

## **Steering Group meeting minutes**

**18<sup>th</sup> June 2009, Glasgow**

### **Attendance**

Steering group members:

Kenneth Boyd (Chair Steering Group)  
Sarah Cunningham-Burley (Chair Research Sub-group)  
Gerry Graham  
Neva Haites (Chair Health Policy Sub-group)  
Mary Porteous

Apologies:

Vikki Entwistle  
Jack Jackson (Chair Education Sub-group)  
Mandy Ryan

In attendance:

Steve Sturdy (Grant holder)  
Jenny Kerr (Network Administrator)

### **1. Welcome and introductions**

Kenneth Boyd (KB) began the meeting by thanking those who were in attendance for coming. Those in attendance who had not previously met introduced themselves.

### **2. Matters arising and minutes of last meeting**

A change in the order of the agenda was proposed by KB who suggested that the meeting commence with verbal feedback on the conference held the previous day (originally item 5 on the agenda) followed by the budget statement and updates on funding and staffing arrangements (items 2 & 3). He then suggested that matters arising regarding the sub-group activities (item 4) should be discussed in connection to the annual report (item 6) and that the review panel should be discussed under any other business. These changes to the agenda were agreed by all members.

KB then invited the steering group members who were present at the previous meeting to consider whether there were any matters arising from the minutes from the previous meeting.

Steve Sturdy (SS) asked if anyone had approached the Scottish Interfaith Council. KB pointed out that no-one had been asked to action this at the last meeting. It was agreed that SS and Jenny Kerr (JK) should draft up a letter

on behalf of KB as chair of the Steering Group, inviting the organisation to join the group.

#### **Action – SS and JK to draft invitation to Scottish Interfaith Council**

KB enquired as to what action had been taken regarding the communication strategy for Gengage.

- increasing the number of links from other websites to Gengage's website

SS confirmed that this was being done on an ongoing basis by ensuring that organisations are informed when their events are publicised on the website in the hope that they reciprocate.

- proposal to get involved in the Edinburgh International Science Festival

it was agreed that this would be one of the aims for next year and would be discussed further in relation to the sub group activities. Neva Haites (NH) suggested that someone take responsibility for booking Gengage into the Edinburgh International Science Festival. Sarah Cunningham-Burley (SCB) suggested that this be done through the Genomics Forum. It was agreed that the storage of biological samples could be a potential topic to cover.

#### **Action – Steve Sturdy and Jenny Kerr to look into booking for the 2010 Edinburgh International Science Festival**

- suggestion that Gengage become more involved with NES

Mary Porteous (MP) informed the group that ScotGen were currently in discussions with NES and suggested that it would be useful to exploit Gengage's existing relationship with ScotGen in order to get more involved. MP offered to represent Gengage when talking about Scotgen to increase awareness of Gengage.

SS pointed out that due to Hilary Osborne's departure some action regarding these issues was yet to be taken. KB asked for these to be added as items for the next meeting.

#### **Action – Secretariat to report back on progress regarding communication strategy**

### **3. Conference**

KB invited SS to give feedback regarding conference. SS reported the conference had been successful and praised work of Hilary Osborne, Claire Alexander and Jenny Kerr in assisting with the organisation of the event.

Over 90 people registered for the event with additional registrations on the day. Representatives attended from many different backgrounds including Scottish Government, Genetics and Counselling, Patient groups, academics involved with public engagement etc.

Those who attended the event commented on the range of participants, high level of turnout and high quality of discussions. Feedback from the evaluation forms and notes from the plenary sessions and workshops will be compiled in a conference report and posted on website.

**Action – SS and JK to compile notes and feedback in order to prepare conference report and update website**

KB raised the issue of confusion surrounding Gengage's role and who it is targeting i.e. whether it is directly targeting the public rather those intending to engage with the public. SS confirmed the main aim was to link people interested in public engagement in Scotland to encourage sharing of practice and build coherent public engagement movement in Scotland. However it is difficult to present this without actually doing public engagement and there is inevitably a certain amount of overlap. It was recognised therefore that there is perhaps an image presentation problem.

Some members commented that future events should address the need for wider public engagement rather than focusing too much on clinical genetics and patient engagement. It was agreed that Gengage should be clear about its aims and where there are tensions between different groups needs to be open and explicit about these.

Gerry Graham (GG) suggested that schools could play an important role in wider public engagement and NH suggested using public engagement officers at universities in order to target schools as well as larger festivals.

MP observed that the Scottish government's Calman Implementation Group were particularly keen that Gengage should promote public engagement of a form that would help to inform policy.

KB gave example of joint conference on genetics between the Medical Research Council and the Women's Institute.

SS suggested that the Steering Group revisit these issues in November when planning for next year's conference by which time further progress will have been made via the subgroup activities.

**Action – Education subgroup to look into ideas for engaging wider public**

It was also recognised that at future events there is a need for discussion of real research rather than making general comments. SCB agreed the research subgroup would look into this further.

#### **4. Budget statement and update on funding position**

SS talked through the budget statement and also provided an update on the current funding position.

In April, Scottish Government had confirmed funding for Year 2 but had decided that funding would not be provided for Year 3. SS has been in negotiations with representatives from the Health Department and has put forward a proposal that savings from Year 1 are carried forward together with additional savings from restructuring of staff during Year 2 (see section 5 below) which would allow Year 3 to run with only a top-up from the Scottish Government required. This has been agreed in principle by the Calman Implementation Group; a final decision will be taken by the Calman Advisory Group in August. MP advised trying to get this money before April 2010 since funds are available in the present financial year but the 2010/11 budget is likely to be much tighter.

All members confirmed that they were happy with projected running costs and KB congratulated SS on the negotiations.

