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NOVEMBER 25 2016

# TABLE OF CONTENTS

Contents	1
Background and Introductions	1
Background	1
Welcome	1
Introductions Exercise	1
Morning Presentations	2
Going the extra Mile, and update from last public involvement leads meeting	2
NIHR Strategic overview	4
Learning and Development for Public Involvement Leads	7
Tree of needs	7
Public Involvement Standards	10
Feedback for developing the indicators	10
Feedback for the next stage of consultation	10
Context issues for the Standards Partnership to consider	11
Afternoon Activities	12
Skill sets for public involvement leads	12
Career pathway for public involvement leads	13
Review of the meeting & next steps	15
Acknowledgements	16
Appendices	17
Appendix 1 – Agenda for the day	17
Appendix 2 – Delegates	17
Appendix 3 – Going the extra Mile Update.	17
Appendix 4 – Additional Questions to the Panel with Responses	18
Appendix 5 – Event Feedback.	18
Quotes	20
Contact Information	21

# BACKGROUND AND INTRODUCTIONS

## BACKGROUND

On 25th November 2016 INVOLVE hosted a meeting for Public Involvement (PI) leads from across the National Institute for Health Research (NIHR), Academic Health Science Networks (AHSNs), and Medical Research Charities. The aim of the meeting was to bring together staff in public involvement posts in key research organisations to:

**Update:** national strategy for NIHR & Public Involvement, INVOLVE and work programmes supporting delivery of Going the Extra Mile Recommendations.

**Identify:** the learning and development needs, career pathways, and skill sets of public involvement Leads

**Shape:** NIHR Public Involvement Standards and indicators

**Network:** with colleagues and support collaboration.

Over 100 public involvement leads and people in other similar roles participated in the day, and there was high demand for places. A list of those attending can be found [here](#). This was the second time a meeting has been held; the first being in July 2014 with approximately half of participants being present at this first meeting.

*[@nihrinvolve](#) [#nihrpileads](#) promises to be a good meeting of patient and public involvement leads today*

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## WELCOME

Zoe Gray, Director of INVOLVE welcomed everyone and commented on the diverse nature of people that have taken up public involvement Lead posts in NIHR, and the range of experience and expertise in the room. Zoe indicated the both geographical spread of participants attending and the range of NIHR and other organisations represented –

illustrated in diagram 1 below.

*[How to influence without direct authority -a key challenge says @Zoe\\_AGray @NIHRINVOLVE pic.twitter.com/I5MPKVypJ0](#)*

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# BACKGROUND AND INTRODUCTIONS

*A new chapter for PPI in NIHR. All PPI Leads together as a collective workforce [#NIHRPILeeds](#).*

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[4 NIHR Biomedical Research Units](#)  
[1 NIHR Health Protection Research Units](#)  
[8 NIHR Biomedical Research Centres](#)  
[1 NIHR Blood and Transplant Research Units](#)  
[2 NIHR Healthcare Technology Co-operatives](#)  
[NIHR Diagnostic Evidence Co-operatives](#)  
[8 NIHR-supported Clinical Research Facilities](#)  
[NIHR School for Public Health Research](#)  
[2 NIHR School for Primary Care Research](#)  
[1 NIHR/CR-UK Experimental Cancer Medicine Centres](#)  
[NIHR Surgical Reconstruction and Microbiology Research Centre](#)  
[9 NIHR Collaborations for Leadership in Applied Health Research and Care](#)  
[6 NIHR Coordinating Centres](#)  
[9 NIHR Clinical Research Networks](#)  
[5 Charities](#)  
[Wellcome](#)  
[11 NHS Trusts](#)  
[9 NIHR Research Design Services](#)  
[4 Academic Health Science Networks](#)

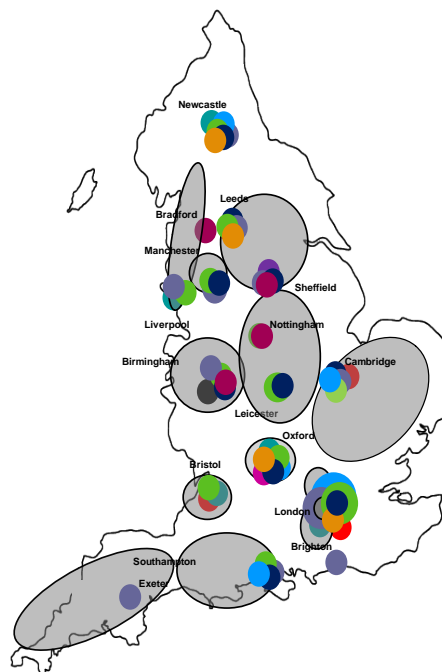


Diagram 1: Organisations represented.



