

## **Retained Organs Commission: A Consultation Document on Unclaimed and unidentifiable organs and tissue A possible regulatory framework**

*A response from the Genetic Interest Group (June 2002)*

The Genetic Interest Group is a national alliance representing individuals and families affected by genetic disorders. We have around 130 groups in membership, and a smaller number of individual members. Some of our member groups and members are involved in research that uses human material and body parts. Some of our members, as individuals, have consented to the use of human material taken from deceased relatives.

The question of what to do with retained organs, particularly unclaimed and unidentified retained organs, arises from the interim report of the Bristol inquiry and the report of the Alder Hey inquiry. As was quickly discovered, many organs and other human material had been obtained without explicit consent and were being held in hospitals and universities across the UK. It was easy to see in this something untoward, and the rapid disposal of some of this material can have only added to that sentiment. However, it is important that we do not rely on such knee-jerk judgements in deciding what to do with the remaining human organs and other human post-mortem material, and in framing future regulations.

Professor Lilleyman, president of the Royal College of Pathologists, maintained that 'there was never any perverse or devious intent' behind the actions of the majority of pathologists. We are happy to accept that assessment. By contemporary standards, past practices have been found wanting. There is no doubt that everyone wishes to ensure that another van Velzen is not allowed to practise; but we must not leap to the conclusion that there was a bit of the van Velzen in everyone.

In this response we focus on some of the questions raised in the consultation. However, there are a number of questions that are not considered in the consultation, but which are equally important to many individuals and families affected by genetic disorders. These centre on the question of what can be done to ensure that human organs and material are *effectively* used in research. Part of the problem with the large amount of material being stored in some centres was that it wasn't being used effectively; in some cases it wasn't being used at all. In considering future regulation, ensuring the widest possible access and use consistent with maximising the potential of the collection should be a priority. We would also wish to echo a concern raised by clinical geneticists concerning the interests of blood relatives in post-mortem research: the law accords the primary role to the spouse of the deceased. However, from a genetic research point of view it is the blood relatives who might have the greatest interest and stake.

**Question 1:** These principles, some of which are ethical in character and some of which are closer to good professional practice, capture the broad approach needed in seeking and securing consent. There will be more to say about *Respect* later however, concerning

a conflation of respect for the feelings of the deceased's relatives and friends, and respect for the dead body itself.

**Question 2:** We do not have any objection to the term human material as such. However, if this term is to be used to cover the kinds of materials used in research and teaching, with a view to legal definition and regulation, we feel it would be burdensome, not to say faintly ridiculous, if it was to include bodily fluids and small tissue samples. From this point of view we would wish to see tissue blocks, slides and bodily fluids excluded from the definition of "human material".

**Question 3:** The questions of consent and respect are important, but raise a number of difficulties and possible confusions. Yes, informed consent should be sought from relatives for the use of human material, and in seeking this professionals should be prepared to go into sufficient detail. However, it must also be possible for relatives to give a general consent for the use of the deceased's body in research, for a specific research project or more generally, without having to go into details. As we understand it this is now the current position, and this should be reflected in any amended Human Tissue Act.

Respectful use raises a possible confusion. Professionals should be respectful to the wishes, feelings and beliefs of the deceased and their relatives and family, but beyond that it is less clear what respect means. Away from the hearing of families pathologists may engage in black humour to lighten the atmosphere surrounding their work. A research technician may play music while doing routine procedures with tissue blocks or slides. For many scientists human tissue that has lain in the freezer for ten years is just biological material. It would be hypocritical to pretend that this is not the case, and unnecessary.

In discussing what to do with unclaimed and unidentifiable material, it is stated in the consultation that 'What the commission believes is paramount is that whatever course of action is chosen should be carried out with respect for the organs and tissue of the deceased—just as society requires respect to be given to the bodies of the dead'. In our opinion it is not possible or practical to do this. In particular if the material is unidentifiable it might not be possible to know the particular beliefs of the deceased or of their relatives. In these circumstances we suggest that material should be documented and used in education or research where appropriate, or disposed of in a straightforward manner: cremation for whole bodies and standard hospital disposal for organs and smaller tissue samples.

