

## **What should happen to your brain after you die?**

### **Glasgow Science Centre**

**4 March 2011**

### **Facilitated Discussions Summary**

- While there was a strong support for brain research generally, many of the groups appeared to be ambivalent about donating their own brains for research. This was identified in one group as being an emotional, rather than intellectual position and hard to explain. Most of the participants agreed having a mix of contradictory feelings due to the extreme complexity of the issue and expressed their concern about different issues.
- From an ethical point of view, the questions of concern were: how is the organ is treated during the donation process? How to be sure specialists will treat the brain with respect? However, some participants noticed that medical ethics were much more stringent nowadays.
- Some participants expressed concerns from a religious vantage point: the brain – is it you? Is it your personality? How will you function in the afterlife? But some participants commented that donation can also *give* life. Participants had different opinions about whether the brain was a special organ or not. Some suggested the brain does not tell us anything special about being human, but then wondered how we should define humanity.
- Some participants were also concerned that their life support might be turned off prematurely if they donated an organ or that they would not to be able to change their mind after having given their consent. The question of commercial gain was also raised as a field of concern, as was specialists' gaining academic glory.
- One of the dilemmas faced during the event was about donating the brain for research or for transplantation. Transplantation was more popular because of the direct benefit for the transplanted person and the support it could be for the bereaved family, and yet it was suggested that donating your brain for research would help humanity in the future and that it was a question of altruism in order to make medicine progress.
- Questions of “public awareness and accountability” as well as the building awareness of the achievements from donation were also

important topics of discussions among the participants. Public knowledge was seen as a key issue to clarify what brain donation and brain banking are as the discussions revealed that people have many misconceptions and they are not aware of how it will be regulated. Additionally, it was said that there was still a lack of clarity around what exactly happens (what is the “tissue” under discussion?) in the medicolegal context.

- Responses to the question of who should be able to consent to brain donation, were quite mixed. Some participants felt it should be done individually, however others felt there are situations, e.g children or people with degenerative diseases, where others may make a decision for their behalf. It was felt it is less tough for bereaved relatives when the choice had already been done before the death of the person.
- Additionally, participants stated that people who sign up to donation would get regular check-ups in order to provide information about their health. This for some this would be a disincentive as they would just want to get on with their life, and suggested that linking up with NHS medical records would be preferable.