

## Steering Group meeting minutes

21<sup>st</sup> November 2008, Edinburgh

### Attendance

Steering group members:

Prof Sarah Cunningham-Burley (Chair Research Sub-group)

Prof Neva Haites (Chair Health Policy Sub-group)

Prof Jack Jackson (Chair Education Sub-group)

In attendance:

Dr Steve Sturdy (Acting Chair)

Miss Hilary Osborne (Network Officer and Secretariat)

### 1. Overview of Gengage – purpose and structure

Steve Sturdy (SS) provided the group with brief information about Gengage's background and the purpose and structure which is being proposed. The main points were:

- Gengage's creation resulted from recommendations in the [Review of genetics in relation to healthcare in Scotland](#) chaired by Sir Kenneth Calman in 2006 that a public awareness and engagement network be created that "would not only link together all those from a variety of backgrounds who have an interest in enhancing public engagement in genomics, but that would in particular provide a means of bringing together all those in social science and the humanities around Scotland who are working in this area."
- The proposal from the ESRC Genomics Policy and Research Forum to manage this network which the Scottish Government Health Department (SGHD) agreed, put forward the following principle activities for the network:
  - gather and disseminate information about current engagement activities
  - coordinate and synthesise existing and emerging initiatives
  - identify gaps and stimulate new initiatives
  - identify and evaluate the most effective and appropriate forms of public engagement
- It is proposed that the network's activities are overseen by the steering group which include the chairs of each of the three sub-groups (Education, Health Policy and Research).

Neva Haites (NH) asked what the reporting mechanisms were for the network to SGHD. SS reported that the network's main contact at SGHD for day-to-day matters was Steven Fenocchi. So far, feedback from SGHD had been that they did not wish to have formal steering membership.

Sarah Cunningham-Burley (SCB) asked what the links were to the other organisations which had been established as part of the Calman review. SS described the advisory group which had been established by SGHD to advise on the roll-out of the Calman initiatives and that this would provide a mechanism for liaising with these other bodies. SS sits on the advisory group.

Jack Jackson (JJ) suggested that it would be helpful to have a map of these various organisations and how they all link together. It was agreed that Hilary Osborne (HCO) would look to develop this.

**Action – HCO to create a map which depicts the various organisations operating in Scotland and how they link to each other, including the links to organisations outside Scotland e.g. the Department of Health.**

It was suggested that some consideration also be given to the links between Gengage and NHS National Services Division and the National Screening Committee.

## **2. Terms of reference**

The group was asked to consider the draft terms of reference and whether there were any amendments they wished to see.

The group's attention was drawn to the possible constituencies for membership outlined in the document. It was suggested and agreed that Biomedical research be added and also that links with the Office of the Chief Scientist and Office of the Chief Researcher be considered.

**Action – Add Biomedical research to the list of constituencies in the terms of reference**

SS also asked the group for its views on the review and evaluation mechanisms for Gengage. He also outlined that the evaluation of the Genetic Interest Group's Patient Engagement Network was also to be provided as part of this.

The group agreed that evaluation should be carried out separately to the steering group and that it might be appropriate to include colleagues from England or elsewhere as part of this process.

HCO informed the group that she had agreed with SGHD that the reporting year for Gengage would be 1<sup>st</sup> June to 31<sup>st</sup> May. It was, therefore, felt appropriate that the network be evaluated in July 2009 following the conference in June.

The question of whether or not Gengage would need to tender for the evaluation process was raised. SS stated that the proposal had not specified that it would be tendered for and that nothing had been said about this needing to happen.

**Action – A proposal for the review panel will be developed for consideration at the Steering Group’s next meeting**

Finally, the group considered the inclusion of faith groups on the Steering Group as well as those of no faith. It was also suggested that the Humanists might be considered.

**Action – SCB to provide HCO with the name of a multi-faith group which might be appropriate for inclusion**

**3. Steering group and sub-group committee membership**

NH asked what was understood by orphan diseases – rare genetic or multi-factorial disease broken down into sub-groups. She suggested that this would have an impact on how and with which groups we engaged.

It was agreed that the public engagement sub-group would not be established and that instead public engagement activities would be seen as part of all sub-groups with the Research sub-group taking on its role of putting social science research into practice.

