

## Legislation Relating to Organ and Tissue Donation and Transplantation: Analysis of Consultation Responses

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A Scottish Executive Health Department consultation on the legislation relating to organ and tissue donation and transplantation took place between 18 March 2004 and 11 June 2004. A consultation paper was issued to which 62 responses were received from a wide range of people and organisations in the public, private and voluntary sectors. This is a summary of the analysis of the responses to the written consultation. The findings will inform the preparation of advice to Ministers on the comments received on the proposal to replace in Scotland the Human Tissue Act 1961.

### Main Findings

- Of those who commented there was unanimous support for a revision of the current legislation in respect of organ and tissue transplantation.
- 88% of those who commented considered that no further proof of wishes should be required if adults and mature children are carrying a donor card or have registered their name on the NHS Organ Donor Register.
- The majority view (72%) was that in respect of deceased children, where both parents cannot agree on whether retrieval should go ahead, it should not proceed.
- Where the wishes of the deceased and the surviving relatives are in opposition, 75% of respondents who commented thought that the deceased's wishes should prevail.
- Views were almost evenly split on whether there should be a separate register for objectors with 52% of those who commented in favour and 48% against.
- Almost three-quarters (71%) of those who commented were opposed to the application of penalties in the context of cadaveric organ and tissue retrieval.
- Around two-thirds (63%) of those who commented recommended that some or all of the functions of the Human Tissue Authority should be extended to Scotland; most of the respondents who commented (86%) favoured extending the role of the inspectorate for the rest of the UK to Scotland
- The majority view (64%) was for changing the previous legislative provision so that rather than repeating brain stem death tests, the doctors removing organs should have to satisfy themselves that the tests had been performed satisfactorily.
- All but one of those who responded (98%) were in favour of extending the scrutiny of live transplants to cover cases where the donor and recipient are genetically related.
- 76% of those who provided a view supported both paired and altruistic live donation in Scotland with a further 9% of respondents favouring paired donation.

## Context

The consultation concerned new legislation aimed at addressing the country's severe shortage of organs for transplantation. It included consideration of ways to help patients needing transplants and ways of improving safeguards for donors. The existing legislation is contained in the Human Tissue Act 1961 and the Human Organ Transplants Act 1989.

The proposals take account of parallel consideration in the rest of the UK of the law relating to organ and tissue donation and transplantation in order to ensure broad consistency of approach. The Human Tissue Bill contains details of the legislation proposed for the rest of the UK. The exercise also followed consultations in Scotland dealing with legislation on hospital post-mortem examinations and the Anatomy Act 1984 respectively.

## The Consultation

The consultation on the Legislation Relating to Organ and Tissue Donation and Transplantation took place between 18 March 2004 and 11 June 2004. Over 100 copies of the consultation paper were distributed to a wide range of people and organisations in the public, private and voluntary sectors. The consultation paper set out specific questions which highlighted proposed changes to the Human Tissue Act 1961. The exercise followed the consultations dealing with legislation on hospital post-mortem examinations and the Anatomy Act 1984, each of which is the subject of a separate analysis report.

A press release helped publicise the consultation paper which was made available on the Scottish Executive website.

The consultation paper was structured into 3 main sections:

- Transplantation of organs and tissue from people who have died
- Transplantation of organs and tissue from the living
- Tissue banking

Sixty-two responses were received from a range of people and organisations in the public, private and voluntary sectors.

## Aims and Objectives

The aim of the research was to analyse the comments contained in written responses to the consultation on the

Legislation Relating to Organ and Tissue Donation and Transplantation, to present the findings of the analysis and to identify any gaps in respondent sector.

## Methodology

Responses to the consultation were sent to the Scottish Executive consultation team either in hard copy or via e-mail. The consultation team sent copies of each response to The Research Shop for analysis. The consultation attracted a relatively small volume of responses but represented a wide range of respondent categories with individual respondents, a mix of members of the public and other individuals who could provide a perspective based on their current or previous professional experience, comprising the largest group of respondents. One gap in respondent organisations emerged as that of representative minority ethnic groups. It may also have been useful to seek further response from young people and from older people's representative bodies.

