.

We have added the following text to improve clarity:

"Synergy has been described as "the power to combine the perspectives, resources and skills of a group of people and organizations (pg.183)," and influences partnership effectiveness (26)."

3. Line 133 – I think the words 'in the study of' are missing from this line, coming immediately before 'trust'.

Thank-you. We have added the text "in the study of" before the word trust.

4. Lines 158-160 – It needs to be clear from the start of the sentence that reference 53 is a scoping review for the second sentence to make sense.

Added the following for clarity: "in their scoping review" (pg 7)

5. Line 184 – the inclusion of the national level in the second research question needs to be justified in the text above. The text references only the local level.

Added "either local or national partners" in the text above (pg 8), to underscore that trust may/may not be developing across both partnership types.

6. Line 222 – it would improve clarity if there were a comma following the word 'confirming'.
Added.

7. Line 249 – insert 'and' following the word 'trust'.
Added.

8. Line 253 – I don't understand what this actually means 'to more concretely elucidate the

conceptual and operational linkages of trust across and within the PHR and social network literature.'

This describes how the thematic analysis (not typically done in a scoping review) occurred to further elucidate how trust was conceptualised and operationalised both within the PHR and SNA literature (which is also not often consistently defined/measured) as well as between the PHR and SNA literature (through, at times, shared thematic categories – i.e., they were defining them in a conceptually cohesive way). We have added the following text to clarify.

"This scoping review (54), included a thematic analysis of the extracted literature, to better identify the conceptual and operational linkages of trust across and within the PHR and social network literature through their thematic groupings."

9. Line 274 – you will need to define a node for those, like me, who don't have experience of social network analysis.

This word has been removed and replaced with individual or organisation throughout.

10. Lines 283-284 – this is difficult stuff and I think naïve readers are going to need more help understanding why the analysis of triads allows us to identify if a certain group is sharing trust throughout the network.

Thanks for this feedback. We have edited the text to hopefully clarify for a wider readership. Please see this via the addition of the following text (pg 13): *"Clustering coefficient measures the degree to which individuals cluster together in the PPI Ignite Network, specifically examining the proportion of closed triads (i.e., triangles) in the network (62). For example, if there are three individuals in a network, A, B, and C and individuals A and B trust each other, and B and C trust each other, then there is a high likelihood that A and C also trust each other. This identifies how trust is shared within groups throughout the network."*

11. Line 296 – I think 'persistent in' should actually be 'existed at'.

Thank-you this has been edited.

12. Lines 336-370 – Use of the word 'similar' needs explaining. Us naïve readers will not have a good enough understanding of the range and distribution of these kinds of network measurements to know what is a big or a small difference between two numbers.

Thank-you. See comment 16 below.

13. Line 354-355 - This underscores important nuances that are distinguishable when trust is explored multidimensionally. This reads more like a sentence from the Discussion than from the Results.

We agree, and this text has been removed from the results section.

14. Lines 458-459 – I still don't really understand what 'trust connections' actually means in this context. Is there anyway in this helpful summary it could be explained again?

We have added the following text in hopes of clarifying (Pg 23):

"This indicates that, at the second time point, fewer individuals agreed or strongly agreed with a given trust statement about the individual they nominated in the network compared to the first timepoint."

15. Line 480 – should read 'consistent' rather than 'persistent'.

This has been edited.

16. Lines 483-485 – please could the authors explain what it means in terms of the relationships between actors in the partnership for networks to be similar and different. I still don't understand the implications of this.

Thank-you for this comment. To elaborate a bit, each network is measuring a different dimension of trust across but with the same actors. So, if individual **A** agrees with the integrity statement about individual **B**, and the subsequently does **NOT** agree with the shared, values, visions and goals statement for individual **B** (both of which are important aspects of trust), then these networks will be visually and operationally (via SNA measures) different from each other. So, some dimensions of trust were more alike (visually and operationally), while others were not. This has important implications including 1) in the literature people often measure trust as a whole and not the sum of its parts, which is problematic as described in the sources below. 2) Where and how we intervene to improve trust will then depend on the dimension. Each social network maps a given relationship. E.g., if I ask the same 10 people who I would play soccer with vs. who I would go to for career advice, I would see very different connections (aka network maps).

Further, the KS-test and HIM distances are two different ways of looking at network differences. The first compared the histograms of nominations and gets the distance between them, the second looks at a structural difference. When we say "similar", we mean two networks have a smaller distance on both of these properties. It would therefore take less changes to one of those networks to get to the other (i.e. change less answers in their network survey).

To clarify this, we have made edits throughout the discussion, namely pg 25, 26 and 27, to help clarify (shown via tracked changes) in hopes that this is clarified.

17. Lines 511-514 - For example, considering the finding that local partners were less central compared to national partners (i.e., had fewer incoming nominations across each dimension of trust), we could recommend immediate interventions, like creating opportunity for local partners to lead on work. I don't understand how the smaller number of 'incoming nominations' suggests that local partners should lead on work. Please could the authors make this more transparent.

We have edited the text on page 26 to underscore what implications of this positioning would look like. Further, we hope the added text on page 23 clarifies what we mean by connection.

18. Lines 526-530 – The Limitations section is itself too limited. It would be helpful for the reader to understand, for example, whether there are any implications for the findings of the fact that there were fewer respondents at time two than at time one.

We appreciate this comment and agree more was needed to add to this section. Thus, the following text has been edited to address these comments (pg 27):

Although embracing context is important, readers should consider this when interpreting and/or applying findings to their own research. This case study examines a small network with two timepoints over a year. Considering that trust takes time to develop, surveying trust at only two time points may be restrictive. Additionally, not all partners in the PPI Ignite Network participated, and some who did participate did not complete both network surveys. To facilitate comparisons across timepoints, those who did not complete both network surveys were excluded, resulting in a smaller sample size. As such, the views reflected in case study might not be representative of the entire Network and should be interpreted accordingly. However, consistent with findings from previous work(55), network properties differed only at the second decimal place, suggesting that the smaller sample size likely had a minimal impact on the results. Furthermore, as trust is inherently contextual, its evolution will likely vary depending on the partnership of interest. This variability should be considered when applying these findings to other settings. Finally, while this study employed a novel approach to operationalising trust across different contexts, it does not reveal why the networks evolved as they did. This limitation is addressed in a follow-up study published elsewhere (see (74)).

19. Lines 532-533 - Areas of future work could include exploring whether trust conceptualised and operationalised in the PPI Ignite Network led to better partnership outcomes. This sounds like a good idea but how do the authors suggest we do this?

Thank-you for this comment. We have added more detail to this section as highlighted in purple text below.

Areas of future work could investigate the conceptualisation and operationalisation of trust within the PPI Ignite Network lead to improved partnership outcomes. For instance, ‘readiness’ for public and patient involvement at a national level and within individual institutions was a priority outcome of the Network. Future studies could examine whether changes in trust networks are associated with achieving the PPI Ignite Network’s objective of building capacity for PPI readiness. Additionally, future research could explore whether certain trust dimensions (among the 7 identified) are particularly relevant to certain aspects of the CBPR model(8, 17). For example, the CBPR model emphasizes power dynamics as a critical factor influencing both context and partnership processes.(75) With our enhanced understanding of trust - particularly the trust dimension ‘power-sharing and co-ownership’ - it may be possible to identify where power dynamics exist by pinpointing asymmetrical trust relationships within the trust

dimension network. Finally, as this is a case study exploring trust in one context, future work could expand to explore the trust development process across other PHR partnerships to compare findings across multiple study contexts.
