INVOLVE

NHS National Institute for Health Research

**Notes of the INVOLVE Annual Members Symposium
held at
The Hawkwell House Hotel
Oxford, OX4 4DZ**

7/8 May 2014

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Present:	Simon Denegri (Chair)	John Hughes
	Ade Adebajo	Tara Mistry
	Jonathan Boote	Una Rennard
	Louca-Mai Brady	Carol Rhodes
	Ann-Louise Caress	Lesley Roberts
	Lynne Corner	Tony Sargeant
	Rosemary Davies	Patsy Staddon
	Jo Ellins	Amander Wellings
	David Evans	Patricia Wilson
Guest Speakers:	Valerie Shanks-Pepper (Evening Day 1 & Day 2)	NHS England
	Jenny Preston (Day 2)	Clinical Research Network
In attendance:	Jim Elliott	Health Research Authority
	Kay Pattison	Department of Health
	Roger Steel	Clinical Research Network (CRN)
	Tony Williams	Department of Health
	Sarah Buckland	INVOLVE Coordinating Centre
	Sarah Bayliss	"
	Sarah Bite (Day 2)	
	Paula Davis	"
	Erica Ferry	"
	Helen Hayes	"
	Martin Lodemore	"
	Marisha Palm	"
	Maryrose Tarpey	"
Apologies	Lizzie Amis	Linda Laurie
	Pam Carter	Diana Rose
	Tina Coldham	Veronica Swallow
	Ian Cook	Christine Vial
	Pete Fleischmann	

1. Introductions, welcome, declarations of conflicts of interest

Simon informed the group that Valerie Shanks-Pepper would be joining us at tea break on day one and Jenny Preston would be joining us first thing on day two.

Declarations of conflicts of interest:

No conflicts of interest were declared.

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2. Business meeting
Notes of meeting held on 16 January 2014 and any actions arising

It was agreed that the notes were a fair and accurate record of the last meeting.

Matters Arising

Simon reported that NHS England received a fairly consistent response to their Research and Development Strategy Consultation. They are articulating some core principles and will produce the next version of the Strategy in a couple of months.

The NIHR strategic review of public involvement in research was launched on 31 March. Over 100 responses have been received so far, mostly from members of the public.

Helen Hayes gave an update on the work she has been doing with Gill Wren from the Coordinating Centre to explore the reach of INVOLVE. She thanked INVOLVE Group members/associate members who have provided information about the work they have been doing to raise awareness of INVOLVE and public involvement in research, which demonstrates an impressive breadth of reach. Helen said there was still time for Group members to submit information to her.

Action: The revised INVOLVE presentation slides are being finalised and will be circulated shortly.

Simon invited INVOLVE Group members to reflect on the diversity and inclusion workshop that took place in March. Members expressed a wide variety of feedback on the event for consideration when planning future sessions.

Chair's updates

OK to Ask: Simon reported that there is not much happening on a national level because of changes to the Networks but there is a lot of local/regional activity, which the NHS regional communications team will support. A facebook site will go live shortly. This is part of a wider strategic plan for engagement and participation.

Care.data: Following the response to the care.data leaflet, a more phased approach is now being adopted, beginning with 500 GP practices. Concerns about governance, lack of transparency and opting-out remain and there is likely to be legislation to incorporate some of these issues, including amendments to the Care Bill around consent and providing data to commercial organisations. Simon is on the Advisory Group which is advising Tim Kelsey about this. Several INVOLVE Group members commented that while the concerns that have been raised are important, this should not distract from communicating and engaging the public in dialogue about the benefits of sharing data.

Localism: Simon reported that there is a growth in regional fora but there is no one to coordinate this.

Future topics/speakers for Group meetings: There was not time to discuss this during the Business meeting so Simon chaired an Open Space session on this topic (see item 3)

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3.   Open Space

INVOLVE group members discussed the following topics in this session:

- How do we pay people for their involvement - methods of payment?
- What is a lay co-applicant ?
- Different purposes/rationales for involvement – and tensions between them.
- Future topics/speakers for Group meetings

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4.   Discussion Topics

INVOLVE members chose to attend one of three group discussions:

- The use of social media in public involvement in research
- Diversity and equality
- What is INVOLVE's role in bridging cultural barriers between involvement in research and service delivery?