An electronic Excel database was used to store and assist analysis of the responses. Most of the analysis was qualitative in nature although where scope for quantitative analysis existed, this was exploited.

## Nature of Responses

The general mood of responses was one of support for the efforts to update legislation, raise the profile of organ and tissue donation and transplantation, and by doing so encourage higher levels of practice.

## Transplantation of organs and tissue from people who have died

There was unanimous support amongst those who provided a view for a revision of the current legislation in respect of organ and tissue donation. All of those consultees who commented agreed that the system of organ and tissue donation in Scotland should rest on the concept of "authorisation".

The majority view was that there was no longer a role for a person nominated to authorise an organ retrieval on behalf of the deceased if someone has decided to carry an organ donor card or has added their name to the NHS Organ Donor Register.

## Balancing views on organ retrieval

Almost all who provided a view considered that no further proof of wishes should be required if adults and mature children are carrying a donor card or have registered their name on the NHS Organ Donor Register. The majority of respondents also held the view that in respect of deceased children, where both parents cannot agree on whether retrieval should go ahead, it should not proceed.

Where the wishes of the deceased and the surviving relatives are in opposition, 75% of respondents who commented thought that the deceased's wishes should prevail. However, many consultees acknowledged that in practice retrieval would not usually be carried out in the face of strong opposition from relatives.

Where there are no next-of-kin and no expression of wishes by the deceased, respondents were almost evenly split between those who considered a continued role for a "person lawfully in possession of the body" and those who considered that organ retrieval should simply not proceed.

Many suggestions were made for witnessing verbally expressed wishes with no single overarching preference emerging.

Views were almost evenly split on whether there should be a separate register for objectors. A common reason for favouring a register for objectors was that such a record would likely reduce any chance of a donation being made against the deceased's wishes. However, others considered that there was no need for such a register, and that it would be too costly and complex to operate.

A slight majority of those who commented favoured the inclusion of "friend of longstanding" in the hierarchy of relatives. Others, however, considered that this addition would be too difficult to define and likely to cause confusion and be open to challenge.

## Other related issues

Almost three-quarters (71%) of those who commented were opposed to the application of penalties in the context of cadaveric organ and tissue retrieval. A recurring theme was that there are already adequate systems in place to ensure that appropriate standards of practice are upheld. Others, however, favoured penalties in order to be consistent with the rest of the UK.

The majority of respondents who commented (63%) recommended that all or some of the functions of the Human Tissue Authority, proposed for the rest of the UK, should be extended to Scotland.

Most (64%) of those who provided a view called for a change to the previous legislative provision so that rather than repeating brain stem death tests, the doctors removing organs should have to satisfy themselves that the tests had been performed satisfactorily. A common view was that requiring doctors to undertake brain stem death tests and retrieval functions would place them in a position of conflicting interests.

Most of those who commented favoured the new legislation permitting the retrieval of organs and tissues by someone other than a registered medical practitioner, but under the latter's supervision.

Almost all (96%) of those who provided a view supported the proposal that the new legislation should include a provision to put beyond doubt the legality of taking the minimum action necessary to preserve a body so that consultation on transplantation can take place.

Four out of five commentators favoured the proposal for the new legislation to make provision for "required request". The introduction of "required request" was seen by many as likely to increase the rate of donation and encourage NHS positive attitudes towards donation. However, some held the view that a "blanket approach" may not always be appropriate and good medical practice and judgement on a case by case basis should prevail instead.

## Transplantation of organs and tissue from the living

All but one of those who responded were in favour of extending the scrutiny of live transplants to cover cases where the donor and recipient are genetically related.

This was seen as promoting consistency with the rest of the UK and ensuring that donations had been made free from pressure and coercion. A slight majority (58%) of the relatively few who commented considered that extending scrutiny of live transplants in these cases would remove the need for genetic blood testing to prove the relationship.

Most (86%) of the respondents who commented favoured extending the role of the inspectorate for the rest of the UK to Scotland.

The majority of commentators (76%) supported both paired and altruistic live donation in Scotland with a further 9% of respondents favouring paired donation only. Many supported altruistic live donation only under certain conditions, such as following extensive counselling or according to strict criteria, to prevent any misuse of the provision.

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