

**The 6th Global Forum on Bioethics in Research:  
“What happens when the research is over? Post-trial responsibilities of  
researchers and sponsors.”**

**Summary of feedback from delegates**

**Introduction**

1. 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.
2. 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.
3. 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’.
4. 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.
5. 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.

<p>❖ “That the various principles of ethics in [biomedical] research will be discussed and emerging dilemmas and possible solutions to these highlighted.”</p>
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❖ “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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## ANNEX A – Full collated responses to feedback form

### Q1. What were your expectations of the meeting?

1. That the various principles of ethics in Biomed research will be discussed and emerging dilemmas and possible solutions to these highlighted.
2. Discussion, ideas, examples, diversity, principles. NOT more fixed guidelines.
3. To understand the concept of ethics and the diversity of subject matter.
4. To achieve a wealth of knowledge on bioethics which I will inturn transfer to other members of our research upon return home.
5. To consolidate knowledge on responsibilities of the researcher, sponsor/funder, IRB when research is over.
6. To participate and learn from discussions around the main topics in order to produce greater clarity around application of principles.
7. This is my first time of attending a Bioethics meeting and so was not sure what to expect.
8. An introduction to discussions of medical ethics in an open forum and an opportunity to meet other people interested in similar issues.
9. To flesh out the issue of post trial obligations.  
Avenues for networking with other delegates.  
High quality of discussions.
10. A vibrant discussion of the ethics of what happens when the research is over.
11. Look at examples of research where post-trial access may be required.  
Application of guidelines in these, determination of the above.  
Participants sharing of their own experiences when they did negotiations for post-trial access.
12. Some initial ice-breaking activities (as many new participants), more group works, some MED type puzzles and more case study presentation.
13. n/a
14. Learn more about what happens when the research is over and how to disseminate the Forum results in my country.
15. It was very interesting and I had the great opportunity to listen great experiences and discussion about topics that are common to the research practice.
16. Have a useful interaction with colleagues on Bioethics.
17. My expectation was to put an answer to the theme of the conference.
18. I didn't have much information about the Forum, so I didn't really know what to expect.
19. v. good
20. To learn and know new trends and scopes in health research ethics.  
To explore possibilities of networking with health research ethics organisations in other geographic areas.  
To explore future collaborations with health research ethics organisations.
21. Discuss ways of tackling new and emerging ethical issues in research using real examples. Provide reading material about ethical issues.
22. Networking with others.  
Exchanging experiences.  
Participating in building and improving bioethical practice worldwide.
23. I expected to attend presentation, meetings & discussion on the forum theme, & I also expected to share my experience and to gain knowledge in this field.
24. Share experiences about ethics in health research. Meeting researchers, funders and sponsors of health research, a network between ethicist and researchers.
25. Network with people.  
Hear about good strategies to deal with post-trial work in developing world.  
Hear about funding opportunities.  
Learn from others' experience.
26. Provocative debate.

27. Series of focused presentations, case studies, plenaries on various aspects of the chosen topic.
28. Gain new insights into the theme “what happens when research is over”.  
Expand the networking efforts that were initiated at Paris Global Forum.  
Meet and network with new people from various parts of the world.
29. I am a neuroscientist, doing basic neuroscience. During my research I did not actively seek information of bioethical issues. However since I am doing some studies using drugs to improve memory in stroke patients I needed more information of bioethics.
30. I learn the standard issue of ethics in research.  
How to write proposal for research application which need to have informed consent and patient information in all appropriate way.  
To have an idea concerning review of research proposals.  
To learn what is the post trial access.
31. I expected to;
  - i) Receive some guidelines evolved over previous meetings about post-trial management of research.
  - ii) Engage in discussion about ethical issues related to post-trial management
  - iii) Network with people who work in ethics in all parts of the world.
32. To learn about the GFBR – who’s in it, how it works, prominent ethics issues.
33. To upgrade my knowledge + skills with reference to Bioethics Research, + to use these in working/country set up.
34. I would like to expect the discussion of the clinically ethical studies (or researches), the things that researchers, the funders, the leaders of research, the Government of nations, ... must do for their communities during or after the studies is over.
35. I hoped that the conference will open my mind more about ethical issues or problems when designing a study or a research.
36. Improvement of my knowledge on bioethics research.
37. Guidelines for research ethics committees.  
Post-trial obligations of researchers.
38. To get a clear understanding of how some ethical issues that are context-specific can be dealt with.  
To test in a Global Forum my concept of the importance of making links and arrangements for continued benefits for research subjects after research is over
39. To acquire advance knowledge on bioethics.  
To draw inspiration from experts on how to form an IRB.  
Networking.
40. I expected a Forum in which many issues relating to the aftermath of research pursuits would be discussed and that answers, strategies and recommendations would be made.
41. To get solutions to a lot of questions that are raised after the research, especially for vulnerable communities.  
Getting a way forward especially regarding end of research.
42. To understand, hear, learn about both the beliefs and experiences of other people on what happens when the research is over.
43. To be able to meet other people working in the area of bioethics and to network with them.
44. What things should be included or considered when writing a proposal for review by the RECs and what one should consider when the research takes place and when it comes to an end
45. Establish contact with Wellcome Trust.  
Meet researchers & bioethicists of different regions.  
Exchange views and get feedback about common issues.  
Update my knowledge about current affairs and development.

