

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

Submission date 29/02/2024	Recruitment status No longer recruiting	<input type="checkbox"/> Prospectively registered <input type="checkbox"/> Protocol
Registration date 21/03/2024	Overall study status Ongoing	<input type="checkbox"/> Statistical analysis plan <input type="checkbox"/> Results
Last Edited 08/03/2024	Condition category Other	<input type="checkbox"/> Individual participant data <input type="checkbox"/> 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

Study website

<https://warwick.ac.uk/fac/sci/med/research/hscience/sssh/research/piper/>

Contact information

Type(s)

Public, Scientific, Principal Investigator

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Additional identifiers**EudraCT/CTIS number**

Nil known

IRAS number**ClinicalTrials.gov number**

Nil known

Secondary identifying numbers

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

Secondary study design

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

Study setting(s)

Home, Hospital, Laboratory, University/medical school/dental school, Other

Study type(s)

Other

Participant information sheet

Not available in web format, please use contact details to request a participant information sheet.

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 measure

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.

Secondary outcome measures

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.

Overall study start date

01/09/2022

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

Age group

Adult

Lower age limit

18 Years

Upper age limit

110 Years

Sex

Both

Target number of participants

Work package 2: 40-60 people, Work package 3: 25-35 people, Work package 4: 8-12 people in each of three case studies.

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**

Australia

Canada

England

United Kingdom

United States of America

Study participating centre

University of Warwick Medical School

University of Warwick

Coventry

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CV4 7AL

Study participating centre

Lab4Living

The White Building
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Study participating centre

Impact Accelerator Unit

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Sponsor information

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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

Publication and dissemination plan

Planned publication in high-impact peer-reviewed journals.

Intention to publish date

01/09/2025

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