INVOLVE

Notes of the sixty second meeting of INVOLVE held at the Double Tree by Hilton, Westminster 30 John Islip Street, London, SW1P 4DD Thursday 14 June 2012

Present:	Ade Adebajo	John Hughes
	Lizzie Amis	Linda Laurie
	Richard Baker	Hugh McLaughlin
	Rosemary Barber	Tara Mistry
	Jonathan Boote	Maria Palmer
	Louca-Mai Brady	Una Rennard
	Ann-Louise Caress	Carol Rhodes
	Pam Carter	Lesley Roberts
	Tina Coldham	Diana Rose
	Rosemary Davies	Patsy Staddon
	Simon Denegri (Chair)	Sophie Staniszewska
	Stuart Eglin	Veronica Swallow
	Jo Ellins	Christine Vial
	David Evans	Amander Wellings
	Alison Faulkner	Tracey Williamson

In attendance:	Roger Steel	Clinical Research Network (CRN)
	Sarah Buckland	INVOLVE Coordinating Centre
	Sarah Bayliss	"
	Sarah Bite	"
	Erica Ferry	"
	Helen Hayes	"
	Lucy Simons	"
	Maryrose Tarpey	"
	Philippa Yeeles	"

1. Introductions, welcome and apologies, declarations of conflicts of interest

Declarations of conflicts of interest:

No conflicts of interest were declared.

Apologies	Lynne Corner	Mark Petticrew
	Jim Elliott	Vanessa Pinfold
	Ray Fitzpatrick	Tony Sargeant
	Pete Fleishmann	Laura Serrant-Green
	Poonam Jain	Patricia Wilson
	Kay Pattison	Tony Williams

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2. Notes of Meetings held on 8 March 2012 and any actions arising

Item 8 – Clinical Research Network Coordinating Centre (Roger Steel), page 10, paragraph 1 to be amended as follows:

Roger also highlighted the importance of developing relationships with NHS Trusts to ensure that research happens. **Some** Trusts do not see research as **a high priority** but the CRNCC wants them to change. This overlaps with PPI, for example how do patients access research? The NHS Constitution says that this is the clinician's responsibility but this does not always happen.

Updates
Simon welcomed all new members to the meeting and went on to outline some activities of relevance. These included:

A review of the NHS Constitution which is being led by Steven Field which will include a consultation in the Autumn.

A review of Information Governance being led by Dame Fiona Caldicott. There will be evidence sessions over the summer. INVOLVE has suggested group members who might contribute from a public perspective. [Update: both Sarah Buckland and Simon Denegri were invited to give evidence at the Research Session on the 10 July 2012 on behalf of INVOLVE].

Jonathan Montgomery has been appointed as Chair of the Health Research Authority, and the new Chief Executive will be announced shortly. Simon was involved in the selection process for both posts. [Update: Janet Wisely (who was acting Chief Executive) has been appointed as Chief Executive].

Recent activities that Simon has been involved in include:

Several activities with the Guardian, organised by the Clinical Research Networks. These included a video interview and a live online question and answer session on public involvement and participation. Members suggested that the links with the Guardian could be used to plug invoNET and expand our reach and raise our profile.

An online survey aimed at getting public and patient feedback on the UK Clinical Trials Gateway (UKCTG). Simon is shortly to post the survey on the web and he asked that we cascade this to patient, supporter and member networks. [Update details of the survey have been sent to all Group members. The survey will close on the 31 July 2012. To date over 500 people have responded. **https://www.surveymonkey.com/s/XK7NTBB**]

Simon and Sarah will be attending the NIHR Strategy Board meeting in July.

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3. The National Institute for Health Research Map - Simon Denegri

This item was included in the meeting after a request from members for an update on the current landscape for health research and the NHS. An update on the changing NHS would be included in a future meeting. Simon gave a short introduction about the establishment and evolution of the NIHR, highlighting the large number of different organisations which make up the whole entity. These distributed organisations are supported by a relatively small central office in the Department of Health.