The use of social media in public involvement in research
Session chaired by Marisha Palm and Louca-Mai Brady

Marisha described the background to this project by explaining that INVOLVE had received a number of requests for information about the use of social media for public involvement. She explained that whilst there are lots of examples of researchers using social media to raise awareness about research and to disseminate information, there are fewer examples of the use of social media to actively involve people in research. It was therefore agreed that we should develop

guidance for researchers about social media and whether its use is appropriate in the context of their public involvement work.

A project working group has been set up comprising of Tina Coldham, Louca-Mai Brady and Marisha Palm with Bec Hanley of TwoCan Associates who has been commissioned by the working group to help develop and write the guidance.

Part of the work will be to conduct some telephone interviews with researchers identified as already using social media to actively involve members of the public in research. These interviews will be written up as short examples and will form part of the guidance. The guidance will also include: a description of social media; a discussion of the types of social media currently being used to involve people; strengths and weaknesses of different types of social media and how they might best be used to involve people; and a discussion about what we don't know, to encourage further contributions and discussion.

The working group is also planning to hold an INVOLVE twitter chat about use of social media in public involvement on 18 June 3-4pm, using the hashtag **#SoMePI**. INVOLVE members suggested that it was important to consider the ethical implications of using social media for research purposes, for example issues around confidentiality, privacy, data protection and informed consent. They also thought it would be important to include in the telephone interviews, questions about the resourcing and cost implications of using social media in research and whether they have evaluated its impact.

Members highlighted that one of the confusions that can be magnified with using social media is getting researchers to make a clear distinction between when people are being asked to participate – as the subject of research – and when they are being asked to get involved in the design, conduct and/or dissemination of the research.

Actions:
- **Telephone interviews should include eliciting views on ethical safeguards when using interactive media (data protection issues), resourcing and cost implications for organisations and public contributors, and experience of evaluating the use of social media.**
- **INVOLVE group members to publicise the planned INVOLVE twitter chat about use of social media in public involvement on 18 June 3-4pm, Hashtag #SoMePI.**

Diversity and equality
Session chaired by Helen Hayes.

Helen reported that the feedback from the equality and diversity workshop was generally positive. The two over-riding recommendations coming out of the workshop were:
- the development of an equality and diversity statement
- the development of a set of values or principles describing how INVOLVE works.

It was agreed that these recommendations are important and to take this forward we should adopt a pragmatic approach with a focus on implementation.

People look to INVOLVE when they are unsure about an issue and they will be searching for resources on diversity and equality, so it is important that we have a statement on the website. However, there is no need to reinvent the wheel as we could use/adapt statements of organisations that we are already linked to (for example University of Leeds or NIHR) and then focus our energy on implementation.

The practical implementation of the statement (including deadlines) could be outlined in a strategy document, which would be regularly reviewed and updated and also used as an example for other organisations. It was agreed that we should also highlight examples of the work we already do in this area, for example our meeting ground rules, finding accessible venues, printing and posting meeting papers, booking train tickets, paying for carers, our accessible website and offering publications in different formats.

It was suggested that we add a third recommendation: the development of a strategy of what we want to achieve in future (including deadlines). We could then review and add to this document and use it as an example for other organisations. Suggestions for the steps we might take in future included: making recruitment road shows more accessible to a range of people, providing a trained mentor for each new Group member, linking to translation sites, writing for a reading age of 10+ years, and targeting groups who are significantly disadvantaged.

Actions:
- **Helen Hayes to draft short paragraph with suggestions for INVOLVE equality and diversity statement and circulate to those interested in this work.**
- **Helen to organise teleconference for interested people to discuss.**
- **Helen to see whether feasible for this group to have a short meeting at the September Advisory Group meeting.**

What is INVOLVE's role in bridging cultural barriers between involvement in research and service delivery?
Session chaired by David Evans and Lynne Corner.

Issues raised:
- Focus needs to be on how research contributes to service improvement. How do people involved in service delivery access research? How to interest them in research?
- Challenge of different timescales in research and service improvement.
- Realism about how much individual research projects and public involvement can deliver.
- Researchers generally have bought into engagement not involvement. Conflation of the two.
- Capacity issues in commissioning/service delivery. Practicalities more important barriers than cultural or language issues. New structures/plethora of guidance on PPI etc. PPI on the service side has fragmented as services have fragmented. There is no service side equivalent of INVOLVE. Trickle down from NHS Constitution to "shop floor" will take time.
- Need to convince serviced providers that research will improve services, benefit patients and staff.

