

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



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# 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

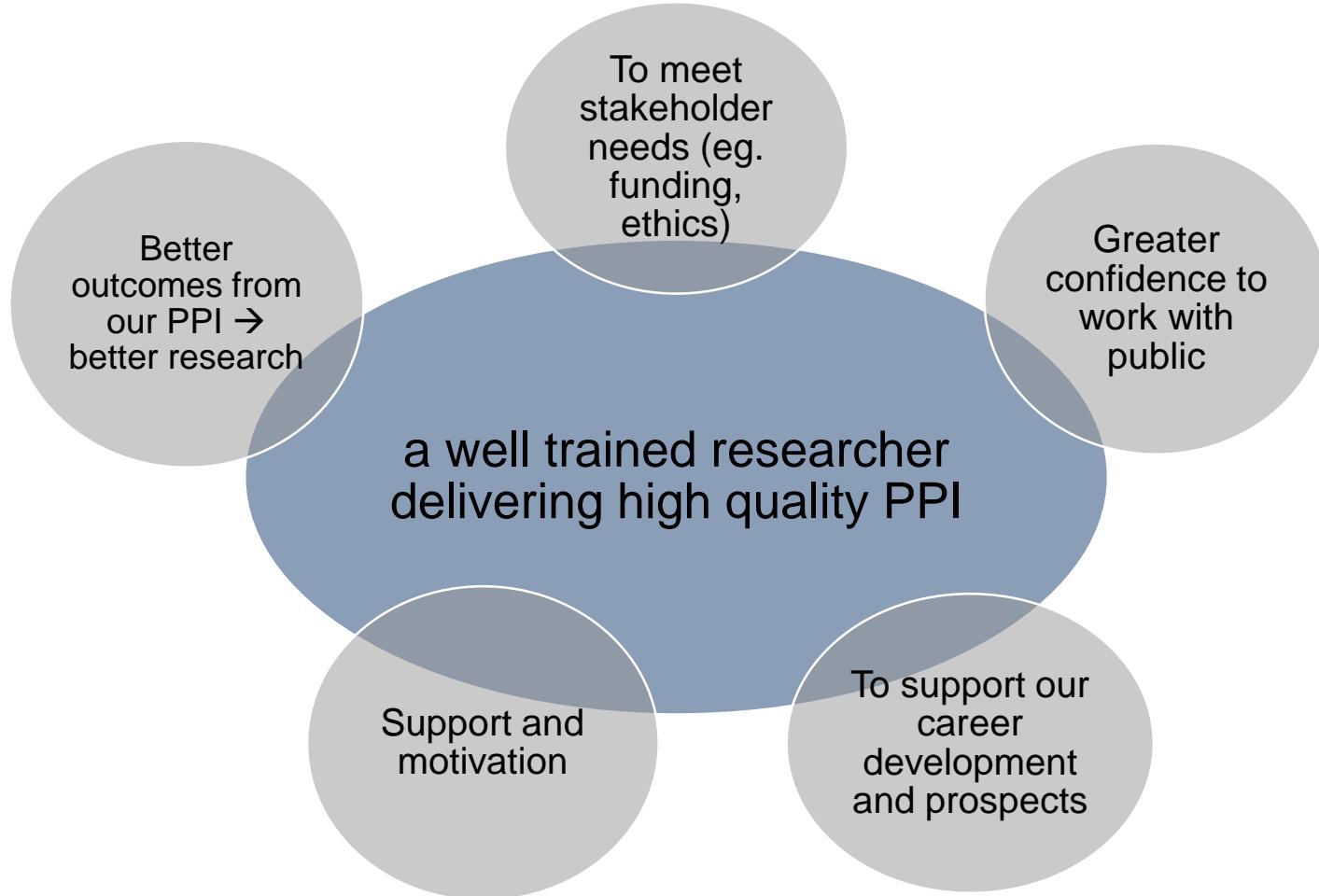
# Patient and Public Involvement

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\*

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

# PPI vs Qualitative research\*

|             | <b>Qualitative project</b>   | <b>Involvement in a project</b>  |
|-------------|--|--|
| <b>How?</b> | Needs ethical <b>approval</b>  | Needs to reflect ethical practice (not usually ethical approval)                                       |
|             | Follows a <b>standard method</b>   | Uses a <b>flexible approach</b>  |
|             | <b>Researchers analyse</b> the data in the way they think is best                                      | <b>Shared power</b> – 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 <b>established networks</b> of people interested in contributing  |
|             | Can be done by <b>one researcher</b> on behalf of a team   | Needs many members of the team as they could <b>each learn something different</b> from the experience |

