

## **Report of Public Involvement Leads' Meeting**

**Tuesday, 22nd July 2014**

**The King's Fund, London.**

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### **1. Introduction**

On 22<sup>nd</sup> July 2014 INVOLVE hosted a meeting for public involvement leads from across the National Institute for Health Research (NIHR) and Academic Health Science Networks (AHSNs). The aim of the meeting was to bring together staff in public involvement posts in key research organisations to:

- Hear and discuss the initial findings of the NIHR 'Breaking Boundaries' review of public involvement in research.
- Facilitate shared learning and mutual support for public involvement leads.
- Facilitate regional networking and collaboration.

Around 100 public involvement leads from across the NIHR attended the meeting, which took place at the King's Fund in central London. A list of those attending is attached as Appendix A. This was the first time that public involvement leads from across the NIHR and AHSNs had come together like this.

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### **2. Welcome from Simon Denegri, chair of INVOLVE and NIHR National Director for Public Participation and Engagement in Research**

Simon Denegri welcomed everyone and outlined the themes for the meeting:

- Leadership
- Collaboration

- Networking
- Shared learning and support
- Cohesion, consistency and continuity.

He emphasised that we all have a responsibility for leadership in relation to public involvement in the NIHR, to working together to achieve a 'one NIHR' approach to public involvement as exemplified in the new NIHR website. One sign of NIHR's maturity is the increasing emphasis on improving consistency and continuity, he said. He quoted Henry Ford: *'Coming together is a beginning, staying together is progress, and working together is success'* and suggested that we need to develop models of involvement that are easy to drive for patients, carers and member of the public.



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### 3. Acronyms busting

Everyone took part in an exercise looking at NIHR acronyms. Participants sitting at each table were given a list of acronyms which stood for a range of organisations that are part of the NIHR 'family' or partner organisations. Everyone was asked to say what each acronym stood for and what role the organisation plays in the research process. A list of the organisations discussed and their acronyms is included as Appendix B.

We talked about the fact that many of us feel that we should know what all the different organisations do, but realise that this isn't always the case. For example, some of us struggle to differentiate between the roles of CLAHRCs and AHSNs. If those of us who work within the NIHR and AHSNs are struggling, what must it be like for patients and members of the public who get involved with us?

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### 4. Breaking Boundaries: Initial findings

During the next session, Simon gave an introduction to the 'Breaking Boundaries' review, and he and Rachel Matthews (North West London Collaboration for Leadership in Applied Health Research and Care), who has been supporting the review, gave an update on progress to date.

## **About the review**

In March 2014, the NIHR announced a strategic review of public involvement in health, social care and public health research called 'Breaking Boundaries: thinking differently about public involvement in research'. The review is examining future options for building an active collaboration with the public and making best use of their skills, knowledge and experience in the work of the NIHR. It is expected to define a vision and set clear goals for the next ten years. The review is being steered by a panel of service users, researchers, clinicians and staff from across the NIHR and the wider research community, and is chaired by Simon Denegri.

As part of the review, NIHR invited views and comments on how it can build on its achievements in public involvement so far to create the sort of active collaboration between the public, researchers and clinicians essential to the delivery of its future ambitions for research and a healthier nation. The review asked questions on 5 broad themes:

1. Overall evaluation of progress to date.
2. What stops public involvement?
3. Doing public involvement differently.
4. How do we do it? Future design and delivery of public involvement in NIHR.
5. Where should we be with public involvement in NIHR in 10 years?

## **Who responded?**

The deadline for providing views and opinions in response to the review's initial call was the end of June 2014. Just over 500 responses were received from individuals. They described themselves as follows:

- Public, service user, patient: 41%
- Researcher: 24%
- Public involvement lead or specialist: 12%.

There were also about 80 written submissions and documents. The majority of these were from organisations, including patient groups, charities, NIHR organisations, universities, NHS Trusts and regulators.

In addition, the review panel took part in four regional events and did presentations as part of other activities, including to the UK Clinical Research Collaboration (UKCRC) Board, the NIHR Advisory Board and the NIHR Strategy Board. Panel members also held evidence sessions with international public involvement colleagues, charities and the pharmaceutical industry, and a workshop with about eight medical research charities.

The final content and profile of the responses to the review will be published as part of the final Breaking Boundaries report.

## About the responses

Rachel and Simon outlined some of the themes that have emerged so far in their analysis of the responses received. These included:

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

- Progress has been made but not consistently across the NIHR
- Research is becoming more relevant to patients and carers
- There is greater potential for implementation of research evidence
- There is evidence of the transformative nature of public involvement, both personally and professionally.

