WHAT CAN WE LEARN FROM HEALTH?

Claire Ballinger and Mark Stafford-Watson

21.05.15

Aims for session:

- To offer a successful model of public engagement in a health research organisation (NIHR CLAHRC Wessex)
- To provide an opportunity for participants to share and learn together
- To identify issues in attributing and measuring impact of public engagement, and to describe one proposal
- To discuss suggestions for moving the 'public engagement' agenda forward within the University of Southampton

A note on terminology:

INVOLVE and CLAHRC Wessex use the following terms to distinguish between different activities:
Involvement – where members of the public are actively involved in research projects and in research organisations (eg as joint grant holders or co-applicants on a research project; identifying research priorities; as members of a project advisory or steering group; commenting on and developing patient information leaflets or other research materials; undertaking interviews with research participants).

Participation – where people take part in a research study (eg people being recruited to a clinical trial; completing a questionnaire or participating in a focus group as part of a research study).

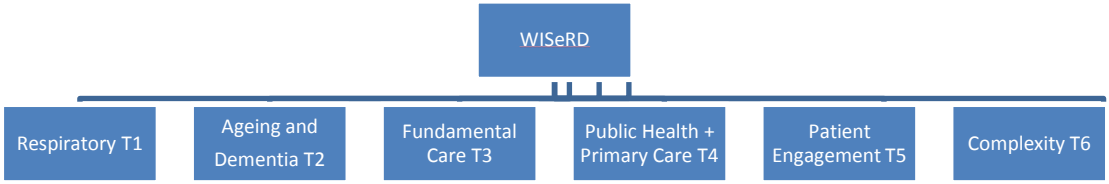
Engagement – where information and knowledge about research is provided and disseminated (eg science festivals open to the public with debates and discussions on research; open day at a research centre where members of the public are invited to find out about research; raising awareness of research through media such as television programmes, newspapers and social media; dissemination to research participants, colleagues or members of the public on the findings of a study).

PLAN FOR SESSION

WHAT	WHO	TIME
Introductions: MSW, CB and group	MSW	11.40
Aims for session, Question for consideration, Terminology, Intro to CLAHRC Wessex Why involve/engage patients and members of the public in health research?	CB	11.45
Why I became involved as a public contributor in health research	MSW	11.55
How do we find public contributors for health research? CLAHRC Wessex exemplar	MSW	12.05
How we plan public involvement in CLAHRC Wessex: the WISeRD group	CB	12.15
Impact of public involvement Visibility and personal impact of PPI	CB: Academic perspective MSW: as public contributor	12.30
Discussion and feedback	ALL	12.40
CLOSE and lunch		12.50

PPI STRUCTURE IN CLAHRC WESSEX

- CLAHRC Wessex PPI lead, CB
- **W**essex **I**nclusion in **S**ervice **R**esearch and **D**esign (WISeRD) group, co-chaired by CB and MS-W (public contributor)
- Public contributors offered £20 per hour (as per INVOLVE guidance) either from central PPI budget or Theme budget
- WISeRD represented on Board, Scientific Forum and Management Group



PPI theme champion PPI staff link	PPI theme champion PPI staff link	PPI theme champion PPI staff link	PPI theme champion PPI staff link	PPI theme champion PPI staff link	PPI theme champion PPI staff link

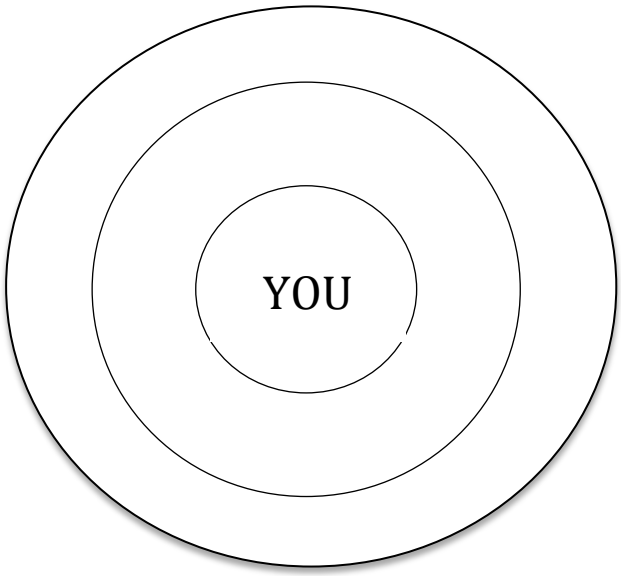
IMPACT OF PUBLIC INVOLVEMENT

Online survey DRAFT:

NPT CONSTRUCT	QUESTIONS
COHERENCE (sense making)	1. How did you start thinking about PPI within your theme? 2. What prior experience of PPI do you bring to your work with the CLAHRC? 3. What, if anything, is different in the way that CLAHRC Wessex are doing PPI, as compared with your previous/usual research experience?
COGNITIVE PARTICIPATION (buy-in, engagement)	4. How do people you work with in your theme respond to PPI? 5. Which people organise PPI within the theme and how do they do this? 6. How do the PPI theme champions influence the research and implementation carried out in the theme?
COLLECTIVE ACTION (doing the work)	7. What do you do in your PPI role within the CLAHRC theme? 8. How does PPI impact on the process of doing research and implementation in the theme (both positively and negatively)? 9. How does the wider CLAHRC influence the PPI work in the theme?
REFLEXIVE MONITORING (measuring the effects)	10. How can you tell if it is working or not? 11. Where would we look for evidence of PPI in the theme's work? 12. What do you personally feel has changed because of PPI? 13. What needs altering to make it more successful?
	14. Is there anything else you would like to share about PPI within your theme or within CLAHRC Wessex?

Social network mapping

Which *PEOPLE* and *RESOURCES* do you work with to carry out PPI within your theme, how *MPORTANT* to you are they, and how *OFTEN* do you access them?



RESOURCES FOR PATIENT AND PUBLIC INVOLVEMENT
Claire Ballinger 21.05.15

WEBSITES:

www.invo.org.uk/
www.publicinvolvement.org.uk
www.peopleinresearch.org
www.northwestpeopleinresearchforum.org
http://www.twocanassociates.co.uk
http://www.clahrc-wessex.nihr.ac.uk/

See also NIHR CLAHRCs and NIHR Research Design Services

BOOKS:

Cartwright J & Crowe S (2011) Patient and Public Involvement Toolkit BMJ Books Wiley-Blackwell: Chichester

Barnes M and Cotterell P (eds) (2012) Critical Perspectives on User Involvement Policy Press: Bristol

HEALTH JOURNALS:

Health Expectations
Research Involvement and Engagement (new)
Patient Education and Counseling
Social Science and Medicine
Health Policy
International Journal of Consumer Studies

TWITTER AND BLOGS:

@anyadei (The Patient Patient)
@DavidGilbert43
@GeorgeJulian
@allyc375
@jonathanboote
@SDenegri
@sally_crowe
@NIHRINVOLVE
http://kristinastaley.com/

REPORTS:

http://www.nihr.ac.uk/get-involved/Extra%20Mile2.pdf Outcome of UK 'Breaking Boundaries' review

MEASURING IMPACT:

http://www.piiaf.org.uk/ Public Involvement Impact Assessment Framework

Brett et al (2014) A systematic review of the impact of patient and public involvement on service users, researchers and communities. *Patient* 7(4):387-95.