

Audit Report:

Secretariat of the Global Forum on Bioethics in Research

Commissioned by
COHRED for the
GFBR

Report by:

Vernon Solomon
School of Psychology
University of KwaZulu-Natal
South Africa

15 February 2009

Table of Contents

1. Executive Summary	3
3. Aim	8
4. Method	9
4.1 Survey Instruments and Interview Guide	10
4.2 Procedure and analysis	11
4.3 Sample	12
5. Results and Discussion	12
5.1 Background to establishment of the secretariat	13
5.2 Familiarity with TOR and Objectives of Secretariat	15
5.2.1 Table 1 TOR and Secretariat Objectives by item	16
5.2.2 Fig. 1 TOR and Secretariat Objectives Summed	16
5.2.3 Table 2 TOR and Secretariat Objectives Summed	16
5.3 How Well the Secretariat has Functioned	18
5.3.1 Table 2 Secretariat Functioning by Item	18
5.3.2 Fig. 2 Secretariat Functioning Summed	19
5.3.3 Table 3 Secretariat Functioning Summed	19
5.4 Website	23
5.4.1 Table 3 Website use frequency, user friendliness, usefulness	23
5.4.2 Fig. 3 Frequency of Website Use	23
5.4.3 Table 4 Frequency of Website Use	23
5.4.3 Fig. 4 Website User Friendliness	23
5.4.4 Table 5 Website User friendliness	23
5.4.5 Fig. 5 Usefulness of Website	24
5.4.6 Table 6 Usefulness of Website	24
5.5 Secretariat Achievement of the TOR	25
5.5.1 Table 7 Secretariat Achievement of TOR by Item	25
5.5.2 Fig. 6 Secretariat Achievement of TOR Summed	25
5.5.3 Table 8 Secretariat Achievement of TOR Summed	25
5.6 Role of Secretariat and Contribution to GFBR	27
5.6.1 Table 9 Secretariat Role and Contribution to GFBR by Item	27
5.6.2 Fig. 7 Secretariat Role and Contribution to GFBR Summed	28
5.6.3 Table 10 Secretariat Role and Contribution to GFBR Summed	28
5.7 GFBR: Effectiveness and Value	29
5.7.1 Table 11 GFBR Effectiveness and Value by Item	29
5.7.2 Fig. 8 GFBR Effectiveness and Value Summed	29
5.7.3 Table 12 GFBR Effectiveness and Value Summed	29
5.8 Participants perceptions and experience of the secretariat and the GFBR	31
5.8.1 Secretariat	32
5.8.1.1 Strengths	32
5.8.1.2 Weaknesses	33
5.8.1.3 Experience of secretariat	35
5.8.2 GFBR	36
5.8.2.1 Strengths	36
5.8.2.2 Weaknesses	36
6. Sustainability of the Secretariat	38
7. Conclusion and Way Forward	40
8. Appendix I Partner Survey	42
Appendix II Stakeholder Survey	49
Appendix III Partner – Secretariat Interview Guide	56
Appendix IV Stakeholder Interview Guide	58
Appendix V Participant Information and Consent sheet	61

1. Executive Summary

The GFBR commissioned an evaluative audit of its secretariat, which was directly funded for 2007 - 2008 with financial support obtained through a two-year grant from the Science & Society programme of the Sixth Framework Programme for Research (FP6) of the European Commission. Prior to this, COHRED had hosted the secretariat functions of the GFBR at the GFBR's request since 2004.

This funding is currently at an end and the secretariat is now precariously placed in terms of its future and major challenges lie ahead for its continuity and sustainability.

The overarching aim of the audit was to evaluate the work and impact of the GFBR Secretariat in terms of its operations, meeting the objectives of the EC grant and furthering the mission and aims of the GFBR and to consider recommendations for the improvement of the functioning of the secretariat and its sustainability.

The audit took the form of a rapid assessment employing an electronic fillable survey form and more in-depth interviews conducted with GFBR partner key informants. Nominated stakeholders of the GFBR also participated in the audit although none were available for interview due to logistical constraints. Eleven partners and four stakeholders completed surveys and all these partners were interviewed.

1.1 Summary of the key findings

1.1.1 The overall evaluation of the secretariat function has been generally positive with almost all participants recognising the constraints of the circumstances under which it was established. This relates especially to the funding and limited person power constraints. The funding was insufficient to attract suitably qualified persons for secretariat functions and only allowed part-time employment, which was deemed inadequate to serve the function. The funding situation has perhaps problematically conflated "pure" secretariat functions with more academic-research-policy and capacity development functions that have impacted on both, constraining achievements in both these areas.

Some participants would have preferred a much stronger logistical and administrative support function from the secretariat regarding:

- a. Logistical support for the GFBR annual meetings
- b. Protocols and policies for participant selection
- c. General administrative policies and administrative infrastructure

Some participants wanted the secretariat to perform a stronger administrative leadership function and would have appreciated more centralised decision-making and decision managing rather than extensive email consultation with unclear outcomes and processes. The overall evaluation yields the following two conclusions:

- a. There is a need for a secretariat with strong leadership and managerial skills and functions.
- b. A stronger managerial hand on the tiller of the secretariat was identified by some participants as an important future priority.

1.1.2 *Capacity building and the fellowship programme attracted diverse opinions across the positive - negative continuum.*

The closer to the secretariat and the fellows participants were, the more positive their view of the capacity development aspect of the fellowship programme. This suggests that the outcomes and experience of fellows are not well communicated and known by many in the GFBR network. It also suggests that the outcomes may only be evident over time rather than within the short timeframe.

Some participants and the fellows themselves report very positive outcomes concerning the fellowship programme and itemise the networking, familiarisation with European and US structures and processes and the opportunity to be mentored on academic work as important positive outcomes.

The organic and relatively loose development of the structure and content of the fellowship programme is both a strength and weakness of the capacity

development component as it at once requires strong self-directed planning and management but also allows personal professional development goals to be set and achieved rather than having a pre-determined programme imposed.

- 1.1.3 *The secretariat has very successfully begun the process of preserving the institutional memory* of the GFBR and the website, documentation of fora, the database of participants and communication and dissemination of information are all itemised in this respect.
- 1.1.4 *The secretariat has very successfully begun the process of establishing the infrastructure and organisational coherence of the GFBR.* Documents, policies, management of steering committee meetings, communication and dissemination of information are itemised in this regard. The development of a coherent central organisational structure, the face and mouth of the GFBR is highly valued. Greater clarity on structure, roles and responsibilities are however needed in the future in respect of the secretariat, partners and steering committee members. The provision of organisational continuity has been valued but this needs to be strengthened.
- 1.1.5 *The intellectual (research, policy, publication) output of the secretariat has probably been the weakest aspect of its functioning;* however, this is accounted for by participants by the constraints of both funding and personnel. An overambitious (perhaps inappropriate) agenda that conflated these objectives with a complex set of administrative objectives is cited as mostly responsible for this.
- 1.1.6 *There is strong support for the need for a secretariat and its continued existence within different views about the nature of its core business.* Conflicting views centre on whether the secretariat should be purely administrative or hold an additional strong academic – research and policy function. The future sustainability of the secretariat is most likely to lie in a combination of these roles given the difficulty of finding funding for purely administrative functions.

1.1.7 *The impact and reach of the GFBR has been questioned* despite it being highly valued for its capacity to facilitate horizontal open dialogue and create a platform for the voices of the South to be heard. The GFBR should however focus on ongoing activity globally and regionally between fora and the secretariat should play a role in mobilising and facilitating this. A more proactive interactive and engaging process of ongoing dialogue is called for together with a concerted effort to reach a wider more diverse population.

1.1.8 *Sustainability of the secretariat is uniformly viewed as an extremely difficult* problem. Strategies to address it span funding and functioning:

- a. Securing long term funding by casting a very wide net.
- b. Integrating research and capacity development into funding proposals.
- c. Increasing funding partners, and partners increasing contributions.
- d. Seeking new funding partners.
- e. Distributing secretariat functions amongst partners and organisations especially in the global South with a central hub.

1.1.9 Overall, all participants (with some minor dissent) complimented the secretariat on the dimensions of efficiency, helpfulness, communication and responsiveness.

1.1.10 The secretariat faces a very uncertain future. The leadership and driving role of the partners needs to be mobilised to map and implement this future for the secretariat and the Global Forum itself. It may be that the evolution of the secretariat has had an unwitting impact on leadership within the partners leaving a leadership vacuum at this critical moment. The secretariat also seems to have brought the challenge of re-visioning the GFBR from an informal partnership to a more formal organisation.

A strong administrative footing together with strong leadership is required for the future of the GFBR if continuity and impact are to be maximised. There is some dissent regarding whether a secretariat is essential for this, but the weight of opinion holds that this would be very strongly preferred.

2. Introduction

The GFBR is approaching its tenth year of operation as a consortium of partners mobilised around a mission to promote a global dialogue on ethical, legal, social and public policy issues related to health research in international settings. The NIH and WHO as founding partners, hosted the first GFBR meeting in Bethesda in 1999. The tenth Global Forum meeting is scheduled for Santiago, Chile in September 2009.

The GFBR has historically functioned as a collaborative consortium of partners who together have administratively, financially and logistically supported the Forum's functions and activities. The increasing complexity and weight of the tasks together with the need for structural coherence and organisational continuity led to the need for the establishment of a centralised secretariat to serve the GFBR. COHRED was asked to host the secretariat on behalf of the GFBR in 2003, and agreed to do so from 2004. It was key in writing the grant proposals to the EU FP6 programme which provided the first direct funding for the secretariat for the years 2007 – 2008. Until then, secretarial functions were an unfunded contribution to the GFBR. An important distinction is made here between secretariat functions versus a directly funded secretariat. The directly funded secretariat was established in 2007 mainly funded through a two-year grant from the Science & Society programme of the Sixth Framework Programme for Research (FP6) of the European Commission. COHRED held the grant on behalf of the GFBR partners and continued to host and manage the GFBR secretariat functions and the directly funded secretariat for 2007 – 2008. The GFBR website was similarly hosted and managed by the Aga Khan University as part of its partner contribution to the GFBR and other partners similarly contributed funding to the GFBR and contributed administratively and intellectually.

