

Public involvement in peer reviewing

A workshop session for lay peer reviewers

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Report

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Report: **Public involvement in peer reviewing workshop**

Background

The Health Research Design Service North West (Health RDS NoW) has been responding to requests to help support members of the public who become lay peer reviewers. We have done some exploratory work with the Mental Health Research Network in the North West about this. The National Co-ordinating Centre for Service Delivery and Organisation (NCCSDO) Programme contacted us through the Chair of the North West Users Research Advisory Group (NWURAG) with an interest in training for their lay peer reviewers and we arranged to pilot a one-day Reviewing Skills course with them. The workshop was designed to allow plenty of opportunities for questions, comments and discussion from the participants, both about the workshop format itself and about the kind of support lay reviewers need. More specifically, the day was to provide the NCCSDO with a chance to gain feedback on the guidance and systems their lay reviewers use.

Who attended

The NCCSDO provided the participants from its lists of lay reviewers. Ten people booked and nine attended. Some lay members are affiliated to regional or national lay groups, others were individuals with an interest in health services research. Those who had reviewed previously had worked with the Research for Patient Benefit, Medical Research Council and other health research organisations and one or two had very recently undertaken an Service Delivery and Organisation lay review via eCAS(the NCCSDO electronic reviewing system), and offered to share their experiences later on in the day.

What we did

The workshop was delivered by Sue Hinder of NWURAG, Barbara Langridge and Chris Langridge of the NCCSDO and Sara Morris of Health RDS NoW. The programme is attached as Appendix 1. Sara Morris as facilitator introduced the workshop; the resource packs sent out prior to the workshop formed the backdrop for the day. Sue Hinder and Barbara Langridge gave presentations in the morning; Chris Langridge was on hand to advise on the arrangements for reimbursement of expenses and offer expert support on eCAS. There were opportunities throughout the day during breaks for information gathering, informal questions and answers, support and networking.

Informal introductions were made around the table. It was noted that there was a wide range of experience amongst those attending although for some this was the first opportunity to look at lay peer review.

Presentation 1 – Sue Hinder (see Appendix 2)

Sue gave an excellent presentation on the topic of lay involvement giving a short history to the politics of lay review and the qualitative and quantitative aspects of research methodology. This was a very informative talk and key points from the presentation and discussion are:

- It is important to focus on the research methodology – background knowledge of research may be useful.
- Confidence, not only in reviewing but attending meetings is an issue
- Reviewers for other programmes of research say if they have the condition (this was relating more to clinical research)
- Lay persons should be involved at every stage, not just design and research, but in generating ideas – this is public money
- Lay reviewers will differ in opinion and see different things – users should be allowed to ‘relax’ and look for the pitfalls in the research.
- Plain English is crucial – the researchers should be able to explain what they are doing, if they cannot, there is something wrong with it!
- Lay involvement throughout helps keep researchers ‘on track’

Presentation 2 – Barbara Langridge

Barbara gave a presentation on the aims and processes of the SDO giving a short background to the Programme, its programme of work and commissioning groups. It focussed on the commissioning stages, and in particular, what is required of lay reviewers of full proposals and support systems for undertaking review.

Further handouts were given for the second half of the presentation (not included in the resource pack) which represented annotated screenshots of eCAS. Registration, log-in, and the content of the lay peer review form as it appears on line were demonstrated.

Questions were taken by Barbara and Chris and key from that discussion were:

- How do you define scientific merit? Is it a question that a lay person cannot answer? SDO ask all the commissioning group to consider in addition to the external peer review; the group is made up of a number of specialists, i.e. lay experts, academic experts, patients, public, NHS managers, Programme Board members. (NB: this participant did not realise that other experts do a peer review too)
- Glossary in the guidance resource pack is great.
- Is it possible to see other research calls on screen under MY ECAS – proposals to be reviewed? As a peer reviewer (not a commissioning group reviewer) only those proposals to which you have been allocated by your commissioning manager will be on screen and accessible.

