

**Notes of the sixty third meeting of INVOLVE
held at the
Oxford Hotel, Godstow Road,
Oxford, OX2 8AL**

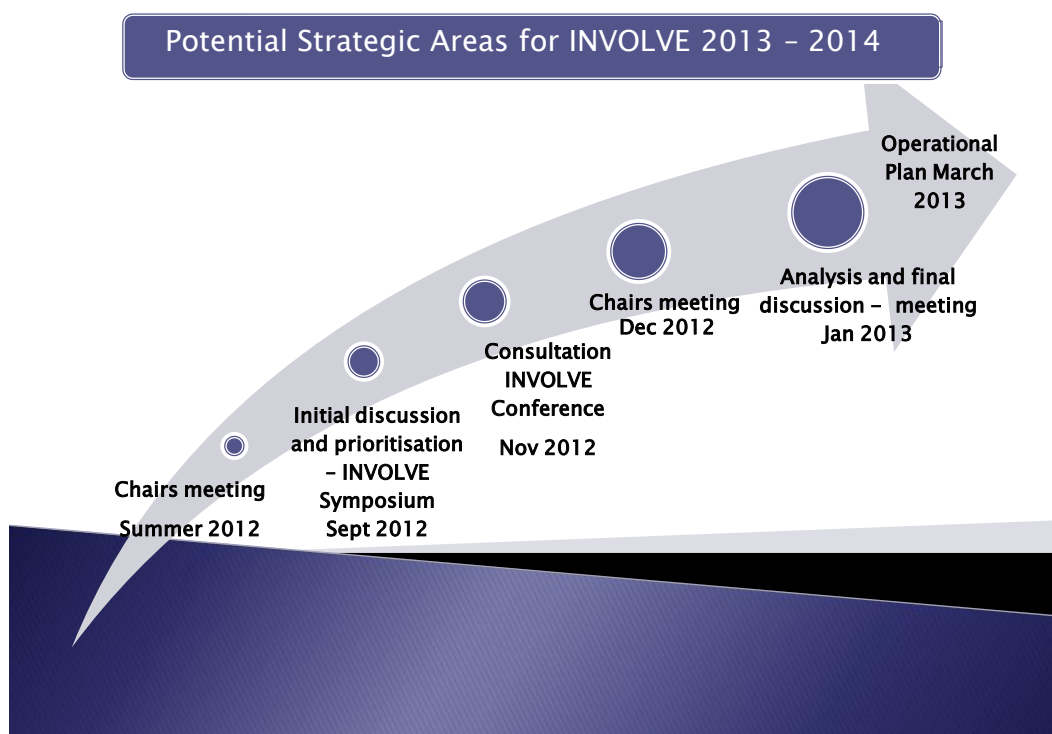
19 and 20 September 2012

Facilitator:	Sally Crowe	
Present:	Ade Adebajo (Day 2) Lizzie Amis Richard Baker Rosemary Barber Jonathan Boote Pam Carter Tina Coldham Lynne Corner Rosemary Davies Simon Denegri (Chair) Jim Elliott David Evans John Hughes	Linda Laurie Tara Mistry Mark Peticrew Una Rennard Carol Rhodes Lesley Roberts Diana Rose Tony Sargeant Patsy Staddon Veronica Swallow Amander Wellings Patricia Wilson
In attendance:	Pete Fleischmann Kay Pattison Roger Steel Tony Williams	SCIE Department of Health Clinical Research Network (CRN) Department of Health
Coordinating Centre:	Sarah Buckland Sarah Bite Sarah Bayliss Paula Davis Erica Ferry Helen Hayes Lucy Simons Maryrose Tarpey Gill Wren	INVOLVE Coordinating Centre “ “ “ “ “ “
Apologies:	Louca-Mai Brady Ann-Louise Caress Jo Ellins Ray Fitzpatrick	Hugh McLaughlin Laura Serrant-Green Christine Vial

DAY ONE – 19 September 2012

1. Developing strategic areas for INVOLVE 2013 – 2014

After welcoming members to the Symposium, Simon Denegri introduced the session. The purpose of the session was to explore potential strategic areas for INVOLVE, to inform development of the Operational Plan for 2013-2014. Sally Crowe then facilitated the discussion.



In advance of the meeting, Simon, the INVOLVE chairs and vice chairs and Coordinating Centre staff had identified and agreed 5 priority areas:

- i) **Value and impact of public involvement** - What do we mean by 'impact' and how can we demonstrate the impact of public involvement on research funded by the NIHR?
- ii) **Improving the quality of public involvement** - What role should INVOLVE have in supporting others to improve the quality of public involvement in research?