Structurally, the funded secretariat comprised a half-day ethics officer, and over the two year funding period, two fellows. COHRED hosted and managed the work of the secretariat and from time to time, partners seconded individuals to work for short periods with the secretariat, either virtually or residentially at the COHRED offices. Under the EC FP6 programme, two fellowships were funded; the first for 9 months and the second for 12 months. Both fellows, the first from China and the second from the Philippines, contributed significantly to the administrative and reporting work of the GFBR secretariat. Up to 75% of their time was spent on secretariat activities.

Reports written by the fellows on their experiences at COHRED and the GFBR are available on request by partners.

The GFBR has commissioned an evaluative audit of the work and functioning of the GFBR Secretariat. The evaluation scope references the European Commission specific support action grant, the GFBR-Secretariat's terms of reference and the GFBR's mission and aims. The evaluation time-frame required that the evaluation adopt a rapid assessment approach mobilised around a set of overarching evaluation questions applied to focal domains. This approach adopted the following objectives:

- a. To evaluate the work and impact of the GFBR Secretariat in terms of its operations, meeting the objectives of the EC grant and furthering the mission and aims of the GFBR.
- b. To develop recommendations for the improvement of the functioning of the secretariat and its sustainability.

The evaluative audit was conducted during December 2008 and early January 2009 using two primary data sources; a perceptions survey of partners and nominated stakeholders and telephonic interviews with partners and stakeholders. GFBR documentation was used to supplement information and to frame the evaluation method and process. The objectives were addressed through analysing interview and survey responses to the following focal domains:

- a. The functional performance of the secretariat.
- b. The extent and effectiveness of the secretariat in advancing the GFBR mission.

3. Aim

The GFBR secretariat evaluation is primarily focused on an overarching question concerning the functioning of the recent phase (2 years) of the directly funded secretariat. The evaluation of the GFBR and its impact in broader terms should be the subject of a larger and longer term evaluation exercise. As such, this is considered beyond the scope of this rapid evaluation. Nevertheless, the current

evaluation focus is likely to generate observations and suggestions concerning the broader GFBR impact and may yield useful guidance for a larger evaluation process.

3.1 The evaluative audit holds the following overarching aims:

- 3.1.1 To evaluate the work and impact of the GFBR Secretariat in terms of its operations, meeting the objectives of the EC grant and furthering the mission and aims of the GFBR.
- 3.1.2 To develop recommendations for the improvement of the functioning of the secretariat and its sustainability.

3.2 The sub-goals for the audit focus on:

- 3.2.1 The functional performance of the secretariat.
- 3.2.2 The extent and effectiveness of the secretariat in advancing the GFBR mission.

4. Method

The evaluative audit took the form of a stakeholder perceptions survey making use of two primary data sources; GFBR partners and GFBR nominated stakeholders.

Two data collection strategies were used:

- a. Two *survey instruments* in the form of fillable electronic survey schedules were developed and used for (a) partner organisation members and secretariat members and (b) selected key stakeholders.
- b. *Telephone Interviews* were conducted with two groups: partner nominated key informants from within each partner organisation including the secretariat and a selected set of key stakeholders identified and nominated by the partner organisations and the secretariat.

The interview schedule and survey instruments are described below and appended in Appendices I-IV.

4.1 Survey Instruments and Interview Guide

The interview schedule and survey design was informed by the secretariat TOR, the EC grant specification and the GFBR aims. Two slightly different survey instruments were developed for partner and stakeholder respondents respectively and included a mixture of closed ended questions, performance rating scales/questions and open-ended qualitative questions.

The survey forms were distributed as electronic fillable form-protected documents comprising drop-down boxes for rating scales and free entry text fields for qualitative data.

The survey instruments covered the following eight operational domains:

- a. Familiarity with the secretariat TOR and objectives.
- b. Extent of achievement of objectives listed in the EC specific support action.
- c. Grant and fulfillment of its TOR.
- d. How well the secretariat functioned across its performance domains.
- e. Perceptions of the need for a secretariat.
- f. Website use, user-friendliness and usefulness.
- g. Role of secretariat and contribution to GFBR.
- h. Effectiveness and value of the GFBR itself

Both forms of the survey instrument included free text entry qualitative sections asking for input on:

- a. Secretariat strengths and weaknesses
- b. Experience of the secretariat

- c. Suggestions for sustainability of the secretariat
- d. GFBR strengths and weaknesses

The interview process intended to allow an exploration and amplification of the domains of inquiry of the perceptions survey and therefore, similarly focused on ten aspects:

- i. The background to the establishment of the secretariat
- ii. The most important objectives of the secretariat and the GFBR
- iii. Appropriateness of the secretariat TOR
- iv. Achievement of secretariat objectives
- v. Performance in respect of fellowship and capacity building; information dissemination and maintenance of institutional memory.
- vi. Overall operational effectiveness and efficiency
- vii. Strengths and weaknesses of secretariat and GFBR
- viii. Role of secretariat and contribution to GFBR
- ix. Need for secretariat
- x. Sustainability of secretariat

4.2 Procedure and analysis

All potential participants (partner key informants and nominated stakeholders) were contacted via electronic mail, invited to participate and a combined information sheet and informed consent form was distributed with this introductory e-mail. This is appended in Appendix V. Once participants confirmed their willingness to participate, they were contacted to schedule a time for the interview and the relevant survey form was emailed. Participants were asked to return the survey via e-mail or fax. Interviews were recorded with the consent of the participants, transcribed and analysed thematically to amplify and explain the survey data.

The survey data was entered into SPSS and given the small sample, simple frequency analyses were conducted for each item. These were subsequently grouped into logical domains and summed to facilitate summary reporting as is explained in the results section below.

4.3 Sample

Sampling for the audit was purposive and generative. All members of the secretariat and partner-key informants listed in the GFBR secretariat's database were emailed. Each partner was asked to nominate a stakeholder key informant and the secretariat also compiled a list of proposed stakeholder informants all of whom were emailed the invitation to participate.

Seventeen (17) secretariat members and partners were invited to participate of whom eleven (11) were available and willing to be interviewed and subsequently completed the survey.

Ten (10) nominated stakeholders were invited to participate of whom only four (4) were willing to complete the survey but had logistical and scheduling difficulties that prevented the option of interviewing them. None of the nominated stakeholders were therefore interviewed. Three nominated stakeholders did not reply to the invitation whereas the balance was unable to participate due to travel and work commitments.

The total sample obtained for the audit was 11 interviews and 15 returned surveys.

5. Results and Discussion

This section presents an integration of the survey findings with the interview data. The themes, specific content and quotations are presented here with the survey data in order to provide amplification, explanation and elaboration of the key domains of inquiry.

Each quantitative section of the survey has been reported here as frequency tables (raw data) accounting for the number of respondents selecting each response option on the survey for each item. This table clearly indicates the distribution of responses for each item, A summary table and graph comprising grouped items follow this for each of the sections of the survey. The items have been grouped into six logical domains and the survey question number is noted in each initial table.

The summary table and graph, simply totals the number of responses for each of the response options to all the items grouped under the main themes and provides an

overall impression for each of the grouped domains. The graph then simply displays the summary total table giving a visual representation of overall ratings across each broad domain. Raw and summed data is reported here given the very small sample. The six domains are as follows:

- a. Familiarity with TOR and objectives of the secretariat
- b. How well the secretariat has functioned (in specific areas)
- c. Website
- d. Secretariat achievement of the TOR
- e. Role of secretariat and contribution to the GFBR
- f. GFBR: Effectiveness and value

Information across these domains (and the remaining domains listed above) derived from the interview analysis is integrated into the presentation of these quantitative data together with the qualitative data from the survey responses.

5.1 Background to establishment of the secretariat

The interviews generated a clear consensus set of background factors that have led to the need for and the establishment of the secretariat. It is also important to note that there was broad consensus on the need to establish a secretariat for the GFBR.

This is easily summarised as follows:

Whereas the GFBR has functioned very well over the past years, the quantity and complexity of the work to sustain and manage it was becoming increasingly onerous for the partners and the steering committee. This factor together with a growing recognition of the need for organisational coherence, continuity and a focal point for communication and coordination drove the decision to establish a secretariat. To this end, COHRED was requested to host the secretariat functions for the GFBR and agreed to do so from 2004. From 2007 – 2008, the secretariat functions were directly funded through the EC FP6 grant which included a set of deliverables which perhaps

went beyond that which was originally envisaged by the GFBR for its secretariat. What this meant was that not all originally envisaged secretariat functions could be performed as the focus and priority shifted to meeting the terms of the EC FP6 grant.

A need was also identified for a secretariat that could provide coordinating oversight over themes and participant selection to ensure broader and changing participation to increase the impact of the GFBR.

Although there was a longstanding wish for a secretariat, the absence of direct funding set some limits on how secretariat functions could be fulfilled. The opportunity for directly funding a secretariat through the EC specific support action grant solved this problem partially, but resulted in a model of the secretariat that went beyond many of the partners' views of what the secretariat should be.

"This was the problem, wish for a secretariat but there was no money. ...The secretariat as listed in the grant is not exactly the same as the secretariat the partners wanted."

"...it is quite tricky, wanting to do too much."

There appears to be a broad recognition that while the pressing need was for an administrative secretariat, the addition of an academic, capacity building role was a valuable aspiration. This has nevertheless potentially compromised the secretariat's ability to fulfil all its objectives. There is some tension and diversity of opinion from the interviewees concerning the administrative role versus the academic and capacity building role for a secretariat.

"The more pressing need is the admin side, the sort of corporate documentation, communication and memory...there was a desire that there was more academic influence rather than having admin staff. The GF being able to contribute to the capacity building instead of admin staff, (is) a better aspiration I suppose."

"I think there needs to be a discussion in the advisory (steering) committee. What do the partners want?"

While this dual role may have been an artefact of the funding requirement, it also reflects the vision of some partners for a secretariat that goes beyond a purely administrative function. This however remains a tension that must be resolved going forward. The preferred vision for the role and function of the secretariat needs to be clarified by the partners.