- eCAS allows reviewers to save work as they go along but this has to be activated by the user. The work is saved to the server, not locally on the hard disk. Pages may be re-edited over and over until the SUBMIT button is clicked.
- The MODIFY button is too small and not necessarily indicative of its task.
- Proposals and briefs appear as PDFs; they may be printed off but most lay users pointed out the additional expense incurred and would prefer hard copies.
- How do peer reviewers receive feedback a) on which projects were funded? It would be good to hear results and if it makes a difference to practice/services etc., and b) on their individual performance as a reviewer?
- Once contracted, the project details are placed on the website but commissioning managers will contact reviewers to advise them; no feedback is given on individual reviewer's performances but this has been highlighted recently as a concern, particularly for first-timers, and will be considered.
- Payment is an issue; SDO are currently more generous than other programmes but the rate was felt to better reflect the work undertaken. SDO follow guidance set out by INVOLVE and this had very recently changed and was somewhat ambiguous – it may be that SDO rates will need to change and the guidance will need to change to reflect this. It was felt important that lay persons have this information up front.
- In the top left-hand task bar on eCAS, the peer review section is 'greyed out' which left one eCAS user confused – greyed out normally means inaccessible which was not the case here. This will be fed back.
- Two of the delegates confirmed that user-friendliness of ECAS and the approachability of all the SDO staff during reviewing. It's a good system – works well and is better than other NIHR systems.
- SDO commissioning managers and eCAS support staff are very friendly and will not 'bite your head off' – there is no such thing as a 'stupid' question.

Small group task and discussion

The delegates were split into two breakout groups, facilitated by Sara and Sue, and supported by Barbara and Chris.

The groups worked through:

- Becoming familiar with the full proposal application (blank template as per resource pack)
- Sharing strategies for moving through the application form
- Sharing useful questions
- Looking at the peer review scoring sheet (blank template as per resource pack)

Feedback on task and discussion

- There is a trend for lay comments to be restricted to lay summary and patient information. Thinks lay peer review should be more than this.
- Agreed entirely. Thinks some professionals would like to restrict it to this only.
- Patient information should be a specialised task. It should be done by communication experts, e.g. Plain English Society.
- How can lay people comment if they don't look at the whole proposal?
- A group now always asks to see the protocol
- Lay people bring all sorts of expertise – to limit them is condescending. One delegated remarked that there is some reticence among some lay people to do too much. Gave an example of a lay group he knows, who only look at information sheets. Full involvement is vital or there will be problems from day one.
- Researchers jump in too quickly. Recruitment and retention of samples in clinical trials. User involvement throughout means that the research team is constantly questioned. Users are independent and will keep researchers focused.
- The question to ask yourself when reviewing: Will it have an impact on practice?
- The SDO questions are not lay friendly – they are the same as go to professionals. They should be comparable, but there should be guidelines or introductory questioned or better wording
- The scoring sheet: Good sheet, but need to know process these are used for [i.e. what happens at the meeting of the commissioning group]

Lunch

Over refreshments and luncheon, delegates were clearly delighted to have the opportunity for further networking, exchanging of information and experiences, and contacts. Members of the SDO Programme were able to answer individual questions and offer further support on peer review, eCAS and general processes and guidance.

The importance of establishing personal contact with experienced lay persons and lay networks cannot be overstated. These connections open a wealth of new possibilities for reaching the lay community, particularly hard to reach groups.

Afternoon session

Small group task and discussion

The morning's groups were reassigned, facilitated by Sara and Sue and again supported by Barbara and Chris. The new groups looked at a genuine full

proposal that had been submitted in recent months via ECAS and had been fully anonymised with the permission of the Principal Investigator for the purposes of training, together with the brief. These had not been included in the resource pack as written consent had not yet been received at the time of the sending the resource out. Therefore, 15 minutes were given for each group to scan through the proposal and the session extended by a further 15 minutes.