46. I am an officer from Govt. of India, from CSIR (Council of Scientific & Industrial Research) – a premier body with 38+ institutions in India. I expected this Forum to provide all information on Bioethics, after “preclinical research” (this is the 1st time I am attending or anyone from CSIR).
47. To perceive/exchange opinions/comments from audiences about how to conduct and follow-up a research/trial. As well, to see how ethical issues have been analysed in different countries regarding to different kinds of scientific activities.
48. To get out with the ideas from other (fellow) scientists on ethical solutions of what happen when the research is over.

Q2a. To what extent did the meeting meet your expectations?

Exceeded my expectations	20
Met my expectations	23
Failed to meet my expectations	
n/a	1

\*not yet included as ticked 2 boxes; no 2, no 6, no 31

\*number 38 adds own option: Partially met my expectations.

Q2b. Comments on answer to Q2a.

1. There wasn't a structured review of currently agreed-upon principles of ethics in biomed research, but prevailing dilemmas of after-trial access were discussed widely/in depth.
2. Better diversity of delegates than I'd expected. Excellent emphasis on groups & discussions.
3. Diverse problems associated with research were highlighted and had the benefit of appreciating subject matter/theme of conference broadly highlighted.
4. Organisation. Logistic arrangements. Sponsorship to delegates.
5. Case studies and the plenary articulated some of the responsibilities and also the discussions in the plenary assisted understand the cases from some experienced members.
6. The meeting produced discussions that were more far-reaching than expected, and allowed all to participate. Perhaps more 'expert' guidance would have been useful e.g. in case presentations as well as discussions?
7. Exposed me to what to expect in future forum on bioethics.
8. n/a
9. I expected a high quality and well organised meeting from Wellcome Trust and they delivered.
10. The discussions were very open and participation was very forthcoming. I felt they could go on forever and the depth of knowledge was superb.
11. These meeting meet my first two expectations, but not my last expectations, which would be helpful to me as a researcher and an IRB member.
12. Basic principles were discussed. Practical problems debated and newer frontiers explored and huge participation.
13. Extremely interesting discussion, thought provoking case studies.
14. n/a
15. I came with the challenge to find new knowledge and meet professionals developing research in the ethics area. It's important since the Latin American stand point where ethics issues are always very underestimated.
16. Gained a lot and the attendance was unexpected.
17. My expectation was adequately met.
18. The forum provided an opportunity to meet people from very different backgrounds, which is always an enriching experience.
19. The theme is v. important. Little time was given to discussion of this important issue.

