
**Notes of the thirty fourth meeting of INVOLVE held at
The Commonwealth Club, 18 Northumberland Avenue,
London WC2 on 8th December 2004**

Present: Nick Partridge (Chair)
John Sitzia
Mary Nettle
Kate Sainsbury (Vice Chair)
Sarah Carr
Peter Beresford
Ruth Sinclair
Vinod Kumar
Derek Stewart
Stuart Eglin

In attendance: Tracey Williamson
Catherine Law
Tony Stevens
Grace Wise
Chris Caswill
Sue Banton
Lester Firkins
Maria Palmer
Deborah Tallis

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)

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- 1. Introductions, welcome and apologies, declarations of conflicts of interest (annex A)**

Nick reminded the members that as usual we were recording the meeting for the sole purpose of recording accurate minutes and that we would be putting the minutes on the website (after they have been agreed).

Nick asked whether anybody had any declarations of conflicts of interest to make for the meeting.

Peter Beresford declared a conflict in relation to User Controlled Research.

Nick advised the group that at the next meeting name badges would be available.

Nick welcomed all the new sub-group members attending their first Group meeting.

Apologies had been received from:

- Robert Johnstone
- Morton Phillips
- Kay Pattison
- David Johnstone
- Carol Lupton

2. Away day report (including notes of Business meeting) Annex A

There were no corrections to be made to the business meeting notes for the Away day report. Nick thanked the support unit for all their help during the away day.

3. Definitions of User controlled research.

Peter apologised that the report was not ready although most of the work had been completed, he had to make some practical changes on how it was done but he had done what he had set out to do.

Peter highlighted the following points:-

- The fieldwork was done by Michael Turner from Shaping Our Lives, unfortunately the involvement of Folk us could not happen due to other

commitments they had, this additional time was taken up by Michael Turner, which was helpful due to the restricted budget.

- It has changed Peter's understanding of where we are with discussion on User Controlled research.
- What struck Peter was how complex and rounded the feedback was, not only from the literature review but from the diverse range of groups of service users they spoke with and from those who submitted information on an individual basis. There was a complex picture.
- There was a remarkable degree of consistency of what people were saying in how it relates to the broader literature although there were a wide range of people involved and a range of different related research approaches that user controlled research touches on. He felt they got more insight from their fieldwork than the literature.
- There was at least one major disagreement, which was very interesting.
- There are big barriers that people talk about, but which are surmountable.
- He thought there were some areas that amount to discriminations which may not be intentional but are what people face in terms of how user controlled research might be perceived more broadly.
- He felt there might come a valuable stage of producing guidance material.
- He felt there was a job of systematic dissemination to break down some of those barriers, not just to offer guidance but to get the message out more broadly, because he felt there was an unnecessary sense of user controlled research frightening the horses.
- He would never again take on a task that was not adequately funded. He felt a good job had been done with £15000.

Nick commented that he looked forward to seeing the report in the New Year.

4. INVOLVE Conference – update and discussion

Kate advised the group on the preliminary feedback findings from the conference

The good feedback was as follows

- Overwhelming support for the Orpheus Centre finale, some felt it was the highlight and should have opened the conference.
- Many felt the accessibility of Nottingham and the East Midlands Conference Centre was good.
- Many felt it was better run over 2 days than 1.

People enjoyed the following:-

- Networking
- Choice of Parallel sessions
- Friendly atmosphere
- The balance between the public and professionals attending.

What did delegates least enjoy:-

- Majority of comments were from researchers or professionals about a confrontational and hostile environment, comments including feeling marginalised, stereo-typed, researcher bashing, alienated, feeling like one of the bad guys.
- Poor quality research, interpretations of research findings that have dubious validity that went unchallenged.
- Being a good quality researcher involves many years of training. Involve seems to allow people to think they too can become researchers with half a days training.

Kate reported that there is a comment that we could take forward which somebody wrote. They said “as an R&D Manger user involvement is a huge challenge. We were hoping to come and learn more about strategies for developing user involvement. We did not feel the programme gave us this. Balance seems to have shifted towards user focus and not how we can work together. Uncertain now if Involve is a resource to assist R&D to improve user involvement or whether it has become the organisation representing supporting users themselves.”