Feedback on task

Each group fed back their thoughts on the proposal and brief via a spokesperson. There were very similar comments:

- It was clear that the groups felt that this proposal should not be funded.
- One group reached the scoring stage only and awarded a score of mostly 3 (with one 2). The other group did not reach scoring.
- Three years is a long time when patients are dying.
- Why is there no statistical information to work from first? Is this information not held in Trusts so that it can be audited? They say they will collect data but do not say how.
- The addition of INVOLVE seemed 'tokenistic' and of no real value.
- The interviewing of patient/parent was sparsely described.
- There did not seem to be much practical benefit to the patient at the upper end of the budget. It is a management/organisational issue and hence SDO-type research. However, is this the best use of public funds? It is possible to correct medicinal errors and save lives but there may be better and quicker ways to achieve this.
- Where is the connection between organisational culture and medicinal errors? It seems unsubstantiated. What is Gagliadi's methodology – it is unexplained.
- There are 6 sites (8 children's hospitals available) but only 3 wards – is this enough?
- As a piece of social research there is much of merit but with the above caveats.
- A particular plus point was the dissemination by seminars run at each site.
- The groups enjoyed sharing their reviews and felt that there was much to be gained by this. Academic reviewers have sometimes remarked similarly especially if they are new to the exercise. It was pointed out that each proposal was scored by 3 persons, the weighting usually being 2 academic to 1 lay reviewer but the commissioning group undertake the same exercise on the same form and this has an equal mix of lay, academic and other members.
- Other comments on the documentation included: there are no page numbers on printed eCAS documents (i.e. proposal).
- The scoring form questions are not in plain English (what is conceptual analysis?). The ordering of the questions is not entirely logical. Better

wording and the inclusion of some specific lay questions would help but it was recognised that the boxes allow for free text and therefore any comment of choice could be added under any question for consideration.

- One group member offered to supply a selection of questions used for the same exercise in another setting as an example (to follow post-workshop)
- Initial impressions: Important subject, but only partially addressed, not well addressed and didn't fit the brief.
- Scored 2 or 3 by whole group

Barbara fed back on the outcome of the proposal which was discussed by the SDO commissioning group last year. The group should congratulate themselves as they had arrived at the exactly the same points as the group, the verbatim feedback very closely resembled that from the lay group above and had considerably less time to consider the evidence. It was noted by Sue Hinder, who does lay reviews herself, that: "One of the things that really amazed me was that the users came to a conclusion similar to the professionals in a relatively short space of time."

All present expressed their delight and increased confidence in their own abilities as lay reviewers.

Coffee and feedback on what support lay reviewers need

Barbara facilitated this discussion with the whole group; flipchart notes reflected the group discussion:

The guidance pack developed with lay persons

- The group felt the guidance resource pack was useful but 'weighty' in that there was a lot of information to subsume.
- The glossary of terms was particularly liked and this could continue to be developed in the light of earlier discussions on terminology. Particularly since working through the proposal and scoring form, some words in the documentation worked through did not appear in the glossary.
- The guidance was clearly written and presented.
- A paper copy is always welcomed – would another format be useful in addition? Possibly a web accessible copy so that this could be 'dipped in and out of' for those who have computers.
- It was a concern that online reviewing may exclude certain groups and a desire for more personal support from commissioning managers in these cases would be welcome; for instance, a paper copy submitted with the data transcribed into the system by staff.
- The group did feel supported by the guidance and the delivery of the guidance and felt that nothing obvious was missing but that the information could have been made available earlier in respect of the workshop.
- Some pointed out that they had not received the resource guidance pack yet – the postal system is not always reliable and takes longer than you

think to arrive. Having the proposal as part of the resource pack before the workshop so that prior reading could be undertaken would have been useful. This is a confidential document though, so this will require thought.

- Working through the proposal was particularly good for confidence-building

The workshop as a means of delivering guidance

- Would more workshops be welcomed? This would depend upon the location. Originally most of those expected to attend were thought to be north or north-west of the country but some of those attending had come from the south of England. It was generally felt that London was a very accessible location but regional workshops would be even more welcomed and would increase the participation and recruitment of new lay members and reviewers.
- The workshops could take many forms - computer access can be a problem for some people, particularly for older people. Perhaps guidance could also be related via further training workshops to relay certain aspects, i.e. reviewing and to deliver general computer skills and eCAS training.
- A mentoring or 'buddy' system could be developed to help users increase potential accessibility via the use of local internet café-groups where information is cascaded down in a local environment.
- Non-computer 'buddying' could also be an option; working in partnerships.
- More up-to-date jargon-busting would help develop the resource.

