

Steering Group meeting minutes

19th March 2009, Dundee

Attendance

Steering group members:

Kenneth Boyd (Chair Steering Group)

Sarah Cunningham-Burley (Chair Research Sub-group)

Vikki Entwistle

Gerry Graham

Jack Jackson (Chair Education Sub-group)

Apologies:

Neva Haites (Chair Health Policy Sub-group)

Mary Porteous

Mandy Ryan

In attendance:

Steve Sturdy (Grant holder)

Hilary Osborne (Network Officer and Secretariat)

1. Welcome and introductions

Kenneth Boyd (KB) began the meeting by thanking those who were in attendance for coming. Those in attendance were then asked to give a brief summary of their professional interests. Biographies of all steering group members can be found on the website at

<http://www.gengage.org.uk/aboutpages.php?ctee=steering>

2. Minutes of last meeting and matters arising

KB then asked Sarah Cunningham-Burley (SCB) and Jack Jackson (JJ) as the only steering group members who were present at the previous meeting to confirm that they were happy with the minutes. SCB and JJ did so.

SCB had been asked to name a multi-faith group; SCB and KB agreed that this should be the Scottish Interfaith Council.

It was agreed that all other matters arising should be covered as part of the planned agenda.

JJ thanked Hilary Osborne (HCO) for drawing up the map of organisations as requested at the previous meeting. He found this a very helpful document in describing the range of organisations working in this field and how they might relate to each other.

3. Steering group

The Steering Group was next invited to consider its terms of reference. These were agreed at the Steering Group's meeting in November 2008 but, as HCO explained, it was felt that they should be revisited in light of the new Steering Group members and also because of the omission of any clause about chairmanship.

KB asked for clarification around the third bullet point describing the Steering Group's remit which states that it is "to ensure the proper use of the network's budget." Steve Sturdy (SS) explained that the grant is managed through the University of Edinburgh's systems and so in terms of accounting etc was well overseen. The Steering Group discussed this point and agreed that the point referred to its role to ensure that resources are well spent in terms of representing good value towards meeting Gengage's objectives.

Action – budget statement to be provided to Steering Group members each time they meet

The communication strategy was then discussed and members made a number of suggestions to useful ways to promote Gengage and increase its profile. These included:

- Increasing the number of links from other websites to Gengage's website. SSERC was recommended by JJ for those working in education.
- Gerry Graham (GG) also suggested using British Science week and SCB Edinburgh International Science Festival as opportunities for promotion.
- KB suggested looking further at how to promote the network to the NHS. NHS Education Scotland together with the NHS e-library were mentioned.

Action

- **Secretariat to investigate these possibilities and report back on progress at the next meeting**
- **Secretariat to circulate the communication strategy to Steering Group members**

HCO confirmed that the annual report would be available at the November meeting of the Steering Group for it to sign off.

The group then moved on to discuss membership of the Steering Group and how it reflected the constituencies listed in the terms of reference. It was noted that a number of these constituencies were as yet unrepresented. The group discussed additional members to invite onto the group.

Action – Secretariat to liaise with KB re inviting additional members onto the group

It was also agreed that the fact that Steering Group meetings are open to the public by prior application should be given more prominence and perhaps noted on the website.

Action – Secretariat to add above statement to website

Finally, SS described the current funding situation to the group.

4. Update on Gengage sub-groups

Health Policy

HCO described the membership of the sub-group. The sub-group had not yet met but would be doing so the next day (Friday 20th March).

Education

JJ provided the group with a brief overview of the first meeting of the Education sub-group which had taken place that morning. There had been a good turnout with only one apology. The group represents a wealth of expertise in a variety of fields. At the meeting, which was very much an exploratory meeting, the group looked at its remit and also discussed areas where it would like to increase its knowledge, specifically around the provision of clinical genetic services.

In terms of what the group might do, it is looking to build on the work already underway in science centres and also the Let's Talk tool with a view to creating new opportunities for public engagement.

KB suggested NHS Education Scotland as a link for the group.

Research

SCB began by describing the remit of the group to take a long term view of genetics and its impact on healthcare. The implications of epidemiological genetic studies for populations particularly in relation to understanding of risk were highlighted as an area of interest.