- Lessons from research can be translated to service development.
- Researchers not focused on dissemination. No money/status in implementation.
- Lots of patient involvement in services we don't see or understand.
- How to ensure patients/patient groups have access to new research?
- How to ensure patients/patient groups actively involved in service development can access learning and development opportunities available to those actively involved in research? Can we share what we have?
- How do people currently use evidence of research outcomes to influence service provision?
- Who has responsibility for ensuring research outcomes are shared with patients/the public, Clinical Commissioning Groups (CCGs)?

Discussions on what can INVOLVE do included:
- Focus on how research can benefit health/how involvement in research can benefit.
- Work with NHS England strategically – barriers are systemic not cultural divide. Opportunity to change this. INVOLVE can step in. Strategic link between those driving PPI in research and service delivery.
- Simple local diagrams of new structures in service delivery and research, with simple explanation of organisational roles.
- INVOLVE to facilitate strategic discussion across NIHR, NHS England, Health Education England.
- Dual track – encourage linkage/mapping at both national and regional/local levels.
- INVOLVE to signpost good local practice in joined up PPI working/shared learning.
- Recognise key drivers on service side (key NHS Trust targets, etc)
- Influence research commissioning to promote dissemination, engagement, implementation.
- Engage third sector re research outcomes.
- Look at effectiveness of dissemination/impact strategies.
- Build on plain English work to help describe research as relevant, getting research into patients' hands, demystifying research.
- Advocate for participatory research.
- Advocate for using existing research not just doing new research.
- Raise research mindedness in service PPI.
- How could INVOLVE help AHSNs and CLAHRCs do all this?
- Look beyond healthcare involvement to learn how others involve/engage the public?

Actions:
- **Simon and INVOLVE Advisory Board to review notes of discussion and consider future work in this area.**

5. **NHS England R&D Strategy and public involvement in research: Valerie Shanks-Pepper, NHS England**

Valerie Shanks Pepper introduced herself to the group. Her background is in social work, trained in Northern Ireland where there is an integrated approach to health and social care. She has managed services for people with chronic diseases, worked as a commissioner within the NHS and now has lead responsibility for development of research for NHS England. In their current business plan reference is made to the importance of evidence informed decisions in commissioning and research activity is included in Clinical Commissioning Groups' (CCGs) guidance as a quality indicator.

Valerie then opened up discussion with the Group asking them how they thought INVOLVE could contribute to helping NHS England weave research throughout the business of NHS England.

Members highlighted the following points:
- Important that patients and the public are actively involved in the development of NHS England – at all levels and that this involvement is properly resourced.
- NHS England should be aiming to work in partnership with NIHR programmes to deliver leadership – example given of a development in the West of England of Health Integration Teams (HITs) which have brought together commissioners, providers, clinicians, researchers and patients. These teams are seen to be a positive development with potential for positive impact. The HIT model was developed by a local collaboration, Bristol Health Partners, and has been adopted by the newly established NIHR CLAHRC West.
- NHS England has a massive drive around patient voice and its concept of 'citizen assemblies' but these seem to be only focusing on service delivery. Research does not feature.
- Commissioners need to send research questions back to the NIHR.
- Academic Health Science Networks are too autonomous with no mechanisms for patients to challenge.
- Need for funding by Clinical Commissioning Groups to support public involvement.
- What is the role of Healthwatch? - the potential of Healthwatch is rarely mentioned.

Valerie thanked the group for their ideas and concluded this session by asking that we work together and exchange information. Valerie requested follow up information from members about some of the work they had highlighted to her.

Actions:
- **INVOLVE and NHS England to continue to work together and exchange information.**

6.   Involving and engaging young people in research

Louca-Mai Brady
Simon introduced Louca-Mai, who gave an overview of her experiences of engaging and involving young people in research, having worked or collaborated with the People in Research West of England Forum, Guys' and St Thomas's Hospitals, the Great Ormond Street Hospital, the National Children's Bureau, and the Medicines for Children Research Network, among others.
Louca-Mai highlighted the language we use and the need for clarity when 'consulting' young people (for their opinions) or 'involving' young people (making a decisive change). She also discussed the moral and ethical need to involve young people in research that may affect their care, expressed in the UN Convention on the Rights of the Child, whose articles stipulate that young people have:
- The right to express their views
- The right to information and ideas
- The right to good healthcare and information about staying healthy

Recommendations for good involvement included the need to involve young people separately from their parents, or other gatekeepers, to ensure their own views are offered without parental (or other gatekeeper's) influences. Timing and practical considerations should be borne in mind when planning involvement of young people, but clarity in language used will be needed while participation / involvement / engagement / patient voice are all being used.