#### **5. Update on staffing arrangements**

SS then provided the group with an update regarding staffing. The Gengage office is currently staffed by one full-time Grade 7 Network Officer and one Grade 4 administrative assistant working one day per week. SS proposed that current requirements could be met by the Grade 7 Network Officer and the Grade 4 administrative assistant both working 3 days each. The group agreed that this adjustment is appropriate and reflects the change in roles between start up in Year 1 and development in subsequent years.

As it will be much easier to recruit for two years rather than one, the funding position has a significant impact on staffing. Furthermore the University of Edinburgh will not allow advertising for the posts of Network Officer until a letter confirming funding has been received from the Scottish Government. MP suggested that a letter from the Scottish Government which endorses the use of grant money already received for a 2 year post may be sufficient to convince the University to allow advertisement of the post. It is likely that the new staff will not be in place until September.

**Action – SS to negotiate with the University of Edinburgh regarding length of contracts to be advertised.**

#### **6. Sub-group activities**

The members were then invited to consider the activities of each sub-group with reference to the minutes from the previous meeting and the draft annual

report. An update on each sub-group's activities was provided by the chair of each group.

## **Health Policy**

NH praised the effectiveness of the group which she attributed to the individuals involved, and reported that the sub-group would play an important role in informing policy decisions. It was also indicated that sub-group members are very willing to take forward initiatives.

NH confirmed that the Health Policy action plan for the coming year is as outlined in the draft annual report and is predominantly based around governance issues concerning storage and use of biological samples. A series of events and activities is currently being planned in collaboration with the Office of the Chief Researcher which shall involve wider public engagement e.g. science festival.

### **Action – SCB and NH to co-ordinate activities which overlap.**

NH expressed some concern about timeframe and organisation of activities in the absence of a Network Officer.

### **Action – NH, SS and JK to liaise in order to discuss potential dates for the first workshop**

NH confirmed that she was happy with the way the Health Policy sub-group is presented in the draft annual report.

## **Research**

SCB reported that the group met in March but will convene again soon perhaps via e-mail. SCB explained that differences between the sub-group minutes and the activities outlined in the draft annual report were due to changes in the sub-group's action plan. It has now been decided that the sub-group will carry out two activities:

- a scoping questionnaire with scientists. SCB, Research Sub-group and Gengage Secretariat would then identify issues and exemplars of research.
- a workshop involving a range of stake holders from the health care system.

GG asked how the group was defining genetic research. SCB confirmed that initial thoughts had been to do with genetic epidemiology and the role of association studies but following recent discussions perhaps should be broader. GG suggested transcriptomics which has huge interest and enormous implications for treatment and diagnosis.

MP raised the concern that it may be difficult to get healthcare professionals other than geneticists to attend. The group made several suggestions to attract as many participants as possible:

- MP recommended holding the meeting in the evening rather than during the day.
- NH proposed tying in with another conference or event.
- SCB suggested trying to get the event registered as CPD for GP's.
- Getting involved in an event already run by GP's themselves or organised through college was proposed by KB as a more targeted approach.
- MP suggested that tying in with an initiative such as the bowel cancer screening programme could make it more attractive to GP's.

**Action – SCB to discuss ideas with sub-group and then report any further modifications to annual report to SS or JK**

## **Education**

In Jack Jackson's absence, SS presented an update of the Education subgroup's activities. The members of the Education subgroup had identified a need for greater knowledge about NHS clinical genetics services surrounding screening, diagnosis, support for patients, relatives etc. The next meeting of the subgroup is therefore planned to take place at Western General hospital on 3<sup>rd</sup> September where there will be an opportunity to meet staff and find out more about the services offered.

It was agreed that all three subgroups should work together as part of the Edinburgh International Science Festival and that materials produced could then be passed on to schools, science centres etc. MP suggested collaborating with Scotgen to put forward a joint bid for funding in order to produce such materials. GG also suggested teacher update meetings as an excellent forum for meeting with teachers.

The group then discussed support and training for patient representatives. It was agreed that these groups played an important role in engaging in effective dialogue in order to influence public policy. A number of issues were raised by the group:

- MP highlighted the importance of positive input from these groups rather than focusing on problems and indicated the need for engagement to take place on a deeper level.
- KB suggested giving groups a task e.g. preparation of a report in order to provide a more structured framework.
- NH pointed out the issue of diversity of participants coming forward.
- KB suggested targeting parents as part of the broader public.

- SCB emphasised the importance of facilitators to ensure broader and more positive discussions and gave the example of “appreciative enquiry” which moves from positive to negative.
- Gengage might consider drawing up guidelines on how patient engagement and feedback could be built into the daily practice of genetic services, and perhaps linked to the revalidation process.

## **7. Annual report**

Once the activities of the subgroups had been reported, members were invited to review the rest of the draft annual report to decide which sections require updating/further information. The main sections which need to be updated relate to the annual conference and the performance indicators. Workshop 6 should be included as performance indicator of the objective “To increase the capacity and capability of those working in Scotland to get involved in public engagement activities” (p.13 of the draft annual report).

### **Action**

- **SS to write up report of conference.**
- **JK to provide feedback regarding conference evaluation forms and repeat business, new contacts etc.**

All points are to be revisited in November before signing off the annual report

## **8. Any other business – Review panel**

Individuals and organisations to approach to be members of the review panel have been identified. It was agreed that in the first instance the role of the review panel will be to evaluate Year One activities and examine how Gengage have fulfilled their remit. KB pointed out that this was a valuable opportunity for feedback and reflections. SS confirmed that results would be reported to the Scottish Government. A checklist should be drawn up outlining what the review panel should examine. It was agreed that further action would not be taken until a Network Officer was appointed.

## **9. Date of next meeting**

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