# INTRODUCTIONS EXERCISE

Participants were grouped in geographical areas as per Diagram 1. To facilitate networking participants were asked to discuss and appraise the cartoon in Diagram 2 and colour in the image that most represented either:

- *The car/cycle that reflects being a public involvement lead?*
- *If you are not a public involvement lead - what car/cycle reflects your role/interest in public involvement in research?*

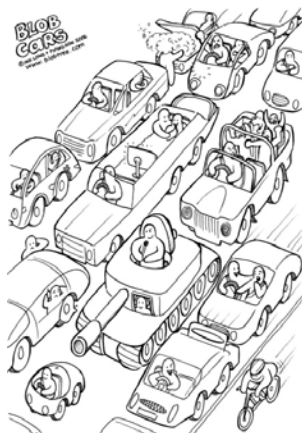


Diagram 2: What car are you? This resource and others like it can be purchased from [www.blobtree.com](http://www.blobtree.com)

Feedback was invited from each table, there were many positive perspectives such as working in partnership and the value of networks (people carrier), feeling that progress was being made in public involvement in research (fast track cycle), and taking turns at steering public involvement in the NIHR (car with two on the wheel). However others were more candid about the challenges of PI, such as the car with the broken engine (what works?) feeling a bit isolated in public involvement (bubble car at the front), and having to work very hard to persuade people of the value of public involvement (tank).



***What is our role in PPI? We chose our yellow car, support and collaboration is key!***  
***[#NIHRPILeads](https://twitter.com/cYf4GcFpPT)***

***We are trying to be bold strong and punch through barriers and obstacles to PPI***  
***[#NIHRPILeads](https://twitter.com/1v4D1PbXmH)***



# MORNING PRESENTATIONS

## GOING THE EXTRA MILE, AND UPDATE FROM LAST PUBLIC INVOLVEMENT LEADS MEETING

**Simon Denegri National Director for Public Participation and Engagement in Research, Zoe Gray Director INVOLVE.**

Simon started by outlining the changes in public involvement that he is observing across the NIHR and beyond, these included collaboration and co-production, more of a focus on outcomes rather than process and the move from committees and meetings to online contact and using social media to reach out. He updated participants on the Going the Extra Mile strategy, key areas of work and what has been achieved so far, this was reflected in a handout given to participants and is contained in the appendices (Appendix 3). He also indicated the wider changes in the NIHR as depicted in Diagram 3.

## Rewiring the house

**NHS**  
National Institute for  
Health Research

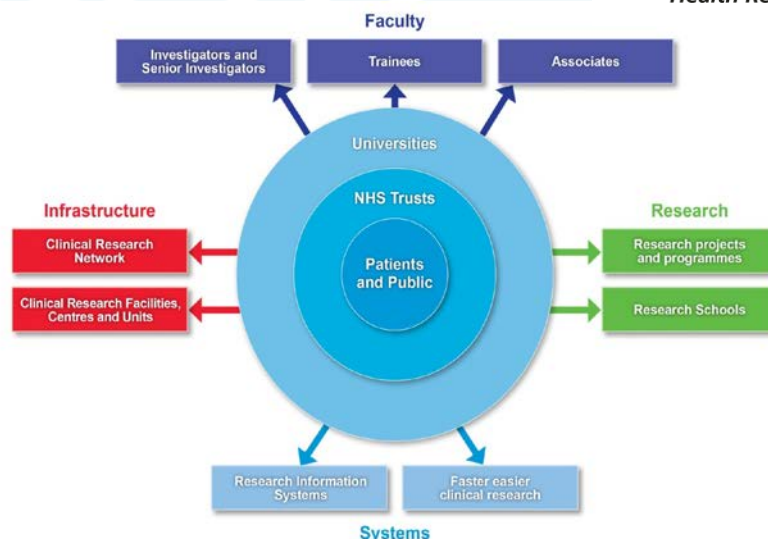


Diagram 3: National Institute of Health Research Structure



# MORNING PRESENTATIONS



*Simon Denegri [@SDenegri](#) gives his take on trends in public partnership in research*  
*[#NIHRPILeads](#) [@NIHRINVOLVE](#)*  
*[@OfficialNIHRpic.twitter.com/ye4a4r91tC](https://twitter.com/OfficialNIHRpic/status/ye4a4r91tC)*

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The presentation from Zoe Gray outlined the new INVOLVE work programme, with emphasis on the national leadership areas of:

- Diversity & Inclusion.
- Learning & Development.
- Community, partnership, networks (Co-production, International PPI network).
- Standards (with NIHR Central Commissioning Facility and wider partnership).

There was indication as to the role of networks at national and regional level and how local intelligence, sharing and co-ordination would all play a role in PI, helping to extend it across NIHR boundaries and respond to the needs of citizens rather than just researchers. The relevant members of INVOLVE staff were introduced for each region and some of the work programmes touched upon, for example the Learning and Development Project Group. The first meeting of this group, chaired by Dr. Gill Hood would benefit from feedback gathered at this meeting.

