



Patient and public involvement in research in the UK: Getting it right?



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Aims

- Put forward a case for success
- Identify flaws and where we can improve

I will argue that....

- Patient and public involvement in research is firmly embedded in the commissioning of research
- Patient and public involvement in research is firmly embedded in organisations undertaking research
- The direction of travel is deeper patient and public involvement

What do we mean by public involvement?

Involvement - research being carried out **'with'** or **'by'** members of the public rather than **'to'**, **'about'** or **'for'** them

Participation – where people take part in a research study

(INVOLVE 2012)

Patient and public involvement is firmly embedded in research commissioning organisations...

“How you’ve involved patients, carers and the public will be assessed when your research application is reviewed by our prioritisation and funding committees. In addition, the Health Research Authority will review how you’ve involved and engaged with members of the public when it assesses your research for ethics approval.”

UK Standards for Public Involvement

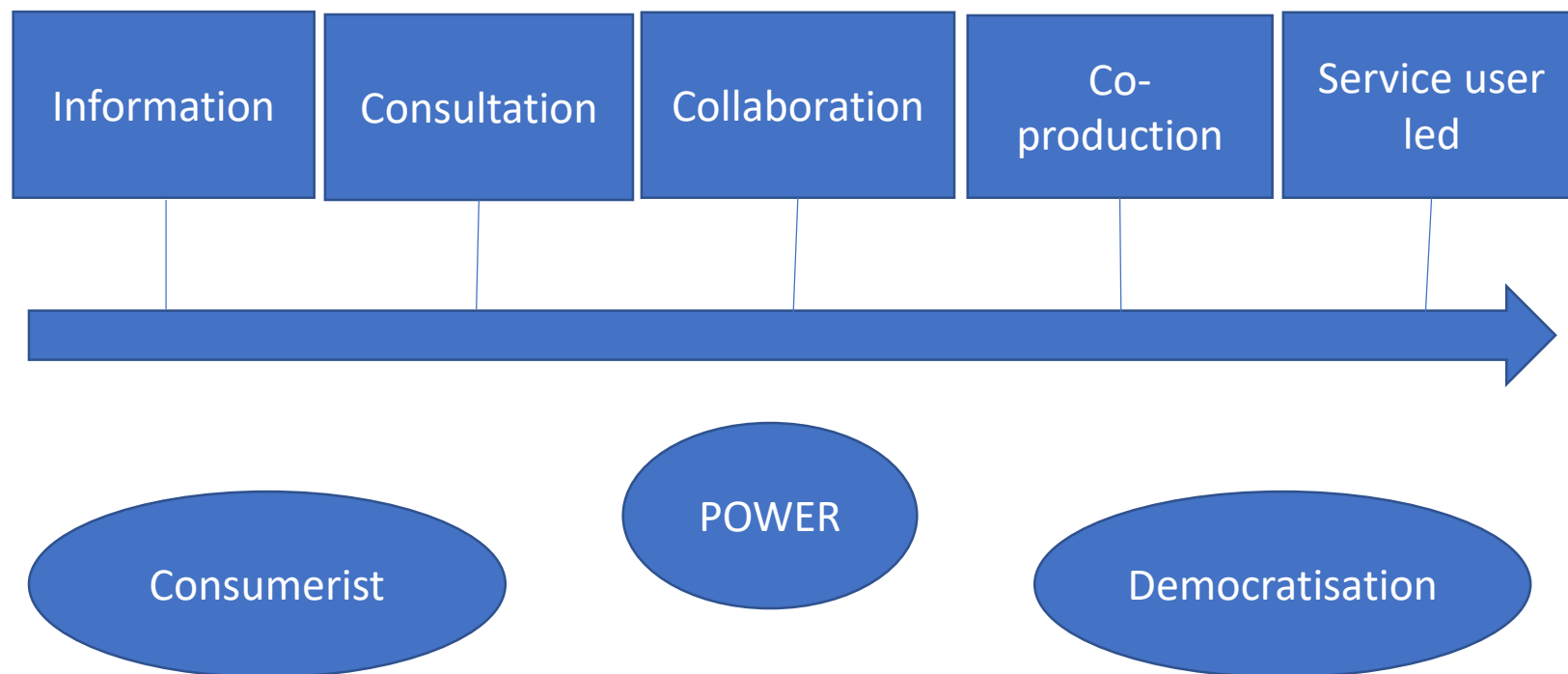


- <https://www.invo.org.uk/wp-content/uploads/2019/11/UK-standards-for-public-involvement-v6.pdf>

Patient and public involvement is firmly embedded in research organisations

- Often have a patient and public reference group
- Policies and processes for paying patients and public
- Researchers are aware of and receive training on patient and public involvement
- Advice available

Hickey's power continuum 2020 ... towards democratisation



In conclusion...

- Patient and public involvement is firmly embedded in our research processes and culture
- No meaningful patient and public involvement no funding
- Moving towards a democratisation of research

Patient and public involvement in research is firmly embedded in the commissioning of research

All very well but

- how do we know that what is intended has actually taken place?
- where are the processes and structures for demonstrating that involvement has taken place?
- where is the accountability if things don't happen as planned?

Patient and public involvement in research is firmly embedded in organisations undertaking research

But is it?

- Approaches to involvement vary and lead to different interpretations
- Amalgamation of terms such as ‘involvement’, ‘engagement’, ‘participation’ muddies the waters
- Pockets of great practice v absence of any involvement or worse – involvement done badly
- Strategic and organisational embedding of involvement is not widespread

The direction of travel is deeper patient and public involvement

Do recent events with Covid-19 tell us differently?

- When resources are stretched and time is short, involvement is often the first thing to disappear
- When decisions have to be made quickly it's easier not to involve the voice of lived experience
- In a time of massive worldwide uncertainty and threats to our mental and physical health, lack of involvement can have devastating effects

In conclusion:

- We have come a very long way but there is still much work to be done
- There needs to be cultural and systemic change
- A universal buy-in and commitment to working in partnership involves giving up and devolvement of power

Links

- PPI Resources

- https://www.nihr.ac.uk/documents/ppi-patient-and-public-involvement-resources-for-applicants-to-nihr-research-programmes/23437#Evaluating_public_involvement_in_research
- [Standards](#)
- [Briefing notes for Researchers](#)
- [Co-Production](#)
- [Payment and recognition](#)
- [Evaluating](#)
- [Assessing](#)
- [Reporting](#)

- Different experiences: A framework for considering who might be involved in research

- https://www.invo.org.uk/wp-content/uploads/2020/03/Different_experiences_FINAL_edit.pdf

- Plain English Summaries

- <https://www.invo.org.uk/resource-centre/plain-english-summaries/>

- Co-Applicants Guidance

- <https://www.invo.org.uk/posttypepublication/public-co-applicants-in-research-guidance-on-roles-and-responsibilities/>