

Steering Group meeting minutes

12th November 2009, Edinburgh

Attendance

Present:

Kenneth Boyd (Chair Steering Group)
Sarah Cunningham-Burley (Chair Research Sub-group)
Vikki Entwistle
Jack Jackson (Chair Education Sub-group)
Mary Porteous

Apologies:

Gerry Graham
Neva Haites (Chair Health Policy Sub-group)
Mandy Ryan

In attendance:

Steve Sturdy (Grant holder)
Krisha Ferguson (Network Secretary)

1. Welcome and introductions

Kenneth Boyd began the meeting by thanking those who were in attendance for coming and Steve Sturdy for hosting the meeting.

SS gave apologies for absentees (refer above).

2. Minutes of previous meeting and matters arising

Scottish Interfaith Council:

KB had contacted the SIC to inquire whether they would be interested in being represented on the steering group. However, the SIC is currently negotiating its funding situation and does not have the capacity to participate at the moment. KB and SS will consider renewing the invitation at a more auspicious time.

Edinburgh International Science Festival 2010:

SS suggested raising this topic under item 4.1 Policy Sub-group discussion.

Communication Strategy:

Secretariat had undertaken to report back on progress. Owing to the delay in the release of TSG funding, however, the Gengage office has been operating at much reduced capacity since June. KB agreed that any discussion of communication strategy should take proper account of events that have occurred in the meantime. Discussion and action should therefore be deferred until a Network Officer is in post.

Whilst the report on the annual conference was circulated to delegates, it still requires posting on the website.

Annual Report

SS confirmed that the Annual Report is now available in draft form, though completion has been delayed owing to the lack of funding to appoint a Network Officer. This will be completed as soon as the new Network Officer is in post.

Review panel

It was agreed to defer scheduling a meeting of the review panel until both the Gengage staffing posts have been filled.

3. Update on funding and staffing position

Scottish Government have now agreed to release the funding for 2009/10. The contract is currently with the ERI and should be signed imminently. Though the renewed funding was ostensibly for the second year of operation, it was agreed that, with savings from the first year of operation, and careful expenditure in future, the funds were sufficient to fund a full-time Network Officer and a 0.2 secretary for 18 months. The Network Officer post will be advertised as soon as possible, with a view to the successful applicant coming into post by January 2010 or latest February 2010.

The funding letter from TSG did leave open the possibility of continuation beyond the agreed period. However, we cannot rely on that, and need to look at ways of sustaining Gengage once TSG funding runs out, SS welcomes advice and input from other members as to how this could be strategised.

KB then opened a wide-ranging discussion around what we should consider to be the unique role of Gengage, and how we might collaborate within other groups and organisations to take forward Gengage's principal objectives. Proposals included;

- Pursuing additional Scottish Government funding for specific policy activities
Soliciting a small annual fee from key stakeholder organisations who benefit from the Network, in order to maintain the core administrative and information exchange activities including the website and newsletter
Seeking Wellcome Trust funding for one-off publication engagement events.
- Looking beyond Scotland to collaborate with English organisations such as Nowgen, as well as with the Edinburgh Beltane Beacon for public engagement, to develop initiatives with a wider geographical spread
- Linking specific subgroup activities to the public engagement and dissemination aspects of research funding proposals

Given the need to build a strategy for sustainability, VE proposed that this be made an explicit responsibility of the Network Officer, and be written into the further details for the post. SS agreed to circulate the job description to the Steering Group members for comment in advance of advertising the post.

4. Update on Sub-group activities

4.1 Policy Sub-group

In Neva Haites's absence, SCB reported on activities that the Policy Sub-Group has been developing, in collaboration with Scottish Government, around issues of human tissue retention in Scotland. A fuller report on these activities will be made available as the issues are clarified and public engagement opportunities are identified.

In connection with this work, SS had made a preliminary approach to Simon Gage, Director of the Edinburgh International Science Festival, to enquire about possibly organising a deliberative event on retention of samples and tissues in the 2010 EISF. The response from EISF was provisionally positive. It was agreed to go ahead if appropriate plans could be drawn up in time for the EISF programme deadline.

A number of suggestions were discussed for specific topics to include in the proposed event, and for possible speakers and venues. SS and KF to progress this as time permits.

4.2 Education Sub-group

The second Education Sub-group meeting was held at the Centre for Molecular Medicine at the Western General Hospital in September. The meeting was kindly hosted by Mary Porteous, who also gave a presentation on the work of the centre followed by a tour of the facilities.

