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How best to involve patients and the public in the implementation of evidence?

Submission date
29/02/2024

Recruitment status
No longer recruiting

Registration date
21/03/2024

Overall study status
Completed

Last Edited
08/03/2024

Condition category
Other

[ ] Prospectively registered
[ ] Protocol
[ ] Statistical analysis plan
[ ] Results
[ ] Individual participant data
[ ] Record updated in last year

Plain English summary of protocol

Background and study aims

The National Institute for Health and Social Care Research (NIHR) spends a billion pounds a year on researching what works and what doesn't work in health and social care. To ensure that this research is not wasted, we need to implement research evidence: to move from 'what we know' about a particular condition or health and social care service to 'what we do' to provide the best quality care.

Most often, clinicians are the main implementers of research evidence. The aim of this project is to explore the potential roles of patients, their families, and members of the public in using research evidence to improve the quality of care, as supporters, co-producers or leaders. It is important for patients and their families to be involved in all decisions about their care, including how research evidence is implemented.

This research has two main aims. First, the researchers want to learn more about how patients and wider communities can be involved in implementing research evidence. Second, the researchers want to partner with patients and the public to develop a toolkit to support patient and public involvement in implementing research evidence. Ultimately, it is hoped that the toolkit will enhance research implementation practices of best evidence and create better quality care for patients.

The researchers have brought together a team of experts, including patients and public contributors, who will achieve the following objectives.

1. To develop an understanding of how, why, in what context, and with what impact, patients, service users, carers and the public involvement can be involved in the process of using evidence to change practice.

2. To develop a set of ideas or theories that help explain how patients and service users can become involved in using evidence to change health and social care practice. Initially, the researchers will review the literature to find out what is already known about how patients and the public can be implementers of research evidence to develop some initial ideas. They will then interview 40-60 people who will help refine their ideas and theories.

3. To develop a toolkit with advice, information and resources to help patients, service users, carers and the public be involved in putting what we know about public involvement in implementation into practice. The researchers will hold four workshops and invite key experts to think creatively about the design of our toolkit, Pathways to Implementation for Public Engagement in Research (PIPER).

4. To test the PIPER toolkit. Patient and public contributors and collaborators will select four case studies to test PIPER. They will invite the case studies to provide feedback and suggestions to improve PIPER so it is ready to be rolled out and used by patients, service users, patient organisations and different health and social care organisations.
5. To better understand how the co-production approach with patients has worked in this project.

Who can participate?
People who have an interest in or some experience of implementation:
1. Have been involved in or are interested in public involvement activity in research or service development in health and social care at different levels
2. Ideally has some experience of public involvement in implementation or knowledge mobilisation
3. Their inclusion in the sample will add diversity of voice or perspective, either based on their characteristics, their experience or their knowledge

What does the study involve?
Participants are invited to be interviewed and will be invited to further contribute to the co-design stage.

What are the possible benefits and risks of participating?
The researchers are not aware of any risks or any specific benefits that participants may take from the process.

Where is the study run from?
1. University of Warwick (UK)
2. Lab4Living (UK)
3. Keele University (UK)

When is the study starting and how long is it expected to run for?
September 2022 to October 2025

Who is funding the study?
National Institute for Health and Care Research (UK)

Who is the main contact?
Prof. Sophie Staniszewska, Sophie.Staniszewska@warwick.ac.uk

Contact information

Type(s)
Public, Scientific, Principal investigator

Contact name
Prof Sophie Staniszewska

ORCID ID
https://orcid.org/0000-0002-7723-9074

Contact details

Warwick Research in Nursing
Warwick Medical School
Division of Health Sciences
University of Warwick
Coventry
United Kingdom
CV4 7AL
+44 (0)7814242114
sophie.staniszewska@warwick.ac.uk

Type(s)
Public, Scientific

Contact name
Dr Julia Walsh

ORCID ID
https://orcid.org/0000-0002-9787-0349

Contact details
Warwick Medical School
University of Warwick
Coventry
United Kingdom
CV4 7AL
None
Julia.walsh@warwick.ac.uk

Additional identifiers

Clinical Trials Information System (CTIS)
Nil known

ClinicalTrials.gov (NCT)
Nil known

Protocol serial number
NIHR HSDR 150711

Study information

Scientific Title
Developing a role for patients and the public in the implementation of health and social care research evidence into practice

Acronym
PIPER

Study objectives

This study will address the key gap in our knowledge and practice, by answering the overall question, ‘how best can we involve patients, carers, service users and the public in the implementation of health and social care research evidence into practice?’

The overarching aim of this study is to understand the role, contribution and impact of patients, service users, carers and the public in the implementation of evidence into practice in health and social care.

