NIHR Imperial Patient Safety Translational Research Centre (PSTRC)

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Patient and Public Involvement and Engagement Manager
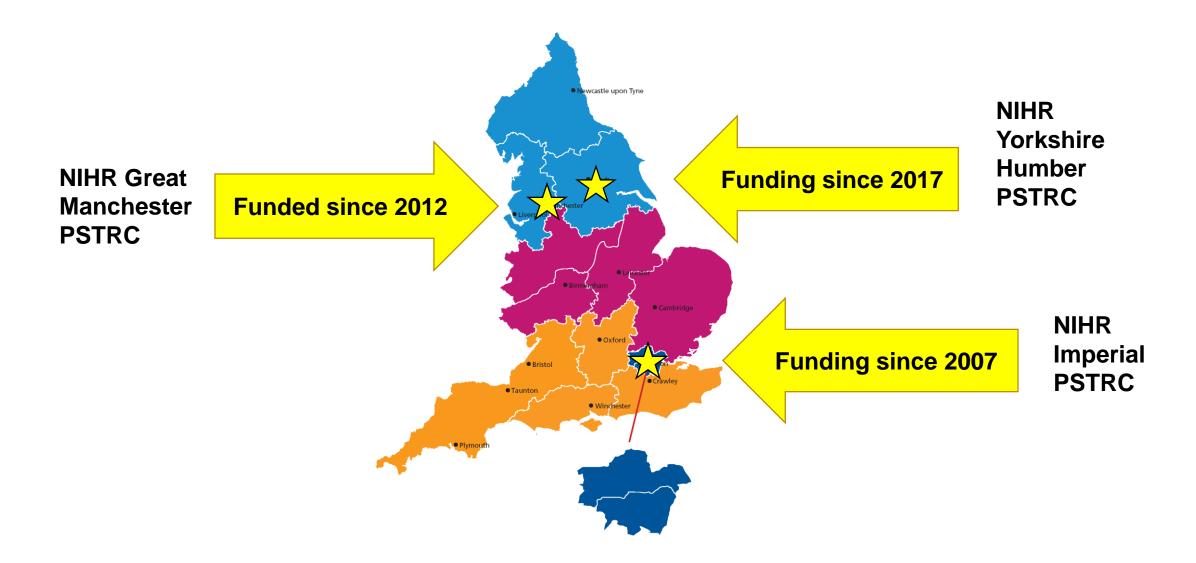
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Content

- Patient Safety Translational Research Centres

- Imperial PSTRC

- Research themes

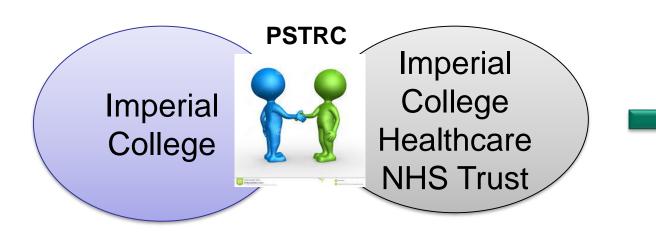- How we involve patients, carers and the public in safety research

A collaboration, working with other partners

PSTRC

Imperial College

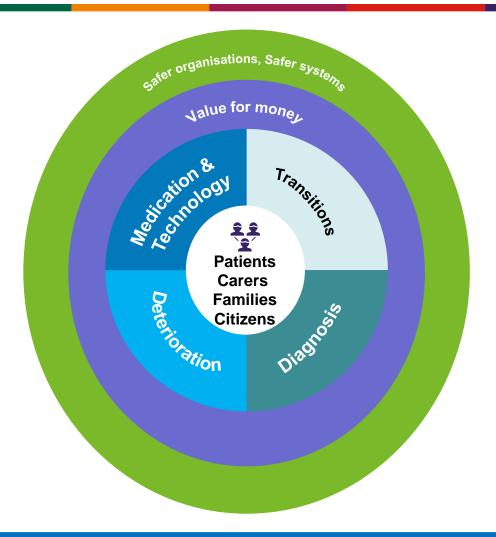Imperial College Healthcare NHS Trust

- Generate new knowledge to address gaps;

- Develop innovative approaches to safety improvement based on robust evidence;

- Pilot and evaluate new solutions as part of a cycle of continuous learning and improvement;

Example partners:

the patients association

THE BEHAVIOURAL INSIGHTS TEAM.

