

Working collaboratively with the public in research

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On behalf of People and Research South West



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bettertogether

Key questions

- Why involve the public in research?
- What national support is available?
- What is the local background to involvement in research?
- What more is needed locally to support involvement in research?
- How is People and Research South West planning to help meet those needs?

Why involve the public in research?

“I have always taken the view that public involvement in research should be the rule not the exception... ‘Involvement’ means an active partnership between researchers and the public in the research process, rather than using people as the ‘subjects’ of research.”

Professor Dame Sally Davies, Director General of Research & Development in Staley (2009)

Evidence of benefits

- Research design
 - o Help reshape research questions
 - o Change the focus of research
 - o Influence what outcomes are measured
- Impact on wider community
 - o Create trust and acceptance of research
 - o Keep projects grounded and focused on benefits for community
 - o Improve relationships between communities and professionals (Staley, 2009)

What national support is available?

- INVOLVE (www.invo.org.uk)
 - Guidance and resources on involvement for researchers and the public
 - National policy development, e.g. with Department for Work & Pensions addressing benefit system barriers to involvement
 - Developing the evidence base, e.g. Staley (2009) review on impact
 - invoNET library of references

What is the local background to involvement in research?

- Bristol Research and Innovation Group for Health (BRIG-H)
- Scoping Study (Davies and Evans, 2010)
 - Good practice by some research groups
 - Few institution-wide approaches
 - Variety of practice
 - Little training available
 - Few opportunities to share or learn good practice

People and Research South West

- New local collaborative initiative to support public involvement in research
- Aims to support
 - members of the public to get involved in research
 - researchers to develop, share and implement good practice in involving the public
- Adding value to existing good practice within partner institutions locally and INVOLVE nationally – not duplicating

Work Programme

- Networking events
- Shared policies and procedures
- Database of good practice
- Training programme
- Induction and mentoring for public
- Web-based signposting to user groups
- Facilitate collaborative bids

Impact of public involvement: local examples

- Patient research partners in arthritis research
- Benefits identified:
- Research related to priorities & clinical need
- Appropriate outcomes, relevant to patients
- Projects include patient perspective and interpretation
- Better recruitment and dissemination
- Better use of resources (relevant issues)

The patients' experience is a valuable resource which should be utilised

Practicalities of involving patients - FIRST steps

- F** -**f**acilitate - early inclusion, enable contribution
- I** -**i**dentify - projects, patients, roles
- R** -**r**espect - views, abilities, confidentiality
- S** -**s**upport - communication, working
- T** -**t**rain - e.g. research methods, ethics, evidence

Hewlett, S, De Witt, M, Richards,P, Quest, E, Hughes, R, Heiberg, T, Kirwan, J.
(2006) Patients & Professionals as research partners: Benefits, challenges, practicalities.
Arthritis & Rheumatism (Arthritis Care & Research) 55: 676-680.

Presenters at our recent launch event

- John Kirwan, Pam Richards and Gerd Jenny Aanerud – *Involving patients as research partners – an example from Rheumatology*
- Mary Nettle – *The value of the patient perspective in research*
- Kathy Pollard and Laure-Ann Donskoy – *Public involvement in research: developing guidelines for good practice*
- David Evans and Angela Stagg - *Involving the public as peer researchers; a National Cancer Action team evaluation.*
- Simon Evans and Christine Donald – *Working with older people as community researchers: learning from the Gloucestershire Partnerships for Older People Project*
- Rachel Gooberman-Hill and Lynden O'Neill - *PEP-R group (Patient Experience Partnership in Research group)*
- Rosie Davies – Helping to develop a study intervention (the CONTACT study)

For more information

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- References

- Staley, K. (2009) *Exploring Impact: Public Involvement in NHS, Public Health and Social Care Research* Eastleigh: INVOLVE. www.invo.org.uk
- Davies, R & Evans, D. (2010) *Public Involvement in Research: How Can Organisations Collaborate to Improve Involvement*. Bristol: UWE Bristol <http://hls.uwe.ac.uk/suci/research.aspx>