Patient and public involvement in health research – what difference is it making?

PIER Group Meeting, 11th June 2019, Belfast.

Simon Denegri, NIHR National Director for Patients, Carers and the Public, United Kingdom
From protest......

Subject

noun noun: subject;
plural noun: subjects

1. a person or thing that is being discussed, described, or dealt with.
…..to partnership and collaboration.

Partner
noun: partner

…..public involvement in research is research being carried out ‘with’ or ‘by’ members of the public rather than ‘to’, ‘about’ or ‘for’ them.
INVOLVE’s re-working of Arnstein’s ladder...

итs all about including the patient, carer and public ‘voice’ in research
The world of research works better with patients, carers and the public involved
NIHR’s approach to public involvement 2006-2019

• Core part of NIHR vision, mission and objectives for doing the best research
• Essential to helping us define future research agenda and priorities
• Integrated throughout our funding, infrastructure and activities
• Clear expectation set with researchers and institutions in application process
• Aim to provide funding and help to support involvement
• Increasing focus on understanding and demonstrating impact

“I have always taken the view that public involvement in research should be the rule not the exception.” Professor Dame Sally Davies, Chief Medical Officer (CMO)
INVOLVE

Est.1996. Funded by, and part of the National Institute for Health Research (NIHR) since 2006.

National Leadership Areas
- Diversity & Inclusion
- Learning & Development
- Community, partnership, networks (Co-production, Intl PPI network)
- Standards (with NIHR CCF)

Resources, Tools & Guidance
- National enquiry service
- People in Research: matchmaking
- Briefing notes for researchers/resources
- Benefits advice service
@NIHRINVOLVE, www.invo.org.uk
NIHR ‘Going the Extra Mile’ 2015 -2025
A population actively involved in research to improve health and wellbeing for themselves, their family and neighbours.

Objectives:
• Improving access to NHS research
• Increasing the diversity of our community
• Developing public involvement standards
• Supporting learning and development
• Enabling regional and local collaboration
• Impact = reach, relevance, refinement, relationships
• Emphasising co-production and new methods
• Maintaining our global reputation
Defining what good looks like – UK public involvement (PPI) standards

NATIONAL STANDARDS for PUBLIC INVOLVEMENT

Standard 1: INCLUSIVE OPPORTUNITIES
We offer public involvement opportunities that are accessible and that reach people and groups according to research needs.

Standard 2: WORKING TOGETHER
We work together in a way that values all contributions, and that builds and sustains mutually respectful and productive relationships.

Standard 3: SUPPORT & LEARNING
We offer and promote support and learning that builds confidence and skills for public involvement in research.

Standard 4: COMMUNICATIONS
We use plain language for timely, two-way and targeted communications, as part of involvement plans and activities.

Standard 5: IMPACT
To drive improvement, we capture and share the difference that public involvement makes to research.

Standard 6: GOVERNANCE
We involve the public in our governance and leadership so that our decisions promote and protect the public interest.

The standards are:
• a description of what good public involvement in research looks like
• designed to encourage self-reflection and learning, including where lessons have been learned when public involvement has failed to lead to expected outcomes
• a tool to help people and organisations identify what they are doing well, and what needs improving
• intended to be used with any method or approach to public involvement in research
• adaptable to your own situation and can be used alongside other resources such as case studies, public involvement checklists, and toolkits.

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Public involvement - making it happen

**Leadership**
- Policy
- Professional
- Patient

**Infrastructure**
- Training
- Tools
- Awareness

**Practice**
- Demonstration
- Measurement
- Coordination
Making it happen – leadership, infrastructure
Our community

What’s it like being involved in NIHR research?* National Survey 2019

• We have a strong, supportive and highly motivated public involvement community
• Vast majority feel they make a difference and that their contribution is valued
• People form their view about research and the NIHR based upon their ‘local’ relationship
• They are partnership builders fulfilling a range of roles for us and other bodies
• Diversity remains a significant issue for us – age, ethnicity etc.
• There is considerable variety and inconsistency in practice ‘Sometimes, but...’
• Communications, feedback and acknowledgement areas for clear improvement

*Full survey results expected to be published May 2019 (n=809)
Experience - Worked with other organisations (N=575)

Key points:
- Our public contributors are involved in many other organisations and have an important role in the future in building partnerships and collaborations.
- Social care and industry are key areas where we need to support the development of involvement.
Key Points:

- People are playing a number of roles within their part of the NIHR.
- But based on comments these may not all be accurate descriptions of their activities. For example: when people ticked the 'co-applicant' and/or 'co-author' boxes, their comments were generally about involvement in reviewing research applications or final reports.