Additional factors associated with the background to establishment of the secretariat are listed below:

- i. The need for coordinated communication between partners and local organising committees for forum meetings
- ii. The provision of support for local organisers
- iii. Organisational aspects of Forum becoming onerous for the partners
- iv. Facilitation of transfer of processes, skills and protocols from one organiser to the next
- v. Preservation and compilation of institutional memory
- vi. Preservation of the structural elements of the forum while allowing and facilitating new content

The preservation of the institutional memory and maintenance and transmission of the ethos of the GFBR was identified by many participants as a key objective for the secretariat.

“it’s very important to explain to local organisers what is the spirit of this project, what has been done in the past. (It is) easier for one central person to lead with local organisers than 10 or 12 people”.

5.2 Familiarity with TOR and Objectives of Secretariat

Most participants have a reasonable knowledge of the secretariat’s TOR. The variability possibly reflects greater distance from and involvement with the secretariat. Since the data includes secretariat members and stakeholders, these two constituencies would be expected to be knowledgeable and less knowledgeable respectively. The same appears to be the case in respect of knowledge of the

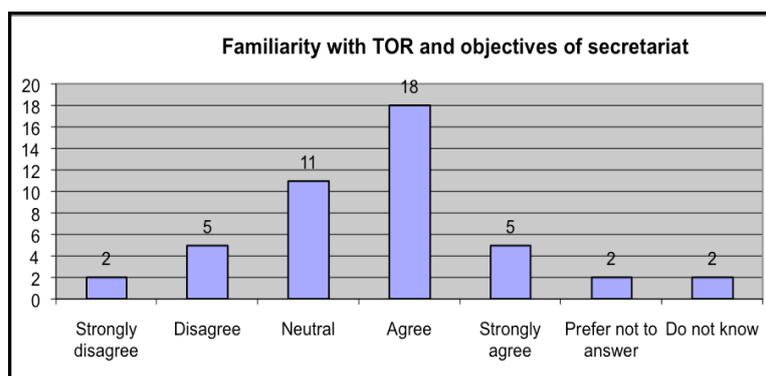
secretariat’s objectives. Variability in these knowledge items amongst the partners may reflect levels of involvement, history of involvement and current role on the steering committee, whether a permanent partner or rotating member. This was evidenced in the interviews with varying levels of knowledge being acknowledged by participants. Several participants had had direct involvement in developing the ideas for the secretariat and the TOR.

5.2.1 Table 1 TOR and Secretariat Objectives by item

4,5,6) Familiarity with TOR and objectives of secretariat	Strongly disagree	Disagree	Neutral	Agree	Strongly Agree	Prefer not to answer	Do not know
Familiar with the GFBR secretariat's TOR	1	2	3	7	2	0	0
Secretariat has fulfilled its TOR overall	0	0	4	7	1	2	1
Familiar with the objectives of the GFBR secretariat	1	3	4	4	2	0	1
TOTAL	2	5	11	18	5	2	2

5.2.2 Fig. 1 TOR and Secretariat Objectives summed

5.2.3 Table 2 TOR and Secretariat Objectives Summed



Familiarity with TOR and objectives of secretariat	
Strongly disagree	2
Disagree	5
Neutral	11
Agree	18
Strongly agree	5
Prefer not to answer	2
Do not know	2

A global assessment of the secretariat's functioning is included in this set of results and show just over half the sample agreeing that the secretariat has fulfilled its TOR overall. Some disappointment with levels of logistical and administrative support communicated in the interviews as well as concerns over how well the secretariat has performed across all its domains may explain the prefer not to answer and neutral responses. The latter may also be accounted for in terms of the confusion and tensions expressed by most respondents concerning the secretariat's roles and functions.

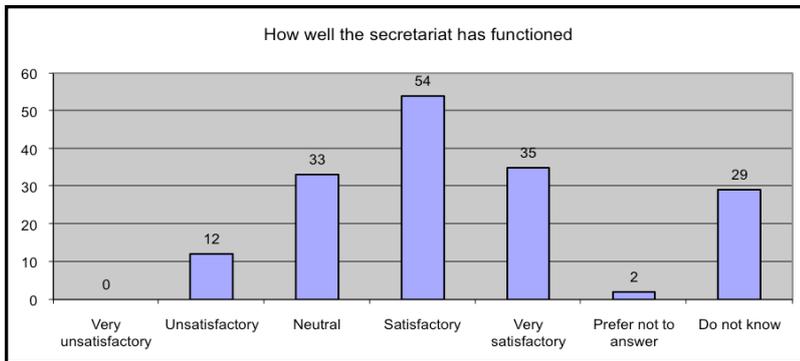
5.3 How Well the Secretariat has Functioned

5.3.1 Table 2 Secretariat Functioning by Item

7) How well the secretariat has functioned.	Very unsatisfactory	Un-satisfactory	Neutral	Satisfactory	Very satisfactory	Prefer not to answer	Do not know
Intellectual support for GFBR conferences	0	2	2	8	1	0	2
Organisational support for GFBR conferences	0	1	4	6	3	0	1
Established structural framework for collaboration	0	1	3	5	5	0	1
Maintain the 'institutional memory' of the GFBR	0	0	3	5	4	0	3
Organisational continuity for the GFBR	0	1	3	4	7	0	0
Helped with identifying emerging/topical issues in international health research ethics	0	2	4	2	4	1	2
Facilitated ongoing debate	0	2	7	4	1	0	1
Advocated for capacity building for health research ethics in European countries	0	0	3	2	1	0	9
Advocated for capacity building for health research ethics in countries in which EU members conduct research	0	0	0	7	2	0	6
Facilitated the fellowship programme for capacity building in research ethics	0	1	2	5	4	1	2
Functioned administratively	0	2	2	6	3	0	2
TOTAL	0	12	33	54	35	2	29

5.3.2 Fig. 2 Secretariat Functioning Summed

5.3.3 Table 3 Secretariat Functioning Summed



How well the secretariat has functioned	
Very unsatisfactory	0
Unsatisfactory	12
Neutral	33
Satisfactory	54
Very satisfactory	35
Prefer not to answer	2
Do not know	29

The range of performance domains in this section is drawn from the secretariat TOR and objectives. The range of ratings and variability is important to notice although the overall impression is generally positive. In the domains of organisational functioning, the secretariat appears to have done well. Establishing and facilitating collaboration, continuity and administrative functioning generally attracted positive views. The interviews uniformly report a very positive view of interfacing with and communicating with the secretariat. Almost all cite responsiveness, professionalism and efficiency in their accounts of their direct dealings with the secretariat. These qualitative aspects are reported below.

The interviews however offer important qualifications in these domains.

For some participants, the role of the secretariat is not to provide intellectual support or facilitate ongoing debate, but rather to facilitate the role of the partners and the Forum itself in this regard. Again, the core tension of what role the secretariat should play is highlighted here.

The unsatisfactory ratings for the administrative and organisational dimensions of the secretariat are most likely rooted in the perceptions of partners and stakeholders and local organisers of unmet expectations concerning logistical, procedural and administrative support for GFBR annual meetings. A high level of concern, disappointment and frustration was reported by a small minority (2) of interviewees who had expected a higher level of support, a manualised set of procedures and protocols for all aspects of hosting. Whereas communication was facilitated and

coordinated, the experience was reported to be cumbersome, involving numerous emails containing multiple disaggregated content. The impression here is of the secretariat having facilitated the flow of communication very well, but that the communication was not well managed leaving decision making ambiguous and difficult. Additional concerns reported here relate to uncertainty about funding for Fora and funding pledges not being realised. This leaves hosts in a precarious situation. Quotations are not included here in order to preserve the anonymity of respondents although one observation provides a measured summary of this issue.

“...local organisers expectations were far greater than what the secretariat could provide.”

On the theme of organisational support, other interviewees commented that the secretariat has done well in beginning the process of systematising processes, but that this represents a start.

“Would’ve been a better focus in terms of the function of the secretariat, should have spent more time on the (secretariat) TOR and the GF as an institution....Given that it’s the first two years of the secretariat. If the secretariat were a long term thing, could start to look at broader sorts of policy.”

While the above holds true for many, others had specific areas of disappointment with the secretariat. For partners the expectation that the secretariat would make their contribution less onerous, this was not sufficiently realised. By contrast, other partners reported very positively on this aspect.

“...the report, of all things, that was not well done.”

A general consensus emerging from the interviews concerns one aspect of the functional role of the secretariat. Almost all respondents would want a strong secretariat that offers administrative and organisational leadership, coordination and management. Most agree that the foundation for this has been laid but not achieved. Again, the diversity of tasks required of the secretariat in its first phase is cited as explanation for the level of achievement in this regard. There was some suggestion

that a key issue in the functioning of the secretariat relates to needing to find the right person with appropriate qualifications. The ideal individual would be a high level administratively skilled person, possess good leadership and management qualities as well as have a sophisticated understanding of health research ethics in international and developing context health research. The paradox here was pointed out in terms of the funding which makes attracting the right person more than difficult.

Some participants respectfully and sensitively commented that they believed stronger management and leadership of the secretariat were needed. At the same time, the GFBR as a whole, in particular the funding partners were identified as perhaps playing a too low-level role in leadership and driving the vision of the secretariat. It may be that with the inception of the secretariat a tacit change in the partners' leadership role has taken place unwittingly. This dynamic warrants concerted attention if the GFBR and the secretariat are to be strengthened. Given the precarious future of the secretariat, the view that the partners need to commit their resources and energy to this was expressed.

As was evidenced in the tensions concerning the role for the secretariat, the items relating to advocating for capacity building in health research ethics attracted a variety of responses. The agreement endorsement for the item advocating for capacity building in health research ethics in countries in which EU members conduct research may be more an artefact of GFBR outcomes rather than the secretariat itself. The interviews do not offer clarity on this issue.

Facilitation of the fellowship programme for capacity building in ethics attracted a diversity of views in the interviews that nicely amplify the overall positive view obtained in the survey.

Many participants were unaware of the experiences and outcomes of the fellowship programme for the fellows. For those who had close contact with the fellows, very positive views were expressed.

“Fellowship is worthwhile. Both as an educational opportunity for the people who did it but also in terms of developing the bioethics capacity of the countries they are from.”