The meeting included a presentation from Marjorie Smith who brought in her 'Let's Talk' educational packs on diabetes and obesity, cervical cancer, and one she is currently compiling on stem cells. The purpose of the packs is to encourage a more discursive approach between teachers and pupils, in both primary and secondary schools. These packs were widely piloted initially in Fife, and are now being rolled out to Edinburgh, East Lothian and Midlothian. The packs are designed to be relevant across a range of areas of the curriculum. They are also being used not just by teachers and pupils but also by parents. Marjorie Smith has now teamed up with Sharon McNab of Glasgow Science Centre to try using the packs with the wider public in the Centre.

There followed a discussion on how Gengage could help to increase the circulation and use of the 'Let's Talk' teaching tool. Suggestions included:

- Using the Gengage and Scotgen websites and Glow, the Scottish schools intranet, to publicise the tool. However, the impact of web dissemination is limited, as teachers often prefer to work with physical teaching resources.
- Organising CPD events around Scotland to demonstrate and distribute the tool. Could eventually become self-funding, but initially Gengage might join with Scotgen to organise and fund pilot events, sharing production and running costs.

Additionally JJ has been in discussion with Peter Finegold from Nowgen, who have been developing school teaching materials on social, moral, and ethical issues to do with genetics. The materials are oriented towards the school curriculum in England, but JJ is interested in spreading involvement to Scotland. Jim Stafford, currently on secondment to SQA, is developing new higher biology courses which are pending release for consultation. Agreed that it would be good to collaborate with Nowgen, and Gengage should provide expenses for JJ and Jim Stafford to visit Peter Finegold or (preferably) for Peter Finegold to travel to Edinburgh. We should also aim to organise a seminar or workshop in Scotland to involve a wider constituency in discussions around developing and rolling out useful teaching materials including 'Let's Talk' and the Nowgen materials. This might conveniently be organised in conjunction with the next Steering Group meeting.

4.3 Research Sub-group

The Research Sub-group has not met, in the absence of a Network Officer to support activities. Meetings will resume once the Network Officer is appointed. Possible activities include input into the EISF event, and other issues identified at previous Sub-group meetings.

SS mentioned a recent meeting with Bella Starling of Nowgen and Steve Yearley of the Genomics Forum. Noting that the House of Lords report on genomic medicine had recommended that the HGC undertake public engagement around the possibility of genomic testing for common complex disorders, BS had suggested that Nowgen and Gengage propose to collaborate with HGC to assess the need and opportunities for public engagement in this area. Since HGC does not have a budget for public engagement, funding would need to be sought from other bodies such as the Wellcome Trust. In the absence of any serious likelihood of meaningful genomic tests for common complex disorders becoming widely available in the near future, the steering Group felt that public engagement activities in this area were probably premature, and the Nowgen proposal was not worth pursuing at this stage. In the meantime, SCB suggested reviewing an earlier citizen's jury on this topic (Iredale and Longley, 1999, 2000).

5. Any other business

5.1 Conference

No thought has been given to the next annual conference as yet, but planning needs to start soon. The previous one was successful in attracting a broad constituency, but the Steering Group felt that it would be preferable this year to develop a more focused programme, exploring some topical aspect of the sub-groups' activities with a particular target constituency.

In the course of a wide-ranging discussion, it was agreed that the conference should target older school pupils (end of year 5) and their teachers, and should aim to promote engagement and discussion. Possible topics for discussion might include:

- a complex disease in which genetics is making a clinical impact e.g. cancer, which would in turn provide a way of raising further issues including
- tissue banking
- clinical testing and treatment
- screening

The Steering Group agreed that such an audience would also provide an opportunity to take forward the current activities of the Policy Sub-group on retention of human tissue into more targeted public engagement. Some element of deliberation on all these issues would be valuable. The venue should therefore be equipped with "clickers" or other voting technology, as for instance the Royal College of Physicians of Edinburgh or Dynamic Earth.

MP offered support from the ScotGen administrator in planning and preparing the conference.

5.2 Resignation of Mandy Ryan

Professor Ryan has tendered her resignation from the Steering Group owing to pressure of work. SS/KB to draft a letter accepting her resignation and thanking her for her support for Gengage. It was agreed that there was no need to replace her in the short term, as the current membership is working well.

5.3 Previous Minutes of Meeting

Minutes from previous meeting accepted and KF to ensure they are posted onto website.

6. Dates for future meetings

Next meeting:

Monday 22nd February in Edinburgh. Lunch: 1.45pm
Meeting: 2.15pm

Agreed, additionally, that JJ will explore with Peter Finegold the possibility of organising an education meeting or workshop in the morning of that day, to bring together representatives of Gengage, Nowgen, ScotGen, Edinburgh Beltane and other organisations and individuals interested in developing and rolling out educational resources for schools and others. To be funded by Gengage; the venue to be provided by the Genomics Forum.