The Role of Patient and Public Involvement in Producing Quality Research

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WHO ARE WE?

An introduction:

• Background
• Personal experiences
• Patient and Public Involvement (PPI) experiences
• Motivation
WHAT IS THIS ABOUT?

• Lived Experience Perspective

• Structure of this Talk: What is PPI?
  Why do it?
  What it looks like in practice
  How to do it/ considerations
  Final message (summary and top tips!)

• How does PPI improve value and reduce waste in research?
REDUCING WASTE IN RESEARCH

**WHAT IS PPI?**

- **Patient and Public Involvement** – where members of the public are actively involved in research projects and research organisations.

- E.g. NIHR, HPRU, ICEP, DATAMIND, ARC West, CRN West of England, PHWE

- **PHWE mission statement** - “To ensure a strong public voice in the pathway of research from inception to delivery”
“PPI helps research and services be... more relevant and subsequently more effective. Gathering meaningful insight also helps us make better use of our resources creating less waste, as aiming to get things right first time prevents costly inefficient and underused services.”

Tameside & Glossop Integrated Care
NHS Foundation Trust
BENEFITS TO RESEARCHERS

- Learning from people who actually have experience of living with the health condition or accessing services for support
- Demonstrates to funders and commissioners that the topic is relevant and important
- A different perspective, which assists with study design, recruitment, identifying participation barriers, sharing results...
  = more effective and efficient research
- Cost savings

“A reduction of wasteful research is possible if the evidence that the research produces is valid and relevant to its users, including patients and members of the public”

BENEFITS TO PPI ADVISERS/PUBLIC CONTRIBUTORS

1. Example: MoTaSTIM-Foot study


- Sense of achievement, purpose, and increased self-confidence
- Learning from each other
- Enjoyed furthering their understanding of stroke from academics and clinicians
- Opportunity to meet others with similar interests

“Whilst the stroke had affected PB physically, it had not hampered his ability to get involved in research and to help other stroke survivors. PB benefitted from being a valued and active member of a team again, which not only gave him a reason to leave the house but restored his faith in his ability to be a useful member of society and, through his contributions, to benefit other stroke survivors.”

2. Louise and Adele’s experiences
THE UK CONTEXT

• National Institute for Health Research
  https://www.nihr.ac.uk
  (Health and care research)

• What is it like to be a member of a funding panel?

• The Developing Picture

• Summary
WHAT DOES PPI LOOK LIKE IN PRACTICE?

A diagram showing PPI activities throughout the research cycle.

Proposed and created by Louise with input from research staff and other Public Contributors.

- PPI resource
- Went viral on Twitter/X in July
- Used globally by researchers to inform practice
- @louisetingbris
WHAT IS NEEDED TO SUPPORT PPI WELL?

• Genuine and reciprocal partnership where you feel valued as much as anyone else in the room
• PPI support/line manager/point of contact
• Understanding and supporting individual needs of Public Contributors
• Good communication
• No jargon
• Training where necessary e.g. research methodology
• Meaningful evaluation
• Real impact for service users - not just academic papers
• Budget to include remuneration, travel etc
WHAT ARE THE CHALLENGES?

• Equality, Diversity and Inclusion (EDI)
• Avoiding tokenism
• Sufficient time and funding
• Organisational attitude/ culture
• Evaluation and achieving meaningful impact
EVALUATING PPI

• Participatory approach – Cube framework

• Pragmatic approach – PPI Impact Log

<table>
<thead>
<tr>
<th>Date</th>
<th>Project</th>
<th>Type of involvement</th>
<th>Who took part</th>
<th>Outcome*</th>
<th>Impact**</th>
<th>Reflections/learning</th>
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FINAL MESSAGE

• PPI is a **key part of producing quality research and reducing waste** in research

• Therefore drives better outcomes for communities, patients and the public

• However, needs **careful planning and resources**
RESOURCES

ARC West PPI guidance (article, diagram, list of useful links)

https://arc-w.nihr.ac.uk/patient-and-public-involvement/working-effectively-with-public-contributors/

@louisetingbris on Twitter/ X

Questions?
FURTHER LINKS

NIHR PPI guidance:

https://www.nihr.ac.uk/documents/ppi-patient-and-public-involvement-resources-for-applicants-to-nihr-research-programmes/23437

Sections on:
• Standards for Public Involvement
• Guidance for researchers
• Payment and recognition of Public Contributors
• Evaluation of PPI
• Assessing impact of PPI
• Reporting PPI