

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





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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 ✓



PPI is Public/patients as active partners



Defining Involved in... research question **Working with** Research funders to conception, review design & applications implementation **Disseminating Proofing** research documents, outcomes leaflets & articles Research **Data analysis** project & identifying steering key findings group **Interviewing** research participants

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

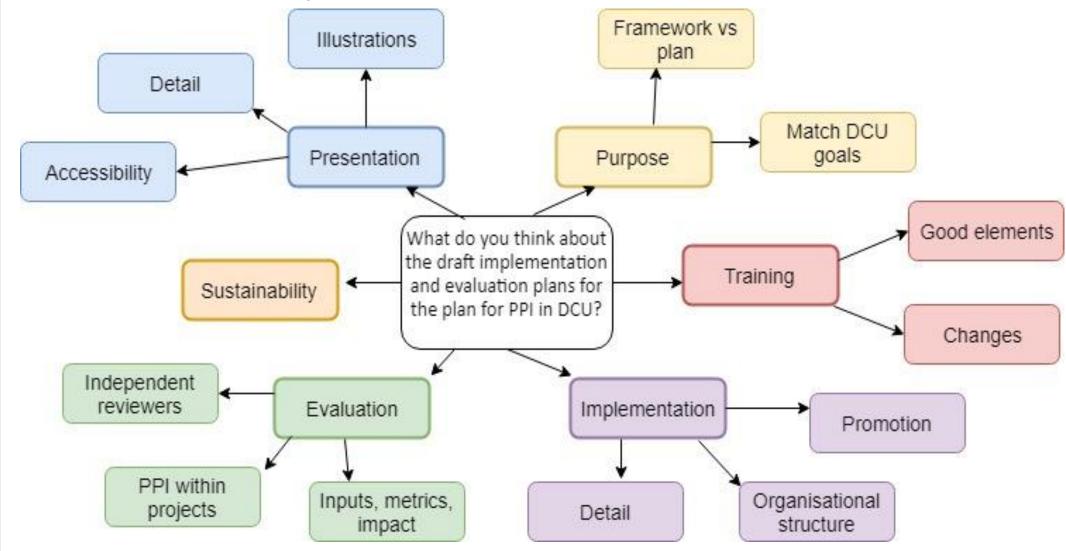
Participants

Characteristic	N= 60	100.0%
Stakeholder group ^A		
Patient/Public/Patient organisation	19	31.7
Research/Academic/Support staff	39	65.0
Clinician/Policy leader	7	11.7
Other	0	0
Missing	-	-
Age		
18-40	19	31.7
41-65	28	46.7
65+	13	21.7
Missing	-	-
Gender		
Male	19	31.7
Female	41	68.3
Missing	-	-



Methods

Thematic Analysis





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



Transferability





Questions?

















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