



The Human Tissue Bill

Some comments from the Genetic Interest Group following Third Reading in the House of Commons, 19th July 2004

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.

One issue in the Bill gives us specific cause for concern. This is DNA analysis performed for the benefit of relatives (Sections 7(1), 7(2) and Schedule 5, Part 2, paragraphs 9(2) and 9(3)).

In seeking consent from the living individual for some purposes, the question arises of what happens if they refuse it. The Bill as it stands allows no possibility of setting aside this refusal in order to benefit other members of the family in a clinical setting. It makes no difference whether the original person is alive and in contact with the relevant medical authorities, alive but un-contactable, or dead. If they refused in the past that holds forever.

We believe this to be fundamentally wrong. In our report Confidentiality Guidelines (1998), available at www.gig.org.uk, we discussed the closely related issue of the use of existing information in some detail. Relevant professional groups have developed guidelines more recently. We are agreed that there should be a mechanism to consider the interests of the wider family in those rare cases where consent to use information is refused and the data would be of great benefit to another family member.

While in some cases there may be differences between the disclosure of existing information and the re-analysis of a sample to gain new information, more commonly there will be similarities and connections. Accordingly in our view allowance must be made for exceptional circumstances. A mechanism should be created through which the reasons for a refusal can be investigated when testing a sample would be of great benefit to another family member. Others who share our concern have suggested access to the Courts to put this case. The requirement to go before the Courts, under a legislative framework which established the importance of consent, would make clear the strong (but not absolute) protection offered to the individual while also allowing a little flexibility in hard cases. We note that Government is proposing such a mechanism in cases where consent is unclear and contact is lost. The suggestion made in this note would extend that mechanism to deal with the set of thankfully rare, but nevertheless vitally important cases that we raise.