

## **Feedback from Participants**

### **Introduction**

The 6th Global Forum on Bioethics in Research was held on 17-19 March 2005 in Blantyre, Malawi. The theme of this forum centred on ethical implications surrounding post-trial issues, including the responsibilities of researchers and sponsors towards research participants.

### **Attendance**

The forum was attended by 150 delegates from over 60 countries, and included participants from a variety of different professional backgrounds including medical researchers, healthcare professionals, social scientists, ethicists, philosophers, lawyers, research field workers and policy-makers.

### **Programme**

The meeting programme was primarily focused around presentation and discussion sessions, with the main part of the meeting focusing on analysis and break-out group discussions of the issues raised by three case studies – namely, ‘the over-researched community: a semi-hypothetical case’, ‘the ADVANCE study (action in diabetes and vascular disease: preterax and diamicon MR Controlled Evaluation)’, and ‘ethical considerations in health services research in developing countries’.

There also were presentations given on a variety of topics within the theme of the Forum, as well as talks by representatives from special interest groups such as the Drugs for Neglected Diseases Initiative.

### **Request for Feedback**

At the end of the Forum, delegates were asked to complete a short questionnaire to feedback their views on the meeting. A total of 48 delegates returned completed forms. The common themes from the answers are summarised below, and a full record of the all responses received can be found in **Annex A**.

### **Key themes emerging**

*Expectations of the meeting and the extent to which these were met*

7. Many respondents commented that they were expecting the meeting to provide time for discussion around the issues surrounding post-trial responsibilities, as well as opportunities to

share their own experiences and exchange views with other researchers. They were also hoping for chances to network with others to help build links for future collaborations and access to funding opportunities.

8. Many delegates were also expecting that the Forum would also focus on general issues surrounding the principles, concepts, responsibilities, guidelines and applications of bioethics in research, and hoping that there would also be a consideration made of new and emerging ethical issues.

. \*"That the various principles of ethics in [biomedical] research will be discussed and emerging dilemmas and possible solutions to these highlighted."

. \*"Gain new insights into the theme 'what happens when research is over'... expand the networking efforts that were initiated at Paris Global Forum [and]... meet and network with new people from various parts of the world."

9. A minority of participants came with the expectation of learning how to write a proposal and a few came with no explicit expectations.

10. The overwhelming majority of respondents indicated that the Forum had either met or exceeded their expectations.

11. Many delegates had been impressed by the high quality of the discussions, the scale of participation and the emphasis on groups and discussions. There were also numerous positive comments about the case studies, which were described as thought provoking and appropriate.

Respondents also appreciated the opportunities to meet people and network, as well as the content of the programme.

. "Better diversity of delegates than I'd expected. Excellent emphasis on groups & discussions."

. "Actually very different from my expectations... Much looser structure, more time spent in case study discussions... Very impressed by the high level of engagement of most delegates"

. "As a basic science researcher most of my thoughts were focused on my research and only peripherally I thought of bioethical issues and the responsibility of a scientist to the people. This forum has changed my outlook drastically and I realise that it is equally important to me as doing good science to make sure that the research is taken to the public ethically."

12. Those whose expectations were not exceeded commented, amongst other issues, that: there was an unmet need for expert input and guidance; too little time was given for discussions; there was a lack of relevant reading material; the topics needed to be more focused; and there was dissatisfaction with the failure to reach a consensus.

### **Format of the meeting**

14. The majority view was that the case study method worked well – however, some delegates felt that the cases needed more preparation to fill the gaps in the background information, with the first case study being highlighted by a number of participants as being especially lacking in detail. Overall though, the case studies were seen to be thought provoking and relevant to the theme of the meeting.

“First case; irrelevant content and questions unanswerable with the information provided... [the] case study method [was] very good, but needed more careful preparation of content and questions to be discussed”

15. Numerous remarks were made about the high quality of presentations and discussions, which were described by at least one participant as “lively”. Commendations were also made about the facilitators and session chairs.

16. Several participants felt, however, that the size of the break-out groups had been too large and the time for discussion too short. Also a few delegates felt that a short synopsis would have been useful.

“The presentations were all very well done with good content exciting ethical thinking and reflection. The groups were a bit large but discussions were good. The plenary sessions were very good generating a lot of discussion and views expressed were very helpful”

### **Meeting preparation and organisation.**

17. The overall consensus was that: the venue had been good, the accommodation was of a high standard; the organisation was efficient; and that the meeting materials had been adequate and relevant.

“I wish to commend the organisers of the programme particularly Claire Griffiths and the local organisers. They did a good job. Their preparation towards the conference was superb. The emails made communication effective. The hotel used was also good and the workers are very courteous.”

“The presentation for the meeting, supporting materials and general organisation is excellent”

18. Several delegates noted that it would have been useful to have all the Forum materials in advance to allow for better preparation by the participants. There was also widely-held view that it would have been helpful to have more references and papers, and that a synopsis of previous Global Forum meetings would also have been useful. Some delegates noted once again that the case study discussions were insufficient and time constrained.

19. A small number of delegates also raised some more minor organisational issues – noting that they had received their tickets quite late on; details of meeting were sent out late; and there were delays in refund of expenditure. Other respondents noted that they would have preferred the freedom to choose where to eat dinner; that the stationary and provided bags were of a lower standard than expected; and that the public address system was poor.

#### **Additional feedback and suggestions for future meetings**

20. Several delegates included comments that future forums should bring on board other stakeholders including: local scientists and institutions; community members (subjects and beneficiaries of research); sponsors/funders; policy makers and administrators; government representatives; and NGO representatives.

“The multi-nationality of delegates was a great achievement.... I hope emphasis will appear in the output document on need to enrol (not just discuss with) local scientists /institutions as (real) collaborators in projects orientating outside – that measure is the best way both to build capacity and effect provisions for ‘after research is over’”

21. Delegates suggested a number of possible areas on which the Forum could have placed greater emphasis, including:

- differences in ethical issues between the developed and developing world;
- post disaster research ethics;
- research which is conducted among minorities including the impact of culture/religion/traditions on the outcomes.

22. There was also a suggestion for the inclusion of a critique of different guideline provisions from the perspective of sponsors, researchers and industry representatives, and a general discussion of the guidelines themselves.

23. A few respondents commented that follow up was needed to continue the success of the forum and maintain the information exchange – one person suggested that the case study discussions should be followed up and produced as teaching aids.

24. A number of delegates noted the positive impact of bringing together the mix of experienced researchers with young and upcoming researchers at the Forum. Indeed, some delegates felt that a greater number of young and mid-level scientists should have been invited.

“One major achievement of the conference is that it has succeeded in bringing the old and experienced researchers together with the young and upcoming researchers. This is a great deal of contribution to capacity building and sustainability.”

25. Delegates noted that future meetings might be based around smaller break out groups, and more focused case studies. Some participants would also have liked more opportunities for networking and chances to share their own experiences.

“More avenues for networking. It might be interesting to have a session where research participants share their research experiences, positive or negative.”

“It would be good to have experience-sharing in addition to gaining informed commentary in applications of guidelines through case studies. Groupings are too large. While I do appreciate that there is little/limited time for feedback, it also limited participation in discussion for some members.”

26. A small minority of delegates suggested that arrangements needed to have been made earlier, and one delegate noted that the inclusion of summary sessions for round up of themes discussed previously in the meeting would have been useful.

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