Simon used an NIHR organisational chart to describe how the parts of the distributed NIHR are organised into 4 thematic areas: Faculty, Research, Infrastructure and Systems and how each of these areas interact with the other parts. He acknowledged it was a complex way of working which rests on good linkages and collaborations between the different parts.

Simon explained that the new challenge for the NIHR will rest on its success in supporting the ability of the NHS to respond to research. The duty to promote research was now enshrined in the Health and Social Care Act, but the NHS is evolving into a consortium which does not have a clear chain of command to realise this duty.

Simon then introduced a discovery exercise for members to take part in. Each table was provided with materials about the NIHR: a leaflet summarising the different parts, two organisational charts and a list of acronyms. Each table selected individual parts of the NIHR to answer three questions: (i) what does it do? (ii) who else does it link up with? (iii) what does the public involvement look like? Each table then fed back to the rest of the group on one part of NIHR and other members of the group contributed their knowledge and understanding.

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4. Chair's hot topic - Open Access publishing

Simon introduced open access publishing as his 'hot topic' for the meeting.
He explained that at present, most published peer-reviewed articles can only be accessed on payment of a subscription. In recent months, both in the United States and in Europe, there have been calls by academics, research charities (such as the Wellcome Trust) and government that the findings of publicly funded research should be made freely available to all those interested.

A UK review led by Professor Janet Finch recommends the move to open access publishing, and discusses the implications of the move and how it can be achieved. This review is due to be published on 19 June 2012.
The report can be downloaded from : http://www.researchinfonet.org/publish/finch/.

Members made a number of comments about open access publishing in the UK.

- It was noted that NIHR already has a policy of open access publishing of all its funded research reports. An example of this is the Health Technology Assessment monographs series which also ranks in the top 10 per cent of medical and health-related journals alongside subscription only journals (such as the Lancet and NATURE).
- Open access publishing does not necessarily diminish the quality of the reporting as articles will remain subject to the rigours of peer review. However members noted that concerns have already been expressed about poor practice over time and the need for governance of open access journals in the long-term.
- The costs of publishing articles placed in open access journals still have to be met and can be expensive. This cost has to be met by academic institutions, research funders or by individual authors themselves. One member gave the example that his research programme had published 100 papers. If they had used open access journals this would have cost their institution in the region of £150,000. Also there is the danger that open access publishing will create a barrier for service user researchers and new researchers such as PhD students who may not be able to finance such publications.
- INVOLVE needs to acknowledge the drawbacks but recognise that open access publishing is the future. Reflecting this, some INVOLVE group members for example, have been scoping the feasibility of setting up an open access journal on public involvement in research.
- It is important to remember that the open access movement is a move to a different business model of publishing. This is not the same as ensuring greater accessibility to research unless it also addresses the way in which research is reported and what is included in the reporting.

Members agreed that this was a topic the Group should continue to discuss at regular intervals.

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5. Reports from:
Clinical Research Network Coordinating Centre – Roger Steel
Department of Health – Tony Williams

Clinical Research Networks
Roger Steel is Patient and Public Involvement (PPI) Manager of the NIHR Comprehensive Clinical Research Network and an observer on the INVOLVE Group on behalf of the NIHR Clinical Research Network (CRN) Coordinating Centre. Roger confirmed that the Clinical Research Network PPI Programme is now fully operational. The shared leadership model underpinning the Programme means that different Networks will lead on aspects of the Programme on behalf of the CRN in addition to their own individual work.

An independent Governance Review of the Clinical Research Networks has taken place and has recommended that the structure of the Networks is reorganised to focus on 16 regions to deliver research. Changes are currently being negotiated with

the Department of Health, but are likely to happen over the next 3 years. It is not known what this means for PPI, but the PPI Programme will be delivered with reorganisation in mind.

The national CRN PPI leads continue to meet to support delivery of the Programme as the CRN PPI Steering Group. The group's members and their work is underpinned by a CRN PPI Professional Development Group with the PPI leads meeting as an action learning set to share knowledge and develop their capacity to meet the changing demands in the environment.

