

Innovative ideas for Patient and Public Involvement (PPI) in qualitative research



Caroline Barker @crbarker91

Strategic Lead Patient and Public Involvement

NIHR Southampton Clinical Research Facility and Biomedical Research Centre, University
Hospital Southampton NHS Foundation Trust
NIHR Applied Research Collaboration Wessex

Carmel McGrath - @McGrathCarmel93

PhD Student

NIHR Southampton Biomedical Research Centre



Outline of today's session

- Why should we involve the patient and public in our work?
- PPI and Qualitative research – what is the difference?
- How can we involve the public in qualitative research?
- Case studies of public involvement in thematic analysis and content analysis

Patient and Public Involvement

Research being carried out **‘with’** or **‘by’** members of the public rather than **‘to’**, **‘about’** or **‘for’** them

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Why are we developing our PPI skills?



PPI vs Qualitative research*

	Qualitative project	Involvement in a project
Why?	Aims to answer research question(s) and advance understanding	Generating new ideas , selecting and refining the question, informing and influencing decisions .
What?	Seeks people's input as data to answer a research question	Two way exchange of knowledge. Seeks input to inform and influence decisions about research.
	Collection of data using qualitative methods	Involvement in the tasks of research.
	Generates evidence for wider society	Insights and learnings may be specific to the researchers and patients/public involved and that particular project

PPI vs Qualitative research*

	Qualitative project	Involvement in a project
How?	Needs ethical approval	Needs to reflect ethical practice (not usually ethical approval)
	Follows a standard method	Uses a flexible approach
	Researchers analyse the data in the way they think is best	Shared power – joint decisions – combining views.
	Way participants identified varies based on the aims of the study (eg. snowball, convenience sampling)	More likely to draw individuals from established networks of people interested in contributing
	Can be done by one researcher on behalf of a team	Needs many members of the team as they could each learn something different from the experience

PPI vs Qualitative research*

	Qualitative project	Involvement in a project
Who?	Seeks views from representative sample (eg. characteristics determined using theoretical sampling)	Seeks range of perspectives from people with diverse experiences. May not have lived experience of the study topic.
	Numbers usually defined	Numbers not defined – usually lower than researcher and participant numbers
	Individuals are participants and provide informed consent	Consent only required if participants are directly quoted (NOT data)
		Individuals should have power and be reasonably compensated

PPI vs Qualitative research*

	Qualitative project	Involvement in a project
When?	More likely to be one-time data collection session	More likely to take place over extended period of time and involve multiple meetings
Where?	Takes into account participant preferences and where is best for data collection	Tends to involve people being invited to join research team meetings in academic settings

*Table created with support from following resources

1) Morgan, H et al (2016) Combining PPI with qualitative research to engage 'harder-to-reach' populations: service user groups as co-applicants on a platform study for a trial. *Research Involvement and Engagement* 2, article 7, Table 3.

2) Doria, N et al (2018) Sharpening the focus: differentiating between focus groups for patient engagement vs. qualitative research. *Research Involvement and Engagement* 4, article 19

