
**Notes of the thirty second meeting of INVOLVE held at
Skipton House, Elephant and Castle, London on 2nd
June 2004**

Present: Nick Partridge (Chair)
John Sitzia
David Johnstone
Mary Nettle
Kate Sainsbury (Vice Chair)
Sarah Carr
Peter Beresford
Ruth Sinclair
Vinod Kumar

In attendance: Carol Lupton
Kay Pattison
Joan Box
Sir Ian Chalmers
Patricia Atkinson
Deborah Tallis
Sophie Staniszewska

Sarah Buckland (Support Unit)
Barbara Dawkins (Support Unit)
Helen Hayes (Support Unit)
Roger Steel (Support Unit)
Sarah Bayliss (Support Unit)
Jane Royle (Support Unit)
Philippa Yeeles (Support Unit)
Maryrose Tarpey (Support Unit)

1. Introductions, welcome and apologies, declarations of conflicts of interest (annex C)

Firstly Nick referred everyone to Annex C – conflicts of interest and asked Group members to complete and return their forms to the Support Unit. He also asked the Group whether anybody had any declarations to make for the meeting.

No declarations were made.

Nick welcomed the following to the meeting:

- Sir Iain Chalmers and Patricia Atkinson both from the James Lind Library
- Ruth Sinclair, Director of Research at the National Children's Bureau (who has joined alongside David Johnstone, as new members of the main Group)

Apologies had been received from:

- Derek Stewart
- Catherine Law
- Mike Kelly
- Jane Durham
- Robert Johnstone
- Morton Philipps
- Chris Caswill
- Elizabeth Mitchell
- Stuart Eglin

Nick advised the Group that Stuart had joined the main Group and had also agreed to be chair of the Strategic Alliances sub-group.

Nick announced that he was very pleased that Kate Sainsbury had agreed to be the new Vice-chair of the main Group. Nick welcomed Kate as the new Vice-chair.

2. Notes of the meeting held on the 4th March (annex A)

There was an amendment to page 1 of the minutes as the spelling of Chris Caswill was incorrect.

Action: Support unit to amend this accordingly

3. Notes of any matters arising (annex B)

Skills and experience of Support unit (annex D)

Sarah advised that the updated Members Information Pack would be available shortly. They had decided to wait to get summaries from new members before updating the pack.

Conflicts of interest declaration (annex C)

Vinod pointed out that on page 2 of the declaration, it states that the Chair will rule on what action to take (for example, a member with a conflict of interest should be required to leave the meeting). However on the form to be completed by each member, there is no mention of this. Nick agreed that an amendment needed to be made to the form to include this.

Action: Support unit to make this alteration

Sarah advised that in due course the Group would be advised regarding who would take the lead on each part of the operational plan.

Philippa reported that the Skills and Experience Report relating to the Support Unit staff was now complete. She explained that this was produced so that Group members would know who to contact regarding specific issues.

4. Sir Iain Chalmers The James Lind Alliance (annex E)

Nick advised the Group to see information regarding this on annex E, which lays out what the three Co-convenors, Nick Partridge (Chair, Involve), Iain Chalmers (Editor, James Lind Library) and John Scadding (Associate Dean, Royal Society of Medicine) hope to achieve from this Alliance. (Iain also circulated copies of an article about the Alliance).

Nick reported that this was a time-limited exercise, which would either work and develop its' own structures or it wouldn't. He advised that there was an exit strategy in 2 years time, which he felt was long enough to see if patient groups, patient organisations and groups of clinicians would find it helpful in identifying and trying to address where there are areas of uncertainty in clinical trials.

Nick thought it was a really exciting initiative. He was really pleased that Iain had pushed the initiative forward and found such a good collaborator in John Scadding. He suggested that INVOLVE could offer a good level of patient and consumer involvement in the on going process of identifying new areas for clinical research.

