

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

Nick welcomed Pete Fleishmann who was attending his first meeting as an observer from the Social Care Institute for Excellence (SCIE).

Nick then informed members that it was Peter Beresford and Mary Nettle's last meeting. He thanked them for their sterling contribution to INVOLVE since joining the Group in 2002 and for the compassion and determination they had shown around service user involvement.

Declarations of conflicts of interest:

No conflicts of interest were declared.

Apologies

Apologies had been received from:

Ade Adebajo

Peter Beresford (am only)

Ann Louise Caress

Alison Faulkner

Ray Fitzpatrick

John Hughes

Hugh McLaughlin

Mark Petticrew

Vanessa Pinfold

2. Notes of the meeting held on 26 January 2011 and any actions taken since the meeting

The meeting notes were agreed as correct.

There were no actions.

3. Director's Report and budget update – paper 1

Sarah Buckland introduced the Director's Report and highlighted some of the pieces of work that the Coordinating Centre were currently working on.

Lucy updated members on the plans to recruit new members for INVOLVE through an open application process. Three open information meetings across England would enable prospective applicants to meet existing INVOLVE members and receive advice and support on the application process. Lucy will be contacting members to invite them to assist with the information meetings once the dates and venues have been decided.

Members were interested to hear about the joint INVOLVE/National Research Ethics Service (NRES) project which had been discussed by Evidence, Knowledge and Learning in the morning. Sophie reported that the working group had considered it to be a very useful and helpful piece of work that provided a good baseline of information for future monitoring. Members thought it would be helpful to identify if there was a possibility of accessing any additional data on public involvement from the IRAS application such as the budget for public involvement in research.

It was agreed that this study would be of interest and have the potential to influence a wide audience.

Helen updated Group members on the development of the new INVOLVE website and the new briefing notes for researchers. Both of these pieces of work are in their second phase and it is planned that they will be launched in the summer.

4. Reports from:

Tony Williams – National Institute for Health Research (NIHR)

Tony Williams congratulated Simon Denegri on his appointment as the in-coming Chair of INVOLVE. Tony reported that 14 people applied for the post and 4 were interviewed. He also extended his thanks to Peter Beresford and Mary Nettle as outgoing members of INVOLVE and for all their commitment and hard work over the years.

Tony reported that the NIHR Evaluation, Trials and Studies Coordinating Centre (NETSCC) Patient and Public Involvement framework has now been signed off and that Manchester Biomedical Research Centre has produced a report on patient and public involvement: <http://www.manchesterbrc.org/AboutUs/News/article.php?id=22>.

Other NIHR updates are available on the website:
<http://www.nihr.ac.uk/Pages/default.aspx>.

Roger Steel – NIHR Clinical Research Coordinating Centre (CRN CC)

Roger reported that the CRN patient and public involvement business case was submitted to Department of Health (DH) in March 2011. An announcement from DH is expected shortly. On behalf of Anthea Mould and Derek Stewart, Roger thanked Simon Denegri for chairing the 'Way Forward' Steering Group and Lucy Simons, Maryrose Tarpey and Sarah Buckland for their contribution to the work groups. The working model proposed in the business case is one of shared leadership for PPI across the networks, with different networks taking the lead on specific aspects of PPI work for all the networks.

Roger also said that the NIHR Clinical Research Networks had just produced a publication edited by Derek Stewart '**Making the Difference: Patient and Public Involvement The Way Forward: Examples and evidence from the Clinical Research Network**'. This can be downloaded from:

<http://www.crnc.nihr.ac.uk/Resources/NIHR%20CRN%20CC/PPI/Documents/Making%20the%20difference%20May%202011.pdf>.

Pete Fleischmann – Social Care Institute for Excellence (SCIE)

Pete began by introducing himself to members and then briefly gave a description of SCIE's work. He explained that SCIE is an independent charity, funded by the Department of Health and the devolved administrations in Wales and Northern Ireland. SCIE aims to provide the evidence base to inform social care practice, similar to the role that the National Institute for Health and Clinical Excellence (NICE) plays for health. It has a wide range of resources available in various formats, including social care online which is a searchable database on social care information and research. The Partners' Council is the key forum for ensuring service user involvement throughout SCIE's work and boards.

Pete reported that SCIE is establishing a new working relationship with NICE on producing joint quality standards for provision of health and social care. It is also working on personalisation of adult social care and publishing a new leaflet on payments for involvement to service users and carers. See SCIE's website for further information <http://www.scie.org.uk/>

5. INVOLVE Strategic Plan consultation – paper 2

Nick introduced this item explaining that we had received thoughtful responses to the survey consultation on the draft Strategic Plan. He reminded the Group that further development of the plan will be in the context of what we are contracted to deliver by the Department of Health. Each working group had discussed the report on the consultation in the morning session and had been asked to consider two questions:

What is your overall view of the ideas and suggestions provided in the report of the consultation?

The overall view was that the main direction of the comments from respondents was supportive of the work we do and areas that we are aware need to be progressed. While the responses included some helpful suggestions for particular areas of future work, many of these were already underway. Therefore we should think carefully about how we can more effectively communicate with our audience about what we do.

