Developing a plan to support public and patient involvement in health and social care research

Whiston, L., Amering, M., Dick, S., Giffin, M., Kennan, A., Murphy, P., Scott, T., Walsh, J., Burke, H., Gallagher, P., MacGabhann, L., Matthews, A. and Lambert, V.

Dr. Lucy Whiston
DCU PPI Ignite Research Fellow,
School of Nursing, Psychotherapy and Community Health, DCU
Public and patient involvement (PPI)

PPI is ‘research being carried out ‘with’ or ‘by’ members of the public rather than ‘to’, ‘about’ or ‘for’ them’ (1)

Who
- Those whom the research will impact or affect

What
- Engagement X
- Participation X
- Involvement ✓
Defining research question

Research conception, design & implementation

Proofing documents, leaflets & articles

Disseminating research outcomes

Data analysis & identifying key findings

Interviewing research participants

Research project steering group

Working with funders to review applications
Context

Importance of PPI
- Growth and interest (2)
- Moral/ethical arguments
- More credible, higher quality research (2-6)
- Research and funding body support

Supporting PPI
- Multipronged (4,7)
- Co-designed for specific settings (8)
Methods

Aim
Co-design of a plan to support PPI in DCU health and social care research.

Design
- 6 dialogue groups
  - Informed by – Available literature
    - Previous DCU PPI Ignite data collection
    - EDGE Tool application
- PPI
## Methods

### Participants

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Methods

Thematic Analysis

What do you think about the draft implementation and evaluation plans for the plan for PPI in DCU?

Framework vs plan
- Purpose
  - Match DCU goals
  - Training
    - Good elements
    - Changes
  - Promotion
    - Organisational structure
  - Implementation
    - Detail
  - Evaluation
    - Inputs, metrics, impact
  - PPI within projects
  - Independent reviewers
  - Sustainability
  - Accessibility
  - Presentation
    - Illustrations
  - Detail
Key Themes

Development and feedback
- ‘It’s really nice to see it coming in to something that you could see being used in the future’ [DG03].
- ‘I think a little bit more clarity about the steps, the roles and responsibilities and some more clarity as to who is doing what, where and how’ [DG05]

Mutual understanding
- ‘What is the PPI role? What do researchers want and what can patients do? What is the point?’ [DG01]
- ‘It just needs some very basic principles in place as to what it’s all about’ [DG02].
Key Themes

Training and support
- ‘There can sometimes be a little bit of disconnection between patients and doctors … it would be very important that if there’s training it’s done all together to break down some of that paternalism’ [DGC]
- ‘Put together say a panel of 150 [patients/public]’ [DG02]

Communication and accessibility
- ‘Accessibility is a big thing and that’s obviously you’ve got the language but also physically for people so who can travel, who can’t travel’ [DG02]
Key Themes

Implementation and sustainability

- Making PPI ‘as easy as possible’ [DG01]
- ‘The continuity of PPI in DCU is going to be important because what’s happening when we sit here today and what happens in four years is a changeover and what happens then?’ [DG04]
Process

Practicalities
- Context
- Facilitation
- Location and timing
- Continuity
- Impact of PPI

Unexpected benefits

Transferability
Thank you

Questions?

www.dcu.ie/ppi  ppi@dcu.ie or lucy.Whiston@dcu.ie  @PPI_Ignite_DCU
References


References

