An Investigation into Conditional Organ Donation

The Report of the Panel
# An Investigation into Conditional Organ Donation

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Annex – List of those from whom information was received
Chapter 1 – Summary

1.1 This is a report of an investigation into an incident which happened in July 1998 following the admission of a man to an intensive care unit in the North of England unconscious, and in a critical condition.

1.2 In such cases the relatives of the individual concerned are asked to agree to organ donation in the event of death. In this instance they did agree, but only on condition that the organs went to white recipients. Attempts to dissuade them from insisting on this were unsuccessful.

1.3 The relatives should have been told at that point that the organs could not be accepted with such conditions attached. It is a fundamental principle that organs and tissues are freely given. Organs (and tissues) are then allocated to patients in the greatest need.

1.4 In this instance, the organs and the condition were accepted and two kidneys and a liver were successfully transplanted into three different individuals. The heart and lungs were judged not suitable for transplantation. The heart valves were retrieved but were later found not to be suitable for use in transplantation. The pancreas and lung tissue were removed for use in research.

1.5 In each case the transplant units receiving the organs were aware of the conditions attached to the donation. In practice this made no difference to the outcome. The Panel have established that the three organs went to the same people who would have received them if no condition had been attached, all of whom happened to be white. So no one was disadvantaged.

1.6 But the incident should not have happened. It was wrong for the organs to have been accepted in the first place, and it is disappointing that no one involved, other than the duty officers at the United Kingdom Transplant Service Support Authority (UKTSSA), sought to object at the time, even though a number expressed unease.

1.7 The Panel’s terms of reference require them to clarify what happened and to make recommendations to ensure that it does not happen again.

1.8 There is very little dispute about the facts, which are set out in detail in the report.

1.9 With a view to ensuring that the incident is never repeated, the Panel make the following recommendations:

i. the former Secretary of State for Health, Frank Dobson, has already made clear that it is not acceptable to attach any conditions to the donation of organs (other than those specifying which organs may
be taken). It follows that organs must not be accepted if the donor or the family wish to attach conditions about the recipient. **The Panel recommend** that that guidance now be formalised by the Department of Health. The guidance should make clear that it applies to all conditions and not just those of a racist kind, and the opportunity should also be taken to set out what the law requires in this area along the lines set out in this report. The Health Departments in Scotland, Wales and Northern Ireland may want to consider issuing similar guidance.

ii. the incident has demonstrated that a number of those involved were insufficiently aware of their obligations under the Race Relations Act 1976. **The Panel recommend** that National Health Service training and induction programmes be reviewed to make sure that they include adequate instruction on this point and that all future development and implementation of NHS training programmes and policies should integrate requirements under the Race Relations Act 1976 from the beginning.

1.10 **The Panel** do not see any need to change the law in this area. Legal advice is clear that organs should not be allocated on the basis of race. If conditions about the race of the recipient have inadvertently been accepted, the NHS could be breaking the law if it did not ignore them.

1.11 **The Panel** have made a number of comments about the role of UKTSSA. They are aware that the UKTSSA has recently been the subject of a review on which Ministers are shortly to take decisions. Ministers are also considering a report by the Royal College of Surgeons of England on organ transplantation. Whatever decisions are taken as a result of considerations of these two reports, **the Panel recommend** that the opportunity should be taken to clarify the UKTSSA’s current role.

1.12 Finally, all those in the transplantation field should be informed, through the induction process, and in other ways, about how to obtain advice on difficult issues, whether in an emergency or not. **The Panel recommend** that the Department of Health should ensure that its arrangements for developing policy and providing urgent advice are clear and widely understood.
Chapter 2 – Introduction and terms of reference

2.1 The terms of reference are:

- To clarify events of the incident in July 1998 and subsequent actions
- To advise whether there have been breaches of the law or of any guidance
- To draw any lessons and to recommend any action required to ensure that such an incident does not happen again.

The Panel

2.2 The investigation was carried out by a Panel under the chairmanship of Chris Kelly, the Department of Health’s Permanent Secretary. The other members of the Panel were:

- Dr June Crown, Past President of the Faculty of Public Health Medicine;
- Professor Stuart G Macpherson, Postgraduate Dean, University of Edinburgh and until recently Transplant Surgeon, Western Infirmary, Glasgow;
- Miss Shushila Patel, Commissioner, Commission for Racial Equality.

2.3 Steve Collins and Sammy Foster provided the Secretariat.

The Panel’s methods

2.4 The Panel interviewed those involved with the incident, as well as the chairs of the United Kingdom Transplant Support Service Authority’s Users Advisory groups, the President of the British Transplant Society, the chair of the UK Transplant Co-ordinators Association and others. The Panel also solicited views from and met with patient group representatives. A full list of those who gave information to the Panel is annexed to the report.