DeepMind

Imperial College London

We do this through 6 research themes

- Citizens at the centre
- Attention to systemic issues
- Focus on four key safety challenges

6 cross-cutting themes

1. Safer systems across the continuum of care

2. Partnering with patients for safer care

3. Avoiding deterioration and delays in the care of patients with complex needs

4. Enhancing the safety of medication and technology

5. Improving diagnostic accuracy and decision-making

6. Ensuring value for money in patient safety

Theme 1
Safer systems across the continuum of care

Key short term goals:

1. Reduce avoidable harm during the transitions of care

2. Learning from patient complaints

3. Learning from incident reporting

4. Understand the drivers of innovation diffusion in patient safety solutions

Key short term goals:

1. Empowering patients to be more engaged with their care

2. Impact of patients correcting errors in an integrated, patient-controlled medical record

3. Evaluate a digital platform for dynamic patient feedback in primary and secondary care

Project example:

• "Patient Academy" (working title) – where patients are supported through an educational programme to be more involved in their care, potentially leading to self management.

 - Patients and carers involved in co-designing the programme

Avoiding deterioration and delay in the care of patients with complex needs

Key short-term goals:

1. Evaluation of sensors in the early detection and intervention of sepsis

2. Evaluation of a digital clinical task management platform, HARK

3. Evaluate "reminders" in electronic primary care records

4. Indicators for deterioration in young adults with serious mental illness

Example project:

- The acceptability of wearables, social media and etc. to detect deteriorating mental health in young people

  - Where young people with past experience of mental health have become "co-researchers" and carried out interviews and analyse of the data.
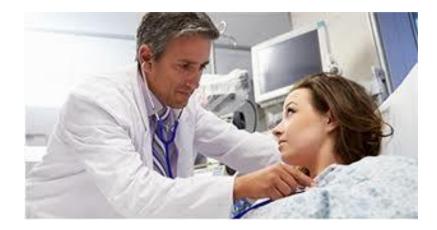
Enhancing the safety of medication and technology

Key short term goals:

1. How patients and carers record and use information about medication to support safe communication across healthcare settings

2. Understand stakeholders' needs for safer medication prescribing, storage and administration systems on hospital wards

3. Create mapping of technology-associated patient safety risks

Key short term goals:

1. Explore the use of a decision support system in primary care consultation aiming to optimise its effectiveness

2. Asses GPs' use of evidence in childhood respiratory infections

3. Explore how novel techniques can aid diagnosis

Example project

- iknife – Collecting real-time tissue diagnostics, to see if it can be effectively and safely deployed during invasive diagnostic procedures.

Short term goals:

- Conduct a systematic literature review of cost-effectiveness evidence in patient safety and on the impact of system-wide policies

- Synthesize evidence on the impact of adverse events on costs and health-related quality of life across NHS settings in England

