

# INVOLVE

## INVOLVE survey of priorities for public involvement across the NIHR

September 2011

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### 1. Introduction

In July 2011 we contacted patient and public involvement (PPI) leads and managers across the NIHR and asked them each to identify three key public involvement priorities that they thought would benefit from being supported nationally by INVOLVE or across the NIHR (see Appendix A). This report highlights the key themes identified.

In addition to the individual responses from the PPI leads across the NIHR, the Clinical Research Network PPI Delivery Group have produced a paper which provides their corporate view on priorities that they would like to see considered in INVOLVE planning. This report is attached as Appendix B.

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### 2. Response

The short questionnaire was emailed directly to PPI leads within the Research Design Services (RDS), Collaborations for Leadership in Applied Health Research (CLAHRC), Biomedical Research Centres and Units (BRC / BRU), Research Programmes and other NIHR organisations such as the School for Social Care, Trainees Coordinating Centre and Research Capability Programme. The PPI manager for the NIHR Evaluations Trials and Studies Coordinating Centre (NETSCC) also distributed the questionnaire to PPI leads within her organisation and the Clinical Research Network Coordinating Centre (CRNCC) distributed the questionnaire to the topic specific networks. Although respondents were identified for their role as being a PPI lead in a particular area (for example RDS) some also noted that their comments were based on their involvement in other aspects of the NIHR as well.

## Number of responses

6	Biomedical Research Centres and Units (BRCs / BRUs)
3	Clinical Research Networks (CRN)
5	Collaborations for Leadership in Applied Health Research (CLAHRCs )
8	Research Design Services (RDS)
8	Research Programmes (including Policy Research Programme, School for Social Care Research, and the two PPI managers for CCF and NETSCC)
2	NIHR Systems and Faculty

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<b>32</b>	<b>TOTAL</b>
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## 3. Priorities identified

Below are the key priorities that respondents identified:

- 3.1 Training and support (21)
- 3.2 Opportunities to share knowledge and understanding across the NIHR (9)
- 3.3 Finding and involving people (12)
- 3.4 Standards for involvement across the NIHR (5)
- 3.5 Advising and encouraging public involvement
  - Convincing researchers of the value of public involvement in research (6)
  - The value of early involvement in research (4)
  - Avoiding tokenism (6)
  - Allowing time for public involvement (3)
- 3.6 Payment and funding for public involvement (5)
- 3.7 User led and user controlled research (4)
- 3.8 Evidence on the value of public involvement in research (8)

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### 3.1 Training and support

The need for training and support for researchers, PPI practitioners / leads and the public were recurring themes raised by many of the respondents. This was the most frequently mentioned of all the priorities and was listed by over half of the respondents as one of their top three priorities.

In addition to the need for training, other suggestions included producing resources and materials for public involvement leads and others to enable them to provide training and support themselves. For example, training the trainer programmes and opportunities to work with other organisations in skills development and community learning sectors.

#### Training

One of the key issues raised by 6 respondents was the lack of openly accessible, NIHR funded training for members of the public who were getting involved in research and the associated costs of providing training.

'All of the Clinical Research Networks are somewhat bereft of open access training opportunities to offer patients, carers, and others looking to get involved in our work. Many of the training opportunities that we have used in the past have been provided by consultants that charge rather high rates for their work. In the current climate this option is untenable. If NIHR funded bodies worked together then we believe that that some excellent training packages could be developed.' (Clinical Research Networks)

'Although RDS leads could provide local PPI training to researchers, RDSs have been told that training is not part of their remit. Although it is obviously not possible to make PPI mandatory, an NIHR-wide / INVOLVE focus on this issue could help?' (RDS)

'We do not have a budget available for training lay members. I understand that this is a common problem across all NIHR Programmes. This seems to also be a key request for all lay members across the Central Commissioning Facility Programmes.' (Research Programmes)

Respondents provided limited information on what kinds of training that they felt were needed. One respondent commented that for them the issue was how best to provide the right sort of training to the right groups of people. Another highlighted

the need to embed PPI skills into the training and continuing professional development for researchers and healthcare professionals.