### Theme 2: What stops public involvement?

- **Attitudes** - scepticism, mistrust, lack of awareness, communication and curiosity.
- **Resources** – time, money, infrastructure to meet increased demand, inconsistent reward and reimbursement policies, procedures and practices across NIHR, NHS, Higher Education and voluntary sector.
- **Training and support** – inconsistent opportunities.
- **Confusing and inconsistent** – expectations from different parts of NIHR, combined with variable performance and limited evidence of effective practice and impact.
- **Leadership** – we need more leaders to promote and practice public involvement.

### Theme 3: Doing public involvement differently

- **Practice** – there needs to be more critical practice, including more publications on 'how' and the introduction of standards.
- **Promotion** – we need better promotion of effective involvement and more outreach.
- We should **learn** from other sectors and disciplines.
- Studies and programmes should only be funded if there is confidence about the **standard** of public involvement.
- Public involvement should be **inclusive** and more reflective of wider society.

### Theme 4: How do we do it? Future design and delivery of public involvement in NIHR

- We need to coordinate and collaborate, and we need better strategic development.
- We should create better models of collaboration between lay people and researchers.

- We need to develop a strategic and systematic approach to the collection of evidence across NIHR.

### **Theme 5: Where should we be with public involvement in NIHR in 10 years?**

- Public involvement will be normal and accepted practice.
- There will be an enhanced evidence base with better consensus on the value of public involvement.
- We will have agreed methods and indicators of impact.
- There will be greater public awareness of research and the NIHR.
- NIHR will demonstrate global leadership in scholarship and the study of public involvement in research.

People who responded to the review suggested that we could learn from other organisations, especially:

- The third sector
- The private sector – e.g. through the use of ‘club cards’
- Urban planning and citizen science
- Sense about Science and Ben Goldacre
- Education, especially the school governor model
- The technology and digital sector.

## **5. Breaking Boundaries: questions, comments and next steps**

Rachel and Simon were joined by other Breaking Boundaries panel members Tina Coldham, Sophie Staniszewska and Philippa Yeeles. Everyone talked at their tables and listed their questions and comments about the review and the presentation from Simon and Rachel.



Each table identified one question or comment to raise with the Breaking Boundaries panel members. These are listed below. All other questions and comments are listed in Appendix C.

- It will be important to ensure the work and report speaks to members of the public as well – how will it do this?
- Will the responses be made public?
- Who will see the evidence and how will you enable it to be used by others?
- Will there be guidance and agreement on how to evaluate or log activities for involvement across different organisations?
- How are the panel using initial findings to influence politicians?
- How does the Clinical Research Network (CRN) transition sit in terms of the Breaking Boundaries review? – will the review include lessons learnt from the transition?
- How has the panel engaged with seldom heard communities, e.g. BME and traveller groups?
- Do we want to do something different where we want to get an NIHR system that has greater diversity?
- Has there been discussion on how we monitor impact and demonstrate added value?
- We have just developed a PPI strategy. If the Breaking Boundaries review says something different do we have to start again?
- Does INVOLVE have plans for finance and training to be a central function where others might refer people to?
- How does feedback from patient and the public differ?
- How can we be ambitious and raise the bar? – Balance between rhetoric and reality.
- How can we encourage long term career development for PPI advisors? We have no time to do our own research.
- How prescriptive will the outputs of the review be? How practical? Will it be a resource that can be used?
- How can we best maintain even what we have achieved so far? It feels perilous and depends on dedicated individuals.
- Will we get a workable NIHR PPI strategy out of this?
- Where will findings have the most impact for change? How will you tackle the urgent areas?

Panel members made some initial responses to these questions and comments at the meeting, and will consider them further along with all of the other questions and comments raised, as part of their continued deliberations.

Rachel explained that she and the panel were continuing to analyse responses to the review and would be testing ideas through meetings and tweet chats. The review panel remains on schedule to publish in late October, a month before the INVOLVE conference in Birmingham on 26th/27th November.



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## 6. Meeting others within the NIHR and AHSNs and identifying good/interesting practice

After lunch, we used coloured shapes to enable people to meet and talk with someone they didn't already know. Each person found a partner, then introduced themselves, explained which organisation they worked for and talked very briefly about one thing related to public involvement they are working on at the moment. We did this three times and then some people were nominated by someone that they met to tell everyone in the room about what they were working on.

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## 7. What issues could we tackle by working across organisational boundaries? How could these issues be addressed?

We spent most of the afternoon looking at some of the issues that could be addressed by working together across organisational boundaries. Before the meeting, everyone who was planning to attend was asked about what issues they felt were important. As a result seven questions were identified for discussion.

What could we do together to:

1. ...improve the sharing of good/innovative practice in public involvement across research organisations?

2. ...improve the consistency of our approach to public involvement?
3. ...improve the reporting of public involvement in research?
4. ...improve the diversity of people getting involved in research?
5. ...better publicise public involvement and how to get involved?
6. ...develop learning and support opportunities for public involvement leads?
7. ...improve collaboration in public involvement at a regional level?

A further two questions were identified and included on the day.

