



Public & Patient Involvement in Primary Care

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Outline

- **What is patient and public involvement in research?**
- **Why involve people**
- **The Basics**
- **NRS Primary Care Network PPI Group**
- **Sources of information and help**



What is patient and public involvement in research?

Patients as research colleagues

ACTIVE involvement: determining research questions, co-applicants, advisors on research, developing study materials, contributing to data collection, analysis, reports, dissemination

It is not about recruiting patients or interviewing them

It's not the same as public engagement



Public and Patient Involvement (PPI) in research is where our research is carried out **‘with’** or **‘by’** members of the public rather than **‘to’**, **‘about’** or **‘for’** them.

Engagement (e) is where information and knowledge about research is provided and disseminated.

These definitions are from NIHR INVOLVE. The term engagement can sometimes be used to mean involvement by other organisations.



Why involve patients and the public in research?

- **Moral duty: being inclusive, accountable, transparent**
- **It's useful:**
 - Draws on real-life experience
 - Focuses thinking on the practicalities of research
 - Brings valuable perspectives to the team
- **[Funders require you to]**
- **Members of the public can find it enjoyable**



A caveat

- Patient and public involvement is essential, useful, enjoyable
- Helps to get funding
- ❖ But:
 - It's a lot of work to do it well
 - Not a one-off event
 - There is no one right way to do it
 - Needs to be adequately costed and time devoted
 - It can be harmful if done badly



“I think we’re all agreed that it is invaluable to have input from local people with real experience of health issues.”



Primary care examples

Research Institute for Primary Care and Health Sciences, Keele University: Research User Group

- 68 people with 'illness experience', supported by a PPI coordinator and a support worker
- Chaired by a senior academic
- Contribute to Centre programmes, projects & management
- Integral, valued, supported, sustainable

<http://www.keele.ac.uk/pchs/involvingthepublic/>



Improving the quality of research: PLEASANT trial: Prevention and Lessening Exacerbations of Asthma in School-age children Associated with a New Term

- Consultation event with children/parents at design stage
- Support++ for the project - useful in the grant application
- Wording of the approach letter refined and simplified
- Timing of the intervention discussed and changed
- The children chose the logo for the project
- Parents contributed to ethics approval documentation
- Parents joined Trial Steering Committee



Clinical Trials

Impact of patient and public involvement on enrolment and retention in clinical trials: systematic review and meta-analysis

- 26 studies were included in the review; 19 were eligible for enrolment meta-analysis and five for retention meta-analysis
- The involvement of people with lived experience of the condition under study was significantly associated with improved enrolment
- The findings for retention were inconclusive
- Adds weight to the case for PPI in clinical trials

Crocker et al BMJ 2018;363:k4738



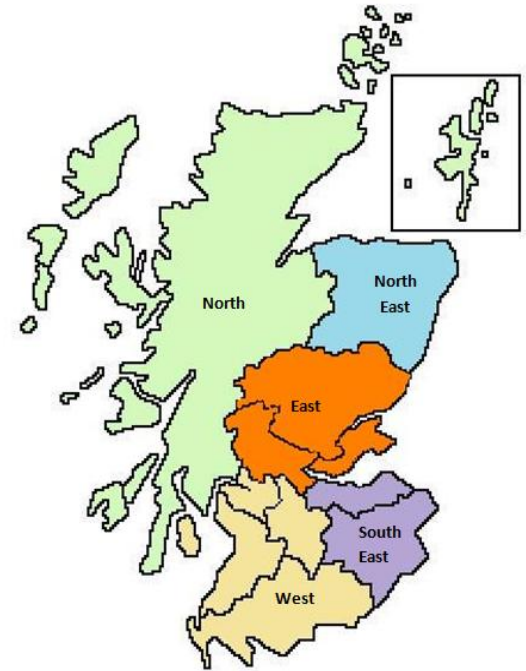
The basics

- Who do you want to involve?
- How to find people?
- What's the best method of involvement for your study?
- Negotiate roles and responsibilities
- Ensure an adequate budget



NRS Primary Care Research Network

- NRS PCN is the national primary care research network for Scotland.
- NRS PCN helps with studies that are of high quality, relevant to primary care and which appropriately reimburse professionals for their time
- NRS PCN streamlines the recruitment process for researchers by providing one access point to a Scottish-wide network of professionals who can help recruit participants into research studies



*Funded by Chief Scientist
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NRS Primary Care PPI Group

- NRS Primary Care Network PPI Group,
General Practice and Primary Care, University of Glasgow
- 12 members of the public supported by a PPI coordinator
 - Meet every three months in Mitchell Library
 - Advise and support researchers and the public to ensure that patient and public involvement is helpful and meaningful for everyone.



National Standards Freestyle Project

- Inclusiveness - We offer public involvement opportunities that are accessible and that reach people and groups according to research needs
- Working together - We work together in a way that values all contributions, and that builds and sustains mutually respectful and productive relationships
- Support and learning - We offer and promote support and learning that builds confidence and skills for public involvement in research.



National Standards Freestyle Project

- Communications - We use plain language for timely, two way and targeted communications, as part of involvement plans and activities.
- Impact - To drive improvement, we capture and share the difference that public involvement makes to research.
- Governance - We involve the public in our governance and leadership so that our decisions promote and protect the public interest.

<https://sites.google.com/nihhr.ac.uk/pi-standards/home>



MVLS PPIe Group

MVLS PPIe PPI Group, University of Glasgow

- **8 members of the public supported by a PPI coordinator**
- **Meet every two months at the University of Glasgow**
- **The role of the Group is to advise researchers and the public so that public and patient involvement is helpful and relevant to the research activities conducted within MVLS.**



Resources

- **INVOLVE**

www.invo.org.uk

- **People in Research**

www.peopleinresearch.org/home/

- **National Standards for Public Involvement**

<https://www.cso.scot.nhs.uk/patientspublic/ppistandards/>

- **National Institute for Health Research (NIHR)**

www.nihr.ac.uk/get-involved

- **NIHR Make it clear campaign**

<https://www.invo.org.uk/makeitclear/>

- **Public reviewing with the NIHR**

<https://www.invo.org.uk/resource-centre/learning-and-development/public-reviewing-with-the-national-institute-for-health-research-nihr/>



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