

## Breaking boundaries: thinking differently about public involvement in research

### Theme 1: Overall evaluation of progress to date

(300 word limit)

We invite you to look back. What difference, if any, has public involvement made to:

- You?
- If applicable, your organisation?
- Research?

Use the following questions to help shape your response:

- Did anything change and if so, how, and with what result?
- Was the difference what you predicted or did it surprise you?
- Can you give examples of favourable factors or difficulties you want others to be aware of?
- What stands out for you from your experience so far?

### Difference public involvement makes to INVOLVE

The INVOLVE Advisory Group is made up of approximately 30 members and includes researchers, practitioners, representatives of voluntary organisations and members of the public (e.g. service users, patients, carers). INVOLVE current and past members are key in contributing to and influencing the direction of the INVOLVE Coordinating Centre and the NIHR.

The INVOLVE Group:

- identify and highlight issues of importance to the NIHR;
- act as critical friends to inform the thinking and direction of travel of INVOLVE;
- champion the value of public involvement in research and the work of INVOLVE; and
- input into the activities of INVOLVE, advising on projects undertaken by the Coordinating Centre.

### Impact of INVOLVE and public involvement in the NIHR

Over the last 5-10 years there has been a significant shift in recognition of the impact that the public (patients, carers, service users) can and do make to research across the NIHR. The research culture has started to shift away from querying the need for involvement towards greater understanding and appreciation of the value of involvement.

Specific impacts of INVOLVE and public involvement include:

- **embedding public involvement within NIHR structures**  
For example: Biomedical Research Centres and Units (BRC/BRU), Central Research Facilities (CRF) Research Design Services (RDS) and Collaborations for Leadership in Applied Health Research and Care (CLAHRCs) are all asked about their plans for public involvement both in their initial applications and annual reports.
- **changes to the NIHR requirements for funded studies and Faculty awards**  
For example: inclusion of questions on public involvement as part of the Standard Application Form for NIHR funding; NIHR Senior Investigators and Trainee applicants are required to provide information on their public involvement activity.

- **increasing numbers of people being funded to support public involvement**  
For example we have recently identified approximately 200 people that have a public involvement lead roles across CRFs, BRCs and BRUs, Academic Health Science Networks (AHSNs), CLAHRCs, Research Design Services (RDS), Research Programmes and Clinical Research Network (CRN).
- **growing body of evidence highlighting the extent and value of public involvement in research**  
See Appendix (in separate attachment) for a selection of recent references illustrating the extent and impact of public involvement.  
  
In a recent INVOLVE / HRA repeat survey of applicants to the National Research Ethics Service we found an increase from 29% in 2010 to 40% in 2012 of applicants who reported plans to actively involve the public in their research (non commercial studies). Amongst the NIHR funded studies in the sample there was an increase from 67% to 78%. There was also an increased reporting of involvement in research funded by medical charities.
- **international recognition**  
The model of INVOLVE and public involvement in NIHR research activity in England are increasingly acclaimed internationally.

## Theme 2: What stops public involvement? (300 word limit)

We know from research evidence that there are factors that prevent or limit effective practice.

- What needs to be 'unblocked' to improve public involvement in NIHR?
- Can we learn anything from other sectors and disciplines?
- Can you give examples where difficulties have been resolved?

How would you complete this sentence?

*I wish that....*

### What needs to be 'unblocked' to improve public involvement in NIHR

- Resources are not widely available to support involvement either prior to research funding or for infrastructure within organisations (in addition to funding for involvement attached to specific research projects).
- At a strategic level within the NIHR, public involvement is still often an afterthought rather than an integral part of core business.
- Currently there is a persistent reinventing of wheels - duplicity of guidance and support for public involvement rather than the use and development of existing resources.
- Public involvement leads who are new to public involvement are often not aware of the body of knowledge, purpose and approaches to involvement that already exists within the NIHR.
- Routine data collected by research commissioning programmes about involvement

activities in funded studies and centres as well as within their own internal processes could be usefully collated and made publicly available. This would provide greater understanding of the extent and nature of involvement as well as raise awareness of the growth of and development of involvement throughout the NIHR.

### **Theme 3: Doing public involvement differently** (300 word limit)

We invite you to look forward. Taking into account the responses you have made to the preceding questions, what could be done differently?

- What should be stopped?
- What could be grown and developed?
- Are there likely opportunities in the next 2 years to set a different direction?
- How can we ensure greater diversity and equality?

#### **What should be stopped?**

It is difficult to specify what should be stopped other than the issue of duplication referred to in section 2. It is important to sustain the gains made in public involvement and learn lessons from the continuous changes to arrangements for supporting involvement in the NHS service delivery sector which have led to confusion and loss of impetus.

#### **What should be grown / developed?**

- INVOLVE needs to continue to adopt a more active leadership / strategic role within the NIHR with further development of coordination across the NIHR
- Whilst it makes sense to maintain expertise and information about what works centrally, we should explore how best to facilitate support and training at regional and local level.
- Recognition of the importance of social care alongside health research

#### **Increasing diversity**

- need for greater support for user led and alternative approaches to involvement
- provide greater opportunities for public to contribute to identifying research topics, research priority setting and dissemination, with a broader focus on involving and partnering with a wider range of people and groups - for example linking with community and education networks, service delivery organisations and others.