“Fellow from... and ...and myself and...have all been in contact and exchanging ideas. Working together and working on reports. ...miniature version of what the Global forum is which is to facilitate communication between different people in different places doing different things.”

Other interviewees identified the excellent networking opportunities for the fellows, the opportunity to be exposed to people, to institutions and mechanisms for “doing ethics” as being instrumental in facilitating the fellowship outcomes.

“...this has really worked, especially in terms of the European partners, increased collaborations, communication, attended meetings. Excellent opportunity for senior scholars to develop.”

The lack of a structured programme for the fellowship was cited as both a strength and a weakness. The open and loose structure required a high degree of self-direction and personal programme structuring. This however did allow the experience to be tailored to suit the fellows’ personal objectives. The fellowship appears to have been loosely managed but with valuable and meaningful access to relevant people for professional and academic development opportunities. The incorporation of secretariat administrative functions within the fellowship was experienced as unchallenging but was accepted and understood as key to “funding” secretariat activities.

The following quote perhaps best summarises this section on the performance of the secretariat capturing as it does the tension between administrative and academic – policy functions for a secretariat.

“...grant tried to be too much to too many people”

To fully capture the general sentiment, the quote should perhaps have ended....with too little resources.

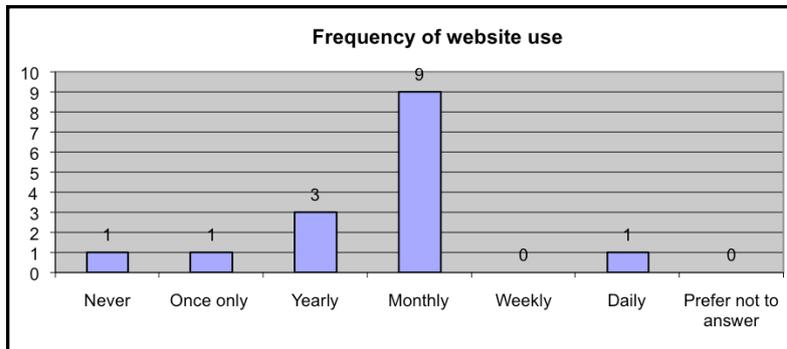
5.4 Website

5.4.1 Table 3 Website use frequency, user friendliness, usefulness

8) Website							
Frequency use of the GFBR website	Never	Once only	Yearly	Monthly	Weekly	Daily	Prefer not to answer
TOTAL	1	1	3	9	0	1	0
Satisfaction with user friendliness of GFBR website	Very unsatisfactory	Unsatisfactory	Neutral	Satisfactory	Very unsatisfactory	Prefer not to answer	Do not know
TOTAL	0	1	3	7	3	0	1
GFBR website is useful.	Strongly disagree	Disagree	Neutral	Agree	Strongly Agree	Prefer not to answer	Do not know
TOTAL	0	0	2	9	3	0	1

5.4.2 Fig. 3 Frequency of Website Use

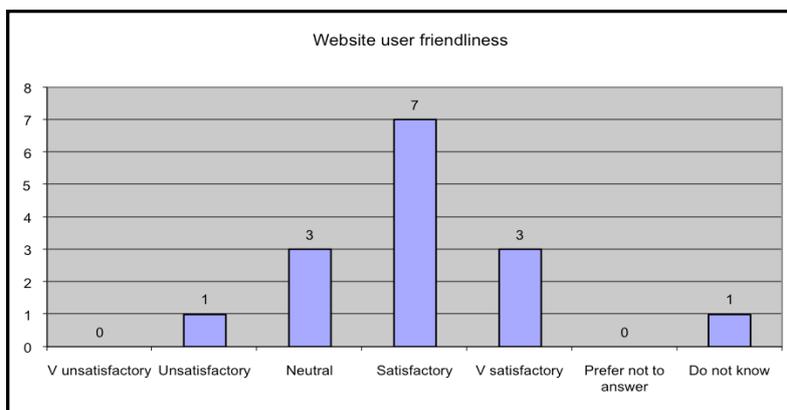
5.4.3 Table 4 Frequency of Website Use



GFBR website Frequency of use	
Never	1
Once only	1
Yearly	3
Monthly	9
Weekly	0
Daily	1
Prefer not to answer	0

5.4.3 Fig. 4 Website User Friendliness

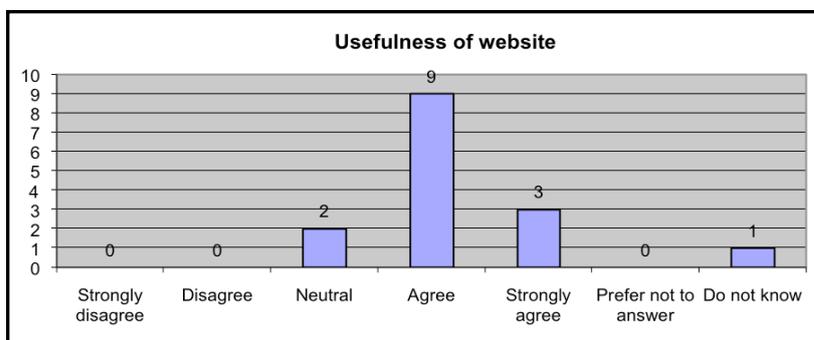
5.4.4 Table 5 Website User friendliness



Website User friendliness	
V unsatisfactory	0
Unsatisfactory	1
Neutral	3
Satisfactory	7
V satisfactory	3
Prefer not to answer	0
Do not know	1

5.4.5 Fig. 5 Usefulness of Website

5.4.6 Table 6 Usefulness of Website



Usefulness of website	
Strongly disagree	0
Disagree	0
Neutral	2
Agree	9
Strongly agree	3
Prefer not to answer	0
Do not know	1

The neutral and do not know responses on the website related items are possibly related to low frequency and never users. The unsatisfactory response is possibly related to one view emergent from the interviews that calls for a more dynamic use and function for the website. Overall, the interviews evidenced a positive view of the website. The general perception was that this is a major improvement although one respondent was unsure whether to attribute this to the secretariat. Most participants associated the improved website and its value as a dissemination medium with the secretariat’s organisational and coordination input. It is important to recognise the historical and ongoing role of the Aga Khan University (AKU) in the establishment and maintenance of the GFBR website. The direct funding for the secretariat allowed for the commitment of GFBR secretariat staff time to collaborate with AKU to develop and improve the website to its current state.

“Has been improved in the time the secretariat has been operational, very good thing.”

“It could be a little more engaging, user friendly, sexier, but it’s alright.”

“Not a lot seems to happen between the annual meetings. GF could develop and make more use of the web, online discussion, maybe moderated discussions...”

The latter quote points to a broader issue taken up in the discussion of the GFBR itself later in terms of its ongoing impact and its reach. The point is made here (and later) concerning the lack of activity between annual meetings that might limit or

constrain the GFBR mission impact. The website is seen here as a potentially important medium for interaction, stimulating debate and facilitating ongoing communication on bioethics. For this to occur, a more dynamic, interactive functionality needs to be conceptualised and built into the existing website.

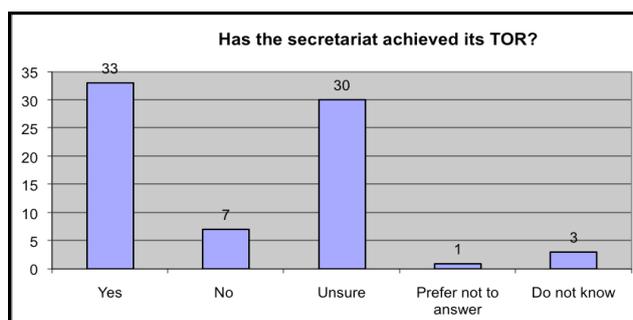
5.5 Secretariat Achievement of the TOR

5.5.1 Table 7 Secretariat Achievement of TOR by Item

9) Has the secretariat achieved its TOR?	Yes	No	Unsure	Prefer not to answer	Do not know
Published policy papers	3	4	7	0	1
Publications have been consistent with GFBR aims	4	1	8	1	0
Facilitated exchange and development of ethics capacities in developing countries	11	0	3	0	1
Disseminated information through publications	7	1	7	0	0
Facilitated a meaningful fellowship programme	8	1	5	0	1
TOTAL	33	7	30	1	3

5.5.2 Fig. 6 Secretariat Achievement of TOR Summed

5.5.3 Table 8 Secretariat Achievement of TOR Summed



Has the secretariat achieved its TOR?	
Yes	33
No	7
Unsure	30
Prefer not to answer	1
Do not know	3

In this section, respondents were asked their perceptions of the secretariat's achievement of selected features of their TOR. The point has already been made elsewhere that in some respects the achievement of at least one of these items (Facilitated exchange and development of ethics capacities in developing countries) relates perhaps more to the GFBR itself. However, in respect of these items, the generally positive views reflect a positive impression of the secretariat's facilitative role. Some confusion may exist concerning publications; this was variously interpreted

as academic publications, policy papers as opposed to meeting reports and the newsletter.

The interviews suggest a positive view overall on the secretariat's performance of the information dissemination function. There appears to be widely varying awareness and knowledge amongst respondents which might relate to website use. Furthermore, knowledge about papers in preparation and publication plans (by the fellows) appears restricted to only a few who have had direct and ongoing contact with the fellows. Despite, newsletters and fellowship reports, this information appears not to be well known.