Ideas for areas to prioritise in the Strategic Plan were:

- Exploring what evidence is needed to convince those sceptical about the value of public involvement, and how to increase the quality/robustness of evidence.
- Link the type of evidence we are producing to what will be the key drivers for our stakeholders to change their practice. For example, for industry the main driver is recruiting participants on time and to target, therefore we need to demonstrate how public involvement can improve the design and patient acceptability of trials.
- Monitoring the implementation of public involvement in funded research, for example through final reports. However members were clear INVOLVE should not have a regulatory or 'policing' role but should be one of facilitating.
- It was important not to lose sight of the necessary variation in involvement practices.

- While there was sympathy for the suggestion for further funding specifically for research into public involvement in research - it was also thought that it was important to embed such research more widely, into existing funding streams.

The next stage will involve further consultation with key stakeholders – who do you suggest we should be talking to in this next phase?

Specific suggestions included:

- those who are sceptical about the value of public involvement in research, for example, traditional clinical researchers.
- top-level people and key leaders, for example, Chief Executives, Vice Chancellors and Deans in Higher Education.
- the large funders (NIHR, Research Councils, key medical research charities)
- journal editors
- social care, for example the NIHR School for Social Care Research
- Healthwatch / Department of Health patient involvement and experience lead.

Members felt that some people may not have responded to the consultation (e.g. some research funders and managers) because they felt that they had other avenues to influence INVOLVE and therefore there was no need to respond. It was felt though that some people may have been put off from responding to the survey because they would not be familiar with contributing to strategic plans and may not understand how they could usefully contribute. Therefore different methods would be needed if further involvement of a broad cross section of people is required.

The suggestion to undertake individual interviews with key individuals from the groups identified was supported.

6. Membership recruitment plans

Nick outlined the audit of current members which has already been completed and which identified current member's skills and experience. The audit identified the need for ensuring diversity amongst the new members. Nick informed the Group that we will be advertising for new Group members in June 2011 and will be conducting interviews in September 2011. In order to encourage diversity amongst members we will aim to achieve a balance of one third of members having a social care or public health perspective and approximately half of all members bringing a public perspective. Therefore, in order to redress the balance we will need to recruit more new members bringing a public perspective than other members.

The application process is being adapted accordingly, and will include a diversity monitoring form as well as offering greater guidance and help for people on how to effectively complete the form. A statement of support will also be required from host organisations where applicable.

There will be three recruitment information meetings for potential members, hosted by the working group chairs. These will be held in Bristol, London and Manchester

and will provide potential candidates with information about applying and about what is involved in being a member. The events will be open to all potential candidates, although attending an event is not a requirement for anyone putting in an application.

Group members will be invited to assist at the events, and it would be helpful if members distributed information as widely as possible. Lucy Simons from the Coordinating Centre will be taking the lead on this work.

In discussion, the members raised a number of suggestions and issues for the events and how they are advertised:

- The advertisements should mention that INVOLVE pay an attendance allowance for members of the public who attend INVOLVE meetings – this may help to encourage people.
- It should be made clear that expenses will also be paid for all members.
- Pete Fleischmann (observer from SCIE) will consider how he might be able to help disseminate information about the membership recruitment to social care users .
- Advertising in local papers may help access a wider range of people.
- Contact papers, for example the Metro in London and Manchester. They may include a short article about the events, which would be free for INVOLVE.
- Consider advertising on the jobs.ac.uk website.
- We need to consider how to access people in areas of the country where the information events will not be held (e.g. the east and north east of England)
- It may be useful to provide contact names and details of some Group members so people who cannot attend the events can phone to find out further information.
- Are there any other events which Group members are attending which we could use to access people who can't attend the main three events?

7. Operational Plan 2011 / 2012 – paper 3

The Chair reminded members that INVOLVE's Operational Plan 2011 / 2012 had been developed and refined as part of INVOLVE's annual planning cycle. Many of the projects in the plan built on what had been learned and developed in previous years. The Group agreed to formally adopt the plan. In discussion the following points were noted:

Strategic Alliances working group – INVOLVE conference 2012

The working group requested to be informed at the earliest opportunity of the outcome of the business case that had recently been submitted to the National Institute for Health Research to hold a conference in 2012.

Evidence, Knowledge and Learning working group – Public involvement in Patient Reported Outcome Measures (PROMs)

The importance of active public involvement in this area was perhaps not reflected as strongly as it could have been in the Operational Plan, particularly in relation to the development of the NHS Outcomes Framework. It was agreed that there was a need to maintain a close watching brief on this area and to continue to consider more substantive action.

8. Feedback on discussions from working groups

The following chairs of each working group gave a post card report from their group:

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|----------------------------------|-----------------------|
| Strategic Alliances | - Stuart Eglin |
| Evidence, Knowledge and Learning | - Sophie Staniszewska |
| Empowerment | - David Evans |

Please see separate meeting notes for each working group.

9. Any other urgent business not included on the agenda

There was no further business.

10. Dates of future meetings

14 and 15 September 2011 – Awayday
14 December 2011.