**Question 4:** Unidentifiable organs and other material from before March 2000 should be audited and retained for education and research if they can be so used. If not they should be disposed of in the manner outlined above.

**Question 8:** It is of course difficult to answer this question. There has been a great deal of publicity, but some people may have missed this. What needs to be considered in the balance is the distress that could be caused to families by further publicity and discussion, which could easily carry with it an intrusive aspect if attempts were made to be as specific

as possible about the material still held. Looked at from this point of view we would say that there has been sufficient publicity.

**Question 10:** No.

**Question 11:** Yes.

**Question 12:** Material should be reviewed now if this hasn't already taken place.

**Question 15:** All material that has not been claimed should be retained and used unless there is evidence that consent was specifically refused in general or for specific purposes. It is not useful or appropriate to apply current standards of consent retrospectively.

**Question 16:** This question assumes that all people belonging to a particular ethnic, cultural or even religious group have uniform views. In the absence of any contrary indication from the relatives, the material should be retained for use or disposed of in line with the general procedures outlined above.

**Question 19:** In future, consent should cover all uses of all post-mortem material. The use of blocks and slides should be explained where appropriate.

**Question 21:** Yes.

**Question 22:** See the answer to Question 3 above.

**Questions 23 & 24:** In the future, the material could be returned to the relatives if that is their wish. If the relatives do not wish the material to be returned to them or do not wish to be present when the material is disposed of, we would suggest that the hospital should dispose of it in line with the standard procedure outlined in answer to Question 3 above.

**Question 26:** No. However, depending on the local situation, hospitals will need to establish a process to enable crematoria to dispose of whole, unidentifiable bodies.

**Question 28:** Since this section is discussing the disposal of unclaimed and unidentifiable material, the question of the attendance of relatives at reverent disposal ceremonies does not arise. If the material is identifiable but unclaimed, then, in line with the answer to Question 8 above, the family should not be contacted.

**Question 29:** In line with the proposals of the Scottish Independent Review Group, we would like to see it established in a reformed and updated Human Tissue Act that an individual has a clear right in law to state in advance what they wish to be done with their body upon death, especially as regards its use in research and education.

The Independent Review Group also highlight the need to consider the significance of genetic information revealed through post-mortem, as this may have consequences for relatives. If the deceased has not left specific instructions and the law is clarified to require

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explicit consent from a spouse for post-mortem, a potential issue arises concerning the interests of blood relatives, who may positively wish to gain information of a genetic character.

**Question 30:** Currently there are a number of relevant consultations running. We would not want to see precipitate action taken in this area. Updating the Human Tissue Act without establishing a new national Human Tissue Authority needs to be considered as a possibility. It is stated in the consultation that 'self-regulation in the light of what has happened in the past is unlikely to be an acceptable option'. We are not sure of that. It would be slightly misleading to term the absence of a national authority as 'self-regulation'. There would be an updated body of law that professionals had to follow, and a number of professional and ethical review bodies that they would be accountable to. Recalling Onora O'Neil's point in this year's Reith Lecture series that we face not so much a crisis of trust as a culture of suspicion, and her argument that more accountability and regulation *per se* is not the solution to this, perhaps a clear public statement of the legal position and best practice, allied to local accountability, would be the best way to facilitate fruitful relationships between professionals and families.

**Question 33:** No. The role of such a body would be unclear. The case first needs to be made for a statutory body. In light of the different possibilities for future regulation we feel it would be premature to answer in detail any of the further questions concerning the role and functioning of an authority. Should such a statutory body be set up its remit should be specific and workable.

If the commission would like us to expand on any of the answers we have given, or to answer any further questions at a later date, we would be happy to do so.