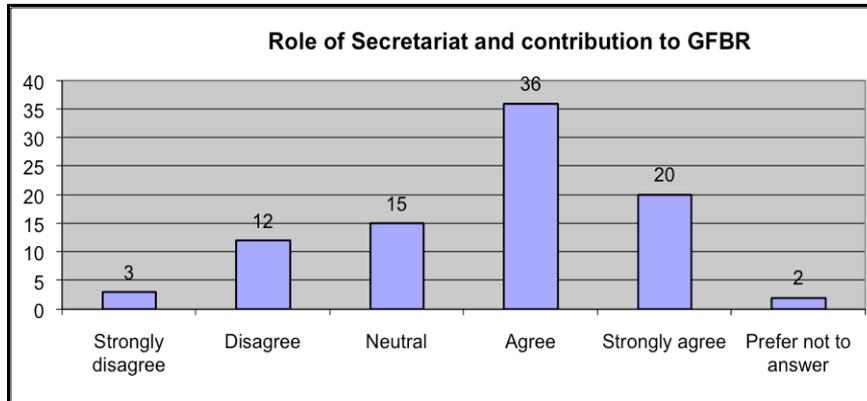
5.6 Role of Secretariat and Contribution to GFBR

5.6.1 Table 9 Secretariat Role and Contribution to GFBR by Item

10) Secretariat has contributed to the GFBR	Strongly disagree	Disagree	Neutral	Agree	Strongly Agree	Prefer not to answer
The GFBR's relevance to global health research would not be possible without the secretariat	1	3	3	4	4	0
The secretariat is essential for ongoing achievement of the aims of the GFBR	1	1	3	3	6	0
The secretariat contributes a great deal to organisational continuity of GFBR	0	2	2	7	3	0
The GFBR cannot achieve it's mission without a dedicated secretariat	1	4	1	4	4	0
There has been a noticeable improvement in organisation and facilitation of GFBR meetings	0	1	3	7	2	1
The secretariat's development of standardised policies and procedures has improved organisation of GFBR meetings	0	1	3	8	1	1
The secretariat has contributed to my ability to benefit from the GFBR	0	0	0	3	0	0
TOTAL	3	12	15	36	20	2

5.6.2 Fig. 7 Secretariat Role and Contribution to GFBR Summed

5.6.3 Table 10 Secretariat Role and Contribution to GFBR Summed



Role of Secretariat and contribution to GFBR	
Strongly disagree	3
Disagree	12
Neutral	15
Agree	36
Strongly agree	20
Prefer not to answer	2

This section of the survey intended to test the strength of opinion concerning the importance of having a secretariat and the role served by the secretariat for the GFBR. There does appear to be an overall endorsement of the importance of the secretariat for the GFBR. Dissenting opinions however must be noted. At least one participant strongly disagrees (and several disagree) on the absolute necessity and indispensability of the secretariat in achieving GFBR aims. Despite criticisms of the secretariat in the interviews however, the large weight of opinion gleaned strongly supports the need for and importance of the secretariat. One of the stronger more positive views (admittedly, a participant who reports not knowing much about the organisational history) states:

"I don't know how things worked before without the secretariat. I find it difficult to see how it could've worked without an organisation like the secretariat. That glue that really cements the organisation."

The necessity for an ongoing secretariat with continuity is emphasised below.

"The advantage of a secretariat is continuity. If it's only for two years and then we need to reinvent it, it's useless."

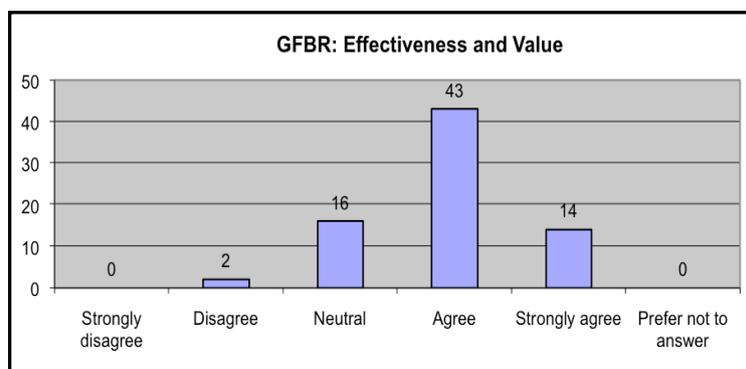
5.7 GFBR: Effectiveness and Value

5.7.1 Table 11 GFBR Effectiveness and Value by Item

16) GFBR: effectiveness and Value	Strongly disagree	Disagree	Neutral	Agree	Strongly Agree	Prefer not to answer
Plays important global role in promoting ethical conduct of research	0	1	1	10	3	0
Has successfully facilitated open dialogue amongst developed and developing world stakeholders	0	0	2	9	4	0
Has created a platform for open debate about ethical issues	0	0	1	9	5	0
Positively impacts the protection of human participants internationally	0	0	6	8	1	0
Is effective in research ethics capacity building	0	1	6	7	1	0
TOTAL	0	2	16	43	14	0

5.7.2 Fig. 8 GFBR Effectiveness and Value Summed

5.7.3 Table 12 GFBR Effectiveness and Value Summed



GFBR: Effectiveness and Value	
Strongly disagree	0
Disagree	2
Neutral	16
Agree	43
Strongly agree	14
Prefer not to answer	0

Here respondents were asked to consider the effectiveness and value of the GFBR itself rather than the secretariat. Items were drawn from the GFBR mission and aims.

The overall picture here is a positive view of the value of the GFBR. Relatively low levels of disagreement occur here and are found in the areas of promotion of ethical conduct of research globally, and building research ethics capacity. Neutral responses seem to indicate a level of uncertainty regarding achievement of GFBR aims in the

latter areas as well as positively impacting the protection of human research participants. This may well be an important area for further evaluation of the impact of the GFBR. It is clear that from the survey and from the interviews, the GFBR's strengths lie in the promotion of open debate and dialogue.

Most participants reported positively on the GFBR as a platform for open dialogue on bioethics. In particular, the way in which the forum is organised as a process of dialogue rather than tied to the need for a product or an outcome (such as guidelines) was seen as an important strength.

“To give people who would not otherwise get a chance to put forward their views and for people to hear them who wouldn't otherwise hear them.”

For others the issue goes beyond creating a platform for voices to be heard, and calls on the GFBR to clarify what it seeks to achieve and calls for a more proactive engagement:

“To what extent the GF is seen as a platform giving voice to the global South and to what extent it is envisaged to be providing a space for proactively encouraging dialogue....proactively stimulating dialogue between global South and global North. Where's the balance? Providing a voice versus proactive stimulating dialogue?”

Most participants highlight the value of North-South dialogue, bioethics empowerment and addressing the domination of the South by the bioethics of the North. Others also point out the problem of “preaching to the converted” and emphasise the importance of ensuring greater reach and greater diversity of participants, rather than the same faces. The question was raised whether the people who really need to hear the debates concerning exploitation in research (for example) may not be those represented at forum meetings.

Some concern was expressed concerning who speaks for the global South, how such representation is determined.

The interviews highlighted the importance of greater involvement of the global South but interestingly also greater involvement and participation from the North. In

marrying the principled issue of reaching the global South and the pragmatic question of sustainability of the secretariat, some suggestions were generated concerning the location of the secretariat. Some suggested that the secretariat should be located in a developing context for purposes of reach, increasing the impact of the GFBR, capacity development and the point was made, that this might attract funding for a secretariat. The robust nature of COHRED as an organisation to host the secretariat was however also pointed out. A staged process was considered and this is described in the section on sustainability.

The lack of GFBR activity between meetings was raised as a concern. A strong opinion was expressed for greater activity between meetings, higher levels of interaction and the need for regional meetings in addition to the annual meeting in order to further the GFBR's aims.

A final comment on impact here notes that the GFBR:

"...has come of age..(there is)...more bioethics on the ground in developing contexts."

Further specificity on the concerns around impact is listed in the GFBR strengths and weaknesses section below.

5.8 Participants perceptions and experience of the secretariat and the GFBR

The following sections document in list format, the participants' perceptions of the strengths and weaknesses and overall experience of the secretariat and the GFBR. These comments are derived from information obtained during the interviews and from the completed survey forms.

These are presented without comment as most issues are accounted for and addressed more generally in the body of this report. However, the value of these lists may lie in their specificity in addition to the selected quotations included above and may hold special interest for the secretariat and GFBR partners.

The lists are clustered and most repetitions are removed.

5.8.1 Secretariat

5.8.1.1 Strengths

- I. Continuity & communication (newsletters):
Some administrative continuity; ability to support forum organisers with experience; provides continuity and support during and between meetings; that it has maintained the continuity from 1999 to the most recent meeting.
- II. Communication:
Strengths (above) COULD BE as a central source of information; provide the communication link between partners but more than just 'pass it on' ; good in maintaining e-mail communication and in disseminating information about GFBR.
- III. Responsiveness to requests
- IV. Consistency
- V. Its existence
- VI. Professionalism & dedication of staff
- VII. Website development& maintenance
- VIII. Fellowship programme
- IX. Maintain institutional memory
- X. Facilitate work of the steering committee
- XI. Collaborative:
It has managed to establish a protocol of communication that recognises and implements a participatory decision making process
- XII. Coherent:
It was able to create a framework for its scope of work and its relationship with its constituency; well organised; Its administrative and coordinating activities in relation to organising and chairing Steering Committee meetings and liaising with the hosts of the annual forum; provision of some degree of leadership and direction for the steering committee; provides central location and mouthpiece for GFBR.

- XIII. Ability to take on administrative role, allowing steering committee to think more strategically.
- XIV. Ability to publish papers, research etc with focus - something that steering committee may not have time to do.

5.8.1.2 Weaknesses

- i. Intellectual – academic role:
Policy papers not produced; not produced any significant ethics policy documents or academic articles; very little academic/intellectual contribution to GFBR role
- ii. Fellowship programme should not be part of functions:
I'm not sure the fellowship scheme has been particularly useful for the fellows in ethics capacity development terms; adequate coaching from supervisor
- iii. Lack of clarity on TOR:
Lack of clear guidelines; no set processes; poor communication
- iv. Under resourced:
Difficulty in maintaining ongoing continuity due to nature of funding
- v. Few possibilities to provide logistic support to local organisers
- vi. Temporariness:
At this point, a self-sustainable operation has not been reached, no matter how good it is functioning now, we all know the project that is supporting it will end at some point
- vii. Unclear value of some outputs
- viii. Under qualified ethics officer
- ix. Lack of direct control over website
- x. Difficulty in securing new faces/stakeholders for fora
- xi. Lack of follow up on local dissemination of outcomes
- xii. Lack of regular networking with official country agencies
- xiii. It has not brought in additional funding for itself

Additional comments concerning the secretariat were made on the survey form and these are listed below and lend greater specificity to the more general evaluative account in the body of the report.

