

Public and Community Involvement and Engagement (PCIE) Team

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Public Involvement

What

Why

How

Who

What's in a name?

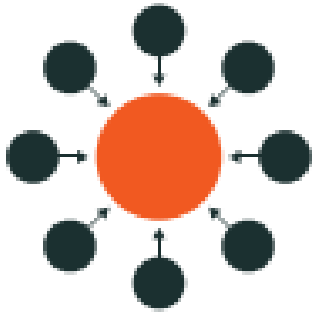
Public & Community Involvement & Engagement (PCIE)



Terminology

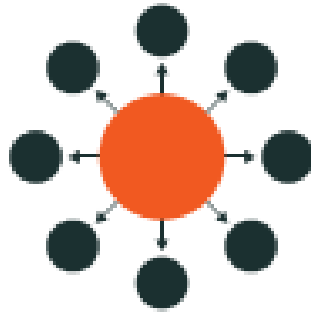


- When using the term **public** we include patients, potential patients, carers and people who use health and social care services, and people from organisations that represent people who use services or members of the public with an interest in research. This is distinct from those who have a professional role in health or social care services.
- We use the term **community** to define a social unit with commonality such as norms, religion, values, customs or identity. Communities may share a sense of place situated in a geographical area or in a virtual space through communication platforms



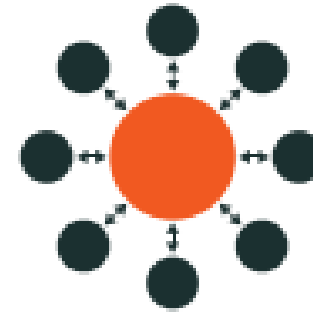
Participation

People take part in a research study.



Engagement

Information and knowledge about research is provided, and disseminated.



Involvement

Where members of the public are actively involved in research projects and in research organisations.

This discussion can help to explore, debate and shape research.
It is by definition a two- way process, involving interaction and listening, with the goal of generating mutual benefit.

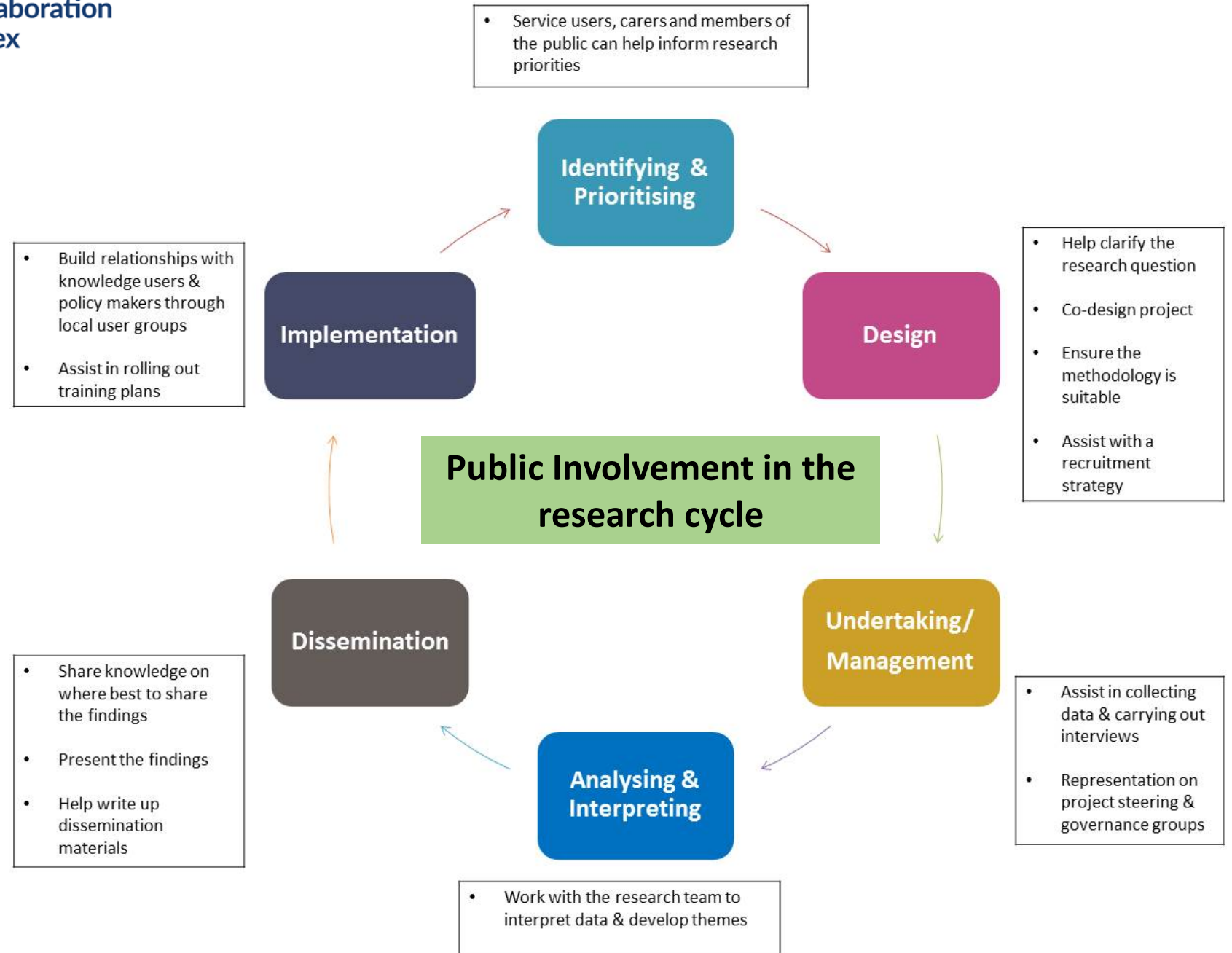
Examples include:

- Reviewing of organisation documentation
- working with research funders to prioritise research
- offering advice as members of a project steering group
- commenting on and developing research materials
- undertaking interviews with research participants

WHY

- Democratic Principal
- Providing a different perspective
- Making the research more relevant
- Improving the quality of the research
- Requirement of (NIHR) funding bodies

HOW



UK Standards for Public Involvement



WHO



**Views from a
Public
Advisor at
ARC KSS: an
interview with
Karin Webb**

Role of Public Contributors

- Requires expert knowledge and experience
- Citizenship
- Being an outsider

Budgeting



Good practice for payment and recognition:

- plan your budget in advance - do not underestimate this!
- ensure that members of the public are not financially worse off as a result of being involved in your research
- at the outset, offer clear information for members of the public explaining what they are being offered, how they will be paid, rate of payment
- be flexible with how public will be paid (consider their individual circumstances) and ensure this payment is timely
- understand your organisation's payment policy for public members, this is different for each organisation including rates of payment

Budgeting Cont.



Other forms of recognition:

- always thank members of the public for their contributions, whatever method of payment and recognition you decide upon
- keep those actively involved updated about the progress of your research, including feedback on how their contributions have made a difference
- offer appropriate learning and development opportunities to support the contributions made by members of the public, with certificates to record what learning may have been achieved or sessions attended
- acknowledge the contribution of members of the public to your research in internal and external reports, publications, posters and presentations
- offer information about other opportunities or involvement and /or participation in research
- celebrate successes with those who have contributed to the research

<https://www.invo.org.uk/resource-centre/payment-and-recognition-for-public-involvement/involvement-cost-calculator/>

- **Why** is feedback important?
- **What** sort of feedback is required?
- **When** should you give feedback?
- **How** should you give it?





IMPACT

- of involvement activities have on research processes and outcomes
- of involvement on participating members of the public and researchers
- of involvement on addressing power imbalances between the researcher and the researched
- what else...?

Methods of assessing impact:

- Qualitative
- Quantitative
- Tools e.g. GRIPP Checklist (Guidance for Reporting Involvement of Patients and Public)
PiiAF (Patient Involvement Impact Assessment Framework),

Problems with assessing the Impact of Public Involvement...

Defining co-production

Co-producing a research project is an approach in which researchers, practitioners and the public work together, sharing power and responsibility from the start to the end of the project, including the generation of knowledge. (INVOLVE, 2018, p.4)

Key questions

- Can you be flexible enough?
- Can you commit the time to build relationships?
- Are there clear benefits for everyone?



Who can help?



- your network/colleagues/previous connections?
- PCIE Team at ARC KSS, including our Public Advisors and Public Contributors
- Public Involvement and Engagement networks with your own organisations or others locally
- financial support from your own organisations
- NIHR website
- other NIHR/research organisations in the region
- contact your regional RDS to find out if you are eligible to apply for their public involvement fund

Resources:



- PCIE Strategy - Available on The Hub
- INVOLVE Report: A Practical Guide to Being Inclusive in Public Involvement in Health Research - lessons from the Reaching Out programme. Katherine Cowan, February 2020 - https://www.invo.org.uk/wp-content/uploads/2020/03/INVOLVE_RO_report_FINAL_180220.pdf
- A Rough Guide to Public Involvement. Produced by the NIHR Imperial BRC Patient Experience Research Centre (PERC) - <https://www.imperial.ac.uk/media/imperial-college/medicine/sph/ide/perc/PERCs-Rough-Guide-to-Public-Involvement---Jan-2020.pdf>
- A Researcher's Guide to Patient and Public Involvement. Oxford University - <https://oxfordbrc.nihr.ac.uk/ppi/a-researchers-guide-to-patient-and-public-involvement/>
- Patient & Public Involvement. A researcher's guide. arthritisresearchuk.org - <https://www.versusarthritis.org/media/1376/patient-and-public-involvement-guidance.pdf>
- Payment guidance for researchers and professionals NIHR April 2020 <https://www.nihr.ac.uk/documents/payment-guidance-for-researchers-and-professionals/27392>
- Online costs calculator. NIHR Involve <https://www.invo.org.uk/resource-centre/payment-and-recognition-for-public-involvement/involvement-cost-calculator/>
- Guidance for Researchers: Feedback. CRIPACC, University of Hertfordshire; 2018. http://www.clahrc-ee.nihr.ac.uk/wp-content/uploads/2016/05/Guidance-for-Researchers-PPI-Feedback_2018.pdf.
- Staniszewska, S., Brett, J., Simera, I. *et al.* GRIPP2 reporting checklists: tools to improve reporting of patient and public involvement in research. *Res Involv Engagem* 3, 13 (2017). <https://doi.org/10.1186/s40900-017-0062-2>
- <http://www.piaf.org.uk/>