The increased INVOLVE communications activity was described along with plans for an international network in PI. Simon concluded with where he saw the biggest future challenges for PI:

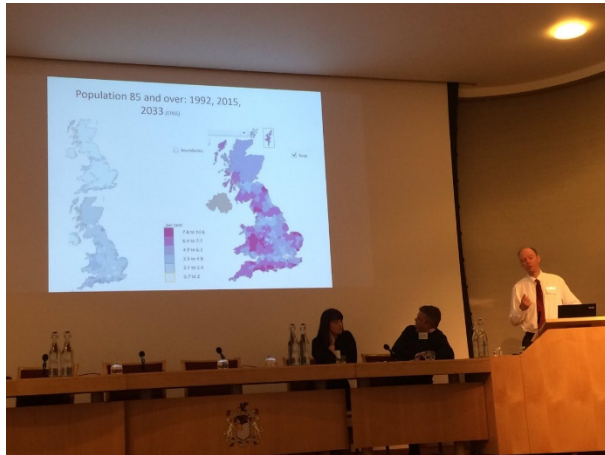
- **Reach** – reaching out diverse communities so our work better reflects the needs of the population.
- **Relevance** – following through on the priorities and needs identified by patients, carers and health professionals.
- **Refinement** – better models, better methods.
- **Relationships** – work and methods that reflect the changing expectations of the public.

Slides from the day including Simon's and Zoe's slides are available [here](#).

# MORNING PRESENTATIONS

## NIHR STRATEGIC OVERVIEW

**Chris Whitty Chief Scientific Adviser, Dr. Louise Wood, Director of Research and Development, Department of Health.**



*We all know about ageing society, but less well recognised that it is rural and semi rural area where ageing society growing*  
[#NIHRPPILeadspic.twitter.com/ln7kxHPjBo](https://twitter.com/ln7kxHPjBo)

Chris used a series of population and disease slides to show the progression of clinical research and the health benefit it can deliver. He concluded that these successes are often due to many small coordinated efforts across different research disciplines, and emphasized the role of networking and collaboration. He concluded with four needs:

Representativeness in public involvement matters - because of disparities in health generally and the difference between rural and urban population health needs.

In health research we have prolonged longevity of our population but we now need to address issues of quality of life in clinical research and public involvement has a role in this.

We need public as well as patient involvement, for informed good public health and for insights into patient experience.

Public involvement needs to be evidence based, with appropriate evaluation built in.

Chris's slides are available [here](#).

Following all the presentations speakers took questions and comments from participants, and the discussion included the following points;



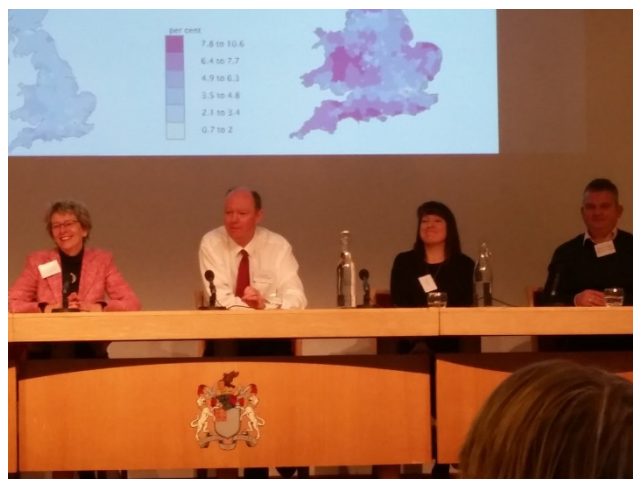
# MORNING PRESENTATIONS

*The panel taking questions from the floor #NIHRPILeads  
[pic.twitter.com/cDND0tWx4H](https://pic.twitter.com/cDND0tWx4H)*

*#NIHRPILeads panel discussion. How to increase  
opportunities to be involved. More virtual and digital  
ways? [@NIHRINVOLVEpic](https://twitter.com/NIHRINVOLVEpic)  
[twitter.com/hPqsKTPLeA](https://twitter.com/hPqsKTPLeA)*

**Feedback point 1:** acknowledging Chris's point about engaging with the elderly, what about working people and children and young people? Are there more innovative ways that the NIHR research management processes could be adjusted to accommodate a wider diversity of involved public? Such as using online processes to review funding applications rather than attending board meetings?