The following are the suggested subject areas for training that were listed by a few of the respondents:

#### Researchers:

- Training for academics about **why** public involvement is important (CLAHRC)
- Informal and formal opportunities for learning and development between PPI stakeholders, Researchers, Academics, Clinicians, Primary Care to improve and integrate partnership working in research as the norm. (NIHR Systems and Faculty)
- Training and support for researchers to improve the quality of PPI in design and conduct of studies (Research Programmes)

#### PPI Leads:

- RDS need support in training their research advisors on PPI and on what patients and the public need to consider in their bids and what quality in PPI advice might look like. (RDS)
  - Challenging assumptions that patients and the public are not enough to consider but actually it's all the people affected, for example the porter, the cleaners etc.
  - PPI is not a cheap version of qualitative research .... The boundaries and overlap between qualitative research and PPI need discussion.

#### Public

- Training and support for public contributors to improve contributors' skills, performance and role satisfaction. (Research Programmes)
- A need to give good quality training to patients and members of the public on what research is and how they might be involved in it i.e. the various role(s) lay people might be involved in. (RDS)

#### **Support**

Several respondents highlighted the importance of providing more informal kinds of support to service users and researchers. For example:

'When research isn't funded what happens to the people? We are concerned that as the amount of PPI in research increases, there will be a

corresponding increase in the number of people ('public') who have helped to develop a bid or do research without the benefit of institutional, professional, and 'collegiate' support that professional researchers or NHS staff have by virtue of being in an organisation.' (RDS)

'The time to provide service users with an adequate grounding in current scientific methods / research - so that they have the confidence to participate in forums with scientists.' (BRC)

'Supporting and engaging those people to remain involved and participate fully, even where their involvement may be occasional (e.g. referees) - and ensuring that their expertise is put to best use.' (Research programmes)

'Each research design that comes to the RDS for support is unique. Therefore advice regarding PPI should also be unique rather than formulaic. This is necessarily challenging as general principles have to be translated into specific, tailored guidance.' (RDS)

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### **3.2 Opportunities to share knowledge and understanding across the NIHR**

'... from my experience of talking with patients and members of the public is that they do not see the boundaries that professionals and researchers see and they can understand research better if there are explicit links to care and treatments that are described in plain English.' (CLAHRC)

Respondents made the following suggestions for how support for public involvement could be improved through closer working with colleagues across the NIHR:

- collaborating in recruiting people to get involved and sharing contacts and data (Research Programmes)
- some unification of guidance for NIHR PPI panel members would be useful (Research Programmes)
- working together on a regional basis (CLAHRC)
- developing 'communities of practice' which allow the various participants to contribute to each other's aims and to meet their own needs (CLAHRC)

- getting support to join up the NIHR family in a region or sector would be helpful from BRU to CLRN to CLAHRC with clear and unambiguous objectives and success criteria for involvement which can be understood by and are relevant to patients and the public (CLAHRC)
- working with NIHR to incorporate PPI and focus on patient benefit within all research strategies and funding programmes.... Incentives for collaborations with patient groups (CLAHRC)
- PPI online interactive newsletter to communicate and share good practice

Another area highlighted by a couple of PPI leads from Research Design Services, was the relationship between the RDS and the Research Programmes and the potential value of closer working. For example for Research Programmes to advise researchers and the Research Design Services on what the research funders are looking for in relation to public involvement in grant applications and why.

'... We feel there is a need to educate researchers on what NIHR review panels are looking for in a bid e.g. the information given to researchers at the latest Programme Grants for Applied Research briefing meeting ..... . It would also be of benefit to us if some members of the RDS could attend such presentations so we have a greater understanding of what they are looking for.' (RDS)

Another PPI lead from an RDS felt that it would be helpful to have feedback from researchers and the Research Programmes of the usefulness and impact of some of the services that they provided. For example the provision of small grants for pre-protocol work (did the researchers submit the bids, were they successful, did they receive feedback on their public involvement from the funders) and the impact and usefulness of the advice given by lay peer reviewers on applications prior to researchers submitting to the funders.