# PPI vs Qualitative research\*

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

# PPI vs Qualitative research\*

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

\*Table created with support from following resources

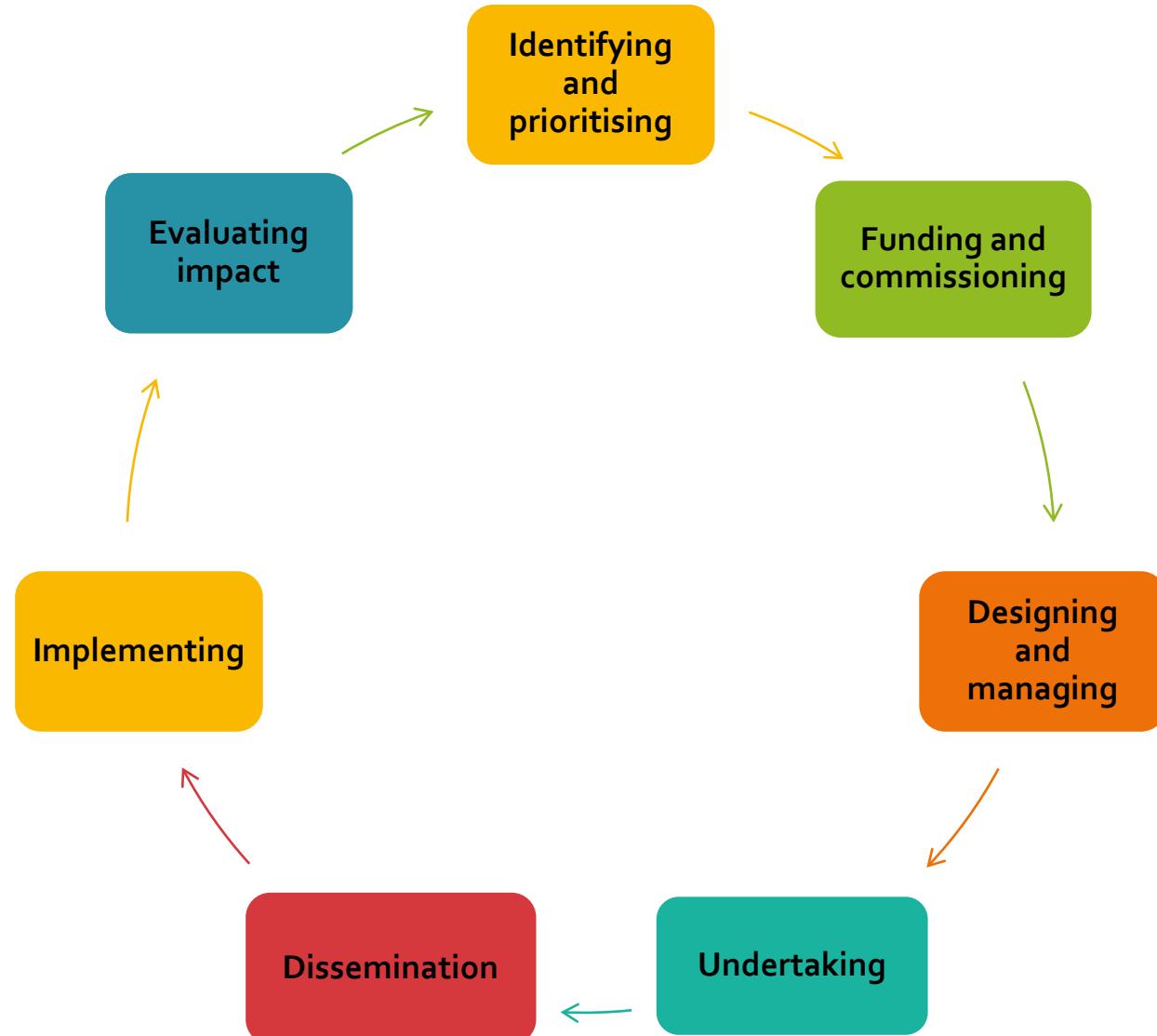
- 1) Morgan, H et al (2016) Combining PPI with qualitative research to engage 'harder-to-reach' populations: service user groups as co-applicants on a platform study for a trial. *Research Involvement and Engagement* 2, article 7, Table 3.
- 2) Doria, N et al (2018) Sharpening the focus: differentiating 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 15<sup>th</sup> 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

**NHS**  
University Hospital Southampton NHS Foundation Trust

**NHS**  
National Institute for Health Research

**NHS**  
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

**NHS**  
Health Research Authority



## After PPI

**NIHR** National Institute for Health Research

**University Hospital Southampton NHS Foundation Trust**

**NHS**  
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: 2,671**

**Pages: 11**

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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  |
|--|--|
| <b>Contributors are held onto by researchers</b> | "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

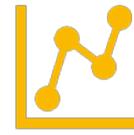


Encouraged reflection/ reflexivity



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?

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Twitter: @crbarker91



# References and additional information

## References

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