She felt this was a point that we needed to debate, she advised that at the Away day Rosemary Telford had reported findings and highlighted that researchers feel a need for more education, more guidance and training and advice on how to access members of the public, so that is definitely a part of Involve’s work but on the other hand some of the work we have been doing on widening Involve’s inclusion of the public in our own research is something we also felt we had to prioritise. She suggested that this was always a balance we needed to achieve.

Kate then asked the group for their comments. They were as follows:-

- Mary felt that were plenty of examples at the conference on how to do it, it was up to people to go to those sessions.
- John reported that 3 separate NHS researchers came up to him during the conference. They had come to the conference thinking that they would be amongst a community of people who thought pretty much as they did and would be able to support them and offer them advice. They had come from an environment that was a pretty hostile environment to public involvement. They thought they would get some support and learn

- something, but all they got was a load more criticism from service users that they are not doing enough. They did not feel part of the conference community.
- Peter felt that we must think more about safer environments and think about how we can address it right at the beginning.
 - Nick suggested that we need to keep our friends and champions, within R&D, Public Health and Social care on our side and provide an encouraging environment, while at the same time remembering how tough the environment is. We need to think how to manage that better.
 - Vinod asked if we were a spokesperson for the users and public as has been perceived by these comments or are we bridge builders between users and researchers. He also thought that you do not make a researcher in half a days training and maybe what role service users can realistically perform in the whole research process, if we duck the issue we would lose a lot of potential support.
 - Nick asked Vinod for his views to his own question, Vinod felt we needed to encourage users to participate but should only be a spokesman and not take on board real problems of involving lay people in some very complex research tasks. We all need to be aware it is a big building role. He thought that some researchers felt threatened by user involvement; therefore we need to be aware of that and devise a strategy in dealing with that.
 - Ruth felt that a bridge needed to be built and we should facilitate users and researchers to engage together. She felt that when training users to be researchers it needs to be recognised what role they can play. She felt that everyone has different skills and it is a vital part to recognise and support.
 - Alison reported that there is a low understanding of research and the bridge building has a long way to go. In the future at the conference there could be an open workshop for NHS and Public Health researchers to come and talk about ways of doing it and to find out ways to do it. This would be a safe environment at the conference.
 - Chris felt that we should have a session where researchers can come together who have different points of view and can argue them out. He felt we need to be more sensitive to researchers.
 - Mary commented that the Poster Session worked very well for lots of people.
 - Stuart reported on the behalf of Strategic Alliances and that they had discussed whether we do things in a different way at the next conference. They felt that 280 was less than 400 the time before but they felt it's not about the numbers but that we get the right mix of people, we need to think about that at the next conference, who we need to engage.
 - It was felt that there were very few NHS and Health Care researchers there and if we want to be successful we need to address the issue.
 - Lester thought that we should involve people who we think should come to the conference into the Conference Planning group.

- Nick felt the great joy was to see such a variety of people including researcher and service users, taking part in research. He felt we should be really proud of how far we have come since 1996.
- Mary felt that maybe a section on Clinical Governance could be included in the next conference.

John thanked the Support Unit for all their hard work to make the conference so successful.

Peter commented that Saul Becker was the only Social Policy Academic at the conference and maybe we need to get on board some fields that are slower than us.

Stuart felt the inclusion was good and everyone had a chance to contribute.

5. Wider involvement in the work of INVOLVE (annex B)

A summary of all the networks, group members were linked to was put up on the wall. Nick advised that a copy would be sent around to everyone with the minutes.

Nick asked the group how the electronic discussion group and road shows needed to be taken forward and the mapping exercise related work which was being considered by monitoring and evaluation sub group.

Nick advised the group that they had the overall range of recommended actions and he wanted to check that the group was content and pleased how this was being taken forward.

Sarah read out the potential roles for INVOLVE members when engaging with wider networks

- Promoting public involvement within wider networks
- Promoting the work of INVOLVE within wider networks
- Acting as feeders / brokers with wider networks
- Providing advice to Support Unit
- Giving talks about INVOLVE to wider networks
- Feeding back to INVOLVE issues raised from wider networks (either as a result of formal talks, or discussions)

Derek asked if the person's initials could be placed against each link.

Sarah advised that we could put initials against each one if that was helpful.

Action: Support unit to put initials against each link and circulate with the minutes.

Nick advised that if anyone was not happy to have their initials next to the links to let the support unit know.