"these categories need greater definition in accessible language for me to understand and answer fully (maybe with some examples)" [Comment from a respondent]
Institutional commitment

• UCLH Biomedical Research Centre (BRC)
• £111M from NIHR over 5 years
• Public involvement strategy and plan a
• Pre-requisite for funding
  ✓ Public involvement as a cross-cutting theme
  ✓ Dedicated PPI team and budget
  ✓ Community panels for each theme i.e. dementia
  ✓ Strong focus on researcher training and support
  ✓ Increasing emphasis on community outreach
  ✓ Strategic partnerships – In2Science, Yale
Careers, training, learning and development

NIHR Academy
• NIHR Infrastructure Doctoral Training Camp
• ≃ 80 early career researchers / 3 days
Includes PPI workshops, PPI surgery sessions, advice and guidance from public advisors, scrutiny from public panel member

“My key learning point from today is ... PPI. I am a lab based researcher and have never heard about PPI before; though I was not very convinced about PPI, by the end of the course I definitely was!

NIHR Trainee

Thank you to the public and patient advisor for useful feedback. Meeting constructive and comments incorporated into our plan.

NIHR Trainees

A really useful meeting which has helped us really think about how we explain complex ideas in our study design. Good to meet the panel.

NIHR Trainees
Making it happen – practice
Research relevance - informing research priorities

James Lind Alliance Priority Setting Partnerships (PSPs) established 2006

80+ completed PSPs - including alcohol-related liver disease, womb cancer and autism

29 + active: Type 2 Diabetes, Emergency Medicine, Young People, Heart Surgery, Mental Health

Canada, Netherlands, Germany, Australia
Research relevance – visual impairment

• Sight Loss and Vision PSP – published May 2013
• Fight for Sight: over £11,000,000 awarded to over 180 projects
• NIHR: £2,000,000 for three clinical trial addressing priorities in cataract, glaucoma and keratoconus
• Macular Society: £700,000 grants for 12 projects
• 2 NIHR horizon scanning reports for new and emerging treatments (corneal disorders and inherited retinal diseases)
• Multi-charity partnership formed to address the top priority in AMD
• www.sightlosspsp.org.uk
Involvement across the research pathway

Moss N, Daru J, Lanz D, Thangaratinam S, Khan KS. Involving pregnant women, mothers and members of the public to improve the quality of women’s health research. BJOG 2016; DOI: 10.1111/1471-0528.14419.

“The unique mobile hearing van will allow us to take our research out to families, and this should mean more of them will be able to participate in this much needed study.”
- Professor Kevin Myers, Emeritus Professor of Audiology

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Involvement to improve people’s access to NHS research
‘Every willing patient a research patient’

83% of the public say that health research is very important.

But 32% do not think research opportunities are offered in their local hospital and almost half do not know

Top 3 research priorities for the UK – cancer (68%), dementia (58%), genetic diseases (32%).

Patient Research Ambassadors

What is a Patient Research Ambassador?

A Patient Research Ambassador is someone who promotes health research from a patient point of view. They could be a patient, service user, carer or lay person who is enthusiastic about health research and is willing to communicate that to other patients, the public, as well as other healthcare professionals.

Why do we need Patient Research Ambassadors?

We would like to involve both patients and NHS researchers to recognise the importance of research in delivering health care. As a Patient Research Ambassador you can help to ensure that people using local NHS care have the best opportunities and choices about taking part in research studies.

Many of us are already Patient Research Ambassadors
Public involvement input has ensured:

- Clarity of purpose
- Mission focus
- Better design: ‘service’ v ‘research’
- ‘Political’ support
- Awareness
- Partnership
Join Dementia Research in numbers

- 916 trained researchers using the service
- 253 NHS, University & commercial sites have used the system
- 102 studies open to recruitment
- 29% of volunteers have participated in a study
- 80,779 volunteers screened for studies
- 40,286 total volunteers
- 371 studies have recruited
- 12,881 participants enrolled in studies to date

These statistics are accurate as of 31 March 2019
Improving access, increasing opportunities

Before JDR I knew how to find a study to participate in.

JDR has made it easier to get into a study.

https://www.stepupfordementiaresearch.org.au/
‘The aim of patient and public involvement is to improve the quality, feasibility and translational value of research...[This] is the first time we can see that patient involvement is linked to higher likelihood of reaching recruitment target – and as a result, study success.’

Professor Til Wykes, Director, MHRN ‘Patient involvement in research boosts success,’
Measuring the impact of PPI
NIHR IMPACT: improving the health and wealth of the nation through research

Interrelated drivers for understanding our impact:

- Evidencing patient and public benefit
- Justifying research investment
- Demonstrating a difference from research
- Understanding the part we play in the wider health research ecosystem - coproduction and the impact of our policies/approaches e.g. Athena SWAN, PPIE, social networks, digital
- REF2021 – broadening and deepening the definition of impact
Where does PPI fit?