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### 3.3 Standards for involvement across the NIHR

A few of the PPI leads referred to the value of developing shared standards for public involvement across the NIHR as well as geographically across regions.

'Top priority needs to be focused on the setting of basic standards and expectations to all parts of NIHR and for those funded by NIHR.' (NIHR Research Systems and Faculty)

'Creating a common set of PPI standards for working relations with Researchers, Clinicians, Academics across NIHR.' (NIHR Research Systems and Faculty)

'Strategic coordination for PPI across the NIHR institutions leading to a common framework and agreed "natural" standards for PPI practices.' (Research Programmes)

'Good working policies to be identified and implemented across all the NIHR Networks. Standardised policies across regions will enable better working practice.' (BRU)

'... it may be helpful to have shared statements on PPI commonalities and differences for the NIHR "family".' (RDS)

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### 3.4 Finding and involving people

- **Diversity**

Several respondents highlighted the importance of working with and valuing diverse groups of people who possess different types of knowledge but also the difficulties experienced in achieving such involvement. For example, involving people from different ethnic groups.

For some respondents they expressed difficulties in knowing how best to increase diversity amongst those that they were involving and for others it was a concern as to how to encourage researchers to consider wider public involvement in their work.

'... clinicians sometimes only involve their own patients and their carers / families in research. However, in doing so they are unable to access invaluable perspectives, skills and experience available from the wider community, including community support groups and voluntary sector organisations that support a large number of people with specific illnesses and conditions to which research relates ....people with learning disabilities are often not given the opportunity to get involved, yet this group of people live with a variety of illnesses and long-term conditions and have a great deal of skills and experience to offer researchers' (RDS)

- **Finding people with specific knowledge**

Another issue raised was how to access expert patients (service users with specific conditions). One respondent for example highlighted how charities with access to such service users often now charge researchers (at pre-protocol level) to advertise involvement opportunities.

Other issues included:

- knowing who to involve if the area of research is not specific to one particular patient group
- where and how to start to approach people outside the NHS
- importance of finding the right people for the task

'Ensuring that the right individuals are identified, sourced and 'recruited' to allow for a fair and adequate assessment of the research proposals being submitted to the research programme.' (Research Programmes)

Another related point raised by one respondent was around the extent that people brought a lay perspective:

'Some of the people who apply to become lay members are ex-health care professionals. Although these people are technically patients / the public they are not technically lay, as they cannot forget their medical training and their experiences in their profession Therefore they are not really what we are looking for .... How do we spread the word out to these people that there are other avenues for them and where it is most appropriate for them to apply.' (Research Programmes)

- **Numbers**

With the growing acceptance of the need to involve people in research commissioning and throughout the research process, some of the PPI leads raised the issue of the support needed to sustain and increase the numbers of people getting involved and also to ensure that people who are keen to be involved are not overburdened.



### **3.5 Advising and encouraging public involvement**

- Convincing researchers of the value of public involvement (5)
- The value of early public involvement in research (4)
- Avoiding tokenism (6)
- Allowing time for public involvement (3)

Many of the priorities highlighted by respondents were related to how to best advise and encourage researchers and others to involve the public in their work. These included how best to convince researchers of the value of public involvement and the importance of early involvement in research as well as avoiding tokenism.

The following quotes illustrate the issues raised:

#### **Convincing researchers of the value of public involvement in research**

- 'Resistance is by far and away the most pressing issue in terms of making progress with PPI....Some researchers still believe that researchers who are themselves service users / patients are not capable of being scientific because of their mental state.' (BRC / BRU)
- 'getting researchers .... to understand the benefits of PPI and requirement to do PPI. I tend to have researchers who do and researchers who don't as opposed to studies that do and studies that don't.' (BRU)
- 'Ensuring that PPI is taken seriously by research advisors and at funding panels (as there have been instances where projects with poor PPI have been funded, although there have similarly been cases where projects have not been funded because the PPI was poor...).' (RDS)
- 'Overcoming cynicism - there are still many people who think this is a political agenda without real substance/impact. Finding ways to demonstrate impact is key.'(RDS)