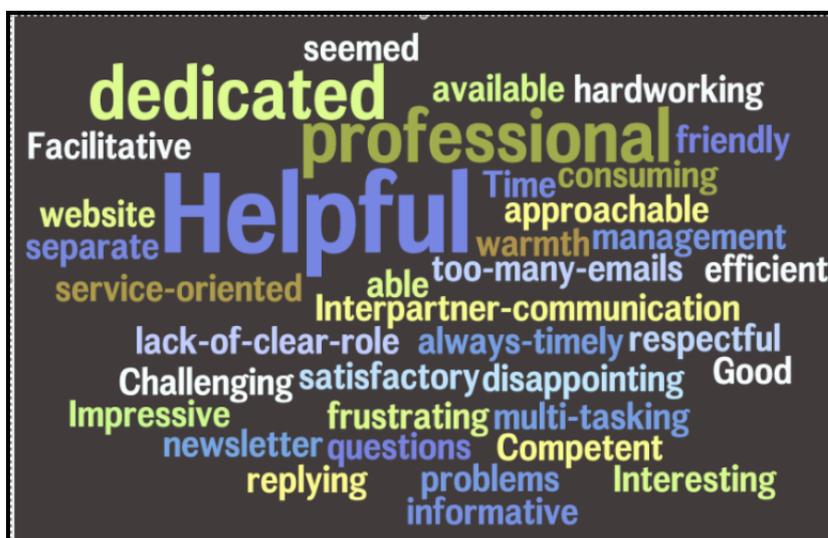
- i. Linkages and support to hosts of 9 GFBR in NZ could have been improved - the format of the NZ meeting limited rather than promoted plenary discussion. It is important that the ethos of the GFBR be clearly transmitted to successive hosts. The role of the secretariat in the organisation or meetings should be clear for the local organisers (avoiding raising too many expectations) .*
- ii. Funds have to be spent wisely. The meeting in England last year may have been a waste of money with apparently no specific goals identified and consequently insignificant outcomes. This is unacceptable.*
- iii. Risk was to set up a secretariat that is under-resourced, as it is a recipe for failure.*
- iv. The status of the secretariat in the steering committee should also be clarified: e.g. is the secretariat considered a partner? Is the secretariat considered as chair of the steering committee?*
- v. I think the success of the secretariat was in large part a testament to particular people who were running it - without them it would not have achieved so much with so little.*
- vi. It has been unclear what the balance between the administrative/coordinating, strategic and academic/ ethics policy development functions of the Secretariat was originally envisaged to be, and I suspect this lack of clarity has led to a lack of clarity about the purpose and utility of the fellowship scheme, and also around the required skills set of the officers of the Secretariat and thus the best people for the role(s).*
- vii. The Secretariat could also play a greater role in facilitating follow-up meetings between annual fora, perhaps at a regional level, and in stimulating the development of regional networks, both of which might look further at how*

issues raised at annual meetings might be tackled locally or regionally, and which could potentially feed into future annual meetings. These needn't necessarily be meetings carried out under the auspices of the Global Forum.

- viii. *One particular area in which I would like to see the Global Forum develop is as a Forum which could be accessed by anyone at any time, not just by the participants of an annual meeting, as useful as that is. There is an obvious role for use of the web, and indeed electronic media generally, here, and the Secretariat could play a facilitative function in this.*

5.8.1.3 Experience of secretariat

Participants were asked in the survey to list words that capture their experience of the secretariat. These are presented below in the form of a “wordle” or word cloud, which is a content analysis tool that represents the relative frequency of key words appearing in a document or list. The word cloud below nicely captures the dominant positive experience most respondents report concerning their experience of the secretariat while retaining the less positive features.



5.8.2 GFBR

As above, the additional qualitative comments on the GFBR are reported in list form below.

5.8.2.1 Strengths

- i. International, not dominated by developed country agendas
International but also has had regional interfaces; non-partisan; international; accessible for developing country delegates (funding) multi-cultural; diverse.
- ii. Dialogue and discussion
Discussion rather than formal papers; open dialogue & opportunity for networking; allows for real discussion; great place for everyone to develop networks for ethics capacity building; dialogue N-S & research ethics; allows networking of individuals and programmes; brings visibility to international research ethics and the importance of talking about IRE; only platform for debate on international health research ethics; providing a platform and a space for the 'unheard voice' of LMICs on ethical issues raised by research in LMICs; providing a space for free and open exchange of ideas; no requirement to arrive at some sort of consensus statement.
- iii. Has addressed some very key topics
Focus on specific ethical issues where there is a need for more debate; responds to current issues in research bioethics; methodology based on analysis of concrete cases and situations.
- iv. The organisation is: *Innovative; means well; led by powerful organisations; multi- & trans-disciplinary.*

5.8.2.2 Weaknesses

- i. Policies should be finalised to ensure continuity of its goals and aims across successive hosts.
- ii. Lack of strong central figure e.g. secretariat needs to take a more leading role.

- iii. Partners not “on the same page”.
- iv. Venue of GFBR should be chosen, e.g. the travel and visa difficulties are part of the criteria but should be taken into account carefully.
- v. Process of selection of participants: *GFBR is often limited to English speaking participants (translation is usually not provided); similar attendees from year to year; selection procedures for attendees must be standardised and transparent; a general lack of delegates from industrialised countries, and the resulting lack of sustained dialogue between delegates from the global North and South on issues of mutual concern, and indeed a generally low profile amongst researchers and other stakeholders in the global North; its general failure to achieve a truly global reach and attract delegates from all regions of the developing world, most notably perhaps those from Central Asian and Middle Eastern/ North African states.*
- vi. Not very well-known outside its circle: *Too small; too little communication capacity to bring debates in the open; never hear of it other than annual meetings; need for more visibility.*
- vii. Questionable impact, no actual studies as of yet: *Difficult to measure positive impact of GFBR on research practices: lacks follow through; lacks monitoring of impact of meeting outcomes on countries where participants come from.*
- viii. Would be a great forum for hands on capacity development, e.g. *workshops as part of the forum on how to start an IRB, challenges in the field, how to get an IRB funded, how to put a workshop together.*
- ix. Heavily dependent on uncertain funding (and on fluctuating exchange rates given the contributions in various currencies from partner organisations).
- x. Tends to be dominated by developed country perspectives: *same people running it since it started (could use some fresh perspective; does not engage*

enough with developing country stakeholders; not clear that the issues discussed are those that really matter to vulnerable groups; activities must be based on a needs assessment as identified by developing countries; special effort must be made to represent all areas of the world.

- xii. It is essentially limited to annual meetings, with little ongoing activity between them.

6. Sustainability of the Secretariat

The very difficult issue of sustaining the secretariat and securing funding for it was uniformly reported as a very difficult problem. There is widespread recognition that finding funding purely for an administrative body is highly unlikely. Whereas many would like to see a strong administrative body undiluted by additional academic and research functions, others see this combination as preferable and endorse a more sophisticated and creative intellectual role for the secretariat. Most agree that a blend of these two functions is necessary and central to the ability to attract funding.

Some disappointment and criticism was expressed that the current secretariat has been unsuccessful in timeously obtaining funding to ensure continuity. Others expressed disappointment at the lack of commitment and leadership of partners in driving the funding efforts. The contribution of partners and future commitments of funding partners was however acknowledged appreciatively. Leaving securing funding to just one or a few people was considered unrealistic and burdensome. A concerted joint effort to resolve this issue is needed.

The secretariat remains in a precarious position. Respondents generated a range of suggestions for sustainability. These include:

- i. The need to obtain funding for a minimum three year period
- ii. Implementing a system of self-funded, partially funded and fully funded categories for forum meeting participants and a clear set of criteria for this
- iii. Reducing the annual meeting to every two years; holding regional meetings in between to ensure ongoing activity and to increase impact

- iv. Locating the secretariat in a developing country context, possibly within the regional office of an international organisation or university

The possibility of locating the secretariat within an institution in the global South has attracted a lot of endorsement amongst respondents for both principled reasons and pragmatic reasons related to the likelihood of funding.

“Another potential problem is its Geneva location, and whilst there are certainly advantages in retaining a Geneva connection (in terms of access to the various relevant international bodies there, as well as closeness to the EU), a developing country connection may also make it more attractive to prospective funders.”

At the same time, respondents affirmed the robust nature of COHRED as an organisation with the capacity to host the secretariat. Many saw the wisdom in COHRED retaining hosting of the secretariat for the next few years with the brief to facilitate the transfer of competencies and skills to a developing context host over time. One perhaps innovative suggestion focused on a model for the secretariat with a central hub with functional spokes located in various institutions in countries in the South.

Increasing recruitment of new partners, particularly those who can be funding partners no matter the size of the contribution was suggested.

Some partners are taking up the possibility of current partner contributions being increased, but others cannot do so. It is also unlikely that those who can do so sufficiently to sustain a high functioning well-staffed secretariat. A clear call for more sustained, long-term contributions from steering committee organisations was also made. Similarly, increasing funding commitments from meeting organisers has been raised as a possibility.

In the short term, it may be possible as has been suggested (and as has been the practice in the past) for the partners to divide the secretariat’s tasks among themselves.

The future of the secretariat and its contribution to the continuity, organisational coherence and functional effectiveness of the GFBR is currently very vulnerable. Whereas some participants argue that the GFBR can function without a secretariat, most agree that the forum's effectiveness will undoubtedly be somewhat compromised and point to the consequent burden for the partners.

7. Conclusion and Way Forward

The GFBR secretariat has been in existence since 2004 and has been directly funded for the past two years. The overall evaluation of its functioning in the recent past has suggested it has done as well as it could have under the circumstances of constrained finances and very limited staffing. It appears to have done well in laying the foundation for organisational coherence, organisational continuity and the compilation and preservation of institutional memory. As the central communication node for the GFBR, the secretariat has done well in information dissemination in person, electronically and through the much improved website. Whereas it may have attracted criticism for not achieving enough by way of strong administrative support, logistical support, robust and clear procedures and policies, most agree that this has been a good start and is a work in progress accomplished under difficult constrained circumstances. Despite this, the secretariat has been described as professional, dedicated, efficient, helpful and responsive. It may have attracted more responses that are positive had it been much more pro-active and adopted a stronger administrative leadership role for the forum rather than an often reactive but helpful response. The need for perhaps a stronger managerial influence in the functioning of the secretariat was noted.