20. This was my second attendance to a Global forum and was aware of the excellent organisation in previous one and the actual and important issues for deliberation regarding health research ethics.
21. The only bit that was not satisfactory was in the area of providing relevant reading material.
22. The presentations were informative, well prepared, focused.  
The case studies were appropriate to the theme.
23. I was able to attend, to listen, to share my experience and to enhance my knowledge.
24. I want to organise a meeting between ethical committees in just Africa. And during the GFBR 6th, I have good contact to support out next meeting in Dakar July or September 2004.
25. I have had good opportunity to meet with people from all over the world. Exchange of contacts was possible.  
Analysis of case studies helped understand how tricky it is to look at what happens when the research is over.  
Forgaty, Wellcome Trust, and other funding programmes were available to me.  
Discussion in small groups and plenary presentation were enriching.
26. The issues were challenging as I expected. And debate was lively.
27. 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.
28. We could initiate a Bioethics Network for Asia-Pacific and also follow-up last year's activities.  
I could meet and interact with many experts from other parts of the world, who were involved in the type o work I am doing.
29. 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.
30. I have heard the discussions in the case study and get the ideas how to evaluate the proposal in different ways depends on many variation and factors including the health policy, the economic status etc. It also gave me the considerations when review the publication or manuscript.
31. Perhaps I had unrealistic expectations, but all in all it has been extremely useful to be here and meet with so many people with different skill sets and experience.
32. I liked the casework but wonder how the output will be used. Will there be guidelines for ethics committees to address the issues considered.
33. Really I feel it's an honour for me to attend such a Forum, which not only upgraded my knowledge but also provided me a more clear vision with reference to Bioethics research.
34. I am a member of the scientific and ethical council (or committee) – Hospital for Tropical diseases, HCMC, Vietnam. Every three months, we must discuss about many new research plans (or protocol designs). It's difficult for us to approve or not which research that will be carry out after that. This is the first time I participate this forum, I feel interested with many problems discussed.
35. Problems raising in the conference are as a large scale leading to very interesting debates and discussions.
36. The topics of the forum should be more focused.
37. Guidelines need to be synthesised.
38. The Forum somehow discussed and fleshed out recommendations for dealing with context-specific ethical issues. The importance of making links and arrangements for continued post-research benefits. But the Forum failed to reach a consensus on how these links can be done and sustained.

39. Learnt the tenets of how one could put up a proposal that could pass an ethical review test.  
Several opportunities advertised for networking.
40. The number of issues raised and discussed in regard to the topic exceeded my expectations. However, the degree of consensus I expected in regard to a number of these issues did not meet my expectation. Nevertheless, I am respectful of the reasons for which consensus on a number of issues did not occur.
41. I now know the role of the IRB: in ensuring that the participants get their benefits.  
The obligations of the policy maker, researchers, sponsors.  
Stake holders should be involved in deciding the benefits.
42. Discussion in groups and plenary session were very rich and allow me to better understand (learn) about some areas of the bioethics in research and also facets of public health and policies.
43. I met people and heard from them about what they were doing and that was wonderful!
44. The meeting has broaden my ideas/views and way of thinking when I am writing or reviewing the proposal.
45. Case studies are great tool to exchange views and learn from others. Meeting people and establishing network was the most successful area.
46. Exceeded my expectations in own way; I could understand the basics of Bioethics; and the bodies available + get to met come colleagues in the same field.  
Since CSIR is only initiating the initiatives of "IND" trialling, and I have direct involvement in the "IND" trials and phase 1, 2 and 3 trials, and information on the Bioethics was very important.
- i) The basics were achieved
  - ii) The basis for future/further follow-up is established by attending this meeting.
47. To learn more than expectations. Since I am working in genomic area, I am lacking R&D feasibilities and post-trial experiences. The meeting gave me a lot of experience from audience and presenters to apply when I fall into the same situation.
48. I do not have any comment but the contents of the programme were well covered.

Q3a. How useful did you find the ...

	Not at all useful			Very useful		n/a
Presentation – session 1; Adnan Hyder				16	29	3
Plenary discussion session 1	1	1	6	18	19	3
Debate – What happens when the research is over?			8	12	23	5
Case study 1 – content	1	3	10	23	10	1
Case study 1 – breakout groups and discussion		3	5	21	18	1
Case study 2 – content	1		7	22	17	1
Case study 2 – breakout groups and discussion			7	21	20	
Case study 3 – content		1	2	19	23	3
Case study 3 – breakout groups and discussion		1	3	17	23	4
GFBR business meeting			6	13	12	17
Presentation – Public Private Partnerships			5	12	19	12
Final session – outcomes of the Forum		1	4	14	17	12

\* number 6 asks if the final presentation and final session happened (rescored as n/a)

Q3b. Comments on answer to Q3a.