Support and advice on involvement will be needed, to steer people appropriately for effective involvement of young people. Tap into existing groups, but consider the views of parents too, albeit separately from their children.

Increasing diversity is a challenge, but engagement of seldom heard communities and a range of involvement models may help this.

Is there a children's and young persons' theme at the INVOLVE Conference? Could INVOLVE set up a Steering Group of children and young people, or coordinate a national event on this theme?

Jenny Preston

Simon introduced Jenny, who started with the NIHR Medicines for Children Research Network back in 2005. At that time, it felt as if there was a lot of public involvement for adult research, but nothing for young people. There was need to think outside the box to engage and involve younger people.

Jenny first established a Young People's group at Alder Hay Hospital, and managed to avoid the gatekeepers to get the group started. This model was then replicated in four other areas in England, which now had more than 100 young people, between the ages of 8 and 18 years, and is now helping to establish similar groups in Canada and the USA.

The groups were given information and training about research, broadening their knowledge at monthly Saturday meetings. Researchers attend to gain comments,

and to offer feedback to the group on progress. The young people groups have also worked with external organisations, such as National Research Ethics Service, Royal College of Paediatrics and Child Health, Clinical Research Facilities, Academic Health Science Networks, as well as Research & Development departments in NHS Trusts.

More than 100 patient information sheets have been reviewed, raising awareness events delivered, and contributions to ethical guidance on assent/consent issues made. The groups have also worked with industry on paediatric studies. In 2012/13, the groups were awarded 'Investors in Children' status.

In 2013, the 'Generation R' event was delivered, showcasing what the groups have delivered and with a high profile guest list. The young people designed the day, interviewed the guests, rather than have speakers, and had video clips and interactive sessions. Jenny also showed a film clip that the young people had scripted and designed, which highlighted what people know (and don't know) about research.

Recommendations included the need to demystify the research process, focusing on the benefits of good research – not what goes wrong – which is what is on offer to young people through the usual channels. There is a need to promote research as a part of routine healthcare, giving a positive view.

The 'Generation R' Report offered 11 recommendations, including one that requires exploration of alternative and innovative methods of engaging young people, and building links to charities and young people's groups.

Questions and comments from INVOLVE members included:

- What we learn from the involvement of young people is appropriate for adults too.
- The need for good, appropriate planning and organisation of events, which includes young people in the process.
- Clear that the value placed on the young people has helped their involvement.
- Use the links with universities and academia to engage young people – what models do schools and universities use?
- The need to position INVOLVE in the debate on including research in the national curriculum – how do we reach teachers?
- The need to separate age groups, as appropriate.
- Do adults have the same rights base as young people?
- Good to see a hands-on approach working – action, rather than words.

Simon thanks Louca-Mai and Jenny for their presentations, and highlighted some potential actions that we need to consider:

- INVOLVE helping strategic thinking – bringing together organisations if necessary
- Make visible what is happening – and scale it up.
- Action learning to support leaders – a possible model for INVOLVE.
- Signposting people and organisations to existing resources including Generation R.

Action: INVOLVE Advisory Board to consider the notes of this session at July meeting.

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7.   Director's Report and INVOLVE Work Plan 2013-2016

INVOLVE members were then divided into three groups and Coordinating staff moved round between groups updating members on some of the current activities of INVOLVE and the Coordinating Centre.

Building the evidence base (Maryrose Tarpey, Paula Davis)

- Research project database

It was noted that, due to recent changes in the Networks, many documents on the website now contain out-of-date links. These will be rectified over time but Paula asked Group members to let her know if they come across instances of web links not working. It was suggested that we invite people to update their invoDIRECT entries in view of the changes to the Networks.

- Examples of public involvement

INVOLVE has also started work on compiling all examples of public involvement that we know about in one place on the website, including examples from the Mental Health Research Network that Thomas Kabir handed over before leaving the MHRN.

- NIHR Health and Services and Delivery Research Programme (HS&DR) /INVOLVE project

A question was asked about plans for the dissemination of the NIHR Health and Services and Delivery Research Programme (HS&DR) /INVOLVE project reports. These will need NIHR sign off first and then INVOLVE will produce a summary overview of the projects and the learning from them, linking to the full reports. The detailed reports will also be added to the Evidence library.