Based on the extensive experience of the investigators in realist inquiry, a realist evaluation approach will frame the study because it enables the exploration of what works, for whom, why and in what way. The framing of realist evaluation in context, mechanism and outcome configurations align theoretically with PPI and implementation (Wilson et al 2015, Brett et al 2012, 2014) and can provide ‘theoretical room’ for other approaches.

Previous studies of PPI used realist evaluation to develop rich theories for public involvement where it was especially helpful because it values the development of theory with key stakeholders (Wilson et al 2018, Rycroft-Malone et al 2015).

Ethics approval required
Ethics approval required

Ethics approval(s)
approved 20/03/2023, Biomedical and Scientific Research Ethics Committee, University of Warwick (Kirby Corner Road, Coventry, CV4 8UW, United Kingdom; No number available; BSREC@warwick.ac.uk), ref: BSREC 45/22-23

Study design
Realist literature review, realist interviews, co-design of the PIPER toolkit, and evaluation of it in three case studies

Primary study design
Observational

Study type(s)
Other

Health condition(s) or problem(s) studied
All conditions and diseases will be included

Interventions
WP1 – Literature review
WP2 – Realist interviews (40-60 participants)
WP3 – Codesign of PIPER toolkit process (20-25 participants) – led by Lab4Living, Sheffield Hallam
WP4 – Piloting of PIPER toolkit on three case studies from Keele Impact Accelerator Unit

The researchers' initial theoretical framework provides the focus for the review. Firstly, PPI in implementation may work at different levels (reflecting identified practice so far), micro (individual patient focused on their own care), meso (patient as part of service user group) and macro (patient working at strategic level e.g. national organisation). Secondly, there may be three broad types of involvement, including patient as supporter of implementation, patient as

co-producer (in collaboration with others), and patient as active agent or leader of implementation, reflecting common theorisations about the operation of PPI (Gibson et al 2012).

Participants are selected because of their likely interest in the research question. They were enrolled via email. Those who consented were invited to be interviewed (WP2) and will be invited to further contribute to the WP3 Co-design stage. Taking part in the WP2 interview does not commit them to any further participation. The co-production group was also enrolled via email and contributed to the research design, methods and findings.

Intervention Type
Other

Primary outcome(s)
The ways in which patients and the public have been involved in implementation, the roles they have adopted, and what support patients and the public require to be involved in successful implementation of evidence into practice, collected using interviews during work package 2 and 4.

Key secondary outcome(s))
As this is a realist study there are no secondary outcome measures. The researchers will develop a set of programme theories that explain what works, for whom, why and in what context.

Completion date
31/10/2025

Eligibility

Key inclusion criteria
1. Individuals across the life course 18 years and over
2. Potential interviewees include patients, service users, carers, public, implementation leads /fellows, health and social care professionals, agencies, PPI/implementation leads in agencies such as SCIE, NICE, ARC, AHSN, research commissioners/funders, health and social care managers, policy and decision-makers and patient organisations.

Participant type(s)
Healthy volunteer, Health professional, Carer, Employee, Population, Service user

Healthy volunteers allowed
No

Age group
Adult

Lower age limit
18 years

Upper age limit
110 years

Sex

All

Key exclusion criteria
Individuals under 18 years of age

Date of first enrolment
01/05/2023

Date of final enrolment
01/09/2025

Locations

Countries of recruitment
United Kingdom

England

Australia

Canada

United States of America

Study participating centre
University of Warwick Medical School
University of Warwick
Coventry
United Kingdom
CV4 7AL

Study participating centre
Lab4Living
The White Building
10 Fitzalan Square
Sheffield
United Kingdom
S1 2FH

Study participating centre
Impact Accelerator Unit
David Weatherall Building
Keele University

Keele, Newcastle
United Kingdom
ST5 5BG

Sponsor information

Organisation
University of Warwick

ROR
https://ror.org/01a77tt86

Funder(s)

Funder type
Government

Funder Name
National Institute for Health and Care Research

Alternative Name(s)
National Institute for Health Research, NIHR Research, NIHRresearch, NIHR - National Institute for Health Research, NIHR (The National Institute for Health and Care Research), NIHR

Funding Body Type
Government organisation

Funding Body Subtype
National government

Location
United Kingdom

Results and Publications

Individual participant data (IPD) sharing plan
The datasets generated during this study will be available upon request from Prof. Sophie Staniszewska (sophie.staniszewska@warwick.ac.uk) and subject to appropriate ethical approval. Interviews will be recorded (via Microsoft Teams) and the audio sent to an approved transcription service which will transcribe and anonymise the data. Consent was both required and obtained in line with Warwick BSREC & Sponsorship approvals. Interview data will be anonymised during transcription.

IPD sharing plan summary

Available on request

Study outputs

Output type	Details	Date created	Date added	Peer reviewed?	Patient-facing?
Study website	Study website	11/11/2025	11/11/2025	No	Yes