- iii) **NHS Research / Clinical Commissioning Groups / Healthwatch** - What are the opportunities and challenges for INVOLVE arising out of the changing boundaries between service delivery and research in health and social care?
- iv) **Public involvement in research governance and regulatory structures / reforms** - What role should INVOLVE play in promoting and protecting the public interest in research governance and regulation?
- v) **Public involvement in engagement and participation** - What role should INVOLVE and public involvement have in raising awareness and increasing participation in research?

After discussion, INVOLVE members voted. Each person had five votes, one for each proposed strategic area. For each priority area they were asked to use a red sticker for areas that they thought should not be prioritised at all, an orange sticker if they were undecided and a green sticker for an area to be prioritised in INVOLVE's operational plan 2013 – 2014.

Voting results

Proposed strategic priority area	RED	GREEN	AMBER	Priority Order
Value and impact of public involvement in research	9	9	2	5
Improving the quality of public involvement	3	9	5	3
NHS Research / Clinical Commissioning Groups / Healthwatch	0	20	3	1
Public involvement in research governance and regulatory structures / reforms	7	10	6	4
Public involvement in engagement and participation	1	15	9	2

In three groups members discussed the three strategic priority areas. Below are the key themes of discussion and ideas that arose from these groups:

First strategic priority: NHS Research/Clinical Commissioning

Groups/Healthwatch - What are the opportunities and challenges for INVOLVE arising out of the changing boundaries between service delivery and research in health and social care?

Themes

- An area for INVOLVE leadership in helping new organisations and structures understand, and implement public involvement in research. INVOLVE needs to “get its’ oar in”.
- General feeling that some of the boundaries between public involvement in research and service delivery are beginning to disappear and this is an opportunity for INVOLVE to have more influence beyond research institutions.
- Critical organisations suggested include Local Authority (Public Health) and Health and Wellbeing Boards, Academic Health and Science Networks (AHSNs), Collaborations for Leadership in Applied Health Research (CLAHRCs) , and Research Design Services.
- INVOLVE needs to be strategic in choices of work in this area due to limited capacity, but also a sense of urgency because of the pace of change, and the need to get in at the beginning of new organisations and structures developing.
- INVOLVE has a role to influence, campaign and inform about the value of public involvement in research.
- Work with ‘fixed point’s’ where there is stability in the system, and work outwards.

Ideas and possible areas for project work:

- Invite someone into INVOLVE to talk about the changes and implications.
- Map out key groups to be working with (in NIHR family) and externally with public involvement in research activity.
- Consider cross cutting patient groups such as GPs Patient Groups.
- Consider INVOLVE members as ambassadors for public involvement in some of the new ‘power places’ such as Health and Wellbeing Boards.
- Explore ways of achieving more connectivity – regional links, sharing exemplars etc.

Key questions:

- What are the possibilities for public involvement in research in the new structures and organisations?
- What should be the focus for this work from INVOLVE’s perspective? To get more public involvement in research agendas, and funding panels? Request to monitor public involvement in research processes?
- How should this work fit with existing expectations from NIHR?
- To what extent should INVOLVE adopt a campaigning role versus offering solutions (expertise, capacity, advice) to the NHS in developing involvement in research?

Risks

- INVOLVE is a national organisation – these changes are often about localising health decision making and research activity – so how will that work?
- Possibility of local groups getting competitive rather than collaborative.

Second Strategic Priority: Public involvement in engagement and participation

- What role should INVOLVE and public involvement have in raising awareness and increasing participation in research?

Themes

- INVOLVE should build on what we do already in relation to collecting information about public involvement activities, compile and share more widely using new technologies (*this links closely to previous priority area of working with clinical commissioning groups etc*).
- National role of INVOLVE – challenge in supporting local public involvement and localism – need for local research ambassadors? Focus on local environment, what is the spread of and interest in patient driven research for example?
- INVOLVE links with the third sector are not formalised and this could be explored – third sector offers a portal to many more people who may be interested in research and getting involved but may not know how. Some charities are very skilled at their own public involvement activity and may be excellent partners to work with. What may start off as engagement may develop into much more active involvement.
- Thinking more simply about research to engage a much wider audience. For example the current research cycle is quite complex – how about 5 stages – research question identification, priorities, commissioning/funding, doing the research, and sharing results in practice (in lay language)?
- Need tools for GPs and others to use to engage the public as easily as possible – how do people raise research issues with professionals in normal health care/social care transactions.

Ideas and possible areas for project work:

- Develop a toolkit – providing guidance on how to raise research issues, demystify research and what is useful to know for each of the key stages of research – linked to people's stories of research.
- Revise research projects database to be more dynamic and show where there are centres/clusters of activity geographically.
- Need to communicate this resource (research database) more widely.

Questions

- How does INVOLVE use technology to access large numbers of people and organisations to raise awareness? i.e. to get much more public involvement in engagement and participation, need to think big – and technology is the only way to achieve reach with the resources available.
- Should INVOLVE audience be wider than researchers and research active people? Is now the time to think more widely about who INVOLVE is for?
- What is special and unique about voluntary sector contribution in this strategic area?