What could we do together to:

8. ...use social media to involve people effectively?
9. ...involve people in the implementation of research findings?

People chose which question they would like to work on and formed groups. Each group began by considering the key issues within this question and identifying one priority that should be taken forward to begin to address the question. The groups then worked on an action plan to address the priorities identified. The action plans addressed the following questions:

- What's the aim?
- Who needs to be involved?
- What do they need to do?
- Who else needs to be involved from within NIHR?
- Who else needs to be involved externally?
- Next steps.

A summary of each of the action plans is given below.

**Question 1: What could we do together to improve the sharing of good / innovative practice in public involvement across research organisations?**

***Priority action identified: Use the NIHR hub to improve the sharing of good / innovative practice in public involvement across research organisations.***

Currently core documents, such as annual reports, are not shared. This means that there is a danger of duplication and of re-inventing the wheel. Public involvement has a financial cost and we need to work as efficiently as possible. The group looking at this question suggested:

- The establishment of a public involvement group on the NIHR hub, which all public involvement leads should be encouraged to use.
- Agreement to share the public involvement sections of all annual reports prepared by NIHR organisations – so that organisations such as the Central Commissioning Facility could then upload these for sharing.

- Monitoring of how much sharing is going on, and encouragement to share more.

**Question 2: What could we do together to improve the consistency of our approach to public involvement?**

***Priority action identified: Set up national and local forums.***

The group working on this issue suggested that a forum could be established to work on a number of tasks - e.g. a forum could be established to look at the issue of paying people who get involved. Each forum should:

- Clarify the task and issue being addressed
- Scope the issue
- Identify gaps
- Involve members of the public in this process
- Agree a timeframe.

The aim would be to create agreement locally, regionally and/or nationally about an issue and the actions to take to address it. This could be taken forward by any group of individuals who have a shared interest or issue they wish to address.

**Question 3: What could we do together to improve the reporting of public involvement in research?**

***Priority action identified: Develop and agree a common framework for reporting public involvement across the NIHR and related agencies.***

The group working on this question agreed that the status of public involvement activity would be increased if the reporting of such activity were to be mandatory. Group members agreed it would be helpful to:

- Establish who has responsibility for the metrics of reporting public involvement.
- Map key areas of public involvement activity.
- Identify key elements of what needs to be captured – this should not be the detail of the activities undertaken, but should capture formal and informal involvement.
- Develop consensus across the NIHR on what needs reporting.
- Develop an agreed system which should be implemented across the NIHR.
- Be clear about how data will feed back into system.
- Ensure there is action and system adjustment as a result.

The group agreed that it would be important to involve external stakeholders (e.g. the Association of Medical Research Charities, the Medical Research Council, National Voices and other charities) in this process.

#### **Question 4: What could we do together to improve the diversity of people getting involved in research?**

Two priority actions were identified for this topic:

***1<sup>st</sup> priority action identified: Implement a charter for public involvement in research, which includes a standard about diversity and inclusion.***

The group that looked at this priority recognised that INVOLVE has been working to develop a framework or charter for public involvement in research. Group members wanted to ensure that all NIHR organisations would sign up to this charter, which will include a standard about diversity and inclusion. They hoped that organisations would want to do this rather than it becoming a requirement.

The first steps towards this goal would be dissemination of the charter and encouragement to organisations to sign up to it. There would also need to be a central resource which could offer support to organisations wishing to sign up. A tool would need to be developed to assess whether organisations that sign up to the charter are meeting the required standards. Meeting the standard about diversity would require a top down commitment to and culture of involvement.

It would be helpful to work in partnership with third sector organisations to develop a common charter or standard relating to diversity.

***2<sup>nd</sup> priority action identified: Learn from other fields about how community engagement and involvement with diverse groups can be effectively implemented.***

The group that focused on this action recognised that there is often a lack of diversity amongst the people who currently get actively involved in research supported by the NIHR – many are older, white and middle class. They agreed that it would be helpful to build a publicly accessible repository of case studies that examine different ways to engage and involve a range of people, to encourage those working across the NIHR to broaden the range of people who they involve. The case studies should include models from a range of sectors, e.g. the ‘researcher in residence’ scheme in schools. The group hoped that these case studies could be included on the INVOLVE website.

The group also stressed the importance of personal responsibility – we all need to take practical steps to ensure we involve a diverse range of people in research.

#### **Question 5: What could we do together to better publicise public involvement and how to get involved?**

***Key action identified: Create a national campaign to raise awareness of public involvement in research.***

How easy is it for people to get actively involved in NIHR research at present? Do people know it’s possible to get involved? The group that looked at this topic advocated the need for a national campaign to raise the profile of public involvement

in research and dispel some myths about research. The campaign should include case studies and examples to illustrate how people have become involved and the impact they have had.