Department of Health
Tony Williams was unable to make the group meeting but has produced an update of activities undertaken by the NIHR Evaluations,Trials and Studies Coordinating Centre (NETSCC) and the Central Commissioning Facility (see page 7).

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6. Update on Conference 2012

Stuart Eglin provided an update on the 2012 INVOLVE Conference. Stuart reported that planning for the conference is going well. The Call for Presentations resulted in over 200 applications which was over twice the number from the previous Conference. Following reviewing and scoring by several members of the Conference Planning Group, there will be approximately 60 workshops and papers, 60 posters, up to 15 speed sessions and several other presentations and exhibitions. Stuart informed members that the draft programme is available on the conference website and the final programme will be available at the end of June. Stuart also reported that Iain Chalmers has agreed to be the key note speaker and Alison Faulkner has agreed to introduce the end note speech of the conference which will be by Simon Denegri.

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7. Director's Report – Paper 1

Sarah reported on recent events and activities not included in the report.

The new INVOLVE Operational plan will be available on the website within the next month and there will also be more information added about the projects.

Two new INVOLVE publications are now available on the website and can be downloaded (anyone requiring paper copies should email Helen Hayes):

- Public involvement in research: impact on ethical aspects of research
- Strategies for diversity and inclusion in public involvement: Supplement to the briefing notes for researchers

At the last meeting we discussed support for new members and we are currently

exploring possible ways of doing this and will feedback on plans in the coming weeks.

8. 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.

9. Any other urgent business not included on the agenda

Simon Denegri briefly reported on the morning discussion with members leaving INVOLVE and plans to establish an associate scheme.

Action: INVOLVE to establish an associate scheme for ex members of INVOLVE, including an opportunity for them to meet at the INVOLVE conference.

David Evans reflected on the Open Space event held in the morning and asked for feedback from members. Members who initiated a discussion were asked to take away the flipchart and send back to the Coordinating Centre a brief summary of 4-6 bullet points on the key issues covered.

Action: Members who initiated an open space discussion to send back notes of discussion to the Coordinating Centre

10. Dates of future meetings

- 19 – 20 September 2012 Annual INVOLVE symposium
- 13 – 14 November 2012 INVOLVE Biennial Conference
- 22 January INVOLVE Group meeting

NIHR update June 2012 Tony Williams

NIHR Evaluations, Trials and Studies Coordinating Centre (NETSCC)

- An internal communications event was held at NETSCC to celebrate the first birthday of the PPI framework.
- The policy on payment to external reviewers continues to be refined, and will be taken through internal approval processes shortly.
- There was a joint meeting between NETSCC, Central Commissioning Facility (CCF) and the National Institute for Health and Clinical Excellence (NICE) to discuss how the three organisations could work together.
- Alison Ford presented on NETS programmes and their commitment to PPI at (1) an event held jointly by the Research Design Service (RDS) South East, and the University of Kent and (2) a similar event at University College London (UCL). At the Kent event Alison also led a workshop on PPI in research proposals, jointly with the SE RDS's lead officer for PPI.
- The PPI team are feeding into a NETS-wide project around External Review, and work is underway to review existing PPI review processes, forms and guidance, including consultation with current NETS programme reviewers.

PPI Working Group in Central Commissioning Facility (CCF)

The PPI internal working group made up of the PPI team, the Head of Research Management and PPI leads and champions from the teams met three times this year. The group finalised a draft working document which sets out the objectives for 2012-13 and a strategic plan for 2012-15. A summary of this plan will be disseminated to a wider audience including the PPI members of committees and panels.

The group addressed PPI topics held in common by NETS CC and CCF including payment for PPI tasks and held a focus group meeting to which a speaker from NICE was invited, together with the NETS CC PPI manager. The aim of the focus meeting was to share good practices and discover areas for future collaboration.

NIHR Themed Call in Surgery 2012 / 2013 – PPI team are sourcing the PPI reviewers for the call in addition to the usual requirement for the lay review for each programme: Research for Patient Benefit Programme (RfPB) grants and Invention for Innovation.

Training - PPI manager and RfPB are progressing the online distance learning resource for PPI members of committees and panels.