Roger wanted to remind the group from where this idea had come from. He advised the group that he had recently had a meeting with Fran Branfield from Shaping Our Lives about the demise of the reference group, the idea for this came out of the 2nd Social Care Workshop. Fran felt that the action points that came out were weak on engagement. She felt they did not address the issue that there were many people out there who are life long users of Social care and Health services who don't have a voice or have communications problems. The idea of a reference group was to provide a safe space, where the dialogue for people in that position could be increased and there could be a wider dialogue across Involve. He advised that she was disappointed on the rejection of the idea, however Roger advised that he was continuing to meet with Shaping Our Lives although he felt there was a long way to go with that and we needed to remember that when engaging with these types groups of people it costs money.

Nick felt that Roger needed to feedback to the people involved with this issue on how we are taking things forward.

Roger agreed to draft a letter in relation to this.

Action: Roger to send a letter to the people who attended the 2nd Social care workshop.

Alison felt that the way forward was to ensure that we talk to people we have involvement with and bringing those views in. The problem was that a reference group could be very large. It would be better to activate a series of smaller focus group around a particular function which ties in with the conclusion which is 'a watching brief needs to be maintained on this issue so that it not just in a sense a series of actions that are about networks but it is about what we are doing to widen public involvement in our work'.

Peter reported that it was all about trust in the second meeting and that we needed to feedback in the proper way. He felt that a lot of people would be disappointed. Peter requested that if it is a question of resources that we spell it out and make it clear to the people who provide the cash. But we need to make it clear as to the real reason why a reference group is not going ahead. He felt that some groups continued to be marginalized especially people who communicate differently, people with learning difficulties and people who do not fit into one

category or another . He advised that we can never over estimate the value of ensuring that as full as possible representation by black and ethnic communities.

Nick advised that we would make it clear when reporting back to all those who attended the workshop and make sure it was made clear that it was around resourcing and we would take it forward with the department.

Kate reported that within empowerment they had moved on and were developing an accessibility strategy. She advised that empowerment had recognised that the first stage should be a communication strategy and then when we have done that piece of work the second stage would be accessibility. She would want to feedback to the people attended the workshop that this has actually become the mainstream work of the group, being driven forward by empowerment.

Vinod advised that he thought the involvement of Black and Minority Ethnic groups should be within the mainstream of all activities of the group.

Grace reported that she thought the hardest group of people to reach as a researcher was the Black and Minority Ethnic groups, who are marginalised in their own communities especially disabled people with severe impairments living with their families who have little links to Social Services Departments. Grace also thought there was a need for training on accessibility for group members and staff of Involve.

Alison asked for clarification is there a difference between Disability awareness training and Accessibility training.

Nick asked if the support unit would take this forward with Grace and Susie.

Action: support unit to determine the difference between disability awareness training and accessibility training.

6. UK Clinical Research Collaboration – update and discussion

Nick gave a Brief description of UKCRC – see separate slides attached.

Nick reported that so far the contract for UKCRC co-ordinating centre has been awarded to the University Of Leeds & MRC led by Peter Selby and Janet Derbyshire. He advised that the contract had not yet been signed. He reported that one of the key elements within the tender was how the applicants would deliver on how to enhance public involvement in research. The tenders for Medicines for Children have been released and the deadline is due soon.

Firstly Nick wanted to discuss what we have learnt through what has happened in the Cancer Research Networks with Derek's help. He reported that as a group we can't provide support to all these networks nor would we wish to. He felt that we would need to be funded within each of these networks. He asked the question of how can we grow if we can grow by linking into the additional resource that the UKCRC has within it for patient and public involvement work. He asked how we see ourselves would it be as advisors or delivers. He advised that we don't know how much of the overall budget Leeds has given to public involvement or how much of that has been squeezed. However we have a huge opportunity here and it's how best we use all of our resources in order to maximize and ratch up public involvement across the networks.

Peter wanted to get a better picture as to whether there can there be money in it for Involve. He was thinking of the model that's developed with the Mental Health Research Network where there is strategic user led bit but also stuff going on in the HUNT?, where there can be a really helpful central role but not take on all bits and bobs in all areas, but where Involve may need the resources to have a central role.

Sarah reported that it had all been a bit rushed and she was not sure what was built into the proposal. She did not know if Involve would need separate money to advise from the outside or how it would pan out. She wanted to get a feel from people as to what was possible.

Nick advised that Involve had an odd constitution. He reported that we had never looked for money from elsewhere as our money had always come from DOH. He advised that we would have to have a discussion with Kay and Professor Sally Davies to see what it would mean to have additional monies from UKCRC.