- *Opportunities to use digital proactively to work with potential research participants to work out acceptability of research processes, were welcomed. Additionally digital working allows us to do different research and gain data on the implications and impacts of interventions on quality of life. Involving diversity of population – there is a commitment to this with a need for research to reflect the patient group that is going to be affected by that research in a much more real sense, and develop new ways of doing this. It is important to think about the routes we need to take to engage, and be careful of consequences.*



**Feedback point 2:** whilst we have excellent buy in to public involvement from NIHR staff and academia, how long are we going to tolerate Industry opting out of PI?

- *The industry culture is changing and they recognise the business case for involving patients and public at the earliest point in research design. The Clinical Research Networks are seeing an increase in involvement in industry. The Association of British Pharmaceutical Industries (ABPI) have a public involvement stream that they didn't have a year ago, and have signed a concordat, as have NIHR, concerning working with children and young people.*

# MORNING PRESENTATIONS

*It can be hard for industry to be visible about this work, due to the current code of conduct.*

**Feedback point 3:** big issue is the lack of resources for PI, and to achieve more diverse representation more resources may be needed. Challenges also with monitoring public involvement within research teams, throughout projects.

- *There is a need to monitor more that people do what they said they would do, beyond standard application forms. Funding panels have been requested to provide ongoing feedback so we can see if any issues can be sorted through RDS. In terms of resources spread it has to account for best practice, and there is a general challenge in working across NIHR 'silos'. Encourage better localism and working together as well as the NIHR infrastructure working better together.*
- *Annual reports of public involvement visible last year on NIHR website, with over 6000 downloads. Public Involvement Standards work will help create a level playing field and thus some consistency of information within framework of reporting. It will be really good to have structured way of sharing information.*

**Feedback point 4:** How might NIHR support harnessing the patient and public voice in getting research outcomes implemented? For example there are NIHR Knowledge Mobilisation Fellowships – are there plans to have a PPI NIHR research fellowship?

- *With the establishment of Academic Health Science Networks we want to work more locally, with a community of patients and public to create a pull to get things implemented. People working in public involvement research should be able to apply to NIHR Fellowship schemes, however an outline proposal for PPI Fellowship scheme has been drafted.*

Further questions submitted following the session are included in Appendix 4, along with the panel's responses.

# LEARNING AND DEVELOPMENT FOR PUBLIC INVOLVEMENT LEADS

## TREE OF NEEDS

As a short exercise before lunch participants discussed and recorded their learning and development needs on colour coded luggage tags. These colours related to the priority areas for public involvement from the Going the Extra Mile recommendations and included; general learning and development for public involvement, diversity and partnerships and networks. This proved a very popular exercise with 219 needs identified from the many luggage tags placed on the tree, see Picture 1.



Picture 1: Learning and Development Tree of Needs

## GENERAL LEARNING AND DEVELOPMENT (YELLOW)

As you would expect there were a lot of skills related requests including, leadership and influencing skills, strategy, project and financial management, relationship development and working with volunteers, facilitation skills, and using social media to name a few. Participants also commented on how general public involvement learning and development could be structured.

# LEARNING AND DEVELOPMENT FOR PUBLIC INVOLVEMENT LEADS

*"Training not from PPI "experts" but from experts in relevant disciplines: psychology (group dynamics, cognitive abilities), education (teach complex ideas / research design), medical communication, professional facilitators"*  
*"It feels like a huge luxury to even be considering this - I don't think I've ever been asked. I would value the chance to network with other senior leads to develop strategies for influence and resilience - just having a group would go quite a long way to supporting this"*

## COMMUNITIES, PARTNERSHIPS AND NETWORKS (RED)

Learning and development in this area seemed to be more situational as you would expect including; building alliances and networks, especially external to NIHR and NHS, examples of successful maps of communities of interest, liaising with industry, and partnering with organisations that may hold the key to 'seldom heard' groups e.g. care homes.

*"How do you get people to put aside vested interests and meet over a common interest?"*

*"I think the challenge or need is around how to map the local community (third sector) context in such a way that we can all understand it, and easily share it and link our researchers appropriately, and having something built in to each PPI role's remit. I think this will also link with diversity and inclusion issue"*

## DIVERSITY (GREEN)

A wide range of expressed needs in this area including; learning from community development approaches, interpreting equality legislation in context of research and involvement, creativity and courage and conviction, examples and ideas of successful (and less so) practices that have worked for others.

*"Need clear indication of who makes up our local demographic (who do we need representation from?)"*

*"Dealing with difficult / controversial opinions and ideas"*

*"....training from OUTSIDE of the PPI world - e.g. health visitors (who speak to all kinds of people), social workers, teachers"*

# LEARNING AND DEVELOPMENT FOR PUBLIC INVOLVEMENT LEADS

INVOLVE expect that many of the needs expressed in this exercise will be met by current and planned work programmes, for example PPI Standards, engaging diverse communities, top tips etc. The Learning and Development group are working with the data generated from this exercise and updates will be available on the INVOLVE website.

