

Patient and Public Involvement

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Aims

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- Introduction
- What?
- Why?
- How?

Who am I?



- Health and social care research
- Organisational ethics and corruption

- Arsenal season ticket holder
- Failed musician
- Yoga

INVOLVE



- Support active public involvement in NHS, public health and social care research
- Centre of expertise in patient and public involvement in research
- Provide advice, guidance and support
- Part of the National Institute for Health Research

Our work



- International network
- Co-production
- Diversity and inclusion
- Learning and development
- Standards

What is patient and public involvement?



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

Participation – where people take part in a research study

Engagement – Where information and knowledge about research is provided and disseminated
(INVOLVE 2012)

Approaches

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- Consultation
- Collaboration
- User controlled
- Co-production

Why?

- Offers a **different perspective** from rest of the research team
- Potential to **improve** the research quality and relevance
- **Moral imperative**, as research targeting populations or services, publicly funded
- **Requirement** for most funding applications

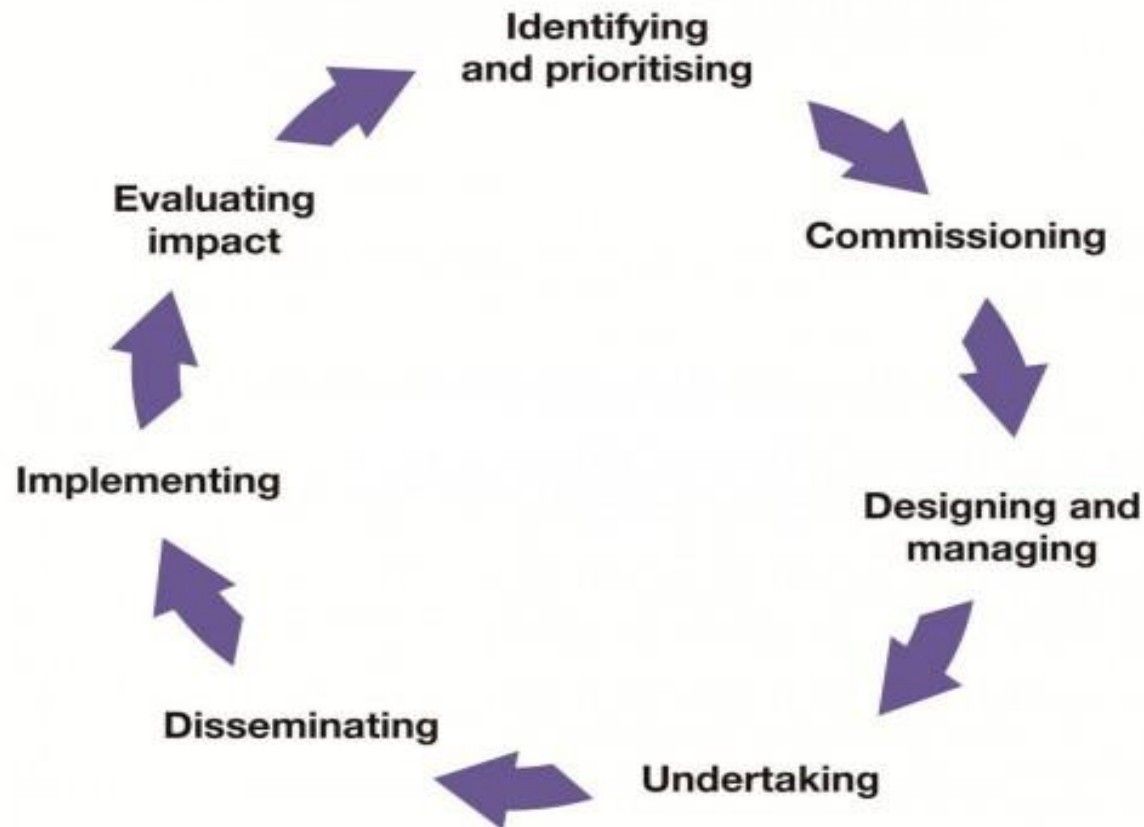


How?



- Research cycle
- Architecture
- Costs

The research cycle



Identifying and prioritising



- Discussions with existing reference groups and networks
- Invite people to an event or holding a workshop or focus group
- Attend meetings held by service user groups
- Surveys and interviews
- Ask organisations who support the public about the feedback they get from people who use services

Commissioning

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- Reviewing research proposals
- Research commissioning panels or boards
- Monitoring
- User controlled organisations commissioning research

Designing and managing



- Identify areas that might have ethical considerations
- Ensure recruitment process is practical and feasible
- Help you to develop a budget for public involvement and the time and the support needed for public involvement is built in to the research
- Suggest ways to ensure diversity
- Ensure written information is user friendly

Undertaking



- Undertake library-based research
- Carry out interviews/focus groups
- Develop research tools
- Gather and review documentary evidence
- Analyse and interpret data