#### **The value of early involvement in research**

- 'Early PPI. This is I feel key to any project development.... How do others attempt early PPI in the consultation or advice sessions?' (RDS)

- 'People should be encouraged to consider PPI at the earliest possible stage.' (RDS)
- 'Finding opportunities / working with researchers so as to ensure that PPI is inserted at the start of a research project. Often the protocol is already finalised before PPI is considered - which makes it difficult for patients / service users to feed in any substantive way.' (BRC /BRU)

### **Avoiding Tokenism**

Several respondents expressed concern that involvement was often tokenistic and not meaningful involvement. For example:

- 'Colleagues who are not persuaded about the importance of service user involvement in research or who pay lip-service to it but don't mean it.' (Research Programmes)
- 'We want PPI members to produce good work so that they are valued and so that their comments can be used by the Panel. We don't want it as a paper exercise.'(Research Programmes)
- 'PPI Education - collaboration/communication between INVOLVE and colleagues at the highest level in NHS Trusts to raise awareness of, and ensure commitment to, PPI good practice in research. Lip service is still being exercised sometimes due to an inability to distinguish the difference between development and implementation of PPI on the ward and research. We are currently establishing approaches to raising awareness which could be supplemented with appropriate publications for example.' (BRU)
- 'Ensuring involvement is throughout the work of the programme and not just about occasional steering / advisory group meetings.' (Research Programmes)

### **Allowing time for public involvement**

The issue of timing was most acutely felt by Research Design Services giving advice to researchers on public involvement in their grant applications.

- 'Many commissioned calls for funding have very short deadlines so there may be insufficient time to obtain input from patients and members of

the public to build good PPI into an application. Can something be done about this?' (RDS)

- 'Time - not allowing enough time for good involvement in the time before deadlines or realizing that involving members of the public and service users takes time.' (RDS)
- 'Often by the time researchers contact RDS they have already developed a draft proposal with little or no involvement, and intend to submit to an imminent funding deadline. Although advice and support is available through RDS PPI leads, this still relies on the researcher wanting to take the advice and support and spend time involving people.' (RDS)

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### **3.6 Payment and funding for public involvement**

A few respondents touched on issues around payment and funding for involvement.

These included:

- the different rates that people are and should be paid for their involvement
- difficulties for those who are receiving benefits
- overcoming bureaucracy and inflexibility as to how users can be involved and recognised for their involvement (financially or otherwise) from universities and funders

One respondent reported experiencing problems with the discrepancies between the payment rates to those involved in the NIHR Programmes and INVOLVE and payment rates to others.

'We have experienced problems with people involved in our network confusing the internal payment rates offered by INVOLVE as payment rates that should be offered generally ... it would be useful if INVOLVE could coordinate or support alternative models of payment rates that could be made for involvement work' (Research Network).

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### 3.7 User led and user controlled research

Addressing and supporting user led and user controlled research was raised by three of the Research Design Services and one of the Research Programmes.

There is increasing interest amongst service users to have greater involvement in research and amongst PPI leads to support service users in this role. However, the PPI leads raised issues around the resources and skills needed to support user initiated research as well as difficulties in getting such research funded within the NIHR Research Programmes. The following quotes highlight some of the issues.

#### Support and resources

'Supporting user-led research at bid development level (especially in relation to team building and finding a mentor for the user researcher).'

(RDS)

'In order to make this a reality it requires immense effort and additional resources. I am involved with a user-initiated traumatic brain injury (TBI) project at the moment which was initiated by 2 TBI survivors. As well as general research and team meeting support, this group does require additional support in order to accommodate their needs appropriately. This is challenging and adds to the time line of the project.'

(RDS)

#### NIHR Research Funding

'An earlier submission to RfPB for this project met with criticism from the panel regarding having lay co-applicants. This has made the research team nervous about re-submitting with lay co-applicants or even with a lay Principal Investigator (PI) - as I would like to see. What is the NIHR position on lay PI's and lay co-applicants? Is there a consistency of view among regional RfPB panels who seem to be nervous regarding lack of research credibility and project management experience of lay co-applicants? How can user-led research be a reality if lay PI's are rebuffed by funding panels?'