This campaign would need to be developed by public involvement leads working in partnership with patient advocacy groups, charities, industry, INVOLVE and the Department of Health Communications team. It should be targeted at both members of the public and researchers.



**Question 6: What could we do together to develop learning and support opportunities for public involvement leads?**

***Key action identified: Address the learning and support needs of public involvement leads.***

The group looking at this question wanted to determine standards to enable the development and delivery of world class training for those working in public involvement. They recognised that public involvement leads have different training and support needs at different stages in their careers, and that they are located across England. They propose to:

- Establish a working group of individuals with relevant experience, i.e. general public involvement experience, people who are new to involvement and those who are already delivering training.
- Identify gaps in learning and support provision.
- Work with public involvement leads to set priorities and determine how to develop a toolkit.

The UK Clinical Research Facility Network PPI workstream has agreed to lead this work and will involve others as appropriate.

**Question 7: What could we do together to improve collaboration in public involvement at a local level?**

***Key action identified: Establish a regional strategic leadership group.***

Two groups looked at how to take forward this action. Their plans have been combined in this summary.

The groups proposed the establishment of a working group in a particular region (to be identified) to:

- Build an understanding of what each partner organisation is doing with regard to public involvement
- Share experience and learn from each other
- Address common strategic issues
- Help meet the individual aims of the partner organisations.

The working group should consist of public involvement leads and members of the public. The group would need a reporting mechanism that feeds back to partner organisations and ensures this information is disseminated within these organisations.

This work could start in any region where people want to work together. The important thing would be to get people to work together in teams across organisations, with all organisations taking responsibility for involvement. This could reduce duplication but more importantly could ensure that resources for involvement are used more effectively.

**Question 8: What could we do together to use social media to involve people effectively?**

***Key action identified: Draw together guidelines for use of social media to involve people in research.***

The group looking at this question suggested that public involvement leads across the NIHR need to develop a shared approach to the use of social media to involve people in research. They proposed developing some guidance which could help public involvement leads and others to:

- Understand the benefits and potential pitfalls of social media
- Think strategically around public involvement in social media
- Think creatively about reaching out to people who currently aren't involved
- Ensure people who don't use social media are not excluded.

First steps could be to start a conversation about social media using the NIHR hub, and then to set up a virtual working group to begin to develop some guidance.

## Question 9: What could we do together to involve people in the implementation of research findings?

**Key action identified: Define what we mean by implementation, and involve the public and not just paid public involvement leads.**

The group that looked at this question advocated involving the public at the planning stage, before any application for funding have been written, in order to ensure that there is effective public involvement in the implementation of research findings.

There are many different definitions of implementation, so a shared definition would be important if action on this is to be taken collectively.

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## 8. Review of the meeting

Simon concluded the meeting by thanking the organisers, presenters and especially everyone who came along.

All participants were asked to complete an evaluation form at the end of the meeting. 38 forms were completed. Most people were enthusiastic about the meeting, with 36 respondents saying they **found the meeting very useful or fairly useful**, and only two respondents saying it was not very useful. 36 respondents said they **had sufficient opportunity to contribute to the meeting**. Two said they did not.

The **aspects of the meeting that worked well** for most respondents were (in descending order):

- The chance to network with colleagues from across the NIHR
- The focus on action planning
- The facilitation
- The chance to hear more about the Breaking Boundaries review and next steps
- The acronyms exercise.

Many people did not answer a question about **what aspects of the meeting should have been included or could have been improved**. Of the responses received, almost all suggestions and comments were made by only one respondent.

Suggestions and comments that were made by more than one person related to:

- The importance of involving patients and the public in any future meetings like this
- More time for networking
- More information about the NIHR infrastructure and public involvement within it.

In response to a question about **what people would take away from the meeting**, the most common responses were:

- Contacts
- New ideas and information
- Inspiration, enthusiasm and increased confidence
- A stronger sense of a shared purpose and a shared agenda.

Comments included:

*“There are a lot of intelligent, passionate people in this area. A nice community of approachable individuals.”*

*“It is going to take a bit of action from all of us to make a change – it’s not just up to others to do.”*

Finally we asked **how INVOLVE could best support public involvement leads in future**. Most frequently mentioned suggestions were:

- Hold more meetings like this
- Support networking and the sharing of information and (good) practice
- Offer more guidance and/or leadership

## **9. Current activities that tackle some of the issues raised**

The following are some areas of work that are currently in progress that link to the recommended actions:

### **Action: Set up national and local forums (Question 2)**

There are currently various groups that bring together people from across the NIHR at a national and local level to discuss issues of shared interest.

