

Health policy sub-group meeting minutes

20th March 2009, Edinburgh

Attendance

Committee members:	Vivian Leacock
Neva Haites (Chair)	Hilary Osborne
Ros Skinner	
Claire Cotterill	Apologies:
Gill Clark	Lesley Wilkie
David Aitken	

1. Welcome and introductions

Neva Haites (NH) began by thanking those present for attending the meeting and inviting them to give a brief overview of their background and current role. NH is Professor in Medical Genetics at the University of Aberdeen, Vice Principal, Head of the College of Life Science and Medicine and an Honorary Consultant Clinical Geneticist at Aberdeen Royal Hospitals NHS Trust. She is also a member of the Human Fertilisation and Embryology Authority.

Next Gill Clark (GC) explained her own role in the Office of the Chief Researcher in Scottish Government and that of her colleague, Vivian Leacock who works on science and society. She described the structure of Scottish Government and how she hoped that by sitting on the group she might be able to act as a signpost for other interested parties in government. GC talked about her interest in knowledge transfer and the work she has done to date with the ESRC Genomics Forum where Gengage is based.

Claire Cotterill (CC) works for the Genetic Interest Group (GIG) which is an alliance of about 140 patient charities. She is working on a project to develop a network for patients with genetic conditions. This receives its funding from the same pot as Gengage, namely the funding allocated to healthcare genetics following Sir Kenneth Calman's review of healthcare genetics in Scotland.

Ros Skinner (RS) is part of the Chief Medical Officer's team at Scottish Government and has a particular interest in genetics and population screening. She led on the Calman review for the Scottish Government Health Department.

David Aitken (DA) is a Consultant Clinical Scientist and Head of Biochemical Genetics in Glasgow. He is particularly involved in the various screening programmes including that for new-born babies. This is an area which attracts quite a high level of interest from the public but which is often poorly understood.

2. Policy drivers of the recent past

RS provided the group with an overview of the *Review of genetics in relation to healthcare in Scotland (2006)* which was chaired by Sir Kenneth Calman. England, Wales and Northern Ireland had also looked at genetics in their countries, conducting reviews in the early to mid 2000s. The reviews varied in their scale and the range of areas at which they looked. The Scottish approach was wide ranging and made a series of recommendations, one of which was the creation of Gengage. It felt that a network in this area would help to pull people together social scientists in particular and be a useful addition to the other networks and measures recommended by the review.

GC described the Scottish Government's vision of a "science nation" as is described in its science framework and strategy. Part of this agenda is to do with keeping the population up-to-speed with developments in science and technology through science centres and other activities as well as encouraging young people to study science. The work of the Chief Scientific Adviser, Prof Anne Glover, in this area was mentioned.

Action – Circulate the science framework to the group

3. The Policy sub-group's role and objectives

The group then moved on to discuss its roles and objectives. It was agreed that it would be helpful to have a brief, formal document describing this which could be included on the website and help to inform those not on the group about its role and objectives.

In reflecting on how group members saw its role, the importance of creating links with the other sub-groups was highlighted. NH commented that such cross links were essential but that the group also needed to be mindful of overlaps and to maintain its focus on health.

Action – Secretariat to draft a brief document describing the group's role and objectives for it to agree at the next meeting

4. Programme

The next area which the sub-group looked at was what activities it might like to undertake as part of the overall Gengage programme in 2009. NH mentioned the issues of free fetal DNA and over-the-counter-genetic testing as areas which the group might consider in terms of how policy might handle such issues in the future. She also invited other suggestions and RS put forward the question of stored biological samples. The group discussed how it could examine this question particularly in relation to governance arrangements and using such samples for research. The group agreed that this would be a very worthwhile area for it to look at, particularly given that it raises a number of questions which could also be applicable in other areas.

In terms of how to take forward this piece of work, the group agreed that it would take a three staged approach. It was suggested that it begin by organising a small meeting of key stakeholders in the early autumn to identify and discuss the various issues which this question raises. A larger seminar would then take place (November) using the public policy seminar model which GC and her colleagues have used in the past. There could then potentially be some form of wider public engagement activity based on the issues raised in the previous workshops in the early New Year.

Action – Secretariat to draft a proposal describing the above project for circulation to the group

5. Gengage conference

The proposed programme for the Gengage conference was discussed in some depth. A number of potential speakers were suggested which will be followed up as part of the preparations for the conference.

6. Date of future meetings

The group agreed to next meet in October. A date for the meeting will be identified and circulated to the group in due course.