

## Ethics Review in Social Care Research: Option Appraisal and Guidelines by Jan Pahl: A response from INVOLVE

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### 1. Introduction

1.1 INVOLVE welcome the opportunity for commenting on the options for ethical review in social care. We also welcome the Department of Health's commitment to involving service users and carers in this development to date.

1.2 In addition to publicising this consultation through our networks, and encouraging service users to feedback independently, INVOLVE have prepared the following response to the above paper.

1.3 For the purpose of this document, where we use the term service users, we mean social care service users and carers.

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### 2. INVOLVE's position

2.1 INVOLVE have a remit to promote active public involvement in NHS, public health and social care research. In addition to facilitating the two workshops with service users on ethical review for social care research (2002 & 2003) on behalf of the Department of Health, INVOLVE have, for a long time, maintained a keen interest in the whole area of ethical review in research. INVOLVE welcomes the attention given to service user involvement in the models proposed in the Department of Health's current consultation documents.

2.2 There are issues in ethical review practice which can affect the active involvement of service users, patients, carers and the public in health and social care research. We are aware of a number of research proposals which we regarded as having good quality involvement that have encountered difficulties because of the perceptions of Research Ethics Committees (RECs) as to the vulnerability and capability of the active participants. What those committees have probably regarded as appropriate protective considerations have often been seen by those who are the subject of ethic review decisions as being overly paternalistic, ill informed, and disempowering. Conversely, we are aware of instances where research proposals have passed ethical review but are nevertheless seen in practice to be unethical from the point of view of service users and patients. Further, the ethical assessment of user controlled research appears to give rise to confusion.

2.3 We would therefore like to highlight the distinction to be made between current ethical research practice and the issues traditionally under consideration by Research Ethics Committees. This is a distinction frequently highlighted by service users and sometimes by researchers themselves. For

this reason, we see service user involvement in research ethics review as necessarily broadening the ethical considerations under review.

2.4 INVOLVE have sought to open up the debate on ethical review within the research ethics review community for the purpose of raising awareness of the issues for public involvement in research. Coupled with this, is a concern that the make up of NHS research ethics committees has for a long time been insufficiently inclusive of the perspectives of those affected by research; people who use health and social care services.

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## 3. Background to response

INVOLVE is an inclusive organisation which networks widely in the arena of health and social care research and public involvement. It maintains strong links with the wider community of health and social care researchers, research managers and commissioners, service users, patients, carers and the public, as well as their 'representative' organisations. This response draws upon the experience of being part of this broad network, the debates which have taken place within the INVOLVE membership, as well as the experience of facilitating the two workshops for service users on ethical review for social care research.

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## 4. Options compared

We have looked at all four options discussed in the consultation paper, and have responded to each.

### **Model 1, A national system of social care RECs, similar in operation to NHS RECs, but organisationally distinct.**

4.1 This is the most cohesive of the options, but also the most expensive. If resources for this were agreed, the model lends itself to a useful level of consistent practice in service user ethics and involvement. If this option is agreed then service users should be involved at the development and set up stages as well as in the review bodies themselves. The structure of the committees, and decision making protocols would need careful attention if user ethics are to maintain a strong profile, which we believe they should.

4.2 We suggest that options for a remote 'panel' including service users from different backgrounds, in addition to service user representation at committee level, could also be considered. This potentially widens participation and the base of expertise available. A remote panel could be attached to each committee working in a similar way to that proposed in model 3.

### **Model 2, a specialist social care committee system, operating with in the COREC structure.**

4.3 The existing COREC institutional system is considered by many people who use services as rather paternalistic and not particularly accessible for

patient and public involvement. To simply embed social care research ethics review within the current COREC structure and culture, even with a separate committee system, is likely to compromise the opportunities for a fresh approach that overcomes the issues already raised in 2.2 to 2.4. However, we think this model could become credible through substantial, meaningful and mutually effective patient, public, and service user accountability and involvement throughout COREC's whole infrastructure, not just at REC level. We are aware that COREC is currently being reviewed and will also be moved to come under the management of the National Patient Safety Agency. This may provide an opportunity for the two systems of ethics review to work together to ensure both a greater acceptance and understanding of public involvement in research, as well as greater involvement of people who use health and social care services in the review process.

**Model 3, A national system of social care ethics review, operating within a tiered decision-making process and using electronic communication.**

4.4 We believe this model offers a potentially accessible, flexible and democratic system of ethical review which has particular potential for service user involvement. It also maintains a national standard. We agree with the advantages outlined in 3.33 in the consultation paper, particularly in respect of the preference of some service users not to attend formal meetings.

4.5 We believe that if three panel members look at proposals as suggested in 3.28 in the consultation paper, at least one of these should be a service user with experience and knowledge related to the research. This means that there needs to be a range of user and carer reviewers on the panel from different backgrounds from which to draw for different kinds of application. It may be necessary to use more than three panel members per application.