1. I think the objectives of the various parts of the process were not very clear, hence poor focus on my part in the beginning.
2. First case was irrelevant content and questions unanswerable with the information provided.

Case study method very good, but needed more careful preparation of content and questions to be discussed.

More frequent reminders of main objective ('after research over') were needed.

3. Too many gaps in cases as background information were not comprehensively available leading to several assumptions for discussions.
4. All presentations of the cases were in light with the theme of the conference. The chairs coordinated all aspects excellently.
5. n/a
6. n/a
7. This is my first opportunity to be at a Bioethics meeting. I have gained a lot criticising other projects. This has given me the opportunity to know the flaws and unethical issues that come up in research. The question "when is a community over-researched" was not being answered.
8. The first case study was not very useful – so much information was omitted that it was difficult to discuss in any depth. The other 2 case studies encouraged more lively debate.
9. Some of the cases were not well fleshed out so a lot of time was spent discussing the validity of the cases, rather than the ethical issues in the case.
10. 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.
11. They were very useful. There must have been another example on vaccine trials since the post-trial issues of this type of clinical research are different.
12. Some of the case studies were not fully informative. However they were related to the ethical context and theme of the forum. Nevertheless, they were though provoking and interesting.  
The facilitators were excellent.
13. There was a gap in the background knowledge of case study 2. It was probably funded by pharmaceutical industry and this should have been stated in the case study. All case studies have insufficient materials – should be better to have included the full reference ...
14. n/a
15. As epidemiologist, the discussion allows me to better understanding the close relationship between the clinical and research practice with the current problems that Latin America (and Mexico in special) related with the ethical dilemmas currently in debate.
16. Very rewarding.
17. I cannot comment on Adnan Hyder presentation because I had not arrived when he presented due to flight delays. Altogether all the case studies added a great deal of experience to my knowledge on ethics.
18. The forum was a very motivating experience that provided useful information and points of view. I think the discussions deserve more time for reflection and discussion.
19. n/a
20. The case study approach was an excellent methodology to know about different approaches in diverse communities settings.
21. Not all information was given in the case studies and most of the time was used by members in debating assumptions. For example REC's letter to the research should have been provided in full.
22. Generally, time was sufficient for the discussions, the choice of cases for discussion were suitable and in most cases were able to generate very useful debate.
23. Adnan's presentation was the most useful, he successfully linked the national health system, national health research or ethic system. I also was able to attend case discussion and actively participate in discussions.

24. The session 1 is an interesting example to bring us reflecting in order to conduct very well studies and explicit for population benefit all result of studies.
25. n/a
26. Cases were appropriate and right to the point.
27. The cases would have benefited from more introduction and explanation of how they related to the forum topic.  
Not immediately obvious how some sessions related to what happens after research is over.
28. Cases were not focused – so discussions often deviated from the main theme. More focussed cases would help.  
Reporting back was not streamlined very often.  
Discussions were excellent and the chairs did wonderful jobs.
29. Case studies 1 and 3 and the breakout discussions addressed the scenarios in my country and I felt very involved emotionally. The case study 2 was also on a disease condition which is also high in India but since I thought it was not relevant as the other two cases.
30. Case study 2 is quite interesting scenario but time for discussion is not enough to cover all the questions. In the group discussion should have mobile microphone so all the members of the group could hear clearly and can follow through the discussion.
31. Overall, all the sessions ranged from useful to very useful. Some of the case studies would benefit from greater detail.
32. Case studies & breakout very informative – I'll be interested to see what the final output is, "take home" messages etc.
33. Found very useful not only for myself but also to utilize this knowledge in institution/ country where I am working in a scientific way.
34. I come from a developing country where HIV patients in particular and infectious disease generally are increasing. Besides, because of low-income country, so in the rural areas the mortality is still high especially the one of infants or newborn children. So I am interested to the case study 1, case study 2 and its discussions. They help me to have many things about the medical ethics, the bioethics, the things that I did not know too much before.
35. I find that the case study ethical problems are very important for researchers. The debates are various; they make me collect many ideas from different persons, many point of view and they are precious experiences for me, as a researcher.
36. Found very useful for my career.
37. Case study 1 and 2 needed more clarity and research methodology.
38. The presentations and case studies were very provocative. They did identify critical areas of ethical dilemmas. The breakout group discussions were very enticing and high powered.
39. The hypothetical studies were very stimulating and provocative thus inspiring. The presentations were good and discussions encompassing.
40. The discussions/questions and answer segment for Thursday morning were disappointing, as the format did not formulate the presenters directly answering to particular poignant questions from the audience. A series of questions were allowed by the session chairman and then the panellists were requested to provide answers to the "many" questions.
41. n/a
42. As I wrote below, long time (1h15') reserved for the group discussion and about 1h30' for the breakout groups, have been ok for me. I think it's not good idea to modify (short or extend), but need of a short synthesis even though it will not be easy to do so immediately after fruitful and diverse set of opinions.  
Chairs, session were goods!
43. Some of the cases were quite hypothetical and we would appreciate it if we get moderators who will be able to steer the affairs of the session effectively.