Derek felt that the great dilemma was to feed this huge beast of NCRN institute which was a task itself. He felt that by being sat on a board you get sucked into doing so much. He reported that it would be a huge cost because Involve could spend every day of every week influencing agendas. He reported that we needed to be clear as to what Involve's role would be. He reported that in cancer they appointed Tony Stevens as full time worker for working for NCRN, who has built capacity and sustainability. He felt that we would need a co-worker in each of those fields, as this would make the long term difference. He also reported that the other role that Involve would play would be to enthuse all those new people that are in there. Derek questioned if Involve would play the role of lighting the fire under the bucket instead of filling the bucket. He reported that Cancer had an advantage as it already had Macmillan supporting its network groups. He felt that the ball that we would be rolling up the hill in these would be greater than in cancer.

Nick reported that he had found Derek's comments very helpful; he reported that each network would be very different. He felt that each network would need an internal staff resource.

Nick asked if there were any group members who wanted to get involved in or comment on the work streams, he asked if any one wished to comment as an advisory role, if they did would they email him over the next few weeks with their input into each of the work streams.

Derek advised that if he had achieved anything it was to persuade Liam O'toole that user involvement was a good thing and he his heading up this movement. He felt that Involve should produce a common response e.g. payment for users.

Sarah reported that there was some concrete work being done with UKCRC, to write the criteria for good practice or how things should be operated. She asked for any feedback from the group.

Alison reported that she was in the process of writing the criteria for Mental Health Research Network; she advised that there would be common issues that cut across all networks.

Ruth asked if we could use other funding streams alternatively to DH.

Sarah replied that we had received other money before e.g. London Primary Care which was money from a regional office. She reported that it sat a bit oddly but we made it accountable as it came to the support unit rather than the group.

Nick advised that it was still public money and commented that there must be way through this. He advised that his key concern was that we do not become victims of own success as there was the potential for over stretching ourselves. His main concern was that the scale and speed of new demands on the support unit and group would have substantial risks. He also advised that he felt lonely at taking this forward at board level; he felt that the UKCRC work should either be held by a sub group or another way would be by involving those interested to support him in this taking forward.

Tony reported cancer was quite different to the 5 proposed areas as the relationship between the research community and their consumers had already been established and the cooperation policy had already been grounded. Also the relationship between the scientific communities was not as hostile as some other areas. He felt that the things developed in cancer are generic to other diseases i.e. constitutions, good practice, reimbursement of consumers fees. He reported that there was full access of this information to others. He also reported that all this information was not put in a black box; they would want others to share this information. Other networks can adopt many things from cancer.

Derek advised that we should make sure we are clear as to what we are doing and not end up as a recruiting agency for all of this involvement. Derek advised that he wanted to help where he could.

John advised that this UKCRC initiative was the biggest thing with an awful lot of funding; he thought it was not fair for Nick to be fully involved and felt it should be up to the support unit staff to build this into their work and attend the meetings along with some group members.

Nick advised that Sarah already spent a lot of time going through the papers and advising him of anything he should be aware of.

Vinod felt that the lure of money was strong; he reported that he was inclined to go with Derek. He felt that if we were to become a recruitment agency this would be beyond our role and we could end up burning our fingers. He felt we needed to be clear in the role we are doing.

Nick replied that for us to do what we did for the cancer network for the 5 new networks and the ones thereafter, we will need an increase in our current staff and structure. Nick hoped we would be there as the generic centre.

Kate felt we can't miss out on the UKCRC and that Involve has to be a part of this.

7. James Lind Alliance – update and discussion

Kate led the discussion about the James Lind Alliance, She saw 5 purposes to the discussion:-

- 1 It was a chance for group to revisit this subject and engage with it and pass back some further information since the presentation made to the group by Iain Chalmers in June.
- 2 How and what can we do to work out a liaison between Involve & JLA's steering group (Lester Firkin is a member of the JLA Steering)
- 3 How to take forward the aspects of the JLA work that we might do in a practical i.e. sending out leaflets, promoting JLA on Involve's website.
- 4 How can our expertise in public and patient involvement be achieved with those groups which is their essential way of working.
- 5 Whether we at Involve can create a relationship with PRP or other funders that might enable an evaluation of the process of the JLA, so that any of the learning that started back in April can be captured towards the way in which uncertainties about prioritising are met.