Iain Chalmers talked briefly on how the James Lind Library had started (www.jameslindlibrary.org). He then went on to discuss the James Lind Alliance.

Iain (part-time) and Patricia (full-time) are funded two thirds by the Medical Research Council and one third by the Department of Health. Their brief is to see how there could be greater engagement in non-commercial clinical trials, amongst patients and professionals. They concluded that the main people to engage, who have to confront uncertainties, are patients and clinicians. The James Lind Alliance will attempt to invite coalitions of patient organisations and organisations who represent clinicians to apply for membership of the James Lind Alliance. Their purpose would be to consider what the most important uncertainties are within their sphere and to lobby for the most important questions to be addressed. Some of these questions would be addressed by industry or they might have to lobby elsewhere, it would be a campaigning enterprise.

There will also be the opportunity for affiliate members from organisations other than patient or professional organisations, for example, the National Electronic Library for Health or the Welsh Assembly.

Sir John Pattison supported the involvement of INVOLVE in the Alliance as a way of helping to ensure that the views of patients and clinicians are being taken seriously.

Iain explained that when he used the term clinician, he meant all those responsible for looking after patients. He commented that the Royal Society of Medicine covers all clinicians including nurses and other health professionals.

Nick advised that there had been a significant fall in non-industry funded trials over the last 15 years. He felt there was now potential with the UK Clinical Research Collaboration, (which Sarah and he attend on behalf of INVOLVE) and the Alliance, to move the whole agenda forward.

The UKCRC has recently been established to encourage trials within this country. They looked at the success of the National Cancer Research Network and plan to replicate it in other areas of research through a collaboration. It will have a small staff based at the MRC, and considerable investment of 2 billion (over several years).

Questions:

Several Group members commented on how they welcomed the initiative. The following specific questions were raised:

What would be the role of the alliance and its objectives?

The objective was to influence the clinical research agenda in a way that is perceived relevant to the needs of patients and clinicians, so that they have more of a say than they currently do.

How could the NICE agenda be influenced?

Currently when NICE makes a research recommendation it is not clear how they prioritise their recommendations or how they should be taken forward. Iain hoped that over the next year or so, there would be an interaction between various bodies (such as the HTA, NICE and the James Lind Alliance) and they would come up with well-founded ideas for future research, having looked at what is available already and how to take them forward.

Whether the Alliance would include both health and social care?

Social workers, particularly in some circumstances have a very important role to play. If questions arise relating to the effects of their practice, then they could become part of it.

What plans were there to ensure inclusive involvement to take the Alliance forward (important to get the structural processes right about involving people on equal terms)?

Would look to INVOLVE for guidance. At least one organisation representing patients and one organisation representing clinicians would have to have an agreement themselves that they will work together - only if they work together would they be able to become a member. By coming to the James Lind Alliance to address important uncertainties, this would force and encourage the development of the sorts of people who are prepared to listen to the other side. INVOLVE could help to decide how the interests of patients can be properly represented and what sort of guidelines would be appropriate.

Will there be individual membership, or will the meetings be open?

There will not be individual members, and meetings will be closed meetings of the coalitions of organisations. Nick reported that within the meeting between each individual coalition, the major challenge would be how to ensure that the diversity of views is heard. We should look to see that the convening Group brings in a range of views.

Not everybody chooses to get involved with patient groups, and even if people join patient groups it can still be difficult to influence the agenda. How therefore can you get the right balance when discussing priorities in a particular area?

INVOLVE should be able to answer such questions as they have the expertise.

What resources are available to support patient / public involvement in the Alliance?

It is planned that there will be no membership fees for the first few years for organisations. Patient organisations must decide whether it is a sensible use of their resources. People need to find ways of getting resources or linking with others.

Whether controlled trials were 'one' way or 'the' way to develop an evidence base to challenge uncertainty?

Clinical trials have a place, it's one place; you need them when there is uncertainty. Iain advised that it was because clinical trials were not done that many people have died unnecessarily. The remit of the Alliance was non-commercial clinical trials as that was where many of the uncertainties exist.