The capacity building contribution through the fellowship programme has evidenced less clear outcomes to many respondents but those closest to the experience of the fellows attest to the value of this programme for the persons involved and the potential value for bioethics in their countries of origin.

The broader view of the value and impact of the GFBR suggest it is highly valued as an important platform for genuinely horizontal open dialogue and debate amongst participants from the global North and South. There is uncertainty concerning the

impact however and respondents would like to see research conducted to document its impact. The need for reaching a wider audience especially in the South but also the North, a more diverse set of participants and increasing the reach and increasing the impact was highlighted. The principled and strategic value of locating the secretariat in the South or transferring the location in a phased way was cited as important both to the sustainability but also to achieving the aims of the GFBR.

The current hiatus for the secretariat requires a high level of commitment and input from partners not purely in financial terms. Rather, the need now is for focused and concerted visioning of the future of the secretariat, its role and a collaborative effort to seek support for its continuity. The weight of opinion lies heavily on a secretariat that will have to perform a dual administrative and intellectual-research role. The caution here is that in the future, suitably qualified persons are recruited that are capable of both functions and that the critical need for solid administrative and organisational leadership and management is not lost. The challenge for the GFBR is to get this balance right if it is to sustain the secretariat and fulfil the terms of any funding it attracts. This is also key to the future clarity of the role that the secretariat plays in the GFBR. The relationship between the secretariat and the partners requires greater clarity particularly in respect of the locus of leadership. The existence of the secretariat has generated a degree of role confusion and perhaps an organisational leadership gap. It seems that the secretariat's existence has given an evolutionary push to the institutional nature of the GFBR, from a collaborating partnership to an emergent organisation that needs its functions clarified and its infrastructure and personnel sustained if it is to continue on this developmental path. Most would like to see this development take place in a systematic and well thought through way.

The partners will need to take the lead in mapping the future. A strong call for greater leadership from the partners in visioning and implementing the future of the GFBR secretariat has been made.

8. Appendix I Partner Survey

Audit of the Secretariat of the Global Forum for Bioethics in Research GFBR Partner and Stakeholder Perceptions Survey

Dear participant

Thank you for agreeing to participate and taking the time to complete this survey.

This is an electronically fillable form-protected document, and consists of nine sections requiring different actions.

You will be asked either to enter your responses into text boxes or to select options from drop down menus.

The text boxes appear here as shaded rectangles. These free text entry fields are of unlimited length. To enter text, click on the shaded box and begin typing.

When requested to select your answers from drop down menus, these will appear when you click on the question or the shaded area marked "click to select one of the following".

On completion please save the document and be sure to retain the protection.

Please email the saved document to Solomon@ukzn.ac.za

If you prefer, fax a printout to Vernon Solomon: +27 33 260 5809

Thank You

Section One

1. Partner Institutional affiliation. Please describe your institutional affiliation in the text field below, e.g. health research NGO, funder, university, health research institution, secretariat, amongst others.
2. For how many **years** have you *personally* been involved in the GFBR? Enter number for years and a number for months e.g. 2 years and 4 months in the text entry field below.

Section Two

3. Are you a member of the steering committee of the GFBR?
4. I am familiar with the GFBR secretariat's Terms of Reference (TOR).
5. I believe the secretariat has fulfilled its TOR **overall**.
6. I am familiar with the objectives of the GFBR secretariat as listed in the EU specific support action grant.

Section Three

The following questions focus on your perceptions of the secretariat's achievement of its objectives. Please rate the performance of the secretariat on the drop down satisfaction scale below.

How well has the secretariat:

7. provided intellectual support for GFBR conferences?
- 7.1 provided organisational support for GFBR conferences?
- 7.2 established a structural framework within which all partners can collaborate?
- 7.3 helped to maintain the 'institutional memory' of the GFBR?
- 7.4 provided organizational continuity for the GFBR?
- 7.5 helped with identifying emerging and topical issues in international health research ethics for future Forum meetings?

Click to select one of the following

- 7.6 facilitated ongoing debate and discussions among GFBR attendees and participants?

Click to select one of the following

- 7.7 supported and advocated for capacity building for health research ethics in the European community countries?

Click to select one of the following

- 7.8 supported and advocated for capacity building for health research ethics in countries in which EU members conduct health research?

Click to select one of the following

- 7.9 facilitated the fellowship programme for capacity building in research ethics?

Click to select one of the following

- 7.10 functioned administratively?

Click to select one of the following

Section Four

8. How often do you make use of the GFBR website?

Click to select the closest match

- 8.1 Please rate your satisfaction with the user friendliness of the GFBR website.

Click to select one of the following

- 8.2 The GFBR website is useful. Please rate the extent of your agreement with this statement.

Click to select one of the following

- 8.3 Please describe the way in which you see the website as useful or not.

Section Five

In your view, has the secretariat achieved the following?

9. Published policy papers.

Click to select one of the following

- 9.1 Publications have been consistent with GFBR aims.

Click to select one of the following

- 9.2 Facilitated exchange and development of ethics capacities in developing countries.

Click to select one of the following

- 9.3 Disseminated information through publications.

Click to select one of the following

- 9.4 Facilitated a meaningful fellowship programme for research ethics capacity building.

Click to select one of the following

Section Six

Please rate the extent to which you agree or disagree with the following statements.

10. The continued relevance of the GFBR's activities to the global health research community would be possible without facilitation by the secretariat.

Click to select one of the following

- 10.1 The secretariat is essential for ongoing achievement of the aims of the GFBR.

Click to select one of the following

- 10.2 The secretariat contributes very little to organisational continuity of the GFBR.

Click to select one of the following

- 10.3 The GFBR would achieve its mission without a dedicated secretariat.

Click to select one of the following

- 10.4 There has been no noticeable improvement in organisation and facilitation of GFBR meetings since the establishment of the secretariat.

Click to select one of the following

- 10.5 The secretariat's development of standardised policies and procedures has improved the organisation of GFBR meetings.

14. Please list three to five words that best describe **your experience** of the secretariat.

1.

2.

3.

4.

5.

15. Please enter any additional comments you wish to make about the secretariat in the text field below.

Section Eight: The GFBR

Please rate the extent to which you agree or disagree with the following statements concerning the GFBR itself.

16. Plays an important global role in promoting ethical conduct of research.

16.1 Has successfully facilitated open dialogue and debate amongst developed and developing world international research stakeholders.

16.2 Has created a platform for open debate on key ethical and related issues in international research in health settings.

16.3 GFBR activities have positively impacted on the protection of human participants in international health research.

16.4 Is effective in research ethics capacity development.

Section Nine: The GFBR

17. Please describe three strengths of the GFBR.

18. Please describe three weaknesses of the GFBR.

Thank you for your time.

**Please save the document retaining the protection for forms
and email to: Solomon@ukzn.ac.za**

Or, fax to: +27 33 2605809

Appendix II Stakeholder Survey

Audit of the Secretariat of the Global Forum for Bioethics in Research GFBR Partner and Stakeholder Perceptions Survey Stakeholder Form

Dear participant

Thank you for taking the time to complete this survey.

This is an electronically fillable form-protected document, and consists of nine sections requiring different actions.

You will be asked either to enter your responses into text boxes or to select options from drop down menus.

The text boxes appear here as shaded rectangles. These free text entry fields are of unlimited length. To enter text, click on the shaded box and begin typing.

When requested to select your answers from drop down menus, these will appear when you click on the question or the shaded area marked "click to select one of the following".

On completion please save the document and be sure to retain the protection.

Please email the saved document to Solomon@ukzn.ac.za

If you prefer, fax a printout to Vernon Solomon +27 33 260 5809

Thank You

Section One

1. Stakeholder Institutional affiliation. Please describe your institutional affiliation in the text field below, e.g. health research NGO, funder, university, health research institution amongst others.
2. For how many **years** have you been involved in the GFBR? Enter number for years and a number for months e.g. 2 years and 4 months in the text entry field below.
3. Please provide some of the reasons why your organisation chooses to participate in GFBR activities.
 - 3.1 Please briefly describe the nature of your association with the GFBR.

Section Two

4. I am familiar with the GFBR secretariat's Terms of Reference (TOR).
5. I believe the secretariat has fulfilled its TOR **overall**.
6. I am familiar with the objectives of the GFBR secretariat as listed in the EU specific support action grant.

Section Three

The following questions focus on your perceptions of the secretariat's achievement of its objectives. Please rate the performance of the secretariat on the drop down satisfaction scale below.

How well has the secretariat:

7. provided intellectual support for GFBR conferences?
- 7.1 provided organisational support for GFBR conferences?
- 7.2 established a structural framework within which all stakeholders can collaborate?
- 7.3 helped to maintain the 'institutional memory' of the GFBR?
- 7.4 provided organizational continuity for the GFBR?

7.5 helped with identifying emerging and topical issues in international health research ethics for future Forum meetings?

Click to select one of the following

7.6 facilitated ongoing debate and discussions among GFBR attendees and participants?

Click to select one of the following

7.7 supported and advocated for capacity building for health research ethics in the European community countries?

Click to select one of the following

7.8 supported and advocated for capacity building for health research ethics in countries in which EU members conduct health research?

Click to select one of the following

7.9 facilitated the fellowship programme for capacity building in research ethics?

Click to select one of the following

7.10 functioned administratively?

Click to select one of the following

Section Four

8. How often do you make use of the GFBR website?

Click to select the closest match

8.1 Please rate your satisfaction with the user friendliness of the GFBR website.

Click to select one of the following

8.2 The GFBR website is useful. Please rate the extent of your agreement with this statement.

Click to select one of the following

8.3 Please describe the way in which you see the website as useful or not.

Section Five

In your view, has the secretariat achieved the following?