Kate reminded the group that Involve's remit is to promote and support Public Involvement in NHS, Public Health and Social Care research and so this falls into Involve's remit and to go back to Sandy Oliver's evaluation of Public Involvement in HTA, where she said there was very little involvement in identifying topics for research.

Kate gave context, the JLA is not going to be the only way of going forward and trying to get more public involvement in identifying topics for research, but it is a way. And we at Involve are loosely linked as one of the sponsoring organisations and what we need to do is flush some of that out in a practical way.

Since our meeting in June, the first public meeting of JLA was held at the NICE conference. We felt we had a good robust meeting in June and raised lots of concerns with Iain. What was very interesting was that at the NICE conference all those problems and concerns came out again. This proved that what Involve had said enabled us to cover pretty much the whole area that got covered again when it went to wider constituency.

There is now a steering group, which is going to take the work of JLA forward, Lester and Nick are members and Sarah is a link person. So we have a channel to feed things through. We need to work on how to practically make a liaison between Involve and JLA steering group. Should we be creating a little sub-group or bedding it into a sub-group .

Peter asked if JLA had any money of its own, Nick explained that there was £20k to support Iain and Patricia, it was not clear to Nick how even for members meeting how those would be funded i.e. helping to meet people's costs to get to the meetings and for their time.

Peter thought that a helpful role we could play would be to offer some helpful critical discussion in a useful way, so that the James Lind Alliance could be more on the ball earlier on.

Kate replied that at the NICE conference the realisation was that the JLA will at best can identify and prioritise research but can only put pressure on and influence others to do the research, so the JLA is foreseen as really only a virtual research organisation.

Vinod explained that it was only a potential alliance but it could be a powerful pressure group with a difference, in that the patients could potentially have a strong voice, where as traditionally clinical research is dominated by pharmaceutical industries. The idea about this alliance is that it is looking at the uncertainties in research. The patients having a voice and determining the priorities and that makes it very different from normal research and makes it worthy of our support.

John thought that sub groups should not do this work. He thought that two formal representatives from Involve should on JLA steering group. He felt that the support unit did not have capacity for this and that we should have group members as representatives and taking the views of INVOLVE with them.

Sarah explained that we were not just an alliance of us feeding in but that what are we actually going to do to take things through.

John responded that we would need to build it in as a project in a sub group or on the main group as a priority.

Kate felt that we had not prioritised this work into our schedules.

Sue felt this was a fundamental shift in how members work and how members might go out and represent Involve. It should not be a project because of the time limit. Maybe people should do a term of say 2 years involvement in this. There are issues in how this is financed which is a big issue that needs resolving. She felt a bit reluctant to make decision as not enough information was available.

Stuart felt this was a bigger issue and was concerned this should not be a sub-group project without thinking about the process of the time commitment of the support unit and the members of Involve. He thinks it needs to be thought how much time and potential pressures this puts on people.

Nick added that he gets a lot of papers from JLA, which are public; he wondered if group members could be fed with some of these papers. He asked the group how best he could keep them up to date with progress.

Peter thinks the principles of JLA are great but was unsure how we can have a practical engagement to operationalise its principles.

Chris felt the JLA should not be the responsibility of the SA sub-group. He felt that Involve was struggling to adapt with all the changes. Maybe somebody needs to think how we can cope with this external work. This should be done positively and with some careful thinking. Chris was concerned that Public Health was being left out as a lot of time was being spent on Clinical Research agenda.

Nick agreed that both UKCRC and JLA talks about Public Health, but it seems to be that we will get around to it in a few years time. Unless we keep chivying it, its default position is going to be clinical interventions. The convenors are most at home with clinical work; our potential role is to ensure a better equity across public health and social care as well.

Lester thought that the JLA was still getting it's thinking together, however he was comfortable to take responsibility for reporting back.

Mary asked if they had decided what topics to be discussed first, Kate replied that when one clinician group and one patients group had got together then it would be decided by themselves.

Kate reported that we could go back to the JLA and at least state the position that we are supporting the work they are doing but we await developments.

8. Reports from sub-groups

See the individual minutes for a record of these meetings.

9. Plans for 2005 / 2006

Nick explained that at the sub-group meetings in October members had suggested plans for 2005/2006. The Support Unit staff had worked with Group members to develop job sheets for each suggestion. Sub groups had discussed these job sheets in the morning and prioritised activities. These priorities are detailed below.