How would the Alliance cover uncertainties regarding quality of life for non-curative conditions?

Would the Alliance be engaging with those organisations and practitioners, who were giving patients the choice of complementary therapies?

Does the Alliance have a role in lobbying research commissioners?

It is for patients and clinicians (including social workers) to decide what the important questions are for them. The way that the Alliance develops, will be for the members to decide.

What is the relationship between The James Lind Library and the James Lind Alliance, and will people get confused between the Library and the Alliance?

The James Lind Library was a way of introducing people to the way that testing treatments have evolved. This would not stop in 2006 and would carry on indefinitely.

Joan Box said that the MRC was supportive of putting patients and clinicians in the driving seat and addressing uncertainties. The MRC Advisory Group on Public Involvement would be keen to help on the patient side as was seen fit.

Nick thanked Iain for coming to the meeting and leaving INVOLVE with a good set of ideas to take forward.

5. Draft INVOLVE Public Health Strategy (annex F)

Philippa reported that she was very interested to get feedback from people along with their thoughts and comments on the paper. She hoped that we could increase positive activity from Group members working alongside the Support Unit in delivering this. In the past we have not known how to work well with public health and it has been easier to pick up the social care remit than the public health remit. Philippa felt this strategy was a way of bolstering up public health and bringing it up to speed, with the expertise we have elsewhere. The strategy is quite modest but aims to be achievable. Nick thanked Philippa and members of the Group who had helped in commenting on the strategy. Nick asked if everyone was happy with the key messages on page 5. No amendments were recorded.

Nick moved on to discuss page 8: Priorities, Aims and Activities, and whether the 3 priorities of Raising awareness, Partnership working and Capacity development, were the right ones.

John Sitzia wished to add a further priority about Monitoring and Evaluation. He wanted INVOLVE to consider what data existed on service user involvement in public health research.

Action: Philippa and John to think about how to include this.

It was suggested that under 'Aims of raising awareness' there could be a third point which would be 'raising public awareness of involvement in public health research'. Philippa advised that we have limited capacity as the plan only covers the next nine months and this was maybe something for the future.

It was suggested that the target on page 10 should be changed to 'To increase INVOLVE's knowledge and understanding of public involvement in public health research'.

Action: Philippa to amend accordingly

Nick reported that Philippa had written INVOLVE's response to 'Choosing Health Consultation'. However the deadline had been extended by 1 month and there was time if others wished to send in comments.

Action: Support Unit to email the INVOLVE response to the Group.

6. Membership of Involve (annex G)

Nick thanked the Support Unit and Group members who were involved in the interviews and all the background work involved. He raised the following points:

- Annex G paper was only confidential because at the time of sending it, not all had replied – (all new members have subsequently confirmed acceptance)
 - There was a good mix of people who applied to become members.
 - An introduction day for new members is planned at the Kings Fund on the 23rd of July. Any members who would like to attend, to contact the Support Unit by the end of June.
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7. INVOLVE's Operational Plan (annex H)

Nick advised that we have not been able to take on as many initiatives as we would wish, due to resource constraints, but it is a good programme of work. The process for this year had been more structured in developing job sheets for each activity. He advised that the sub-groups had been looking at the operational plan that morning. Kate commented that her sub-group thought there was a lot of cross over work between the sub-groups.

There was a suggestion that the links in the electronic Current Awareness sent to members needed to be checked as they did not always work.

Action: Helen Hayes to check these links.

It was pointed out that on page 4 of annex H, it should read 'Investigating options for developing *electronic* discussion forums.....'.

Action: Sarah Buckland to amend accordingly.