- Develop and agree a definition of public involvement impact – akin to the overarching ambition for PPI in the NIHR Value Framework? (aligned with GtEM & NIHR Strategy)
- NIHR public contributors feedback exercise – will give us a sense of how far we are from achieving our ambition
- Facilitate a ‘Community Conversation’ on impact – sharing best practice and stimulating the community to pull together in the same direction.
- NIHR ‘microsite’ to share – creating systems to identify, collate and curate examples of impact
- UK standards for public involvement & PPI routine data – understanding what we have already got, how we can use data to greater effect and highlight what where the gaps are to direct future work.
- Case studies/ stories: Develop a framework for refreshing and reporting case studies tailored to the interests of specific audiences
- Opportunities to share the load – nationally/internationally.
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Measurement and evaluation

Reach

Relevance

Refinement

Relationships, partnerships, collaboration
“Yes ‘I feel that it has been appreciated by the teams that I work for, but I haven't had direct contact with NIHR to know what they think.’”

“I think it is valued but it is not always clear that it is or why.”

“Sometimes researchers have given the impression that they are involving the public because they have to 'tick the box'.”

[Comments from respondents]
Do you think you are making a difference?

Qu 11. Do you think your involvement made a difference (N=607)

- Yes (69%)
- No (3%)
- Sometimes (15%)
- Don't know (13%)

“Yes but can only tell when you get feedback which I have mostly but not always had….

Quite often the feedback is that it was very useful but then there is little or no indication after the event of anything happening as a result. … it may just be a task too many but lack of feedback makes it difficult to know whether my involvement is useful”

[Comment from a respondent]
What difference you would like your involvement to make (N=519)

**Final outcome:** result in tangible changes to the health care system – improved services and better treatments for patients

**By:**
- influencing the research itself – inclusion of patient voices - improving the quality and relevance of the research
- supporting research participants in clinical trials or studies – better understanding of and access to taking part in research.
- working with researchers – acknowledging the benefits of involving patients in their work
- producing information about research for the public - providing accessible/ easy to read articles / presentations
Creating a culture of learning – feedback, the missed opportunity

NIHR Survey
• 45% of respondents (n=607) said that they did not, sometimes did or didn’t know if they had received feedback on their contribution
• 51% said (n=608) they had never, only sometimes or did not know if they’d been asked for feedback on the contribution they had made

NIHR CLAHRC East of England

• Acknowledgement only versus opportunity for learning.
  “[I] can only tell [if I have made a difference] when you get feedback which I have mostly but not always had….Quite often the feedback is that it was very useful but then there is little or no indication after the event of anything happening as a result. … it may just be a task too many but lack of feedback makes it difficult to know whether my involvement is useful”
What does the future hold?
Our changing relationship with the public

Past and present
- Involvement, engagement and participation
- The individual
- Clinical research, clinical trials, clinical studies
- Process
- Centrally controlled and driven
- Partnership
- The committee room
- Patients, carers, the public
- National focus
- NIHR and ‘the few’

The future
- Co-production, co-creation
- Mobilisation
- The community
- Public health, social care research
- Outcomes
- Citizen driven, Grassroots
- Collaboration
- Digital, tech, AI, social media
- Consumers
- Global movement – thinking ‘globally acting locally’
- Charities and industry
@albert_mceyeson with the Action Youth Boxing Intervention young people and Charlotte Woodhead (@ucl_dahr @UCL_IEHC) taking it out of the park with their speech! Winners of the @UCLEngage Public Engagement Community award for their work.

#uclCoPro pilot #CoProduction
‘Reaching Out’ to diverse communities

- Pilot programme launched by INVOLVE and the Research Design Service (RDS) in 2018
- Aim is to encourage the development of new public involvement and engagement relationships
- Emphasis is on parts of the community who are not usually, or consistently, involved in health, social care and public health research
- Four pilots – RDS South Central, RDS North East, RDS Yorks & Humberside, RDS Eastern Region
The future will be about empathy and coding
Partners in shaping research

2017/18 Milestones:
• More than 700,000 people in clinical studies
• Public involved in the design and delivery of 100% NIHR research
• Over 80% of contributors feel their involvement has made a difference to NIHR research
• UK ‘PPI’ Standards launched at the AMRC/ABPI ‘Patients First’ event in March 2018
• Guidance produced on co-production, diversity and inclusion
• Pilot service launched for industry partners to involve patients
• New international PPI network set-up and active programme of Community Engagement and Involvement in NIHR Global Health Initiative
A few references


• Reviewing progress in public involvement in NIHR research: developing and implementing a new vision for the future, Staniszewska et al, BMJ Open, April 2018, https://bmjopen.bmj.com/content/bmjopen/8/7/e017124.full.pdf


• Well-led Research in NHS Trusts, NHS R&D Forum Briefing: https://spark.adobe.com/page/msDL652NBVBM0/

• UCLH BRC website: https://www.uclh.nhs.uk/Research/BRC/Pages/Home.aspx

• UCL Centre for Co-Production in Health Research: https://blogs.ucl.ac.uk/public-engagement/2018/03/12/ucl-centre-for-co-production-in-health-research-the-adventure-begins/

• Follow #WhyWeDoResearch on Twitter
Thank you

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