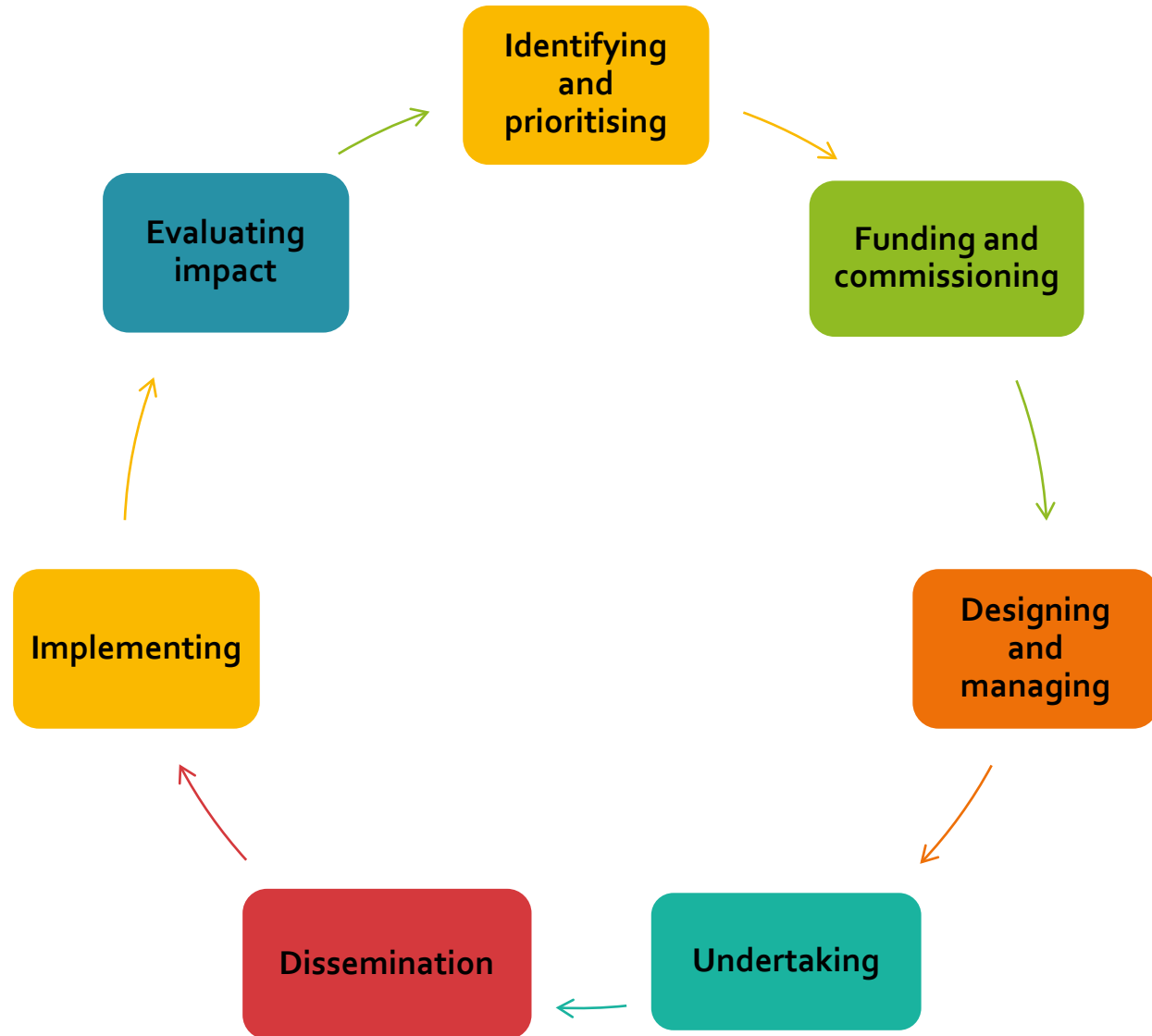
3) Staley K. Patient and public involvement in research: Wordpress. 2019.[Available from: <https://kristinastaley.com/2019/02/25/how-is-involvement-in-research-different-from-qualitative-research/>] (Accessed 15th March 2021)

Ideas for Public Involvement in qualitative research.



NIHR INVOLVE's Research Cycle

Involving public contributors in qualitative research.





Ethics protocol and lay summary



Recruitment strategies



Participant facing information



Interview questions

Designing

Before PPI

University Hospital Southampton NHS Foundation Trust NHS National Institute for Health Research Health Research Authority

PARTICIPANT INFORMATION SHEET- INTERVIEWS

Study Title: What do Patient and Public Involvement (PPI) stakeholders' consider most important in terms outcomes and impacts of PPI in health research?

Researcher: Carmel McGrath **NHS ethics reference:**

Dear Sir/ Madam

You are being invited to take part in the above research study. To help you decide whether you would like to take part or not, it is important that you understand why the research is being done and what it will involve. Please read the information below carefully and ask questions if anything is not clear or you would like more information before you decide to take part in this research. You may like to discuss it with others but it is up to you to decide whether or not to take part. If you are happy to participate you will be asked to sign a consent form.