INVOLVE staff that are responsible for the range of work areas that relate to these learning and development needs include;

- Paula Wray - Diversity and Inclusion
- Martin Lodemore - Learning and Development
- Gary Hickey - Communities, Partnerships and Networks
- Kate Sonpal - Children and Young People

**Contact details can be found at the end of this report.**



# PUBLIC INVOLVEMENT STANDARDS

## Public Involvement Standards

Philippa Yeeles, Director of Involvement and Engagement, NIHR Central Commissioning Facility and Paula Wray, Senior Public Involvement Manager INVOLVE

Philippa and Paula outlined the work of the partnership between England and Wales which has been convened to develop PPI Standards. So far the group have gathered and appraised existing examples of PPI standards and developed six draft standards that have been agreed by the partnership including a strap line (what), rationale (why) and key elements of the standard. The draft standards are:

- Inclusive opportunities.
- Working together.
- Support and learning.
- Communications.
- Impact.
- Governance.

Groups tackled one standard each and commented on the standard itself, and then suggested areas for indicators. They also provided comments on consultation for the standards, context and implementation issues.

### **Feedback for developing the indicators**

Minimal changes to actual standards.

Standardizing language e.g. co-production/involvement.

Standards are interlinked - all must be worked on in order for PPI to be a success - need to be explicit about this?

Define what we mean by indicators.

They need to be measurable – not 'woolly' and broad.

'Less is more' but need to be specific.

### **Feedback for the next stage of consultation**

Need to rethink the layout - it is currently confusing.

Need to make the next stage simple and clear for contributors.



# PUBLIC INVOLVEMENT STANDARDS

Direct people to one standard at a time, and have an overview in sight also?

Link to Values and Principles.

## Context issues for the Standards Partnership to consider

Adapting these to existing terms and conditions of NIHR/NHS (and devolved nations) employers

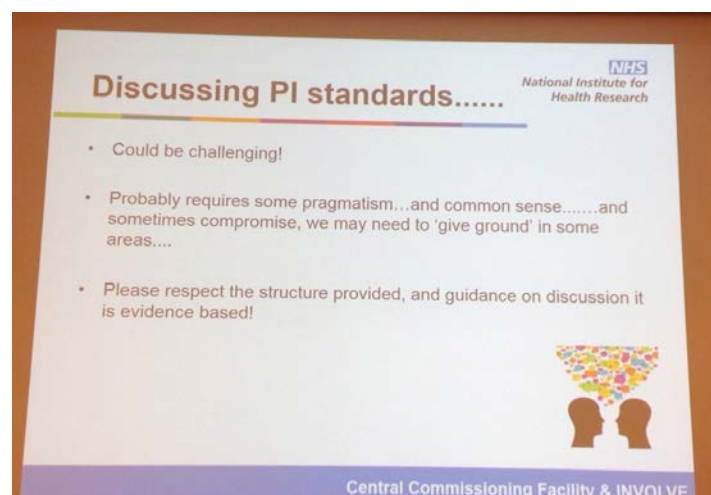
How will this be operationalized? Need to make clear which research networks these are designed for.

What happens if NIHR and other organizations don't address or maintain standards?

Public involvement leads need to be able to give a voice to the public about research processes managed outside the NIHR organization e.g. ethics committees will the standards address this?

All the suggestions for indicators and other feedback will be taken into account for the next stage of development. See the website for information and to sign up for updates <https://sites.google.com/nihr.ac.uk/pi-standards/home>.

***#NIHRPILeads Discussing 6 PI standards - Working Together:  
what should this look like for organisations, research projects &  
individuals? [pic.twitter.com/GZMkW0d7nb](https://twitter.com/GZMkW0d7nb)***



# AFTERNOON ACTIVITIES

**#NIHRPILeads** Talking about the skills and future career pathway for PPI Leads: steps towards a more developed and embedded PPI future.

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## SKILL SETS FOR PUBLIC INVOLVEMENT LEADS

Using the metaphor of a 'Public Involvement Super Lead Person' (Picture 2) participant groups discussed and suggested skills, knowledge and attributes for public involvement leads in the NIHR and other related public involvement roles in other organisations.