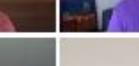Patient and public involvement and engagement
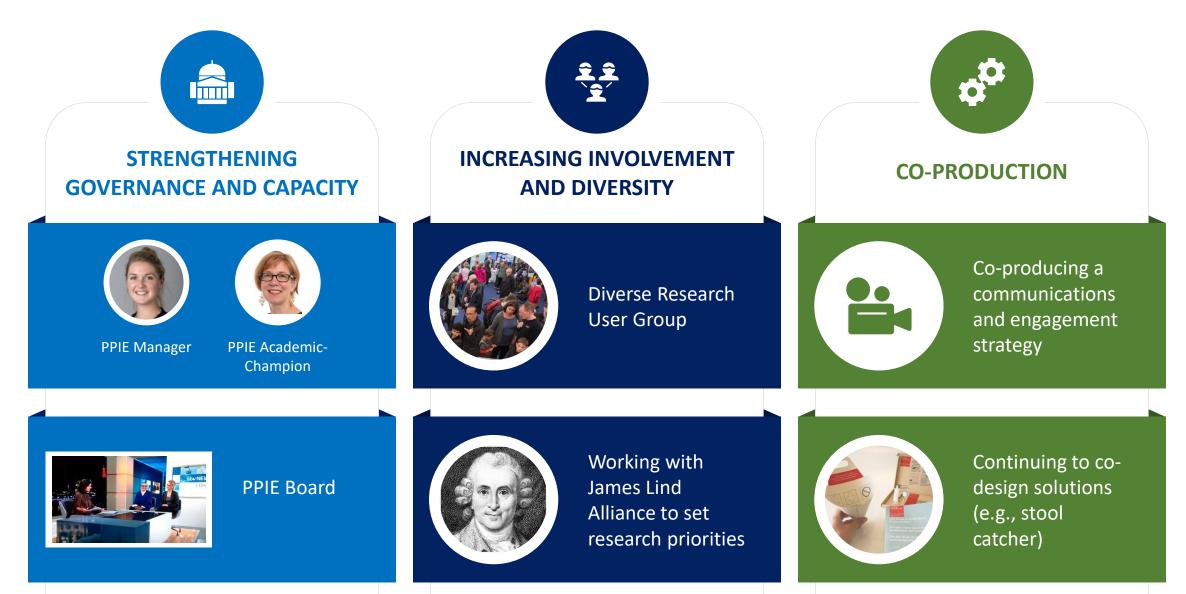
Patient and public involvement and engagement (PPIE) at PSTRC

NHS
National Institute for Health Research

STRENGTHENING GOVERNANCE AND CAPACITY

PPIE Manager

PPIE Academic-Champion

PPIE Board

INCREASING INVOLVEMENT AND DIVERSITY

Diverse Research User Group

Working with James Lind Alliance to set research priorities

CO-PRODUCTION

Co-producing a communications and engagement strategy

Continuing to co-design solutions (e.g., stool catcher)

Strengthening governance and capacity

PPIE Advisory Board

- Role: to provide governance and strategic advice in PPIE across the centre
- Meets 3 times a year reports to the PSTRC Executive Board

Learning and support

- PPIE Manager and PPIE Researcher Champion
- PPIE training for all staff
- PPIE handbook with links to resources
- Induction and development day for lay partners
- Payment policy based on INVOLVE

Increasing involvement and diversity

Research Partners Group

Diverse group of 11 patients, carers and members of the public, who:

1. Review patient involvement plans of research projects

2. Act as a link to other patient and public networks

3. Provide advice to researchers throughout the research cycle

James Lind Alliance Priority Setting Partnership

● Topic: Safe care for adults with complex health needs

● Process involving surveys and consensus workshop to agree the top 10 priorities for research

"The Research Partners Group is exciting, as we scrutinise PPIE plans in research projects, co-design how to involve seldom heard groups and find the best way to expand and evolve the RPG to make it as inclusive, representative and successful as possible." **Patient Representative**

Co-production and engagement

- A play about medical error in surgery preformed at the Bush theatre, with a safe space for discussion afterwards.

- Being innovative with how we engage with the public about controversial subjects to spark conversations between healthcare professionals and the public.

- The play written by David Alderson (ENT consultant at Torbay), using real verbatim text from patients and healthcare professionals

What to think about when you involve people

- **Be open to "critical friends."** You don't know what you don't know

- **Build trust.** Show what they will get out of the opportunity, as well as what they can contribute

- **Make patients feel like equal partners in decision making.** Set principles for interactions and manage expectations e.g. no jargon, active listening etc

- Have a good facilitator for face-to-face interactions, to ensure everyone has the opportunity to voice their opinions

- **Think inclusively.** Be mindful of the diversity of people you are involving, to be sure you hear from seldom heard voices. Think about access and barriers and how to overcome those e.g. some people may not be able to come to a meeting on a day of worship or because of child care or might have disabilities and need extra support to contribute

- **Go out to where communities will be** to reach out to them, work with trusted community leaders to understand how to engage with that particular group

- Patient/carer views can also be gathered in other ways e.g. online or through art

Patients should be central to research and healthcare

"Nothing about us without us!"

Thanks!

Anna Lawrence-Jones

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