(RDS)

'There is still a limited amount of user-led research, and NIHR systems / processes do not always make it easy for user-led research to be funded

and conducted. For example service user organisations face a number of barriers if they apply to an NIHR funding stream, despite NIHR advocating the development of more user-led research.' (RDS)

#### Awareness raising

'INVOLVE recently published "Changing Our Worlds: examples of user controlled research in action". This could form the foundation for more work across NIHR to develop user-led research and also raise awareness of user-led research both with researchers and also the patient / service user groups and organisations themselves that could potentially develop research ideas and support user-led research. Indeed, such an organisation could be commissioned to lead such work across NIHR.' (RDS)

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### **3.8 Evidence on the value of public involvement in research**

Respondents highlighted both the need for methods to measure and capture the impact of public involvement in research as well as the importance of further developing our knowledge and understanding through building the evidence base.

#### **Methods for measuring and capturing impact:**

- Measurements / tools needed to assess the impact and implications of the quality of involvement (which in turn would assist with helping identify the issues) (Research Programmes)
- Guidance needed on capturing the impact of involvement (RDS)

#### **Evidence to:**

- showcase involvement, good or bad, to help raise awareness of what is currently going on (Research Programmes)
- assess the impact of PPI through all forms of involvement in the research cycle (Research Programmes)
- persuade researchers of its value to research planning (Research Programmes)
- develop lay panel members skills in assessing PPI in applications (Research Programmes)

- increase the effectiveness of PPI in the deliverability of studies (Clinical Research Network)
- know if PPI is working and creating a benefit. There is no point of doing PPI for the sake of it. (Research Programmes)

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#### **4. Next Steps**

This report provides a useful snapshot of the current priorities for public involvement leads across the NIHR. It is being discussed as part of the INVOLVE members Annual Symposium in September and is also being distributed to all who contributed to the report. It is a first step in trying to identify how we can better support and work with our colleagues across the NIHR in the future.

**Sarah Buckland**

**August 2011**

**INVOLVE**

Supporting public involvement  
in NHS, public health and  
social care research

July 2011

Dear Colleague

**INVOLVE Survey of NIHR Patient and Public Involvement (PPI) leads**

In your role as PPI lead you are often at the forefront of identifying ways to support others to involve people in research as well as involving the public in your own work.

We are therefore contacting PPI leads like yourself to identify the key issues facing you and others in supporting public involvement in research which would benefit from being supported nationally by INVOLVE and across the NIHR. We would like to know what you believe are the most pressing issues to address, and whether these are similar or different for those involved in the various parts of the NIHR.

We will collate your suggestions to present and discuss at our INVOLVE group meeting in September when we begin to develop our action plan for 2012 / 2013. We will of course also share this information with you. This is a first step in trying to identify how we can better support and work with you in the future.

I appreciate that this is the summer period when many of you may be going on holiday (or are already on holiday), but if you could find 10 minutes to fill in the attached sheet listing your key priorities we would be very grateful.

Please would you return the attached form **by Monday 15<sup>th</sup> August** to:

[NIHRsurvey@invo.org.uk](mailto:NIHRsurvey@invo.org.uk)

I look forward to hearing from you

Best wishes



Sarah Buckland, Director INVOLVE

## INVOLVE Survey of NIHR Patient and Public Involvement leads

Please would you list in the boxes below the key issues (maximum of three) that you feel are the most pressing and that would benefit from collaboration with other NIHR partners (either INVOLVE or other colleagues working within the NIHR)

### Three key issues in supporting public involvement in research:

1.

2.