4.6 Final decision making may be the weak point in this model. There will sometimes need to be a wider dialogue between panel members about problematic applications. This might be achieved through utilising conference calling or similar. There seems to be a specific weakness in respect of the accountability of the co-ordinator and chair. One suggestion is that conclusions and recommendations made by the co-ordinator and chair are fed back to the panel members involved before final decisions are made. Should panel members think it is necessary in a given instance, there might be a brief opportunity for a wider discussion before conclusions and recommendations to an applicant are finalised. We believe this feedback loop will also be important in maintaining the motivation and learning of remote panel members.

4.7 We think it is likely that this model, if it is to be truly democratic and accessible, will cost more than is implied in the paper. Training, equipping and maintaining a strong panel network can absorb considerable start up and ongoing resources. There is a saving on travel expenses as well as time and inconvenience for panel members, but involving service users well, may mean that there are additional support needs for their use of various communication media.

## **Model 4, A pluralist system of ethics review based on local diversity.**

4.8 This is barely different to what exists in social care now, except that it proposes an accreditation system. Having widely differing CSSR ethical review structures risks lack of continuity of systems and standards as well as accountability. There would need to be a strong commitment to national standards in ethics review, training and monitoring, all of which are important to service users we have talked to. In particular, there would need to be clear guidelines supported by training for consistent service user involvement in the ethical review process as well as in the assessment of applications. National standards need to be developed with input from service users to ensure that ethical issues important to them are included in assessment criteria.

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## **5. Summary**

5.1 There are distinct advantages in both options 1 and 3, and we suggest that elements from each of these two options might be combined to produce a satisfactory formula within resource limitations. Option 1 has all the advantages of centralised decision making based on expert interaction and discussion, and option 2, the potential advantages of wider, flexible involvement, speed and economy. Both have drawbacks too, but we think that the two models have elements that could be introduced into the other which address these.

5.2 Whichever formula for ethical review in social care research is settled upon, we believe that training for committee/panel members should play an important role. We would particularly point out the need for training in service user and carer ethics preferably delivered by users and carers. For an inclusive and effective process in ethics review, training for skills such as effective communication, could be as important as training on the legislation committee members need to be aware of. INVOLVE has commissioned a study into training for public involvement in research<sup>1</sup>, hosted a seminar on training<sup>2</sup> and is currently developing training pages and a training provider database to add to the INVOLVE website in early 2005. This work should be helpful when considering training for research ethics review bodies.

5.3 The support needs of some service users should not be underestimated if they are to be able to participate fully and equitably in any of the described options for ethical review. The more inclusive the review system the more resources there need to be. For example, people with severe communication

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<sup>1</sup> Lockey R, Sitzia J, Gillingham T, Millyard J, Miller C, Ahmed S, Beales A, Bennett C, Parfoot S, Sigrist G, Sigrist J. (2004) **Training for service user involvement in health and social care research: a study of training provision and participants' experiences (The TRUE Project)**. Worthing: Worthing and Southlands Hospitals NHS Trust.

<sup>2</sup> Steel R. (2004) **Training for Public Involvement in Research: Seminar Report 22<sup>nd</sup> April 2004, 89 Albert Embankment, London.** INVOLVE

problems, who may well have a view on the ethical elements of research applications, are likely to need support workers/facilitators and/or special media.

5.4 We think that any ethical review body for research should be knowledgeable about service user research, and in particular, user controlled research. INVOLVE have commissioned a piece of work which is intended to help define what is meant by user controlled research and the report will shortly become available.<sup>3</sup> We hope that this will be helpful to ethical review bodies when faced with user research applications. We also recommend that the reports of the consultations with service users on research ethics for social care which INVOLVE facilitated on behalf of the Department of Health, continue to be utilised and are used by research ethics bodies for reference, along with other service user research ethics literature.<sup>4</sup>

5.5 INVOLVE will be commissioning a guide to involving service users on research ethics bodies, and this will include practical guidance on service user ethics in research. We hope to work with the Department of Health in the development of this guide which should be available by the end of 2005. We look forward to the Department of Health, and the new research ethics review bodies for social care utilising this guide as a key resource.

5.6 We hope that the Department of Health will continue its support for service user involvement in ethical review, and in the further development of research governance plans for social care. INVOLVE would be pleased to provide advice as needed.

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<sup>3</sup> The report will shortly be available from INVOLVE, Wessex House, Upper Market Street, Eastleigh, Hants, SO50 9FD. Tel: 023 80 651 088. Email: [admin@invo.org.uk](mailto:admin@invo.org.uk).

<sup>4</sup> Boaz, A. (2002) **Department of Health consultation on research ethics in social care: A summary of the consultation event with social care service users and their representatives.** INVOLVE

Boaz, A. (2003) **Department of Health consultation on research ethics in social care: A summary of the follow up consultation event with social care service users and their representatives.** INVOLVE

Faulkner, A. (2004) **The ethics of survivor research.** Joseph Rowntree Foundation

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Promoting public involvement  
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