What is the purpose of this study?

The research is part of a PhD project that is being supported by the University of Southampton, the National Institute of Health Research Biomedical Research Centre (NIHR BRC) and University Hospital Southampton NHS Foundation Trust.

University Hospital Southampton NHS Foundation Trust NHS National Institute for Health Research Health Research Authority

Word count: 2,671
Pages: 11

After PPI

NIHR National Institute for Health Research University Hospital Southampton NHS Foundation Trust

Participant information sheet

Study Title:
What do Patient and Public Involvement (PPI) stakeholders consider as the most important outcomes of PPI for health research?

Researcher name: Carmel McGrath
IRAS ID:
Study N:


What is

This research is part of a PhD project supported by the University of Southampton, the National Institute for Health Research Biomedical Research Centre (NIHR BRC) and by the University Hospital Southampton NHS Foundation Trust.

The aims of the study will be to find out what PPI outcomes are important and to show the difference PPI makes for health research. To do this we will ask those who have been involved with Patient and Public Involvement (PPI) about their experience and opinions of it. The findings from this study will be used in further research to develop a tool to help researchers assess, identify and report the impact of PPI on their research.

Patient and Public Involvement (PPI) enables medical researchers to improve their research by taking into account the views and experience of those affected by the research. PPI does not necessarily include public engagement, which is the sharing of knowledge and information obtained from the research with the public.

- Patient and Public Involvement (PPI) is becoming an increasingly important part of research as organisations such as the National Institute for Health Research (NIHR) recommend its use in research for best practice and suggest that it be done at every stage of research.
- There is limited evidence about the difference PPI makes to research; it is important to fill this gap, as it will better enable researchers to understand how they can work with PPI contributors in ways that are meaningful, resourceful and of value to contributors, researchers and the research.



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Participant information sheet V 2.0 22_08_2019

Word count: 1,621
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Undertaking

Interviewing

Peer interviewing



Running

Running focus groups



Analysing

Analysing data



Disseminating



Evaluating the impact of public involvement

Ask evaluation questions at the end of the activity

Impact logs

Public involvement impact assessment framework (PiiAF)

GRIPP2 Reporting impact

Impact logs

Public Involvement Log				
Date	What & with who	Ideas/Suggestions/Output	Outcome/Impact	Notes/Next steps



Public Involvement Log

Date	Project	Type of involvement	Who took part	Outcome*	Impact**	Reflections/learning

Examples of working with public contributors during the data analysis phases of research.

Thematic analysis (April 2020)



Worked with seven public contributors



Held online using breakout rooms



Discussed my main themes, codes and illustrative quotes.



Captured discussions, interpretations and disagreements (recordings and facilitators).



Helped to validate themes and refine codes.

Example

Code A6	Quotation
Contributors are held onto by researchers	“So that (research project) was with (name of University and Trust removed) ... that was my first chance into PPI and that was in 2011- and I’ve not been allowed to go away since”.

Secondary data analysis (March 2021)



Content analysis Researchfish data (2,582) open text responses)



2 public contributors



Collaborative approach



Developing the coding framework and analysing data together



Meetings held online

What have been the outcomes so far?



Enjoyable learning experience (for both public contributor and researcher).



Motivating experience



Encouraged reflection/ reflexivity



Informed and progressed the next phases of research.

How would my analysis have been different without public involvement?



Enabled me to think about my data in more depth.



Helped to prevent potential researcher bias.



Promoted accountability

What preparation was required?



Knowing who to involve and why.



How the input from contributors could affect the overall data analysis.



How would I show the changes made as a result of this activity?



What would I do if the public contributors did not agree with my interpretations of the analysis?



Information required in advance of the meeting.



Payment for the public contributors' time.



Requires additional time and planning



You may need to revisit your work



Difficult to receive criticisms of your work



Cost of public involvement



May need ethics for certain activities (i.e peer-interviewing)



Support is required for public contributors

Challenges of public involvement.