44. They are all useful but time has been the main limitation as we needed to discuss more rather than in rush.
45. Discussion could be done around a particular theme of the bioethics principle. We have not discussed much about monitoring of ethical issues related to ongoing research projects. Mechanisms of establishing rule for mandatory periodic monitoring & setting up local guidelines are critical.
46. Every item above provided deep insight into the aspects of ethics. I could, as a beginner, get a lot of information on “where to start”, “where to look for help”, “whom to contact”, etc. Above all the case studies provided me with enough provocation to streamline my thinking to consider the ethics problems in a more wider view.
  - ❖ Case study 1: information was limited.
  - ❖ Time was short
47. HIV vaccine is a special one, not to be implicated over 1 million population. Antibody check takes time, but the immunity lasts only 1 year. So, blood taking must be repeated several times on the participants – this case is not very realistic. Case study 2: whether it is drug-trial. If so, difficult to follow-up. Participants of 20 countries are not equally having living standards, so difficult for those developing countries to get drugs. Most clear is the assess in following-up trial. Case study 3: content and breakout was good.
48. There should be prepared rapporteurs who they will move around to collect written questions from the audience so that the respondent would give the right answers to these specific questions.

Q4a. How did you find the ...

	n/a	Not at all good			Very Good	
Venue				1	9	38
Supporting materials for the meeting.	1	2	1	2	19	23
Preparation for the meeting			1	1	8	38
General organisation			1	2	9	36

\*next to general organisation 28 adds; EXCELLENT is the word I will use.

Q4b. Comments on answer to Q4a.

1. Might be good sometime for organisers to carry a small amount of cash to bridge emerging gaps, e.g. airport tax for participants.
2. See above comment for Q3b
3. Highly/well prepared accommodation. Organising secretariat very useful and friendly.
4. Venue of the meeting was superb, good structures, services etc. Supporting materials were not adequate. We expected electronic versions of the presentations which is still pending.
5. If only participants would receive case studies earlier even as mail attachments.
6. Would have been very helpful to have all materials (including references for suggested readings for case studies) before the meeting.
7. 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.
8. n/a
9. Bella, Claire and other organisers – great job!!
10. The venue was good, rooms were excellent and they made up for whatever was lacking with grace in their manner of service. The preparation was excellent and this showed in the way everything went spic and span. They went out of their way with organisation to the last detail and the organisers must be commended very highly for their efforts. They were wonderful.