Disseminating



- Develop your dissemination plans
- Presenting at conferences, speaking to patients, support groups and service providers
- Co-authors in journal and newsletter articles

Architecture



- Provide public with necessary knowledge/skills
- Respect the skills, knowledge and experience of public
- Provide researcher with training on how to involve public
- Establish good relationships and avoid recruiting public
in a hurry

Architecture



- Budget appropriately
- Build in additional time needed
- Provide personal support and supervision
- Involve patients and public as early as possible in the research
- Define roles of public and researchers

Architecture

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- Ensure good communication
- Payment processes
- Timing of events
- Accessibility

Costs



- Clear policy for payment and expenses
- Discuss with HR/finance that policy can be implemented
- Payment is consistent with other members of team
- Consult with people how they would like to be paid/recognised
- Don't underestimate

Deciding on a fee

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- What skills/expertise and experience are required?
- What are the time commitments?
- What is the level of responsibility?

Some examples



- INVOLVE
 - Daily committee fee, including preparation - £150
 - Reviewing documents up to 50 pages - £50
 - Reviewing documents 51 to 200 pages - £125
 - Reviewing documents 200+ pages - £200

- University - £19.40 per hour for attendance at a meeting.
£120 per day for research work

Key tips



- Involve people as early as possible
- Clarify responsibilities
- Resource public involvement in research
- Offer training and support
- Document and record public involvement

Impact

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“...a growing agreement that all aspects of the research process can and should be examined and held to account.”

INVOLVE 2014

Is there an impact?



The PIRICOM Study: A systematic review

- Weak evidence base re quality and detail of impact
- Little focus on developing instruments for capturing and measuring patient and public involvement impact
- Processes and context – important for beneficial impact

The Public Involvement Impact Assessment Framework (PiiAF)

| Intervention | Impact assessment question | Identify indicators | Develop measures | Data | Method | Design |
|--|----------------------------|---|---|---|--|---|
| What is your public involvement trying to achieve? | Who, what and how | What will you look for in order to decide whether this has been achieved? | How will you assess whether it has been achieved? | Where will you collect the data from and how will you collect it? | What approach to collecting data will you use? Eg qual or quant? | What will your design be? Eg case study, rct? |

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|---|---|---------------------|----------------------------------|---|--|--------------------------------|
| PPI in writing recruitment leaflets will lead to leaflets being written in a more accessible language | Does involving carers of people with cancer on the steering committee lead to better recruitment letters? | Changes in language | Clarity Ease of understanding | From 10 carers of people with cancer from Berlin. Q'res sent by post. | Q're comparing two leaflets; a) written by researchers b) revised following consultation | Comparison of two case studies |

Reporting



“At present, the PPI evidence base is like an iceberg, only partly visible within the literature, with much information hidden, either not reported or poorly reported.”

Staniszewska et al. (2011)

Guidance for Reporting Involvement of Patients and the Public



1. Abstract
2. Background
3. Aims
4. Methods
5. Capture of PPI impact
6. Economic assessment
7. Results
8. Discussion and conclusions

Research Involvement and Engagement
Staniszewska et al 2017

5. Impact



5a: Qualitative evidence of impact

- If applicable, report the methods used to qualitatively explore the impact of PPI in the study

5b: Quantitative evidence of impact

- If applicable, report the methods used to quantitatively measure or assess the impact of PPI

5c: Robustness of measure

- If applicable, report the rigour of the method used to capture or measure the impact of PPI

Summing up....



- Active involvement
- Approaches
- Reasons
- Stages
- Impact and reporting



“No matter how complicated the research, or how brilliant the researcher, patients and the public always offer unique, invaluable insights. Their advice when designing, implementing and evaluating research invariably makes studies more effective, more credible and often more cost effective”

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Danke!

Quiz



1. Can health/social care ‘academics’ be patient / public contributors?

1 for Yes

2 for No

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2. Patients and the public can't be involved in the analysis of research as this requires specialist skills?

1 for Yes


2 for No

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3. I need ethical approval to involve patients/public in research?

1 for Yes

2 for No

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4. If I involve members of the public on my research steering committee then they must be representative of the public?

1 for Yes

2 for No

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5. We involve patients and the public for which of the following reasons?

1. Because patients and the public have a right to influence what we do because we are spending public money
2. Because we incur financial penalties if we don't involve patients and the public
3. Because having the input of patients and the public improves the quality of the research
4. Because patients and the public offer insights into research that are different from those of clinical and academic advisors
5. Because the people we recruit are representative of all people with a particular condition

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6. What sorts of judgements is it reasonable to ask patients and the public to make?

1. Whether what the researchers are setting out to do makes sense from a common sense point of view.
2. Whether a project will work/is practically feasible
3. Whether the project is well designed
4. Whether a study would be able to recruit participants

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7. Are Arsenal the world's greatest football team?

1 for Yes

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