Planning and organising group work



Listening to different perspectives



Facilitating discussions



Create a safe space for contributors to provide their views



Practising reflection/ reflexivity

Skills that
translate to
public
involvement

Thank you!



Questions?

Contact details:

Carmel McGrath

Email: cm31g13@soton.ac.uk

Twitter: @McGrathCarmel93

Caroline Barker

Email: caroline.barker@uhs.nhs.uk

Twitter: @crbarker91



References and additional information

References

1. Staley K. Patient and public involvement in research: Wordpress. 2019. [Available from: <https://kristinastaley.com/2019/02/25/how-is-involvement-in-research-different-from-qualitative-research/>] (Accessed 15th March 2021)
2. Research Design Service *Patient and public involvement in health and social care research: A handbook for researchers*: Research Design Service; 2015. [Available from: https://www.rds-yh.nihr.ac.uk/wp-content/uploads/2015/01/RDS_PPI-Handbook_2014-v8-FINAL-11.pdf]. (Accessed 12th March 2021).
3. Frost J, Gibson A, Harris-Golesworthy F, Harris J, Britten N. Patient involvement in qualitative data analysis in a trial of a patient-centred intervention: Reconciling lay knowledge and scientific method. *Health Expect*. 2018;21(6):1111-21 doi: <https://doi.org/10.1111/hex.12814>
4. NIHR Imperial BRC Patient Experience Research Centre (PERC) NIBPERC. A Rough Guide to Public Involvement 2020 [cited 2021. Available from: <https://www.imperial.ac.uk/media/imperial-college/medicine/sph/ide/perc/PERCs-Rough-Guide-to-Public-Involvement---Jan-2020.pdf> (Accessed 10th March 2021).
5. Collins M, Long R, Page A, Popay J, Lobban F. *Using the Public Involvement Impact Assessment Framework to assess the impact of public involvement in a mental health research context: A reflective case study*. *Health Expectations*. 2018;21(6):950-63.
6. Staniszewska S, Brett J, Simera I, Seers K, Mockford C, Goodlad S, et al. *GRIPP2 reporting checklists: tools to improve reporting of patient and public involvement in research*. *Bmj-British Medical Journal*. 2017;358.
7. Oxford BRC *Patient and public involvement webinar: qualitative research*. 2020 [Available from: https://www.youtube.com/watch?v=LN9ZGltvPRE&ab_channel=OxfordBRC] (Accessed 16th March 2021)
8. Doria N, Condran B, Boulos L, Curtis Maillet DG, Dowling L, Levy A. *Sharpening the focus: differentiating between focus groups for patient engagement vs. qualitative research*. *Research Involvement and Engagement*. 2018;4(1):19 doi: <https://doi.org/10.1186/s40900-018-0102-6>
9. Morgan H, Thomson G, Crossland N, Dykes F, Hoddinott P, on behalf of the 'Bst. Combining PPI with qualitative research to engage 'harder-to-reach' populations: service user groups as co-applicants on a platform study for a trial. *Research Involvement and Engagement*. 2016;2(1):7 doi: <https://doi.org/10.1186/s40900-016-0023-1>
10. Rolfe DE, Ramsden VR, Banner D, Graham ID. Using qualitative Health Research methods to improve patient and public involvement and engagement in research. *Research Involvement and Engagement*. 2018;4(1):49 doi: <https://doi.org/10.1186/s40900-018-0129-8>
11. Muller I, Santer M, Morrison L, Morton K, Roberts A, Rice C, et al. Combining qualitative research with PPI: reflections on using the person-based approach for developing behavioural interventions. *Research Involvement and Engagement*. 2019;5(1):34 doi: <https://doi.org/10.1186/s40900-019-0169-8>
12. INVOLVE (2012) *Briefing notes for Researchers: public involvement in NHS, public health and social care research Briefing note eight: Ways that people can be involved in the different stages of the research cycle* INVOLVE, Eastleigh [Available from: <https://www.invo.org.uk/wp-content/uploads/2012/04/INVOLVEBriefingNotesApr2012.pdf>] (Accessed 17th March 2021)