

Evaluation of 9th December 2008 consultation and launch event

What we did

In December 2008 Gengage and the Genetic Interest Group (GIG) jointly organised an event to give those with an interest in healthcare genetics the opportunity to comment on the Scottish Government's public consultation on a Patients' Rights Bill for service users of the NHS in Scotland. The event was also used to mark the launch of Gengage and of the GIG Patient Engagement Network.

Participants

More than sixty people attended. They were interested in the event because:

- they or their families had a genetic condition;
- they worked for charities or patient organisations working in this area;
- they worked for the NHS; or
- they were university academics, science communicators, educationalists and ethicists.

Venue

We used a large room with participants grouped around tables (this seems to be known in the conference trade as "cabaret style"!)

Each table had a facilitator.

Structure and content

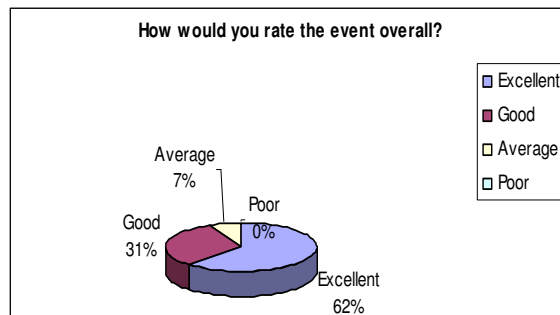
- We began the day with an introduction to Gengage and the GIG Patient Engagement Network. We explained what the day would involve so that participants knew what to expect and why Gengage and GIG had chosen to run the event.
- Overview of the Patients' Rights Bill given by someone from the Scottish Government Health Department. The aim of this was to spark the subsequent discussions and to put the bill in context.
- Sharing different perspectives on the bill and its implications. Participants discussed:
 - what they liked in the bill
 - what they didn't like
 - if anything was missing from the bill
- Each table then fed back their main points to the room before breaking for lunch.
- We then held a "world café" to allow participants to talk about three of the eight rights in detail or whether or not any rights were missing. Participants spent half an hour on each table before moving on to the next one. Again we had facilitators on each table to help keep discussion going.
- The tables then fed back their discussions to the room.
- We provided refreshments afterwards and many people decided to remain to network and continue their discussion.

What people said about the event

“Thank you for the opportunity to contribute!”

A participant

There was very positive feedback from those who attended the event which we collected with the aid of feedback forms. 93% of delegates said that they thought it was good or excellent.



What went well

“I appreciated the opportunity to be able to have a say in how the Patients' Rights Bill will be used”

A participant

- The event meant that the particular implications of the proposed bill for patients and families with genetic conditions were raised with the Government.
- Participants were largely able to set their own agenda and talk about the issues which they felt were most important rather than being directed by us.
- The day allowed us to collect sufficient information to create a detailed response to the Government consultation.

- People had plenty of time to network and talk to each other.
- Many people who would not otherwise have had the opportunity to comment on the consultation did so. Participants welcomed this.
- This was the first event which GIG and Gengage have run in partnership and demonstrated the effective way in which the two organisations can and will collaborate to meet shared objectives.

What we might do differently next time

- Involve more people from a wider range of ethnic backgrounds. It was noted that although we had managed to get a number of participants from minority groups, that some groups were missing.
- Ask participants to prioritise which points were most important. When it came to writing the report for the event it was difficult to say which points delegates felt more or less strongly about because we hadn't asked them to prioritise their points. On the other hand, there probably wouldn't have been enough time for participants both to have a detailed discussion about the points that mattered to them and prioritise those points.
- Use separate rooms for the discussion groups. Some participants found the noise and bustle of a big room distracting.

Find out more

If you are planning a similar event or would like to find out more about this event, please contact us on 0131 651 4750 or by email to genadmin@gengage.org.uk