- INVOLVE facilitates an NIHR wide public involvement strategy group, to discuss strategic priorities for public involvement across the NIHR.
- INVOLVE facilitates the Public Involvement Collaboration Group, a shared learning group for public involvement leads involved in research commissioning.
- INVOLVE facilitates a Patient and Public Involvement in CLAHRCs group which provides a forum for shared learning and support for the CLAHRC public involvement leads.
- The RDS Involvement Forum (a shared learning group previously facilitated by INVOLVE) and the RDS Public Involvement Strategy Group have recently merged to form one group.
- The Biomedical Research Centres have set up a National Patient and Public Involvement work stream. Their first meeting will take place in October.

- The UK Clinical Research Facilities held its first Patient and Public involvement working group meeting in July 2014. The group will next meet in September 2014.
- There are several local groups established across the country where people from CLAHRCs, RDS, AHSNs, Clinical Research Networks and others meet together to jointly address issues of shared concern.

For example, the West of England recognises the benefits of a collaborative approach to PPI and recently established a joint PPI Strategy Group and PPI team. This group includes public members and works with, and is funded by, the CLAHRC, AHSN, Local Clinical Research Network and the local Bristol Health Partners. The joint PPI team also works with the local Healthwatch organisations, the Research Design Service South West, and People and Research West of England.

**Action: Implement a charter for public involvement in research, which includes a standard about diversity and inclusion (Question 4).**

INVOLVE has recently completed a report reviewing work that has already been done on principles and standards for public involvement in research. INVOLVE is currently developing a framework including standards and examples of activity, based on the values and summary principles. This will include standards on diversity and inclusion. INVOLVE is also developing a diversity and inclusion statement and approach for INVOLVE linked to these standards which may have wider applicability.

**Action: Address the learning and support needs of public involvement leads (Question 6).**

For the last 12 months, INVOLVE facilitated a NIHR wide group to discuss learning and development across the NIHR. This work included the development of standards and indicators for learning and development. A report of this work and the recommendations from the group will be available in the near future.

**Action: Draw together guidelines for use of social media to involve people in research (Question 8).**

INVOLVE is currently developing guidance on the use of social media to actively involve people in research. This will be launched at the INVOLVE conference in November.

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## 10. Next steps

This meeting generated a wealth of questions and comments for consideration by the NIHR Breaking Boundaries Review panel. They will be considered by the panel

as part of their continued deliberations. The report of the Review will be published in advance of the INVOLVE conference.

There were a range of actions generated from the afternoon discussions. Some of the recommended actions link to work currently being undertaken (see previous page for examples), and others may be actions that specific groups or organisations from different geographical areas may begin to address.

However, we suggest that to help facilitate greater coordination and collaboration across the NIHR and AHSNs, that the next meeting of the NIHR wide public involvement strategy group discuss how some of the actions that would benefit from NIHR wide involvement, might best be taken forward and who might be involved.

Currently this group has membership from the Clinical Research Network, Research Design Services, Biomedical Research Centres, Research Programmes, Trainees Coordinating Centre, CLAHRCs and Health Research Authority. We plan to widen this group to include representation from public leads from the Clinical Research Facilities, Academic Health Science Networks and Local Clinical Research Networks. We will also explore mechanisms for how best to feed into and share discussions from this group in the future.

**We will update you following discussions of the NIHR wide strategy group meeting. Meanwhile, please get in touch to let us know of any actions that in the short term you propose taking forward.**

**Thanks go to Bec Hanley of TwoCan Associates for facilitating the meeting and for producing the first draft of this report.**

## Appendix A: Attendees at the meeting

All acronyms are spelt out in Appendix B.

<b>Name</b>	<b>Organisation(s)</b>	<b>Region</b>
<b>Ade Adebajo</b>	CLAHRC, CRN	Yorkshire & Humber
<b>Jennifer Allison</b>	BRC, BRU, CRF Southampton	Wessex
<b>Kayleigh Astin</b>	CRF	West Midlands
<b>Gillian Baker</b>	CRF Exeter	South West Peninsula
<b>Carly Ballan</b>	NETSCC - HTA Programme	National
<b>Claire Ballinger</b>	RDS South Central, CLAHRC	Wessex
<b>Duncan Barron</b>	RDS South East	Kent, Surrey & Sussex
<b>Jane Batchelor</b>	BRC Queen Mary University of London	North Thames
<b>Peter Bates</b>	AHSN	East Midlands
<b>Deborah Beirne</b>	CRF Leeds, CRUK	Yorkshire & Humber
<b>Steven Blackburn</b>	RDS West Midlands, Keele University	West Midlands
<b>Karen Boardman</b>	CRF Birmingham	West Midlands
<b>Karen Bonstein</b>	BRC, CRF Moorfields	North Thames
<b>Alison Bowser</b>	RDS South Central	Wessex
<b>Laura Brannon</b>	BRC Guy's & St Thomas'	South London
<b>Catey Bunce</b>	BRC, CRF Moorfields	North Thames
<b>Lorraine Burgess</b>	BRC Royal Liverpool	North West Coast
<b>Lucy Chatwin</b>	AHSN	West Midlands
<b>Ian Cook</b>	HRA	National
<b>Lynne Corner</b>	BRC, BRU Newcastle	North East and North Cumbria
<b>Sebastian Crutch</b>	BRU Queen's Square, London	North Thames
<b>Kate Dack</b>	BRU, CRF, CRN, Nowgen	Greater Manchester
<b>Amy Darlington</b>	AHSN Imperial College	North West London
<b>Rosie Davies</b>	CLAHRC, AHSN	West of England
<b>Lisa Doughty</b>	CRN	National
<b>Vikki Develin</b>	Nottingham BRU, Nott. University Hospitals	East Midlands
<b>Hildegard Dumper</b>	CLAHRC, CRN, AHSN	West of England
<b>Kryisia Dziedzic</b>	RDS, CRN	West Midlands
<b>Susie Edwards</b>	CLAHRC	North Thames
<b>John Etheridge</b>	RDS	National
<b>David Evans</b>	CLAHRC, AHSN	West of England
<b>Carol Fitzgerald</b>	BRC Imperial	North West London