General open discussion

- An SDO 'road show' would be a nice event that could be rolled out regionally. This could be advertised via lay networks and receive promotion from Cohort 1 as the group considered themselves the first of many.
- A form of 'pyramid-selling'; this idea was amusing to the group but was taken up and discussed in the form of 'preaching the word'. Each 'learning exercise' taken and passed on by one member of the cohort onto several new lay members. In turn, this would again be cascaded by each of those to two or three more and so on.
- Recruitment is an issue but the group felt that where there is confidence in what is being 'sold', there would be less difficulty recruiting new members. Retention of those members is equally as important – keep in touch with lay people and let them know what is happening. A newsletter was suggested but rejected on the grounds that lay information should be relayed in exactly the same way as every other organisational information, i.e. The Newsletter, not Lay Newsletter. A short article or editorial by a lay member who had been 'trained' or involved in SDO processes could help 'sell' the idea to others.
- The lay reviewers suggested that they could look further at the reviewing form and would send in any suggestions on how to improve it.

- A tangible form of contribution would be appreciated, i.e. a 'certificate of attendance' or 'lay passport' gives confidence and helps build a portfolio of lay expertise as evidence.

Some key points from the day

About lay reviewers

It should always be remembered that lay reviewers will differ in opinion and see different things, just as their professional counterparts.

Lay involvement throughout is important as it helps keep researchers 'on track'

There is a trend for lay comments to be restricted to lay summary and patient information. Lay peer review should be more than this and include all aspects of the research proposal.

Lay reviewers are likely to ask: Will this project have an impact on practice?

How to support and enable the processes of lay reviewing

The importance of establishing personal contact with experienced lay persons and lay networks cannot be overstated. These connections open a wealth of new possibilities for reaching the lay community, particularly hard to reach groups.

Plain English is crucial – the researchers should be able to explain what they are doing, if they cannot, there is something wrong with it!

Lay reviewers need:

- to know the context in which they are providing comments.
- to know about the process through which a proposal goes from submission to acceptance/rejection
- to receive feedback on which projects were funded. It would also be good to hear results and if it makes a difference to practice/services.

Working through a real proposal with others can be particularly good for confidence-building. In this workshop the lay participants came to a conclusion similar to the professionals in a relatively short space of time.

Evaluation

The event evaluated well. Eight completed evaluation forms were returned and Table 1 sets out the overall ratings for aspects of the day.

	<i>Strongly Agree</i>	<i>%</i>	<i>Agree</i>	<i>%</i>	<i>Disagree</i>	<i>%</i>	<i>Strongly Disagree</i>	<i>%</i>
The aims and objectives of the workshop were clear	2	25	6	75	0	0	0	0
The workshop was interesting	4	50.0	3	37.5	0	0	0	0
The workshop was well organised	5	62.5	3	37.5	0	0	0	0
Teaching in the workshop was good	4	50.0	3	37.5	0	0	0	0
The facilitators encouraged me to participate	5	62.5	3	37.5	0	0	0	0
The facilitators were helpful in clarifying points raised	4	62.5	3	37.5	0	0	0	0
We know that people attending the workshop have different knowledge and experience of the NHS and research. We have tried to tailor the workshop content to suit everyone's experience and knowledge. Did we succeed in doing this for you?	5	62.5	2	25	0	0	0	0

Three further questions on the evaluation sheet allowed some free text answers.

When asked: "Which aspects of the workshop did you particularly enjoy?" participants wrote that they enjoyed meeting the SDO personnel and learning from others and the experts. The group work and discussions were particularly appreciated, as they gave a chance to learn and hear people's different perspectives. One participant simply wrote that they enjoyed it all.

When asked about how the workshop could be changed or improved, and in what ways, participants wrote that they would like to have had pre-reading materials earlier. They would have liked a longer session and nearer to home. One participant would have liked a world cafe format.

