

## **Gengage Health Policy Sub-group Minutes**

**Thursday 12 August 2010**  
**ESRC Genomics Forum, Edinburgh**

### **Attendance**

#### **Committee members:**

Neva Haites (Chair)  
Claire Cotterill  
Gill Clark  
David Aitken  
Vivian Leacock

Steve Sturdy  
Kathryn Hunter  
James Kelly

#### **Invited guest:**

Craig Gilbert

#### **Apologies:**

Lesley Wilkie

### **1. Welcome and Apologies**

Neva Haites began the meeting by welcoming those in attendance and conveying apologies from Lesley Wilkie. As it had been some time since the last committee meeting, NH asked each member to re-introduce themselves and say a bit about their contribution to the group.

Kathryn Hunter, Gengage Network Officer, advised the committee that she would be leaving the Forum at the end of September to take up a Lectureship at the University of Northumbria. She expressed regret at leaving, as she has thoroughly enjoyed working with everyone involved with Gengage and at the Forum. NH thanked KH and wished her the very best in her new appointment. Claire Cotterill also advised the Committee that she would be leaving her post as Development Officer with the Genetic Alliance UK (formerly GIG) at the end of the month to return to university. She said that they are currently recruiting for her post and thought that the new Development Officer would, if invited, be happy to join the Policy Sub-group. NH wished her all the best for her future studies.

Gill Clark (CRO) noted that the Chief Researchers Office is currently undergoing a period of review and reprioritisation of work. Depending on the outcome, she and Viv Leacock may have different roles and they are unable to commit to further involvement with the Policy Sub-group until they know what their future postings will be.

## **2. Minutes of last meeting and matters arising**

The minutes of the meeting on 20 March 2009 were approved.

The Policy Sub-group's role and objectives (as outlined in the document circulated prior to the meeting) were agreed.

With regard to the Policy Sub-group's programme of activities related to stored biological samples, Craig Gilbert noted that the Academy of Medical Sciences has launched a second call for evidence to inform its review of the regulation and governance of UK medical research, in particular research involving human participants, their tissues or data. He suggested that Gengage should not duplicate work that was being done elsewhere. Discussions about the Policy Sub-group's future work plan are outlined below.

**Action:** KH and JK to put the agenda and minutes of the meeting on the Gengage website.

## **3. Sub-group members and replacement of Dr Skinner**

As Dr Ros Skinner has now retired, a new member will need to be appointed to the Policy Sub-group. NH noted the enormous contribution Dr Skinner made to Gengage and public health in Scotland generally, and advised that she will write a letter to Dr Skinner to express the Committee's gratitude for her work.

A number of suggestions were made for Dr Skinner's replacement, which will be followed-up.

**Action:** NH to write a letter to Dr Skinner; potential new members to be approached by NH and SS.

## **4. Update on stored biological samples project**

At the first meeting of the Health Policy Sub-group in March 2009 it was decided that the group would focus on governance issues connected with stored biological samples, particularly in relation to their use in research. Since the first meeting, the group has facilitated discussions between Scottish Government, National Health Service Scotland, and academics with a specialist interest in this area. Although the public policy seminar and wider public engagement activity scheduled for the autumn and winter were not able

to proceed at the time dialogue is ongoing and stakeholders are involved in exploration of models of governance and other work to inform policy development in this area. As part of this ongoing work, Gengage organised a public engagement event on brain banking and brain donation for research for the Edinburgh International Science Festival in April.

## 5. Future work plan

A number of suggestions were made for the future work of the Sub-group. These included:

- Free foetal DNA
- Predictive genomics – over-the-counter genetic tests and quality assurance
- The outcome of the Calman review – how has it been implemented and how successful has the implementation been in Scotland?
- Facilitating public engagement around
  - lifelong anonymous data linkage
  - brain banking and brain donation for research
  - cord blood banking
  - other tissue or organ donation generally

Steve Sturdy noted that Gengage has only 11 months of current funding remaining and it is, therefore, necessary to consider ways to take Gengage forward, and to think strategically about what Gengage as a whole can do and what the Sub-group can do to advance that strategy. He suggested that it would be worth exploring the possibility of embedding Gengage in other projects and linking into other funding streams.

Claire Cotterill commented that the Genetic Alliance would be interested in cord blood banking as a topic.

Gill Clark noted that the funding councils are very keen on ‘public or added value’, and suggested that Gengage might consider further events for the Science Festival and/or Book Festival around ‘the human body’.

Kathryn Hunter suggested a cord blood event, similar to the brain bank event, for the Science Festival next year, which might be held in collaboration with the Genetic Alliance and other interested organisations or groups.

Steve Sturdy stated that, ideally, Gengage should look to link to other organisations and activities. In terms of topics, he noted that ‘tissues’ seem to create excitement.

Craig Gilbert suggested that Gengage could provide an education role about the value of tissue donation and research.

Neva Haites stated that, with only 11 months of funding left, Gengage should look at ways the Sub-groups could work together.

Gill Clark noted that the policy priority at the moment is on economic recovery, and that questions about how to make the best use of the genetic resources of the people of Scotland are directly relevant to the Government's focus on sustainable economic growth. Increasing public involvement in Pharma research could contribute to job creation, as well as the knowledge transfer and education agendas. The involvement of pharma in genetic research could be a seminar/dialogue topic.

Neva Haites commented that the group could look at 'tissue' for research generically, and might, on the back of events being held by the Chief Scientist's Office in Dundee and Glasgow on wet and dry science, hold public events (possibly in collaboration with Dundee) on issues around the use of data and tissue for research generally.

Steve Sturdy noted that activities to promote and coordinate public engagement around the use of research resources and participation in clinical trials would link nicely with the Education and Research Sub-groups also. He stated that the discussion had been tremendously helpful and that the ideas would now need to be reflected on.

**Action:** NH, SS and KH to discuss further and develop a work plan for the group to consider.

## **6. AOB**

Gill Clark wanted to thank Viv Leacock for all her work on the stored biological samples project thus far.

## **7. Date of next meeting**

It was agreed that the next meeting would be held in October 2010.

**Action:** KH/JK to set up a Doodle poll.