11. Although over-all the venue was good, the plenary session room was crowded a bit.
12. Synopsis of earlier GFBR meeting outcomes would have been helpful if made available. Excellent organisation. Thank you very much.
13. Case studies are insufficiently discussed.
14. n/a
15. Thanks Claire for having all the attention for me and it was very pleased to visit this nice country.
16. Excellent arrangements.
17. The presentation for the meeting, supporting materials and general organisation is excellent.
18. I think some of the supporting material should be available earlier (it could be posted on the internet) in order for us to read it.
19. n/a
20. I was very please with the excellent support from the secretariat from the very beginning, starting with travel arrangements, support throughout the meeting and timetable for returning travel.
21. It is always good to let participants choose where to have their dinner by giving out money for dinner to individuals other than arrange for every meal.
22. There were no problems to complain about that the organisers could handle.
23. n/a
24. I feel good. That's a very good meeting.
25. High standard hotel, enabling environment, good food provision.  
Good materials.  
Excellent preparation.  
Perfect organisation.
26. Claire and all the staff were excellent.
27. Very well organised. Thank you.
28. I was really impressed by the pains taken by organisers. Everything was simply superb!!! Special heart-felt thanks & congrats to Claire & Bella.
29. n/a
30. n/a
31. A well organised meeting although the location meant travel for over 60+ hours to get here and back.
32. Details of meeting sent out very late – made final planning difficult.  
Would have been good to get the case study CD beforehand.
33. I wish to congratulate the entire team of Wellcome Trust in organising event in such a nice way. It will not be justice if I won't submit special thanks to Claire who right from the first day till end managed each of our (questions on mails) + arrangement + care here, also thankful Dr Bella for her cooperation.
34. I would like to have more references or papers about Bioethics and the full texts of presenters of the forum.
35. All are very well prepared. I much appreciate the general organisation.
36. n/a
37. Excellent organisation.  
Congratulations to Claire & Bella. Well Done!
38. Materials were adequate and relevant.
39. The venue was excellent.  
The programmes were not crowded.  
Pre meeting preparations were okay.
40. The venue was sufficiently secluded to avoid distractions. The ambiance was good and support staff hospitable. I was particularly impressed by the pre-conference communication from Claire Griffiths, and the detailed documentation sent in advance of my arrival in Malawi.
41. Venue was excellent – accommodation and hospitality.  
Getting tickets was late.

- Delayed refund of expenditure  
 No per diem.  
 Stationary was poor.  
 The public address system was poor.
42. I have nothing to add because I was fully satisfied. Please, report to the next page for the detail comment.
  43. The hotel facilities are excellent and the organisers did a good job of it. They need to be congratulated.
  44. Things were well arranged/packed before the meeting. However, the bags need to be improved next meeting as they are of poor quality if you compare with the title ("Global Forum...") so even bag material should be of superior quality.
  45. Very expensive initial access. Telephone facilities for overseas calls poor. These are important for people while travelling.  
 Overall the meeting was organised very well.  
 The hotel people are fantastic. Specially Prudence.
  46. Venue: the best part was the self-containment. Everything needed was available. This could have been a larger venue, but it offered every comfort, and was very conducive to the ... program. (Clean, spacious rooms, well maintained, good food, courteous staff).
  47. n/a
  48. It will be better if supporting materials were to be provided as hard copy so that the participants would go through before the discussions or breakout sessions.

Q5. Additional feedback on the issues raised in the workshop.

1. Many of these issues were raised in the group feedback. There is need to analyse the state of development of ERCs, especially how they operate and their output in all the regions. Need to bring on board the various stakeholders and ...
2. 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'.
3. No
4. No. If available later I shall write to the organiser.
5. Please circulate the finalised plenary discussion note on paste (?) then on the website.
6. n/a
7. Difference in ethical issues between the developed and developing world has not been addressed properly. The demands of international funding bodies IRB at times become unnecessarily demanding.
8. n/a
9. Need to follow up on the discussions in the cases – would be nice if they were written up and sent around to be used as teaching aids.
10. I think it was generally agreed that researchers have some ethical responsibility to the participants. They need to do a lot of preparatory work to collaborate with private and public partners as well as participating communities to ensure that they can pull this off and fulfil all their ethical obligations.
11. The theme of the meeting is very relevant. But I would have wanted to hear more detailed critique of the different guideline provisions from a sponsor, 'researchers' and from representatives of industry perspective as a more balanced presentation, also information on how difficult/easy it is apply them.
12. Involvement of more stakeholders: policy makers, participants, community leaders etc.  
 Organisation of the sessions: group session or case study first followed by main or thematic presentation.

