

**Director's Message No 4**

Involving patients and the public in proposals for research for patient benefit can seem an obvious step. However, when it should be done, how it should be done and how far it makes a difference, all remain the subject of debate. Two recent events are worth mentioning. The first was a conference at the Royal Society of Medicine in June 2007. It highlighted the reasons why clinical trials do not always address questions that will directly benefit patients and their clinicians and brought the James Lind Alliance - with its listings of areas of uncertainty and its working partnerships between clinicians and patients - into focus<sup>1</sup>. The second was the report of early findings from Sheffield University study of researchers' attitudes to Patient and Public Involvement (PPI) and their fears that we were in danger of simply producing a 'tick box culture'.<sup>2</sup>

What is to be done? INVOLVE, our partner organisation has already been active in giving information and advice. Timely engagement with the resources on their website [www.invo.org.uk](http://www.invo.org.uk) and attention to the events they sponsor will always be a good move for potential applicants to this Programme. In due course, INVOLVE will be taking a look at what we fund and how far they might be able to draw out best practice examples both from within the Programme and beyond. Meanwhile, for this message, I have taken collaborative working to heart.

Two PPI members sit on each of the 10 regional funding committees for RFPB and the main part of this Director's Message has been written by the PPI members of the London Regional Funding Committee (RFC). Christine Gratus and Carey Ostrer produced the report that follows based on their experiences of the first meeting of the London RFC. The issues they raise are not confined to the London region and there are implications in their comments for the Programme as well as for applicants. Some of these comments influenced an earlier Director's Message and we are also amending some of our guidance in response.

Christine Gratus also offered us another resource - a quick quiz to test how well informed you are on PPI. Can you tell the difference between different ways of involving patients and the public in research? Follow this [link](#) to test yourself. It relates to the involvement grid (Question 14) on the application form.

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<sup>1</sup> See [www.lindalliance.org](http://www.lindalliance.org) for more details.

<sup>2</sup> For details contact [Jill.Thompson@sheffield.ac.uk](mailto:Jill.Thompson@sheffield.ac.uk).

**Patient and Public Involvement: a message for applicants to the Programme**

1. Guidance is given on the application form, but there is still a high level of misunderstanding about the nature of public patient involvement in research. For example:
  - Interviewing research participants – for instance, to find out what they thought of an intervention with a view to possible modification - is not public patient involvement. By involvement we mean ‘an active partnership between the public and researchers in the research process, rather than the use of people as the subjects of research‘. (INVOLVE). The guidance given on the application form is expanded at [www.invo.org.uk/Questions.asp](http://www.invo.org.uk/Questions.asp).
  - Keeping research participants informed of progress is not public involvement (but is good practice and rarely mentioned).
  
2. Many of the first round applications were weak on these aspects of PPI:
  - Specifying the detail of lay involvement. The adequacy of lay involvement can only be judged if the nature and extent of the anticipated involvement is made clear. Vague generalities can be construed as lack of provision.
  - Public involvement in developing the proposal itself. The majority described future plans for involvement. Real PPI begins at the development stage.
  - Budgeting adequately (or at all) for PPI.
  - The quality of the lay summary. Cutting and pasting paragraphs of technical prose does not constitute a lay summary. Putting scientific terms in quotation marks fails to make them instantly understandable to the lay reader. Some proposals made successful attempts at plain English. Many did not.
  
3. In terms of treatment of research participants, there were weaknesses in:
  - Plans for informing participants of the progress and outcomes of the research.
  - Absence of any indication of black and ethnic minority participation in proposed projects. If it is proposed to exclude black and ethnic minority participants, the decision should be explicit and justified. If exclusion is on language grounds, this should also be specified and justified.
  
4. There were a few fine examples of good practice among the proposals we reviewed. The best were collaborative and had some of these characteristics:
  - Involved patients in the early development of the proposal
  - Had equal steering group representation for professionals and lay people

- Involved service users in designing questionnaires and topic guides, conducting interviews and focus groups, reviewing transcripts and contributing to interpretation and preparing patient information.
- Arranged for participants to be informed of research findings
- Involved patient groups and charities in disseminating the findings among patients and service users.