**Theme 4: How do we do it? The future design and delivery of public involvement in NIHR**  
(300 word limit)

Building on your responses so far, can you say:-

- Who needs to be involved in design and delivery?
- Are there specific approaches that should be used to turn ideas into effective and embedded practice?
- What would you need to see demonstrated to know that public involvement was happening differently in NIHR?

**Engagement / involvement / participation**

- Involvement, engagement and participation are all important activities within the NIHR. Involvement needs to continue to have a distinct remit that overlaps and complements the functions of the other activities.
- The present push towards greater linking of involvement activities to engagement and participation comes with risks as well as benefits. There is the risk that public involvement work will become diluted and it could result in involvement taking a back seat to engagement creating confusion over the boundaries and nature of the three activities.
- Others have taken a lead on engagement work. There would be merit in establishing partnership working with these organisations thus reducing duplication of functions.

**Language**

- INVOLVE has continued to use the term public involvement as a way of:
  - avoiding the move towards the use of acronyms (e.g. PPI, PCPIE, PPIE)
  - providing an inclusive term that can be used to cover public health and social care as well as health research

**Learning and development**

- The recommendations from the NIHR wide learning and development working group that are currently being drafted include the recommendation for there to be a post located centrally (within the INVOLVE Coordinating Centre) to facilitate and encourage learning and development for public involvement across the NIHR
- Need for induction for people new to public involvement roles

**Theme 5: Where should we be with public involvement in NIHR in ten years?**

(300 word limit)

How ambitious should we be?

- What can we achieve in the next 10 years?
- What would public involvement look like?
- Who would be involved?
- What would be happening?

In 10 years time:

- public involvement should be part of NIHR's core business.
- There should be 'no need to ask' **whether** the public are involved in NIHR funded studies - the public should routinely be part of the research team and integral to research planning and delivery.
- We should no longer be needing to seek evidence to argue the value and contribution of public involvement but instead will have moved to an evidence base that informs our practice.
- Public involvement will continue to be a requirement of funding and be routinely monitored, audited and reported.
- INVOLVE Coordinating Centre or an equivalent central programme will continue to exist in recognition that the value of public involvement can be quickly lost without a continual presence.
- Increased public involvement and partnership working between INVOLVE and other sectors regionally, nationally and internationally.

**Question 1: What question(s) didn't we ask that you would have liked us to ask and what would your answer(s) be?**

(150 word limit)

**Question 2: Is there anything else you would like to tell us?**

(150 word limit)

**INVOLVE Coordinating Centre**

England is unique in having a centrally funded Coordinating Centre to support public involvement since 1997. This has provided consistency and continuity and has enabled us to push for acceptance of the value of public involvement across NIHR funded research. There are now far greater numbers of people involving and getting involved in health and social care research. As a result the remit and scope of INVOLVE Coordinating Centre has changed and expanded in the last 5 years beyond what was originally specified within our existing contract (2011-2016) which expected us to focus on generating and sharing knowledge and providing advice and support to researchers, public involvement leads, research funders and the public.

Over the past 5 years we have also taken a greater lead role in developing strategic collaborations to assist in coordinating, facilitating and influencing public involvement across the NIHR. As well as facilitating shared learning groups for the CLAHRCs, Research Programmes and Research Design Services, we have also acted to ensure greater consistency across the NIHR. For example, the establishment of a time limited NIHR wide group for learning and development, an NIHR wide strategy group on public involvement and an event planned to bring together public involvement leads from across the NIHR (over 100 people attending). Recent specific areas of work include obtaining consensus on guidance for plain English summaries, developing principles and standards for involvement, contributing to the development of the Health Research Authority Strategy for public involvement and developing payment support and guidance.

We have embraced and developed this broader strategic remit in addition to our current contract. However, the INVOLVE Coordinating Centre is a small unit with limited resources and leverage (budget of £740,000 per annum and a team of 9 wte). Moving forward, to effectively deliver these multiple roles there will need to be a greater recognition of these functions from the Department of Health and the NIHR as well as the resourcing to sustain and develop this work.

**About you**

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**What is the main perspective you bring to the review?**

Please choose one of the following:

- ☐ Public e.g. service user / patient / consumer / carer
- ☐ User researcher
- ☐ Voluntary sector
- ☐ Researcher / academic
- ☐ Other research role (e.g. research manager, commissioner)
- ☐ Clinician / practitioner / service provider or manager
- ☐ Public involvement lead / specialist
- ☒ Other

**Confidentiality**

A list of contributors and submitted evidence may be made publically available.

Excerpts may also be included in publications arising from the review. Please notify us at the time of submission if you do not wish your name or evidence to be published. If you are submitting evidence on behalf of an organisation please provide the details of a named contact.

**Thank you for your time and contribution**