13. The Tsunami that affected Indian ocean rim countries has raised important ethical issues. Post disaster research ethics would have been important theme.
14. n/a
15. I would like to listen more about international regulations and the impact or effect on regulations in developing countries.
16. n/a
17. 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.
18. Thank you
19. n/a
20. To maintain a permanent exchange of information and follow up with the participants.
21. It is important to have representatives of some of research funders such as pharmaceutical companies to come and participate. This is especially in respect to post-trial access to interventions.
22. n/a
23. n/a
24. I want to receive the final report of the meeting.
25. Claire, Bella, Brechje, you were fantastic organisers. Keep it up!
26. I would like to listen to other voices, community, patients, etc.
27. Very good cases for discussion. I suspect it would have helped to have briefed the chairs more in advance.  
Select rapporteurs in advance?
28. The thematic discussion was confined to case studies. Some more deep discussions based on available guidelines from various parts of the world could have been more useful. The Forum should have discussed latest available materials in this case.
29. n/a
30. The participants (some of them) speak English too fast and sometime could not follow and could not hear clearly.
31. The case discussion format allowed certain issues to be discussed insufficiently because of circular reasoning within groups.
32. Could GFBR take on training ... of ethics committees ..., they frequently 'obstruct' research due to poor working practices, not understanding documentation submitted etc etc.
33. In next forum representatives from public sector.
34. Next forum of Bioethics should be taken at Asia, where there are many developing countries that they do need more skills and knowledge about research.
35. I would like to participate or have more exercises in the way how the ERC makes for solving in the ethical problems of researchers.
36. Member of national/Government ethical committee should have presentations.
37. n/a
38. The issues of capacity and representativeness of Ethical Committees. Members should undergo training in ethics reviews and committees should have representatives from communities, private sector, Govt, legal firm and social science.
39. None.
40. Nothing more than those that were added in the discussions that followed the plenary sessions and case studies.
41. No.
42. Please, put on the website, as soon as possible, all of the presentations including the summaries of the breakout, debates and discussions. I have to remind you that for the 5th held in Paris, we never got some feedback on the website!!
43. No
44. Consider increasing the number of young researchers/participants from research institutions and from developing countries and supporting them.

45. We need a forum to discuss consent forms.  
Different country should present their views & recommendations, researchers (?) hearing global views only.
46. I strongly feel that "The Global Forum on Bioethics" can slowly develop into a global body that oversees and advise on Govts and decision makers (not necessarily as a mandatory requirement) on problems in Bioethics on a region and ultimately bring a Global standard everywhere.
47. Ethical situations when research/trial conducted among minorities. Relations of culture/habits/religion/tradition and scientific research.
48. No

Q6. In what ways, if any, could future meetings of this kind be improved?

1. Indicated in Answer 4.
2. Missed the business meeting when plans for improvement were made.
3. Sending case scenario to participants by post/internet before meeting.
4. Provisions of adequate supporting materials (CDs, photocopies of presentations) so that delegates can read well in advance before coming to the sessions.  
Young scientists in mid-career level should be invited also if finances permit. These are the people usually involved in research work in the field. Some of them with little or no formal training on Bioethics.
5. Encourage discussion on activities and progress being made by some selected regional ethics groups.  
Give out case studies in advance so that some member would be able to understand details that would stimulate much participation during breakout.
6. As mentioned before, more expert input might be useful e.g. case presentations, planned debates to layout an approach to dealing with issues as well as issues themselves, perhaps round table discussions as well as giving participants good time to air/exchange their views.
7. Inviting more researchers and some community members who are the subjects and beneficiaries of research will increase awareness of what the people feel and think about research particularly in developing nations.
8. The discussion groups would be better if they were smaller.  
For delegates for whom English is not their first language the meeting was difficult to follow. The translators (for French and Spanish) could be heard by everyone as the back of the room and this made it difficult to concentrate on the speakers. The translator's booths should be sound proof or in another room.
9. More avenues for networking.  
It might be interesting to have a session where research participants share their research experiences, positive or negative.
10. I think groups should be a little smaller to ensure fuller participation at that level.
11. 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.
12. More networking during the gap period. Involvement of local committees.
13. Email and web access for participants should have been accessed free. Also more free time for networking, including study of case presentations ... ideal.
14. n/a. [Many thanks to Wellcome Trust].
15. n/a
16. n/a
17. Probably by having more sessions and longer period (5 days).
18. n/a
- 19.
20. Case studies should be mailed in advance prior to the meeting in order to have time to analyse the issues under consideration.