**Ready for the next task! Public involvement leads as super heroes... I like it! #NIHRPILeads @OfficialNIHR @nuhresearchpic.twitter.com/x3qfgV9N9W**

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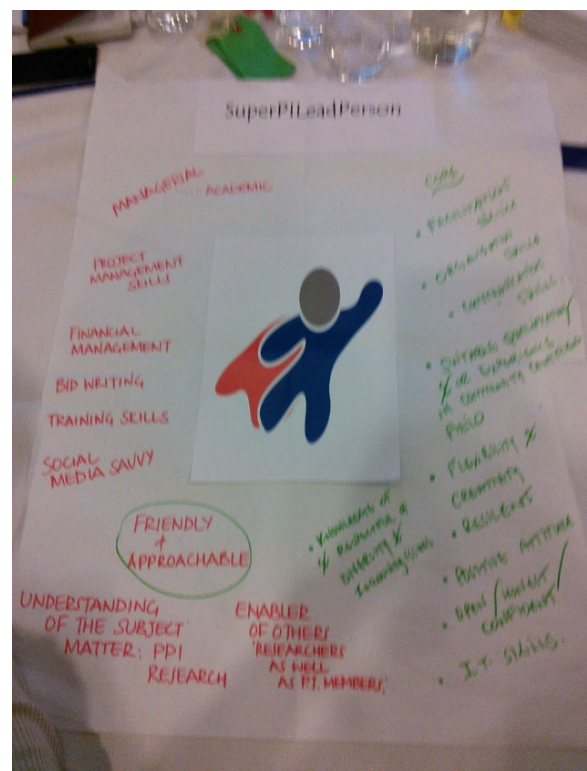
Picture 2: Super Public Involvement Lead Person

### Knowledge and understanding

- Broad understanding of health and health/social care
- Research literate - do you need a scientific background?
- Knowledge of specific disease and health states
- Emotional intelligence e.g. sensitive and empathetic
- Culturally and politically aware

**Elements of a super patient involvement lead #NIHRPILeads.**  
**[pic.twitter.com/C8smpCZHpe](https://pic.twitter.com/C8smpCZHpe)**

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# AFTERNOON ACTIVITIES

## Personal qualities:

- Professional and approachable
- Sense of humour
- (Unlimited) Optimism
- Resilience (dealing with cynics and knock backs), thick skin!
- Managing expectations
- Nurturing and supportive
- Energetic and a 'doer'
- Tenacious and entrepreneurial
- Committed to PPI and have conviction in it
- Knowing personal limits, but also possibilities.

## CAREER PATHWAY FOR PUBLIC INVOLVEMENT LEADS

Participants considered the different issues associated with a career as a public involvement lead in the NIHR and whether it was possible to describe a career path. Using the metaphor of the Yellow Brick Road, Picture 2, groups attempted to draw out a pathway.



Picture 3: The Yellow Brick Road



As public involvement is often an applied role and can be very context specific to the research organisation or setting, groups found it a challenge to design or define a clear career pathway. However there were many commonalities across the group work.

Groups acknowledged the different (and valid) entry points for a career in public involvement and these tended to group into three categories:

1. Academic route: academics, science, researcher, different disciplines e.g. neuroscience, communications and public relations.
2. Voluntary community route: patient organization and activist, communications and public relations.

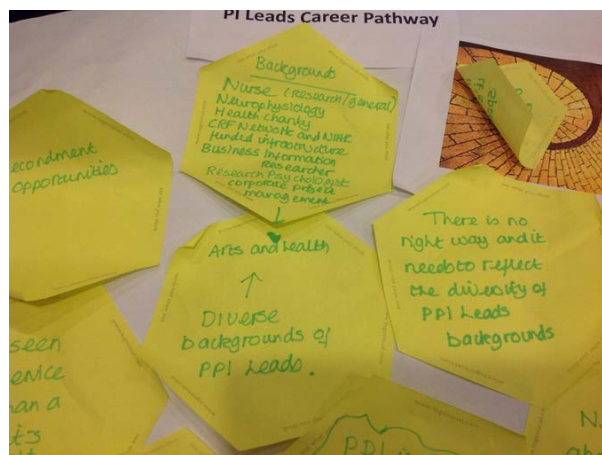
## AFTERNOON ACTIVITIES

3. Public sector route: health and social care, local authority, different disciplines e.g. psychology, communications and public relations and service users.

When reflecting on what motivates people to get involved in public involvement roles there seemed to be several factors such as making a difference to research, e.g. improving relevance, reach and rigour of methods, giving people a voice, and enlightenment and empowerment of those involved (public and professionals). There seemed to be a strong moral undertone to the role and a sense of personal commitment and values that motivates people to consider public involvement as a career.

**#NIHRPILeads - PPI career pathways. Diverse entry points - suggestion: formalising a career pathway for PPI - detrimental to the role? [pic.twitter.com/hvyoXNJyXu](https://pic.twitter.com/hvyoXNJyXu)**

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Public involvement has yet to mature as a profession and is sometimes seen as a 'service' rather than a distinct role. However it should be seen as a career opportunity and probably needs more ambassadors, role models and examples of success to illustrate the possibilities. It was also suggested that as there is no 'qualification' for public involvement there is no recognised benchmark. However there are many relevant and associated qualifications that will contribute to effective public involvement work e.g. research fellowships, PhD's and masters, coaching and communications qualifications, and leadership programmes.