Risks

- Some felt that the focus and link of this priority area with an explicit increase in numbers of participants in research studies may take the focus away from public involvement as INVOLVE sees it – but conversely more study uptake may also impact on public involvement in INVOLVE activity.

Third Strategic Priority: Improving the quality of public involvement - What role should INVOLVE have in supporting others to improve the quality of public involvement in research?

Themes

- Public involvement in research is ethical, imperative, provides accountability and transparency to research – INVOLVE does not need to justify it.
- Public involvement should be integral to normal research processes.
- Should be minimum standards for public involvement (difference between principles and standards for public involvement).
- How do we capture what actually happens in public involvement do people do what they say they were going to do?

Ideas and possible areas for project work:

- Draw out minimum standards for what the public can expect if they are involved in research – short and clear.
- Develop a formal reporting/monitoring process that will be used as part of research funding programmes. INVOLVE to champion this – develop exit interviews as involved public leave the research project for example.
- Guidance for peer reviewers of public reports, re public involvement standards and outcomes.
- Role for INVOLVE in distilling what is known about good practice and quality indicators and checklists.
- NETSCC Journal Series to include a standard report on public involvement or use a template.

- Asking researchers how they have come to their research questions – how do they know it is a priority for patients (in peer review for funding for example).
- INVOLVE report on poor quality of reporting of public involvement in research and how this contributes to low expectations and aspiration.
- INVOLVE collect and debate and agree the indicators of quality and publish these.

Questions

- Who checks on the quality standards?
- How does INVOLVE define good quality public involvement?
- What are the direct and indirect measures of quality in public involvement?

Risks

- If INVOLVE produces quality standards it may be perceived as a governance organisation rather than providing a supporting and influencing role.
- Reduces public involvement further to a tick box exercise.

Notes from initial discussion prior to voting

Fourth Strategic Priority: Public Involvement in research governance and regulatory structures and reforms - What role should INVOLVE play in promoting and protecting the public interest in research governance and regulation?

- Recognise that research governance and regulatory structures are there to promote good research and reduce harm in research, so it is an important part of the bigger picture that INVOLVE contribute to.
- Existing relationships exist with the Health Research Authority (HRA), Care Quality Commission etc. Do these need reviewing and prioritising, and what is the relationship achieving for public involvement in research?

Fifth Strategic Priority: Value and impact of public involvement in research - What do we mean by 'impact' and how can we demonstrate the impact of public involvement on research funded by the NIHR?

- INVOLVE has spent time and money on this area before – although it does contribute to our understanding of how involvement adds value to research and why INVOLVE is needed at all!
- Too easy to get bogged down in process of involvement (though important) and not the impact that involvement has had on the research outcomes and benefit.
- Need for basic standards of public involvement expected in any research activity (counter view that INVOLVE is not there to judge standards and research projects are too diverse to produce generic standards).

- Close links between this area and that of quality of public involvement – also dependent on the qualities of the people that are involved in research – “it’s all about the people”.
- Auditing public involvement – how do we know what is put in proposals is actually carried out in reality?
- What do we mean by public involvement – not just about treatments but also experience of treatments for example?

Other key point made:

Who are the knowledge producers in research? The current system is predicated to a professional knowledge producing context – so the impact of public involvement is always potentially going against this current.

2. Diversity and Inclusion

Lucy Simons and Patsy Staddon introduced this discussion session. Below is a summary of the main suggestions and discussions from the meeting.

Approximately in order of consensus from participants

Idea/project	Potential impact	Feasibility Factor	Possible actions
INVOLVE as a diverse and inclusive organisation	Influencing other organisations as a role model Authenticity of INVOLVE values and aspirations Organisational learning that can be shared as a case study “Getting its house in order”	Tried and tested models exist in health and other social care organisations Member expertise can be used Budget could cover specialist consultancy to advise the work Build on existing gains in INVOLVE ways of working	Organisational audit – impact assessments on INVOLVE products, activities and strategies - what do we already do and what could we do differently? Target for next round of recruitment for membership in under represented areas Review conference contributions for examples of good practice in research Plan for more diversity and inclusion contributions at next conference Analyse how INVOLVE works

