

Gengage Health Policy Sub-group Minutes

Monday 25th October 2010
ESRC Genomics Forum, Edinburgh

Attendance

Committee members:

Neva Haites (Chair)
David Aitken (DA)
Natalie Frankish (NF)

Steve Sturdy (SS)
Jane Wilkin (JW)
James Kelly (JK)

Apologies:

Lesley Wilkie
Gill Clark
Vivian Leacock

1. Welcome and Apologies

NH began the meeting by welcoming those in attendance and conveying apologies from Lesley Wilkie, Gill Clark and Vivian Leacock.

Natalie Frankish was introduced as the new Development Officer with the Genetic Alliance UK (formerly GIG).

Jane Wilkin was also introduced as the new Gengage Network Officer, in replacement for Kathryn Hunter who left the network at the end of September.

It was noted that it was still unclear whether Gill Clark and Vivian Leacock from the Chief Researchers Office (CRO) would be involved in the sub-group in the future as the result of the period of review and reprioritisation of the work of the CRO was still unknown.

2. Minutes of last meeting and matters arising

The minutes of the meeting on 12 August were approved.

SS updated the meeting that funding for Gengage, sufficient to cover staff costs, had been received for a further year, and as a result the network now had funds in place until July 2012.

Action: JW and JK to put the minutes of the August meeting on the Gengage website.

3. Sub-group members and replacement of Dr Skinner

It was noted that all actions to write letters concerning changes of sub group membership had been carried out from the last meeting. However, no reply had as yet been received from the Chief Medical Officer's (CMO) office on the request for nomination to replace Dr Skinner. It was acknowledged that it was difficult to find an appropriate person, but that it was very important to have someone from the Health Department who was able to give a public health perspective on issues covered by Gengage.

Action: NH to make informal enquiries to the CMO office on the best way to take this issue forward.

4. Future work plan

SS stated that the 2010/11 work plan for Gengage was now in its final format and that the discussion held at the last subgroup meeting had been very useful in informing the main document. Whilst the plan had been written with the funding level as known at the time, it was still appropriate with the extended timescales the additional funding enabled.

The plan was focused on providing public engagement opportunities to promote public involvement in healthcare research and governance in Scotland.

The main events to be held by Gengage over the coming year, with suggested dates

- Brainbanking (November)
- Direct to Consumer Genetic Testing (February)
- Pre Implantation Genetic Diagnosis (April)

These three events would be followed by the annual conference in June. The topic of the conference has yet to be finalised, but would have public involvement in healthcare research governance as an agenda.

The Gengage office has the capacity to organise these events, and the planning for the first event is well underway. However, there was a need for input from sub group members for the subsequent two events. In addition whilst the office was able to handle most of the organisation, sub group members would be required to assist in activities such as: networking, engaging stakeholders, and taking forward actions after each event.

SS noted that the Education sub group had taken a lead on the last conference, and that it would be helpful if the policy sub group could take a lead this time.

Discussion then focused on each of the planned events.

Brainbanking

SS introduced the brainbank event and stated that it would be based on the event held by Gengage earlier in the year as part of the Edinburgh Science Festival.

DA asked what it was about the brain bank event that took forward the brain bank agenda. SS described the brain bank event; presentations, round table discussions and electronic voting, and then highlighted some of issues that had been raised such as the shortage of brain tissue available, especially normal tissue, and the difficulty some participants had expressed in finding out how to donate. SS said that the event had been organised jointly with James Ironside, Director of the UK Brain Banks Network, who had been very impressed with the outcome and feedback from the event.

SS also stated that building on the success of the first event Brain Bank event Gengage had put in a bid for Wellcome Grant to run a series of Brain Bank events around the UK.

Direct to Consumer Genetic Testing

The second event would be held in February 2011, although NH noted that the timescales looked quite tight. JW agreed but felt they looked manageable at this stage, but could be reviewed after the first event.

DA commented that the subject of Direct to Consumer Genetic Testing, seemed to generate polarised views, with very little middle ground.

The discussion then centred on themes to address and stakeholders that should be represented. It was felt that the topic is timely given the growth of companies such as 23andMe and the fact that UK pharmacists are now offering over-the-counter paternity tests. In addition, there has been considerable recent policy interest, including reports from the HGC and the Nuffield Council.

The location of the event was then discussed. While Gengage staff had been considering holding the event in a location outside the central belt, such as Aberdeen or Dundee, NH suggested that Edinburgh would be best for attendance of both speakers and participants. It was agreed that Edinburgh was the preferred venue.

Pre Implantation Genetic Diagnosis (PGD)

It was felt policy questions around PGD are salient at the moment because of continuing innovations in the tests available including genome wide screening for 'healthy embryos'.

SS suggested that more thought needed to be given to the audience and to the precise issues to be discussed.

It was suggested that the event could be organised around a number of key speakers who would present scenarios – then lead on to a debates and questions around each scenario. NH suggested that a scoping/ planning meeting be organised in December with a small sub-committee, which could be attended by video or teleconference if necessary.

Action: JW/JK to organise a meeting for NH, DA, SS, JW and one or two others in December to take forward the planning of this event.

Conference

The suggested topic for the conference was involvement of the public in clinical research and the governance of that research. NH confirmed that there was significant interest in Scottish government in this topic, which was also of interest to SAHSC. It was agreed that this topic would be taken forward for the conference.

There was some discussion as to whether the remit should be confined to drug trials or extended to cover other medical procedures and technologies for example stem cell therapy.

It was agreed that more consideration is needed of the audience and aims and this should be addressed by a small organising committee.

The type of event was discussed and it was agreed that in line with Gengage's remit to move beyond information giving, it should have a significant deliberative dimension.

SS suggested that a small organising committee for the Conference should be set up and NH put forward a number of people to approach.

Action: JW/SS to identify and approach members for an organising committee for the conference.

5. AOB:

DA asked if, following on from the presentation given by Craig Gilbert at the last meeting on stored biological samples, there had been any update on the issue.

Action: JW to contact Craig Gilbert and arrange a meeting with NH to give an update on this issue.

6. Date of next meeting

It was agreed that the next meeting would be held in December, preferably on the same day as a meeting to take forward the conference agenda.

Action: JW/JK to set up a Doodle poll.