# AFTERNOON ACTIVITIES

## SUMMARY

Stage/level	Nature of public involvement activity
Entry level	<ul style="list-style-type: none"> <li>Assisting in single project</li> <li>Secondment opportunities</li> </ul>
PPI delivery/facilitatory practitioner	<ul style="list-style-type: none"> <li>Facilitating PPI to happen practically e.g. organising meetings and engagement activities, interactions with involved and wider public</li> </ul>
PPI research role	<ul style="list-style-type: none"> <li>All of above plus thinking about methods for engagement, involvement and co-production, reaching different groups, advocating for PPI in wider groups</li> </ul>
PPI specialist	<ul style="list-style-type: none"> <li>Experienced in PPI and taking on an advisory role for multiple groups, teams and projects</li> <li>May work for PPI organisation/network e.g. INVOLVE</li> </ul>
PPI strategic lead	<ul style="list-style-type: none"> <li>All of above plus strategy and policy development for PPI</li> </ul>
PPI Director	<ul style="list-style-type: none"> <li>All of above and in an influential role in organisation, may have team of staff and be on organisational board or senior management team</li> <li>May work across several research/healthcare NHS organisations</li> </ul>
Retire (early!)	

***#NIHRPILeads Thank you to @NIHRINVOLVE what a fantastic day with a very pragmatic look at the future of PPI. Positive and productive!***

## REVIEW OF THE MEETING & NEXT STEPS

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

All the information shared on the day has been captured and will either feed into the relevant work programmes or may be used inform future priorities. For updates please check the INVOLVE website, or contact a member of the team.

# ACKNOWLEDGEMENTS

## Acknowledgements

This report has been prepared by Sally Crowe, Crowe Associates Ltd, Martin Lodemore and Paula Wray, INVOLVE (February 2017).

This was the second time a national leads meeting had been held; the first being in July 2014 with approximately half of participants being present at this first meeting. You can read the report from this meeting [here](#). This report should be referenced as NIHR Public Involvement Leads National Meeting Report 2017.

We would like to thank all our speakers on the day; Simon Denegri, Zoe Gray, Prof. Chris Whitty, Dr Louise Wood and Philippa Yeeles.

Thank you to Sally Crowe for facilitating the day and sharing new techniques and skills.

Thank you to everyone who attended and shared so much on the day, it will all be utilised. INVOLVE will continue to keep you updated and involved in our work programmes.

Thank you for all the tweets, these can be found by searching for the **#NIHRPILeads**.

Further information is available from the INVOLVE website ([www.involve.nihr.ac.uk](http://www.involve.nihr.ac.uk)).



# APPENDICES

## Appendices

### APPENDIX 1 – AGENDA FOR THE DAY

PROGRAMME		
Time	Activity	Presenter/Activity lead
10:30	Refreshments, registration, networking	
11:00	Welcome and meeting overview	<b>Sally Crowe - meeting facilitator</b>
11:30	Going the Extra Mile and update from last public involvement leads meeting	<b>Simon Denegri and Zoe Gray</b>
12:10	NIHR Strategic overview	<b>Chris Whitty and Louise Wood</b>
12:45	Public Involvement Leads; learning and development needs; diversity and partnerships	<b>Sally Crowe</b>
13:00	Lunch	
13:45	Public Involvement Standards Development Partnership	<b>Philippa Yeeles and Paula Wray</b>
14:45	Refreshment break	
15:15	Public Involvement Leads; ideal skill set and career pathways	<b>Sally Crowe</b>
16:15	Reflection on the meeting - next steps	<b>Simon Denegri</b>
16:30	Meeting concludes	

### APPENDIX 2 – DELEGATES

The complete list of delegates for the event can be found [here](#).

### APPENDIX 3 – GOING THE EXTRA MILE UPDATE.

The document shared with attendees updated on the Going the Extra Mile Recommendations can be found here, [GEM update Nov 2016](#).

# APPENDICES

## APPENDIX 4 – ADDITIONAL QUESTIONS TO THE PANEL WITH RESPONSES

The questions that were raised by the audience following the panel session were collected and presented to the panel members for their responses, these can be found [here](#).

## APPENDIX 5 – EVENT FEEDBACK.

**There were many positive aspects of the meeting including:**

- Hearing about progress in Going the Extra Mile, giving an insight on the areas of PPI we need to focus on and Chris Whitty's presentation
- Networking with others and meeting other public involvement leads (it can feel isolated), support from peers.
- Hearing about the public involvement standards and looking forward to contributing more.
- The round table discussions in the last session of the day – looking at what good PPI looks like and PPI careers.
- Mix of facilitation techniques. Nice to model approaches.