3.

i) Name:

ii) Role / Job title:

iii) Organisation:

iv) Type of NIHR organisation:

(e.g. RDS, Research Programme, CLAHRC, BRC / BRU, CRN)

v) Email address:

**Note:** We will not identify individual responses in our report but we will include the nature of the organisations that individuals are working in e.g. Research Programmes, Research Design Services

**Please would you return the form to [NIHRsurvey@invo.org.uk](mailto:NIHRsurvey@invo.org.uk) by Monday 15<sup>th</sup> August**



## Appendix B:

### NIHR Clinical Research Network Patient & Public Involvement (PPI) Delivery Group: Priorities and recommendations for consideration in INVOLVE's planning 2012/13

The PPI Delivery Group was formed in the spring 2011 in order to deliver the requirements of the new PPI Programme within a shared leadership model. The PPI Delivery Group membership includes all the Network PPI Managers and Coordinators, and PPI Associate Directors working nationally in the 8 Networks. Through its governance framework it is closely linked with the Clinical Research Network (CRN) Assistant Directors group, the CRN Executive, and with patient groups in each individual Network. The CRN is managing £284 million of research support infrastructure this year alone and approximately £3 million for PPI over the next 3 years. It is estimated that currently the CRN actively involves in the region of 1,200 and 1,300 patients, service users, carers and lay people in its research support infrastructure (not including those actively involved in individual studies).

The following priorities emerged from the CRNs PPI work to date and in particular arise from the PPI Way Forward Review, and work since, on transition to the new NIHR CRN PPI Programme. The PPI Delivery Group ask INVOLVE to consider the following in its planning process.

	Area of opportunity	Arising from	Current CRN activity if any
1	<b>Concerted leadership</b> to rationalise/harmonise PPI activity across different organisations in the <b>strategic context of the research pathway</b> from inception to reporting in order to maximise on	Discussion about the research pathway through organisations inside and outside the NIHR as part of the Way Forward and evident in its report.	This issue is <b>outside the CRN CCs immediate area of control</b> , yet can influence impacts for CRN CC study performance significantly. Some

	<p>impact and reduce overlap and possible wasted resources.</p>	<p>This issue was highlighted in a presentation to an INVOLVE PICG this year with much interest.</p> <p>Anecdotally we are aware that for researchers more coherence on PPI would be helpful as their study progresses through different organisations.</p>	<p>initial but individual discussions with NIHR funders and NRES have taken place covering specific areas of work but do not individually this strategic overview.</p>
2	<p>Agreed <b>formal structures</b> to ensure NIHR organisations <b>links with INVOLVE planning</b>.</p>	<p>Discussions during the Way Forward review period highlighting a need for connectivity between INVOLVE priorities and CRN PPI activities and priorities.</p>	<p>New CRN PPI national governance structure will make this easier as will the clearer focus for PPI in the CRN.</p>
3	<p>Regularly host an NIHR wide (and beyond) <b>PPI Forum</b></p>	<p>The CRN PPI Forum has demonstrated <b>a positive need among NIHR and related organisations</b> to regularly meet to network on PPI and identify opportunities for collaboration.</p>	<p>The new CRN PPI Delivery Programme means that we may no longer be hosting this Forum as other formats for stakeholder work are being mooted that more specifically meet CRN PPI plans.</p>
4	<p><b>Collaboration potential</b> in new shared leadership areas for PPI in the CRN. Suggested areas that may be of interest to INVOLVE:</p> <ul style="list-style-type: none"> <li>• Setting up a learning &amp; development</li> </ul>	<p>NIHR CRN PPI Programme</p>	<p>Under the shared leadership model now being utilised in the CRN PPI Programme different Networks are leading on different aspects of PPI work on</p>

	<p>infrastructure and network for CRN</p> <ul style="list-style-type: none"> <li>• Capturing evidence and impact of CRNs PPI work</li> <li>• Work with NRES on improving patient friendliness of consenting processes &amp; lay summaries</li> <li>• Work with NETSCC and IRAS re Portfolio improvement</li> </ul>		behalf of all the Clinical Research Network
5	<p><b>Active engagement and mutual transparency</b> with people at national, regional and local levels utilising MS SharePoint Portal and other electronic networking technology</p>	<p>MS SharePoint, available from NIHR IS has proved to be a good way of collaboratively and democratically working across different organisations and individuals.</p>	<p>CRN PPI is increasingly utilising this technology in a more 'joined up' way. There are opportunities to increase transparency and allow individuals and organisations to observe and contribute to work in progress.</p>