21. Let sponsor/funders attend so that they can respond to some of the issues being raised.  
Let the organisers cater for bed and breakfast and lunch but give more to participants to take care of their dinners.  
[Thank you for organising such important meeting and inviting me as well].
22. Expand the dialogue to include policy makers and sponsors of research. The forum has to a large extent met its objectives.
23. n/a
24. n/a
25. It has been a good point to have people who interpret what is being said from English to French or Spanish. It will be also useful to have people presenting their paper in French or Spanish and have someone to interpret from these languages to English.
26. Invite people from other sectors (I'm thinking in disabled people, mental health "survivors", and the like). Think in participatory and "emancipatory" research.
27. Final day – would have been good to have summary session – presenting themes from previous days – what was agreed, what was highlighted as a problem – for a plenary discussion.
28. Make available the latest information available about the theme & discuss more focused cases.  
Bring in policymakers and administrators to the forum.  
One can really point this Forum as the Benchmark for organisation.  
Organization starting from day 1 of informing the delegates about the forum (which took place months back) till they were seen off from the airport was simply excellent.
29. In most discussions the involvement of policy makers/government officials – health department was stressed. Hence it would be good is we had representatives of government health policy makers from some of the developed and developing countries participate in such meetings.
30. n/a
31. Provide supporting material before the meeting.
32. Inclusion of policy-makers, NGOs who do research (often badly!)  
[Did we answer the question of what happens (should happen?) when the research is over?]
33. Always improvement needed in all areas + always there is a chance of improvement.
34. Yes, it could.
35. n/a
36. Yes, I totally agree.
37. n/a
38. Next time, it would be most helpful to go beyond identifying ethical issues in protocols or case studies. The forum should discuss "how" the identified ethical issues may be dealt with.
39. May be increase the number of days to 4 and increase number of participants.  
The meeting materials could be increased, i.e. case studies published in journals to be circulated as working documents.  
The meeting bags should be improved.
40. Perhaps instead of or in addition to, one the three case studies scheduled, there could be a general "open" forum in which participants could raise issues particularly pertinent to their setting inviting comments, advice, guidance, or general discussion from other participants who may provide diverse perspectives.
41. Send the programme and literature in advance.
42. First of all, I have to emphasis that the programme seems to be fine with plenary and long time for the discussion. I do not think the forum need to be focused on teaching of ethics. There are specific training courses for that duty! Therefore, debate and exchange are the priorities to justify the "forum". However, maybe a short commentary or synthesis at the end of each session could be useful? On the other hand, inviting policy makers and some leader of developing countries could be useful

even though I am aware that politicians have not much time and will not be very enthusiastic to discuss. Indeed, they usually require support for all the fees related to their input. Finally the theme of the next forum in PAKISTAN is exactly the topic we need to discuss about. The public health integrated as presented by Dr Adnan Hyder is our challenge for stakeholders especially for those who work in ethnic approaches!! Once more, even though it will not be easier to make a short synthesis immediately after a fruitful discussion of breakout groups, discussion with the diversity of the opinions, it will be useful to have it. The high quality of the chair you selected will facilitate that duty.

43. The organisers have done a very good job and deserve to be congratulated! The only small problem was the fact that there was some delay in informing award winners that they had been selected and so things had to be rushed at the last minute.
44. Consider next meeting to provide allowances for participants so that they can have their own dinner elsewhere they would like to rather than eating in the same hotel from breakfast to dinner. Also issues of airport taxi, next time please come with emergency money as this time a lot of people have been inconvenienced as they have to borrow or become beggars so that they can pay the 30 \$ airport taxi. This refund is urgently requested once you reach home (the UK) and you should ensure that the refund you will send out to participants will be taxed by the banks in their respective countries so take note of that also.  
Good luck and thanks so much for organising this conference.
45. Avoid backward countries. I lost my luggage. Airport was inefficient.
46. This was discussed in the Business meeting – by bringing in “decision makers” to participate in the forum throughout. A word of caution; I do not sponsor an idea like that, since I look at the forum as one which is not influenced “politically”. Best thing is to submit a report to the decision bodies with suggestions after a Forum at least to the local Government/agency; as well as to the decision makers of the “case studies” made in a Forum. It is for them to take this up or not. But slowly this will have a strong impact on such regions.
47. Case studies of the relevant issues.
48. Early arrangements and confirmation of booked tickets and payments so that all participants could manage to attend the meeting at time without being kept under pressure.