9. Published policy papers.

Click to select one of the following

9.1 Publications have been consistent with GFBR aims.

Click to select one of the following

9.2 Facilitated exchange and development of ethics capacities in developing countries.

[Click to select one of the following](#)

9.3 Disseminated information through publications.

[Click to select one of the following](#)

9.4 Facilitated a meaningful fellowship programme for research ethics capacity building.

[Click to select one of the following](#)

Section Six

Please rate the extent to which you agree or disagree with the following statements.

10. The continued relevance of the GFBR's activities to the global health research community would be possible without facilitation by the secretariat.

[Click to select one of the following](#)

10.1 The secretariat is essential for ongoing achievement of the aims of the GFBR.

[Click to select one of the following](#)

10.2 The secretariat contributes very little to organisational continuity of the GFBR.

[Click to select one of the following](#)

10.3 The GFBR would achieve its mission without a dedicated secretariat.

[Click to select one of the following](#)

10.4 There has been no noticeable improvement in organisation and facilitation of GFBR meetings since the establishment of the secretariat.

[Click to select one of the following](#)

10.5 The secretariat's development of standardised policies and procedures has improved the organisation of GFBR meetings.

[Click to select one of the following](#)

10.6 The secretariat have contributed to my ability to benefit from the GFBR.

[Click to select one of the following](#)

16. Plays an important global role in promoting ethical conduct of research.

[Click to select one of the following](#)

16.1 Has successfully facilitated open dialogue and debate amongst developed and developing world international research stakeholders.

[Click to select one of the following](#)

16.2 Has created a platform for open debate on key ethical and related issues in international research in health settings.

[Click to select one of the following](#)

16.3 GFBR activities have positively impacted on the protection of human participants in international health research.

[Click to select one of the following](#)

16.4 Is effective in research ethics capacity development.

[Click to select one of the following](#)

Section Nine: The GFBR

17. Please describe three strengths of the GFBR.

18. Please describe three weaknesses of the GFBR.

Thank you for your time.

**Please save the document retaining the protection for forms
and email to: Solomon@ukzn.ac.za**

Or, fax to: +27 33 2605809

Appendix III Partner – Secretariat Interview Guide

Interviewee identity:

Preamble: Confidentiality, limits of it, did you read the information sheet, are you happy to proceed?

Audit is really about the secretariat rather than the forum itself, so will be focussing more on the secretariat but I will ask a few questions about the forum itself a little later.

1. The secretariat is relatively new; could you tell me a bit about what led to it being established?

Probe for how you saw the importance (or lack of it) of its establishment?

Did you see it as an important or positive step in the life of the forum?

The survey questionnaire will be asking you to rate the secretariat on its achievement of objectives, the interview will cover more general aspects of the functioning of the secretariat.

2. How aware are you of the TOR and objectives of the secretariat?

3. Do you think the TOR and objectives were/are appropriate?

3.1 Are there any that you believe are inappropriate?

3.2 Are there any important omissions in your view?

3.3 What do you see as the most important objectives and functions of the secretariat?

4. How do you think the secretariat has done in fulfilling these...its objectives and functions?

4.1 And the ones identified in 3.3?

4.2 Can you comment on the dissemination, institutional memory, website aspect of the secretariat's activities?

4.3 Can you comment on the fellowship and its contribution to the capacity building aim?

5. How do you think the secretariat has functioned structurally and operationally? (effectiveness and efficiency)

Can you illustrate by way of examples?

6. Please describe three strengths of the GFBR secretariat

7. Please describe three weaknesses of the GFBR secretariat

8. How could the secretariat's functioning be improved?
9. Do you think **the GFBR has changed since the establishment of a secretariat?**
 - 9.1. **In what way/s has it changed?**
10. Do you think the secretariat has contributed to achievement of the GFBR's mission?
 - 10.1 Can you illustrate this with a few examples, can you tell me in what ways?
11. What do you think are the most important functions of the GFBR?
12. How could the GFBR be improved – made more effective?
 - 12.1 Could the secretariat play a hand in making these improvements?
13. Should the GFBR have a secretariat?
14. What form do you think this should take, or what changes if any should be made to its objectives?
14. Do you have any suggestions on how the secretariat could be sustained in the future?
15. List three – five words that best describe your view – experience of the secretariat

Appendix IV Stakeholder Interview Guide

Preamble: Confidentiality, limits of it, did you read the information sheet, are you happy to proceed?

Audit is really about the secretariat rather than the forum itself, so will be focussing more on the secretariat but I will ask a few questions about the forum itself a little later.

1. Tell me a little about your association with the Forum

And what you know about the GFBR

1.1 How aware are you of the existence of the secretariat?

1.1.1 Can you tell me what you know about it and....

1.2 The secretariat is relatively new; could you tell me what you know about what led to it being established?

Probe for how you saw the importance (or lack of it) of its establishment?

Did you see it as an important or positive step in the life of the forum?

The survey questionnaire will be asking you to rate the secretariat on its achievement of objectives, the interview will cover more general aspects of the functioning of the secretariat.

2. How aware are you of the TOR and objectives of the secretariat?

3. Do you think the TOR and objectives were/are appropriate?

3.1 Are there any that you believe are inappropriate?

3.2 Are there any important omissions in your view?

3.3 What do you see as the most important objectives and functions of the secretariat?

4. How do you think the secretariat has done in fulfilling these...its objectives and functions?

4.1 How do you think the secretariat has done in fulfilling the ones you think were most important?

4.2 Can you tell me a bit about your experience of the secretariat?

4.3 Can you comment on the dissemination, institutional memory, website aspect of the secretariat's activities?

- How do you gain access to GFBR content and outputs?
- How do you make use of GFBR outputs?

4.4 Are you aware of the fellowship programme?

4.4.1 Can you comment on the fellowship and its contribution to the capacity building aim?

5. How do you think the secretariat has functioned structurally and operationally? (effectiveness and efficiency)

Can you illustrate by way of examples?

6. Please describe three strengths of the GFBR secretariat

7. Please describe three weaknesses of the GFBR secretariat

8. How could the secretariat's functioning be improved?

9. Do you think **the GFBR has changed since the establishment of a secretariat?**

Or: Could you comment on any impact the secretariat has had

9.1. In what way/s has it changed?

10. Do you think the secretariat has contributed to achievement of the GFBR's mission?

10.1 Can you illustrate this with a few examples, can you tell me in what ways?

11. What do you think are the most important functions of the GFBR?

- How is the GFBR useful to you and your organisation?

Probe for less important and why, and prompt for missing items

12. How could the GFBR be improved – made more effective?

12.1 Can you comment on the value of the GFBR in your experience of it?

- What would your organisation want from the GFBR in the future?

12.2 Have you noticed any changes in your experience of the forum since the secretariat was established?

- 12.1 Could the secretariat play a hand in making these improvements?
13. Should the GFBR have a secretariat?
 14. What form do you think this should take, or what changes if any should be made to its objectives?
 15. Do you have any suggestions on how the secretariat could be sustained in the future?
 16. List three – five words that best describe your view – experience of the secretariat

Appendix V Consent sheet

Participant Information and



GLOBAL FORUM
On Bioethics in Research

COHRED hosts the Secretariat for the Global Forum on Bioethics in Research. For information, please contact us at the address below.

Audit of the Secretariat of the Global Forum for Bioethics in Research. Participant Information and Consent Document.

Dear GFBR Partner

I am Vernon Solomon and I have been commissioned to conduct a stakeholder audit of the secretariat of the Global Forum for Bioethics in Research. I hope that you will agree to participate in this audit. More details are provided below. I hope that you will agree to assist in this process.

Objective of the audit

The secretariat was established some two years ago with a specific set of aims. Funding to support the establishment and running of the GFBR secretariat was obtained from an EU specific support action grant. GFBR partners further contribute to the functioning of the GFBR as a whole.

The funding period is at an end and the GFBR seeks to review the functioning of the secretariat.

This review process has three primary aims:

- To evaluate the work and impact of the GFBR Secretariat in terms of its operations, meeting the objectives of the EU grant and furthering the mission and aims of the GFBR.
- To assess perceptions of the value of the secretariat amongst partners and nominated stakeholders and obtain views on its continuity.
- To develop recommendations for the improvement of the functioning and sustainability of the secretariat.

The audit process will yield a report before Dec 31st, 2008, in respect of these three foci.

The process

GFBR partners and nominated stakeholders of the GFBR are hereby invited to participate in a telephonic interview and to complete a separate short perceptions survey concerning the GFBR secretariat function. The perceptions survey will be emailed to you. The telephone interview is unlikely to require more than 30 - 45 minutes of your time, and the survey a further 20 minutes.

If you agree to assist, you will be emailed to set up a date and time for a telephonic interview within the next ten days. You will be asked at the start of the interview to consent to having the interview electronically recorded and should you choose to decline, the interview will not be electronically recorded and hand-written notes of your responses will be made instead. You are free to decline to respond to any of the stimulus questions in either the interview or the survey and to withdraw from the process at any time.

You will be asked to complete a short perceptions survey instrument and to return this via e-mail or fax within 24 hours of receiving it.

Confidentiality

All participant details will be kept confidential and responses to both the interview and the survey will be anonymised. Given the small number of participants (16-20) in this audit, it is difficult to guarantee that qualitative comments will be completely non-identifiable. Every effort will be made to ensure that respondents' identities are however protected. All participants will be offered the opportunity to review responses made during the interview for purposes of accuracy in the final report.

Participants will be asked to identify their institutional affiliation on the survey instrument. However the report will not identify or link responses with institutions. The survey data will be reported in an aggregated way and may, if relevant, seek to show an association between certain perceptions and types of institutional affiliation.

Informed consent

Participation in the interview and completion and return of the survey instrument serves as an indication that participants give their informed consent for their participation in this audit process.

Publication and dissemination

The final report will be submitted to the GFBR only and by the GFBR to the funder (EU).
The GFBR will then decide on dissemination of the report beyond the funder.

Concerns

Should you have any concerns regarding the process or your participation please contact me:

Vernon Solomon

Contractor: GFBR Audit

School of Psychology

University of KwaZulu-Natal

Solomon@ukzn.ac.za

(Office) +27 33 2605680

(Mobile) +27 82 8080 352

(Fax) +27 33 260 5809