**Individuals reported many items they took back from the meeting including;**

- I liked the ideas tree at the back
- The 'vehicle' opening exercise was an interesting way to examine how people see PPI. I may use this model for a future Patient Advisory Group meeting.
- That the NIHR is focused on what is important locally and reinforcement that locally driven work is seen as valuable
- We can only do our best – little car versus tank picture!
- Understand more about the different PPI roles in the NIHR which will be good to identify opportunities for potential collaborations in the future.
- Update on the standards work. It was a challenging task I think that our group did get to grips with it and provided useful feedback. Going to do a workshop about standards with our PPI group to see what they think is important.
- Good ideas for future proofing my PPI/E work i.e. the ability to plan and develop our strategy.
- Need to involve more 'oldest old'.
- Importance of patient, carers helping to set research priorities.
- Lots of inspiration and new ideas.

The majority of respondents reported that they met someone new, and they described how this would benefit them in the future;

# APPENDICES

- Finding out what priorities there are from other sectors of the NIHR
- Finding it stimulating meeting people with such a range of experience
- I met a contact from NOCRI, who will now be working with us to help work out and address barriers to patient involvement in industry

Useful guidance for subsequent meetings was given and will be taken on board, particularly as all respondents requested a similar meetings in the future, depending on finances. It was felt that these should be ideally at least annually to keep momentum and ensure that progress is made within appropriate time frames.

**There were many suggestions as to how INVOLVE can best support public involvement leads in the future (listed below). These will inform the INVOLVE work programme where possible.**

## **Public involvement training, learning and development, support**

- Develop a clear and effective training and support system highlighting core skills and an attractive career pathway. In conversation with some of the other delegates it seems that many of us 'stumbled' into PPI from a number of different routes and backgrounds. Whilst this diversity provides a very rich set of skills and body of knowledge the expertise could be better harnessed and shared when considering best practice.
- Reassuring to know that INVOLVE is somewhere where we can turn to for advice and support.
- Share resources, provide training, signpost to best practice.
- Work with institutions to establish clearer career pathways for engagement practitioners.
- More/occasional meetings/conferences/opportunities for us to get together, share best practice, at both a local and national level.

## **Guidance, resources**

- 10 key things to know/consider when setting up your PP/E.
- More resources – forums for sharing ideas/good practice.
- What about a series of webinars?

## **Communications**

- Short email reminders, updates on upcoming activities/key website additions
- Quick hints and tips on good public involvement/engagement
- Database and network of public involvement contacts, and contacts with other groups e.g. CHAIN and Mentor.

# APPENDICES

## Regional Managers

- Continuing to provide access to the regional managers who provide practical support and reduce duplication of effort through their awareness of what is happening regionally
- INVOLVE has been really helpful to our regional network!

## Key decision making in Public Involvement

- Any key decisions should involve some form of consultation.
- Flag up opportunities to contribute and give feedback on issues

## Other

- Really looking forward to development of the standards

## QUOTES

***“Meetings such as this can do much to reduce the isolation experienced by many in these roles and I would certainly be keen to attend subsequent meetings if their structure and purpose are made clearer and if they are able to deliver useful outputs.”***

***“Thank you for a great conference it was extremely interesting and informative, and great source of advice, excellent day – Thank you! 😊”***

***“Thank you for an interesting event which got us all thinking; I particularly liked the tree of ideas!”***

***“ A great opportunity to hear first-hand about the progress that the NIHR are making towards delivering the recommendations of Going the Extra Mile by tapping into and sharing existing pockets of good practice throughout the network via the Regional Public Involvement Leads, whilst providing support and oversight nationally.” Liz Ralph, NIHR Sheffield Clinical Research Facility.***

***A fantastic day and it was great to be able to meet PPIE leads from across the NIHR. Mary-Anne Darby, Head of PPIE, Clinical Research Network West Midlands.***

***Working with charity involvement colleagues is always hugely valuable but to share insight at a national level, with so many passionate yet pragmatic involvement leads, was fascinating and rewarding.***

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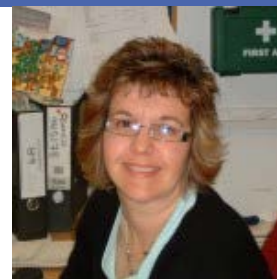
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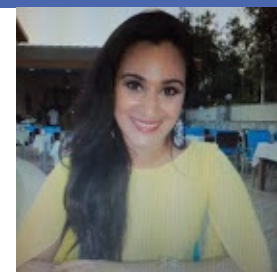
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The INVOLVE logo is displayed within a light grey rectangular box. The word "INVOLVE" is written in a bold, dark blue, sans-serif typeface.

INVOLVE is a national advisory body that is funded by the National Institute for Health Research to support public involvement in NHS, public health and social care research and development.