<b>Name</b>	<b>Organisation(s)</b>	<b>Region</b>
<b>Alison Ford</b>	NETSCC	National
<b>Andy Gibson</b>	Peninsula CLAHRC	South West Peninsula
<b>Karen Glover</b>	CLAHRC, AHSN	East Midlands
<b>Margaret Hall</b>	CRN	Kent, Surrey & Sussex
<b>Tracy Higgins</b>	BRU, BRC Royal Brompton	North West London
<b>Justine Hill</b>	CRN	East of England
<b>Adele Horobin</b>	BRU Nottingham	East Midlands
<b>Diana Hull</b>	BRU Birmingham	West Midlands
<b>Jenny Ingram</b>	RDS South West	West of England
<b>Tracey Johns</b>	CRN	National
<b>Zena Jones</b>	CRN	National
<b>Meerat Kaur</b>	CLAHRC	North West London
<b>Aris Komporozos-Anathasiou</b>	RDS	London
<b>Keith Lincoln</b>	AHSN	Wessex
<b>Caroline Magee</b>	TCC	National
<b>Elsbeth Mathie</b>	CLAHRC	East of England
<b>Rachel Matthews</b>	CLAHRC	North West London
<b>Katherine May</b>	CRF Royal Marsden	North West London
<b>Pauline McGlone</b>	CRN	South West Peninsula
<b>Fiona McKenzie</b>	AHSN UCL Partners	North Thames
<b>Alex Mendoza</b>	CLAHRC	East of England
<b>Natasha Mitchell</b>	RDS	Yorkshire & Humber
<b>Delia Muir</b>	RDS	Yorkshire & Humber
<b>Danielle Neal</b>	CRF Imperial (Hammersmith)	North West London
<b>Sarah Nicholson</b>	CRN	East Midlands
<b>Raksha Pandya-Wood</b>	RDS	East Midlands
<b>Sheila Parker</b>	CRN	North Thames
<b>Helen Payne</b>	NETSCC	National
<b>Maggie Peat</b>	CRN	Yorkshire & Humber
<b>Sophie Petit-Zeman</b>	BRC Oxford	Thames Valley & South Midlands
<b>Clemence Pinel</b>	RDS London	South London
<b>Claire Planner</b>	NSPCR, University of Manchester	National
<b>Nikki Pocket</b>	RDS	East of England
<b>Jenny Preston</b>	CRN, CRF Alder Hey	National / North West Coast
<b>Rebecca Pritchard</b>	BRU Leicester	East Midlands
<b>Liz Ralph</b>	CRF Sheffield	Yorkshire & Humber
<b>Megan Rees</b>	CRN	National
<b>Dan Robotham</b>	BRC King's College	South London

<b>Name</b>	<b>Organisation(s)</b>	<b>Region</b>
<b>Gill Sadler</b>	CLAHRC	North West Coast
<b>Caroline Saunders</b>	CRF Cambridge	East of England
<b>Rowena Sharpe</b>	BRC Royal Marsden	North West London
<b>Julia Simister</b>	CRN	Kent, Surrey & Sussex
<b>Tim Skelton</b>	BRU Leicester	East Midlands
<b>Jacqueline Smart</b>	CRN	West Midlands
<b>Susan Smith</b>	BRU Leeds	Yorkshire & Humber
<b>Kate Sonpal</b>	CRF, BRC, BRU Southampton	Wessex
<b>Sophie Staniszewska</b>	CLAHRC	West Midlands
<b>Roger Steel</b>	CRN	National
<b>Lynne Stobbart</b>	RDS North East	North East & North Cumbria
<b>Eileen Sutton</b>	BRU Bristol	West of England
<b>Joanne Thomas</b>	CLAHRC	Greater Manchester
<b>Wendy Thomson</b>	BRU Manchester	Greater Manchester
<b>Carly Tibbins</b>	CRN	West Midlands
<b>Steven Towndrow</b>	CLAHRC	North Thames
<b>Dawn-Marie Walker</b>	RDS	East Midlands
<b>Erin Walker</b>	BRC Great Ormond Street	North Thames
<b>Tony Watkin</b>	CRN	West of England
<b>Justin Wilson</b>	AHSN	Thames Valley & South Midlands
<b>Patricia Wilson</b>	University of Kent, LETB	Kent, Surrey & Sussex
<b>Gail Woodburn</b>	CRF Central Manchester	Greater Manchester
<b>Paula Wray</b>	CLAHRC	East Midlands
<b>Philippa Yeeles</b>	CCF	National
<b>Rosamund Yu</b>	BRC University College London	North Thames