The group at its first meeting on 2nd March agreed to run a programme of two workshops to look at current research underway in Scotland in relation to its likely clinical utility. The first workshop would bring together researchers to map the research which is already happening. The second workshop would bring together a wider group of stakeholders to discuss the findings of the first workshop.

Vikki Entwistle (VE) asked to what extent the focus will be on public engagement. Is it research into public engagement or involving the public in the current research agenda? SCB explained that the workshops would be the first step to creating an informed overview of current research which could then provide a basis for public engagement, outputs from which could then be fed into government.

GG suggested that it would be good to define what the group means by “research.” He described basic and clinical research with translation research in-between, and observed that the Medical Research Council (MRC) is in favour of maintaining the basic research because of the benefits it may bring in ten to twenty years. SCB agreed and said that it was important to communicate this point to the public and show the benefit of basis research.

The British Association of Science Writers and the Scottish Public Health Observatory (ScotPHO) collaboration were proposed as potential partner organisations.

5. Gengage conference

The Steering Group then moved on to discuss the first annual Gengage conference which will be held on Wednesday 17th June in Glasgow.

KB outlined the objectives and proposed theme for the conference which the group agreed.

The group then discussed possible individuals to invite to address the conference. It was agreed that another couple of opportunities for such slots would be introduced into the programme to allow a greater number of individuals to be invited to participate in this way.

Action – Secretariat to contact agreed individuals in liaison with the Gengage chair

The proposed workshops for the conference were then discussed in some detail. As part of this the group made suggestions about individuals and organisations who could be invited to participate.

Workshop 1

It was suggested and agreed that the proposed workshop should change its title from “Running focus groups and stakeholder events” to “From consultation to engagement: tools for deliberation.” The session will look at the different methods available for public engagement with a focus on moving towards more deliberative approaches.

Workshop 2

The topic of “Genetic conditions are family conditions” was welcomed by the group. It was suggested that it should look at some of the issues of advocacy and confidentiality alongside attitudes to who gets told what when.

Workshop 3

The proposed workshop on providing services for patients with rare conditions was discussed in some detail. It was agreed that, in view of the increasing awareness of genetic involvement in many common complex disorders and other diseases, the workshop should look at what makes a disease a genetic disease, and at what implications this designation has for providing services.

Workshop 4

“Involving “hard-to-reach” groups in dialogue and other activities” was the next proposed workshop to be discussed. A number of suggestions for speakers were made for what was thought to be a valuable workshop.

Workshop 5

“Healthcare genetics in the media” was agreed as a topic and speakers suggested.

Workshop 6

The idea of discussing direct-to-the-consumer genetic testing was agreed as a topic and suggestions made for including a couple of speakers and organisations to include in the debate.

Workshop 7

The session on “Telling stories – using stories to communicate information and ideas” will be led by Pippa Goldschmidt, ESRC Genomics Forum Writer in Residence. It will allow delegates to explore the uses of story telling in communication and draw on a number of instances where this is already happening in practice around genetic issues.

Workshop 8

The group made a number of suggestions about how the session on perceptions of illness could be improved and possible speakers to invite.

It was suggested that delegates should indicate which workshops they would like to attend ahead of the event and that this would need to be incorporated as part of the registration process.

Action – Secretariat to arrange for the allocation of workshop places ahead of the conference

JJ highlighted the importance of making sure that the workshops are indeed that. They need to provide activities which will meet the audience's needs and interests and did not just involve formal presentations and discussion among people sitting around the table.

Action – JJ and HCO to discuss the workshops in detail to ensure that they provide appropriate activities which meet delegates' needs

6. Review and evaluation

The proposal which was submitted to the Steering Group was agreed. VE made the point that if qualitative case studies are to be used, it is important to keep an eye on collecting them on an on-going basis.

SCB suggested that Gengage look at the evaluation form developed by the Talking Stem Cells project as a possible model for evaluation Gengage activities.

It was agreed that the review panel should have just three members and individuals and organisations to approach in the first instance were identified.

Action – Secretariat to identify appropriate individuals and find a time for them to meet

7. Dates of future meetings

Thursday 18th June 2009 10am – 1pm, Glasgow
Thursday 12th November 2009 1 – 4pm, Edinburgh

Steering Group members may also like to note Wednesday 17th June in their diaries as the date of the Gengage conference in Glasgow.