The final question asked for any further comments. Two participants wrote that it had been an enjoyable and interesting day. A couple felt that the day had been pitched too low, given that many of the group were well informed and experienced. One person felt that it would have been useful to have a small computer network setup running a simulated or actual eCAS proposal.

Several participants emailed the SDO Commissioning Officer to say much they enjoyed the day and how dynamic and informative it was. One member took the trouble to email a detailed reflection on the workshop, which included an acknowledgement that "The tough bits to plan are the didactic bits and given the diverse experience of the group it is almost impossible to guess what is needed." Nevertheless, the participant felt that "the things we came up with were startling"

in the afternoon when an actual bid was examined and discussed. The discussion was “very perceptive, but it was a poor bid, and that dawned on me after about five minutes, but putting the detail on the commentary is quite difficult given the questions we were asked. It was easy in this case to give a 3 or less for the score, but converting that into tangible answers would have been difficult.”

Future plans

The workshop was considered a success by those involved and provided lots of useful feedback, both about how a lay reviewers’ workshop can best be delivered and suggestions specific to the SDO programme. It is planned to take up the learning from this first workshop and use it to deliver future training for lay reviewers.

We would like to thank the lay participants, who provided such excellent feedback, and were happy to be our ‘guinea pigs’ on the day.

**For further details and/or to register an interest in Public Involvement in North West health research, please contact:
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Appendix 1: The programme

Public involvement in peer reviewing

*Training Room, Waterside Conference Centre, Wigan
February 19th 2008*

- 10:30** **Registration and Coffee**
- 11:00** **Welcome and overview of workshop agenda**
- 11.05** **Meeting each other**
Introduction
- 11.20** **Learning Session 1: Introduction (Sue)**
*Why is it important for the public to be involved?
What is peer reviewing?
The research process and methods*
- 11:40** **Questions**
- 11:50** **Learning session 2: The SDO process and aims (Barbara)**
*What the SDO does
What the SDO wants from its lay reviewers
Policies and procedures
eCAS*
- 12.15** **Small group task and discussion**
*Becoming familiar with the application form
Sharing strategies for moving through the application form
Sharing useful questions
The scoring sheet*
- 12. 45** **Feedback on task (whole group)**
- 1:00** **LUNCH**
- 2.00** **Small group task and discussion**
Example of an application for discussion
- 3.00** **Feedback on task (whole group)**
- 3:30** **Coffee and feedback on what support lay reviewers need**
- 3:45** **Evaluations and close**

Appendix 2: Presentation 1

Why is it important for the public to be involved

Sue Hinder
Lay representative

1

Providing focus

- Reminding people that they are there for the benefit of the NHS patient or carer.
- Providing the patient or public "perspective"
- Looking at user involvement in research design

2

Research design

- Experts in the community
- Getting the question right !
- Small changes, large effects.
- Applicability
- Value for money in research

3

Democracy

- Embedded democracy
- How is public money spent
- House of Commons- the ultimate form of user involvement

4

Confidence to participate

- Confidence Discovery
- Basic Committee Skills
- Knowledge of research methods

5

What is research?

- Information gathering
- Systematic
- Answering a specific question
- Prioritisation of research questions
- Generalisable??

6

Qualitative research

- The "why" question.
- What do people know about the situation, what do people feel?
- One-to-one interviews
- Focus groups
- Observation
- Asking people to keep diaries

7

Quantitative research

- The "how many" question
- Randomised controlled trails
- Statistics
- Don't worry -leave it to the statistician

8

Research study sample

- Can't do research on everybody
- Is the sample representative?
- How do researchers get in touch with people in the sample?
- How do researchers explain why someone is in the sample?

9

User Involvement

- Service users and carers can be involved in all stages of the research process
- Early involvement essential
- Services users need to be as close as possible to the study sample.
- Staff service users

10

What is peer reviewing

- Researchers in a similar field commenting on the proposal
- Often differ widely
- Lay peer reviewing
- User perspective – general and specific
- Looking for the pitfalls in the research proposal

11

What is peer reviewing?

- Emphasis on the research methods
- If they can't make the methods clear to you then there's probably something wrong with it !
- "Simplicity is the ultimate sophistication" Leonardo da Vinci (1452-1519)

12