8. Planning for the awayday

Nick made the following points about what will be happening at the awayday:

- This will be the first Group meeting for the 9 new members.
- Sandy Oliver had agreed to come and give a presentation in the evening of the 5th October about the evaluation they are doing on public involvement in the HTA programme. This could be part of a session around building an evidence base re the value of public involvement.
- A discussion will take place regarding the paper that will be produced by the working group around inclusion. This will be on how we could consider possible structures and processes by which we can take forward the issue of integrating public involvement more successfully into INVOLVE.
- Nick suggested that there could be a wider discussion around accessibility, which might link across to how we integrate public involvement more successfully in INVOLVE itself.

Other suggestions from Group members were:

To spend time taking stock, and discussing the implications of where we have got to so far, and where we might be going next in terms of process issues. (To

discuss how we mirror some of the difficulties we are trying to resolve because of the constraints on us, for example in terms of resources).

To discuss what we could tell the James Lind Alliance or others, about involving consumers. INVOLVE has already produced a lot of material about how to involve the public, but there are issues around how to interpret this information in particular circumstances. What are the tricky issues that can be faced in practice.

**Action: Support Unit to send members details of the venue and timing of the awayday.
Nick and Sarah to consider how to construct the agenda for the awayday. Sarah to email the draft agenda to Group members.**

9. Reports from sub-groups

John, Kate and Nick gave post card size reports on the sub-group meetings (see the sub-group minutes). Items covered included:

Empowerment

- Colliding worlds video (capturing the experiences of the researchers involved in the TRUE project)
- Public health flyer
- Public perceptions of public health
- Guide to involving young people
- Occupational health interviews
- Training seminar and dissemination of TRUE report
- Database of training
- Leaflet about public health for the public
- Terms and conditions / code of practice for people getting involved in research (article by Peter Beresford)

Action: Support Unit to re-circulate Peter Beresford's paper to all Group members

Monitoring and Evaluation

- Evaluation of London Primary Care Projects
- Evaluation of Folk.us
- Definitions of user controlled research
- Duty of care of INVOLVE when commissioning research
- Toronto Group Seminar
- Routine monitoring of the Support Unit activity
- Plans for monitoring of public involvement in NHS Trusts

There was some discussion regarding what duty of care INVOLVE has as commissioners of work. Points were made around the balance between not putting undue pressure on individuals and being supportive and flexible with projects, alongside being fair in the allocation of funding. Issues around external and independent review and research governance were discussed alongside the imprecise science of scoping the extent of the work involved (for both researchers and commissioners). The Joseph Rowntree Foundation for example have a 10% margin for unexpected additional costs.

The sub-group asked whether additional money could be made available towards the cost of producing the final report for the Toronto Group seminar. Roger replied that as far as he understood, the original £1,000 that was given to the Toronto Group by the Empowerment sub-group in March 2004, was sufficient.

Strategic Alliances

- Ethics and public involvement
 - Strategic work with NHS Trusts, ESRC etc.
 - Working with National R&D Programmes
 - Conference plans
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11. What's new in the Department of Health (annex Q)

Kay Pattison reported the following:

- Professor Sally Davies would be taking over from Sir John Pattison as Director of Research and Development. A copy of the new structure will be sent around shortly.
- The Department of Health are losing a lot of administrative staff. As a consequence they will no longer be able to book rooms at Skipton House as they have not got the staff to do the tasks. There will also be changes as to how the Department of Health makes payments for INVOLVE. A lot of these will be taken over by Leeds University. There are also problems with their new computer system and therefore the budget paper will follow at a later date.

Carol Lupton then gave a presentation about the work of the Policy Research Programme. Annex Q provides some background information about the PRP. Carol also circulated copies of the overheads of her presentation.

A brief discussion then took place regarding this presentation.

11. Director's Report (annex I) and budget update

Sarah had nothing additional to report.

12. Any other urgent business not included on the agenda

No further urgent business was reported.

13. Dates of next meetings

- Awayday 5th and 6th October – sub group meetings to start at 2.00pm
- 08 December – next full Group meeting
- INVOLVE Conference 10th and 11th November