Priority	STRATEGIC ALLIANCES	Estimated Budget
Comm	6.1 Developing guidance for public involvement in commissioning research (ongoing)	£5,000
Comm	6.2 Guide for involving service users in research ethics review bodies (ongoing)	£4,000
Comm	6.3 INVOLVE conference	£10,000
Comm	6.4 User controlled research project – Phase 2	?
1	6.5 Discussion forum	£2,000 (initial costs)
2	6.6 Public health research	£10,000-£15,000

3	6.7 Legal responsibilities of public involvement in research	£10,000
4	6.8 Developing links between the public and the research community	£3,500 (phase 1)
	TOTAL	£44,500 +

Priority	MONITORING AND EVALUATION	Estimated Budget
Comm	6.1 Dissemination workshop – evidence on the impact of public involvement in research	(separate budget)
Comm	6.5 Development of forum for researchers with an interest in researching public involvement in research	£5,500
1	6.6 Public motivation to get actively involved in research	£35,000
2	6.3 Publication of articles in relation to public involvement in research	£10,000
3	6.9 Barriers to involvement	?
4	6.2 Learning the lessons from evaluations (analysis of workshop)	£8,000
5	6.8 User led analysis of the experience of being involved in research	£25,000
6	6.7 Evaluation of public involvement in research committees and advisory boards	£2,000 (05/06) (£50,000 06/07)
7	6.4 Review of evidence / scoping study – concerns and criteria re public involvement	?
	TOTAL	£88,000+

Priority	EMPOWERMENT	Estimated Budget
1	5.7 Accessibility	£12,000
2	5.2 INVOLVE position statement on terms and conditions of involvement	£500
3	5.1 Leaflet on involvement in research	£600- £1,200
4	5.6 National training follow up event	£5,000
comm	Information pack update	
5	5.3 Information pack and guide for getting actively involved (public) Phase 2	£20,000
6	5.8 Dissemination of colliding worlds video	£3,000
6	5.9 Guide to doing user controlled research	£3,000?

Future?	5.4 Specific guidance on payment rates	£7,000
Future?	5.5 Research, risk and public awareness of research	??
	TOTAL	£51,000 +

Nick asked if there were any questions or concerns

Sue was concerned about the time to do 6.7 Evaluation of public involvement in research committees and advisory boards; she advised that Maria was going to speak to the R&D forum to see if they could do this piece of work.

Mary was concerned that we were not doing commissioning research any more.

Sarah replied that the DOH did not say we could not do commissioning but we could just do vital bits of commissioning that others could not do. There are implications on how we do it as Maryrose will only be with the support unit until April.

Stuart felt some of the pricing was a bit low. He thought that the some of The National Programmes could commission them themselves.

Nick advised that work plans would be available at the next meeting

Ruth would have found it useful if the strategic aims of Involve were linked to each job.

10. Director's Report (annex C)

Sarah advised that there was some confusion on the budget Annex D to say the email budget was wrong and a new one is available.

She also reported that the Helen had been monitoring the activities that we have been doing and a statistic sheet was attached to the director's report.

There are consultations coming up if anyone wants to feed anything back to the support Unit. Firstly The Academy of Medical Science were looking at use of patient data in medical research, the deadline was 10th December we will be doing a brief response, please get back to the support unit as soon as possible with any input.

Secondly the Social Care Ethics one that Roger is working on, if any one has any comments.

Thirdly there is a consultation on the Health Care Commission which is due in February, again please feed back to us.

Sarah advised the group that there was an Ad hoc Advisory group with Harry Cayton and Janet Derbyshire are on it. It is around ethics and reviewing and looking at COREC. We will be contributing to that, any ideas forward to us.

Lastly we came across through the NHS R&D forum, a letter from the Inland Revenue in relation to Lay people or users being involved in research that they should not be taxed at source for ad hoc activities. A copy of this is available from Helen Hayes at the support unit. Tony and Sarah will be taking this up with Leeds University to see if group members can be exempt from Tax and National Insurance payments for attending group meetings etc.

11. Any other business

None recorded

11. Dates of future meetings

Tuesday 08 March 2005 - The King's Fund

Tuesday 07 June 2005 - Royal College of Nursing

Thursday 08 December 2005 - Royal College of Nursing

Awayday - 05 / 06 October 2005 - venue to be confirmed