<b>Simon Denegri</b>	INVOLVE	National
<b>Bec Hanley</b>	TwoCan Associates	Facilitator
<b>Sarah Buckland</b>	INVOLVE	National
<b>Sarah Bite</b>	INVOLVE	National
<b>Tina Coldham</b>	INVOLVE	National
<b>Helen Hayes</b>	INVOLVE	National
<b>Marisha Palm</b>	INVOLVE	National
<b>Maryrose Tarpey</b>	INVOLVE	National

## Appendix B: NIHR organisations and their acronyms

<b>Abbreviation</b>	<b>What does it stand for?</b>
AHSN	Academic Health Science Network
BRC	Biomedical Research Centre
BRU	Biomedical Research Unit
CCF	Central Commissioning Facility
CLAHRC	Collaborations for Leadership in Applied Health Research and Care
CRF	Clinical Research Facility
CRN	Clinical Research Network
HRA	Health Research Authority
LCRN	Local Clinical Research Network
NETSCC	National Institute for Health Research (NIHR) Evaluation, Trials and Studies Coordinating Centre
RDS	Research Design Service
NSPCR	National Institute for Health Research (NIHR) School for Primary Care Research
TCC	Trainees Coordinating Centre

## Appendix C: Questions and comments about the Breaking Boundaries review

Below we have listed all of the questions and comments that were written in response to presentations from Simon Denegri and Rachel Matthews about the Breaking Boundaries review of public involvement in the NIHR. All of these comments and questions have been passed to the Breaking Boundaries review panel for their consideration.

Will we get a workable NIHR PPI strategy out of this? This is needed if we are to get consistency and better focus.
Where does PPI fit with public engagement, participating etc? Is it all part of the same spectrum of activities?
How will this review inform the work of INVOLVE going forward?
How can any future surveys be more inclusive of the various organisations (e.g. different research departments)?
Should Chief Investigators have been contacted as part of an organisation to try and get more input and be able to track PPI development?
Are we getting an NIHR PPI strategy?
Is there going to be a standard set of training and support programme for PPI?
What is the future of funding?
I understand that this is about policy and strategy, but don't absolve responsibility by not then going onto actively recommend and be prescriptive about the implementation.
We want there to be action not just a talking shop – there needs to be an operational / implementation plan.
Is there a plan written yet, or if not, when will there be?
If PPI is to be fully embedded, research itself needs to be fully embedded and this is not yet the case. Still an 'optional extra' in some areas.
Importance of PPI should be reflected in level of appointment / recompense for posts such as RDS PPI Officers etc.
How will the panel respond to requests for training for members of PPI groups / communities? Perhaps a broader 'public understanding of science' issue (i.e., don't wait till individuals volunteer).
"Doing things differently" – how can we get the balance between having <u>options</u> available: traditional as good as digital!
<u>Policy and Politics</u> : raising the bar for PPI. Being bold.
10 years issue.
Recommendations setting strong signal for PPI, but will it identify key priority area for urgent <u>action</u> and <u>implementation</u> ?

Finance / training?
Increasing diversity.
How will the panel link PPI to value for money?
Agree with Zena's comment: call for less overlap in PPI, but not 'centres' overlap
Sometimes a 'socialist' model does not work. Strong steer with some 'top down' is needed, e.g. Impact Matrices.
How have you engaged with hard to reach communities, e.g. BME, 'Traveller' groups?
Can INVOLVE provide workshops for training – staff and PPI?
How do we fund training for PPI work?
How to maintain involvement during major change?
How to identify the good practice across the NHS and ensure it influences the implementation. There is already great PPI across the NHS. We can add research to that agenda other than seeing research something different.
How do we go about increasing the general awareness of the NIHR and health research?
How do we promote the development of PPI in the running of the NIHR?
How will we develop a systematic approach to developing evidence for PPI as a methodology and its impacts?
How to future proof PPI focus – what happens when Sally Davies retires?
Were children and young people involved? How will you ensure their voice is heard?
How can we learn from this to reach a more diverse population? Keep engaged?
How can we prove action on people's comments? I.e., people who have taken the time to complete may need reassurance their point is valid /considered.
How will organic development of relationships between researchers and patients be supported in a PPI environment where outcomes are dictated centrally?
How can we best maintain even what we have achieved? Also, it feels a bit perilous – heavily dependent on individuals rather than embedded - e.g. Sally Davies.
Link to your question re person dependent – what happens when Sally Davies retires?
How were public contributors involved in the process and how will they continue to be involved?
What does cost effective PPI look like? How do we know it's value for money?
How will priorities be decided and who will determine, i.e. they were fit for purpose?
To what extent (and in what ways) do you think the recommendations of the review influence the specification of the new INVOLVE contract?
What does success look like?
How does feedback from public and patients differ from that of organisations and