Actions:
- **Research Projects Database**
  - Maryrose Tarpey and Paula Davies to follow up with Marisha Palm suggestions for encouraging researchers to add their projects to then revised Research Projects Database and to explore possibility of linking project entries to relevant invoDIRECT entries
  - Paula to let Group members know when the new database submission form is live
- **People in Research website**
  - Coordinating Centre to ensure those advertising clearly state whether expenses/payment are offered

Capacity and Capability (Martin Lodemore, Sarah Bite)

- INVOLVE Conference

Martin and Sarah updated the groups on progress, with a record number of abstracts received and ongoing assessment of these. We also discussed proposed speakers and need to put out a call for exhibition stands.

- Payment for Involvement

Updated the groups on proposed changes to the structure of the guidance notes, and incorporating earlier discussions on issues around processing payments. We also updated the groups on the updated internal policy, which has been drafted and is close to finalising. There were discussions on the proposed resurrection of the CAB benefits helpline to support individuals with queries, and the need for this to support organisations too. The disparity between the cultures of involvement in service delivery (which tends to not offer payment) and involvement in research (which tends to offer payment) was also highlighted, and will require sensitive negotiations as the two move closer.

- People in Research

Feedback included the need for those advertising to state whether expenses/payment would be offered.

- Changes to NIHR CRN

There were uniform concerns about the introduction of another acronym for involvement: PCPIE (patient, carer and public involvement and engagement), which had been adopted by the clinical research networks. Martin agreed to feed this back to CRN.

Influencing Policy and Practice

- Public involvement leads workshop

David and Lynne offered to check the contacts lists of AHSN and BRC / BRU public involvement leads that the Coordinating Centre had collated.

- Standards for public involvement in research

Members suggested that this work could take account of some additional recent publications.

- School for Social Care / INVOLVE webinar

Members commented that future webinars might benefit from some discussion after each of the presentations. They also suggested that in future the balance between showing the powerpoint presentations and seeing the speakers could be considered. Helen said that we would be looking to review the feedback on the sessions

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8.   Introduction to NIHR Strategic Review of Public involvement in research

Simon reported on the NIHR strategic review into public involvement in research 'Breaking Boundaries: thinking differently about public involvement in research'. The review was launched on 31 March 2014 and information about the review was circulated widely by the NIHR and INVOLVE.

The review is asking for patients and the public, researchers and clinicians, the NIHR and other research organisations to contribute ideas, views and evidence by 26 June 2014. Information about the review is available on the NIHR website (www.nihr.ac.uk). The information is being collected through a range of methods, including an online survey using survey monkey, audio and video clips, individuals presenting information to the review panel and through self-facilitated local discussions. In addition there will be 'twitter chats' to collect further information.

It is anticipated that a final report and recommendations will be available in October 2014.

Group members discussed the importance of the review but noted the tight timescale for collecting evidence, limitations of word limits when submitting evidence and the length of time it takes to complete the online survey.

Simon informed the group of some of the key dates in the review:
- 23 May 2014 – Charity and industry representatives will present their approach to public involvement and discuss their relationship with the NIHR
- 12 June 2014 – Panel to discuss the role of INVOLVE
- June 2014 – Local and regional events will be taking place
- 26 June 2014 – Final day to submit evidence
- 22 July 2014– Discuss and test the ideas raised with NIHR public involvement leads at INVOLVE national meeting.

The review panel has already received evidence from international representatives. Discussions covered the role of INVOLVE, embedding public involvement in research in NIHR structures, the priority and focus of public involvement and the benefit of having a National Health Service to roll out national programmes.

A query was raised regarding the purpose of the review. Simon responded that the landscape has changed considerably over recent years and the review is needed to clarify boundaries and consider new approaches to public involvement in research. There also needs to be a justification of the money that is spent on public involvement in research and its impact and effectiveness.

The importance of making sure that information about the review has been widely disseminated was also discussed.

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9. NIHR Strategic Review of Public involvement in research

INVOLVE members divided into four groups to discuss their feedback to the Strategic review. Ade, John, Lynne and Tony and facilitated the discussions. Notes of the discussions have been circulated separately.

Actions:
- **Simon to feedback to the review panel that the online survey should provide an indication of how long it will take to complete.**
- **All members to consider submitting evidence to the NIHR review**
- **Coordinating Centre to re circulate details of web address for submitting evidence.**
- **The Coordinating Centre will distribute notes of the INVOLVE discussions to facilitators as well as all members.**
- **The facilitators will produce a brief document for submission to the review summarising the main points raised by the discussions.**

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10. Final discussions, any other business

Simon confirmed the dates of the next Advisory Board (3 July 2014) and Group meeting (10 September 2014)

There was no other business.

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11. Dates of future meetings

10 September 2014 – Group meeting
26/27 November 2014 - INVOLVE Conference