			with other organisations
Using and adapting research tools to influence diversity and inclusion	By providing diversity and inclusion guidance as part of existing common research tools (research protocol) not making diversity and inclusion 'special' but more mainstream	Developing new guidance takes time and money – think more about looking at existing guidance and assessing how much it addresses diversity and inclusion and filling in gaps	How can researchers develop research protocols that are inclusive and address diversity issues How do research ethics committees assess research proposals for diversity and inclusion?
Follow up activity with one group that tend to be excluded in involvement	Doing one group well rather than trying to spread across a whole population	Already know that this is time and resource intensive How to decide which group to work with and on what basis?	
Using new technology to reach out to marginalised groups – twitter, blogs etc	Broad sweep approach that is for awareness raising and information only	How will INVOLVE know that it has reached anyone? What will success feel like Does INVOLVE have experience of using new technologies in this way	Mass mailings and email alerts Pod casts and talking heads of what INVOLVE does and how people can get involved in research
Use existing platforms for reaching out – NHS Trusts and Local Authorities have track record in achieving this	What can INVOLVE learn from others and how can this be translated for researchers?	Probably need to develop some strategic partners but probably do able within resource allocation	
New and emerging communities e.g. children with life limiting disease that are living longer – ageing populations	How does INVOLVE work with these groups? Developing ideas and guidance with older people would address a growing area of health research	??	??

DAY TWO – 20 September 2012 – Business Meeting

3. Notes of Meetings held on 14 June 2012 and any actions arising

The meeting notes were agreed as correct.

There were no actions.

4. Matters Arising

Simon Denegri updated us on events that had taken place:

Former members were being identified for the Associate Member scheme and there will be some space on the web site dedicated to them. INVOLVE will write to all previous members and invite them to become Associate Members and there may be events each year which they would be invited to attend.

The Clinical Trials Gateway survey had received 645 responses with 80% of those from patients. Only 1 in 4 reported knowing about the Gateway in advance of the survey. Simon reported that those who responded, thought that it was a good innovation and they particularly liked the fact that it was an unbiased but high quality clinical research website. Respondents recommended improvements to the content and usability as well as addressing the lay summaries. Feedback indicated that people who wanted to participate in trials did not want to go via their doctor and would like to be able to contact the trial directly via the Gateway. Amongst the respondents, 165 responded saying that they would like to be involved in a user panel to discuss the future of the Gateway.

Kay Pattison updated INVOLVE members on the recent government re-shuffle:

- Earl Howe has continued responsibility for Research and Development.
 - Jeremy Hunt replaces Andrew Lansley as Secretary of State for Health.
 - Norman Lamb was appointed Minister of State at the Department of Health.
 - Anna Soubry was appointed Parliamentary Under Secretary of State at the Department of Health.
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5. Directors Report

Sarah reported on recent events not included in the report. The Coordinating Centre have produced a set of slides about INVOLVE and the work that we do as an organisation and will send these out to everyone..

Communications

Helen Hayes reported that several new INVOLVE publications would be available

shortly:

- Strategies for diversity and inclusion in public involvement in research.
- Public involvement in systematic reviews.
- Diversity and inclusion: What's it about and why is it important to public involvement in research.

We are also currently developing a set of three postcards to publicise INVOLVE and our publications:

- General postcard
- Evidence library
- Briefing notes for researchers

We plan to have packs of these postcards available at the Conference. If these prove successful we plan to produce more.

The conference blog will start on 5 November and it will be used in the build up to the conference for discussion/debate. There will also be a Twitter feed during the conference. The Twitter feed currently has 90 followers and Helen asked that anything for tweeting to be sent to her.

Plain English Summaries

Sarah briefly updated members on a recent piece of work that we are undertaking at the Coordinating Centre to produce a question and guidance on writing plain English summaries for grant applicants to the NIHR. TwoCan Associates are assisting with this work. The deadline for producing this work is December 2012. Sarah asked that if anyone had any useful resources or references on this topic to send to her. Linda Laurie and Lesley Roberts offered to send some information.

6. Reports from Task and Finish Groups

The following chairs of each Task and Finish group gave very brief reports summarising the morning discussions:

invoNET - Tina Coldham

Support for learning and development – David Evans

Mapping public involvement networks and activities across England - Ade Adebajo

Please see separate meeting notes for each Task and Finish group.

7. Examples of impact of involvement

For the final part of the symposium INVOLVE members divided into small groups to share personal stories of the impact of involvement. Members were encouraged to recount examples of where their involvement or the involvement of others they were working with, had made a difference – however small. Sally Crowe spent time in each of the groups and identified some themes that emerged:

- The ‘eureka’ moment of realising that public involvement was effecting change in people’s attitudes, and understandings.
- The power of personal testimony.
- The influential and moderating effect of public members of decision making groups – making professional and research members think more carefully about how they behave and what they say.
- Different perspectives of core aspects of research such as outcomes – and how this can change research to measure more meaningful outcomes for patients and the public.
- The courage that is needed for involved public to challenge the orthodoxy and prevailing ‘way of doing things’.

How consultation in research methods and widening out stakeholder groups presents challenges in how much can be achieved in a single research project – how do diverse groups participating in research harmonise often conflicting agendas and expectations from that research?

8. Dates of future meetings

13-14 November 2012 INVOLVE Biennial Conference
22 January 2013 INVOLVE Group Meeting