The group also discussed whether as a Scottish network it was appropriate to have committee membership from other parts of the UK. It was agreed that in the first instance, membership should be sought from within Scotland.

The need to consider actively ethnic diversity and disability in establishing the network was agreed.

The group considered the list of possible members which had been prepared and made additional suggestions. It was agreed that HCO would take away the names and create proposed membership for the steering group and sub-groups which would be agreed by email with steering group members after the meeting. Following this, HCO would then approach the suggested members with a view to arranging sub-group committee meetings in the first few months of 2009.

**Action – HCO to circulate proposed membership for the steering group and each sub-group based on the afternoon’s discussions for the steering group to agree**

The chairmanship of the Steering group was also discussed and a name agreed for HCO to approach in the first instance.

**Action – HCO to approach the agreed chair on behalf of the steering group**

#### **4. Gengage plan for 2009**

The group then moved on to discuss the proposed plan for Gengage which would take the network to the end of 2009.

JJ sought clarification on whether the objectives could realistically be met. HCO felt that they were achievable but that it was important to look at the specific proposals for each sub-group as well as at present these might be a little too challenging.

##### **Health policy sub-group**

NH described the proposals which had been put before the group and reflected on the fact that there could be some overlap with the work of other organisations – how do we manage this?

The group discussed the proposals and agreed that the two issues of over the counter genetic testing and free fetal DNA were felt to be of particular current concern and, therefore, worthy of consideration by the group. It was also felt that the sub-group could do worthwhile work to help increase understanding of the health policy process. It was, therefore, agreed that the Health Policy sub-group would develop a programme which explores the health policy process, using free fetal DNA and other examples to aid this exploration and perhaps also drawing on what has happened in the past with other policy developments.

**Action – HCO to create rough draft of what this might look like for consideration at the sub-group's first meeting**

##### **Education sub-group**

JJ outlined the proposals for the education sub-group and the group discussed how they would be taken forward. This would include cataloguing the various materials already available for teachers and how these could be shared with teachers as well as what support could be given to help them use them.

The support that would be given to developing capacity and capability in the NHS for engagement in genetics was also discussed. It was agreed that HCO should proceed with the proposal developed with GIG and would keep the sub-group informed of progress.

The final matter discussed which related to the Education sub-group was the creation of a programme of training workshops as part of Gengage's role to increase capacity for public engagement. The group agreed that a careful needs assessment needed to be undertaken to ensure that the programme provided training which was of use to those involved in healthcare genetics public engagement. It was, therefore, agreed that a period of consultation and

commissioning would take place in the first half of 2009 with a view to running workshops from the middle part of the year onwards.

**Action – Education sub-group to discuss and develop the above work programme at its first meeting**

**Research**

SCB told the group about the main areas which she thought that the Research sub-group might consider in its work. She felt that the Research sub-group would need to take a longer term view of developments and how they might have an impact on healthcare. The following areas were proposed:

- Genetic epidemiological research and the implications of large population studies. This could lead to a consideration of both educational and engagement needs across sectors.
- Psychiatric genetics including definitions of health and illness and ideas of what is normal and abnormal.
- Developments in technology and how they impact on genetic services (technology driving events rather than the other way around). This could include:
  - Bioinformatics
  - Other technological developments

**Action – At its first meeting the Research sub-group will develop these proposals into a workshop programme for 2009**

**Budget**

The group felt that it would be appropriate to offer to pay for expenses and the cost of locum/ supply cover to encourage people to attend workshops.

**5. Communications strategy**

It was suggested and agreed that a short leaflet describing Gengage and its work be produced which could be used to promote its activities with others.

Otherwise, the communications strategy was agreed by the group.

**Action – HCO to develop leaflet**

**6. Dates of future meetings**

Thursday 19<sup>th</sup> March 2009 1 – 4pm, Dundee

Thursday 18<sup>th</sup> June 2009 10am – 1pm, Glasgow (This meeting is likely to follow the first annual conference of the network on 17<sup>th</sup> June which steering group members may also be interested in attending)

Thursday 12<sup>th</sup> November 2009 1 – 4pm, Edinburgh