professionals?
We are just finalising (after a year...) our PPI strategy for the BRC / BRU (and by extension our NHS Trust). When Breaking Boundaries concludes, will we have to start again?
Will there be more top lead guidance from the report, such as quality of involvement that researchers should be carrying out, as with this training for RECs, CTUs, researchers etc.
From report, will there be structured guidance, such as payment for patients and public, so it's consistent across the board?
Provide a national framework for local integrated strategies for public involvement across research and service improvements with specific elements that make it real.
National policy – payments for involvement – rather than <u>guidance</u> .
Help for involving seldom heard groups.
Evaluation: guidance / agreement on how to do this at different levels – recording activities to systematic evaluations (of impact etc.) and in different bits of PI / PIR infrastructure. Some agreement on approaches across NIHR. So we don't have 200 different resolutions to what we evaluate and how we do it. <u>And</u> what we record of our own work. PI staff / and actual activities out there and of impact etc., and process versus outcome evaluations etc. <u>Also</u> , what can be done varies in different context / situations as well.
How can NIHR take a lead on communications, e.g. producing materials that help us explain what different research organisations do and how they relate to each other?
DIG Guide to research for Mr San (17). This is about easier understood communications that make it relevant to people, especially young people.
How will the panel ensure the findings are noted and acted upon in <u>all</u> areas of the NIHR? Will there be an ongoing role in terms of governance to ensure key findings are not lost?
How will NIHR / INVOLVE embrace the rise of websites, such as PatientsLikeMe.com and think about how this can be used as a tool for PPI?
How will the report feed into the simplification of acronyms, e.g. PCPIE?
How will the report feed into developing standards for measuring and evaluating PPI?
How did the transition to CRN shape / impact on the report?
How do we monitor the impact of PPI? Demonstration of added value.
Can we get across that PPI is not difficult? Sometimes it gets over complicated and people become scared and intimidated by PPI.
There needs to be continuity in the PPI 'co-ordinator' job description and training, grading and career path.
How do we ensure events like today are more representative of our population? Surely indicative of the barriers we have in engaging more diversely.

How did you engage with hard to reach / non-internet / web savvy people?
How are the panel using the initial findings to influence the politicians and the developing manifestos?
How do the findings / recommendations from Breaking Boundaries link to the NIHR 'Promoting a Research Active Nation'?
The panel membership doesn't have a north-west / northern perspective. How are you going to ensure this is captured? More deprivation / more difficult populace to engage etc.
I like the idea of experiential knowledge – how do we best capture this?
Can you tell us more about the measures you expect to introduce for PPI? How has the 'Breaking Boundaries' review informed these?
How much is this review about communicating and engaging with the public about research? I think this is really important, but the questions were not asking about raising awareness and reaching new people, so probably haven't captured views about this. <u>LOTS</u> to learn from other fields about engagement and marketing and communicating successfully.
Can PPI leads be given a PPI 'fund' to make themes 3 and 4 work? Develop new systems – evaluate them, refine them. INVOLVE hold the money away from NIHR?
How can we encourage long-term career development for PPI advisors, e.g. raising the status, training, development? Management versus academic – two paths.
Pushing inclusion agenda.
Are we aiming for international... <ul style="list-style-type: none"> <li>- learning</li> <li>- leadership, or</li> <li>- arrogance?</li> </ul> How do we learn more from international development and pioneering PPI activities in other countries?
Resource adequately, especially in the forthcoming deepening austerity, PPI will be first for the chop!
Capture other impacts of public involvement lead role: <ul style="list-style-type: none"> <li>- support for resources</li> <li>- improve quality research</li> </ul>
<u>Where</u> will the findings have the most impact for change? E.g. if review identifies issues that need immediate / urgent attention – what is the plan? E.g. use of resources.
To what extent were PPI leads asked for their opinions?
How prescriptive the outcome of the review will be?
Alignment with local strategies?
Transformational role of social media and PPI. How do we use social media to involve PPI?

# INVOLVE

INVOLVE is a national advisory group funded by the National Institute for Health Research (NIHR) to support public involvement in NHS, public health and social care research.

If you would like to know more about what we do, please contact us:

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