2.5 As background, the Panel consulted a number of individuals involved with transplantation in the United States of America, South Africa, Israel and Northern
The report

2.6 Chapter 3 provides a background to cadaveric transplantation. It describes the scientific and clinical aspects of transplantation as well as the supply of and demand for organs. It then discusses the organisation and process of transplantation, describing especially the kidney allocation process. Finally it describes the groups of people central to the incident, the transplant coordinators, the UKTSSA and its advisory groups.

2.7 In Chapter 4 there is a detailed account of the events of the incident and the discussions that happened afterwards.

2.8 Chapter 5 deals with the legal position.

2.9 Chapter 6 sets out the Panel’s conclusions and recommendations.
Chapter 3 – Cadaveric transplantation and how it is organised

Introduction

3.1 The incident covered in this report concerns a donor certified dead while still on life support (referred to as a cadaveric donor). There are different rules and systems for live donation, which are outside the scope of this report.

3.2 The beginning of this chapter describes the scientific and clinical basis of transplantation. It then explains how transplantation is organised and summarises how organs are acquired, allocated and transplanted. Central to transplantation are the transplant procurement co-ordinators, the key links between the surgical teams, the donors’ families, the recipients and the UK Transplant Support Service Authority (UKTSSA). This chapter describes the co-ordinators’ role, their management arrangements and their professional support. It also describes the role and function of UKTSSA and its users’ advisory groups.

Clinical and scientific aspects of transplantation

Present transplant programmes

3.3 The major transplantation programmes in the UK involve hearts and lungs (the cardiothoracic programme), livers and kidneys. The pancreas transplantation programme is currently much smaller. The transplantation of small bowels is in the early stages of evaluation.

3.4 The transplantation of human tissues (rather than organs) is also widespread, for example with corneas in sight-saving operations, skin for the treatment of burns and ulcers, and heart valves in cardiac surgery. To focus on this incident, the description below is confined to the three major organ transplantation programmes.

Criteria for donors

3.5 Only about 1 per cent of people who die are potential donors.

3.6 Most cadaveric organ donors are patients who are certified dead while on a ventilator in an intensive care unit having suffered an intracranial
catastrophe, due either to a stroke or to head injury. Strict criteria\(^1\) are used to certify death in these circumstances.

3.7 Before a donation can take place, the family will have been consulted to confirm that the deceased did not object to donation and that there are no known medical or lifestyle factors that would put potential recipients at risk. It is important that, in transplanting an organ from donor to recipient, disease is not passed to the person receiving the organ. Donors who are or might be suffering from malignant disease or certain serious infections are not normally accepted.

3.8 In addition it is necessary to assess whether the donor suffered from other diseases that might affect the quality of the organs. For example, a kidney significantly damaged by previous hypertension or diabetes, a liver by excessive intake of alcohol, or a heart with significant atherosclerosis would not be used in a transplant operation.

**Criteria for recipients**

3.9 Patients become potential recipients if:

- transplantation is the best or only treatment for their condition,
- transplantation is likely to give them a good chance of survival with an improved quality of life,
- they are judged likely to be able to comply with the post-transplant regime.

3.10 Patients suffering from chronic renal failure can usually be maintained on haemodialysis or continuous ambulatory peritoneal dialysis (CAPD) while awaiting transplantation. There is no equivalent support for those awaiting cardiothoracic or liver transplantation. A proportion of such patients will therefore die before an organ becomes available.

3.11 Once identified and appropriately counselled, potential recipients are added to a waiting list.

**Criteria for matching donor organs and recipients**

3.12 In all transplants there must be some compatibility between the donor and recipient. Incompatibility may result in immediate rejection of the organ by the recipient.

3.13 The recipient’s immune system may contain pre-formed antibodies that are directed against the donor organ cells. These antibodies do not occur

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\(^1\) A Code of Practice for the Diagnosis of Brain Stem Death March 1998
naturally, but are produced following previous transplantation, blood transfusion or pregnancy. A test involving recipient blood and donor cells will determine whether these antibodies are likely to influence the outcome of the proposed transplant.

3.14 Tissue typing of donor and recipient is particularly important in renal transplantation as it allows clinicians to determine how well the organ is matched to the recipient.

3.15 In the case of liver and cardiothoracic transplantation, the size of an organ is important. Normally there needs to be a degree of compatibility between the size of the donor and recipient.

3.16 Kidneys become more damaged as age increases. This damage is caused by the degeneration of the walls of the blood vessels due to fatty plaques resulting in reduced blood supply to renal tissue. Clinicians do not, therefore, usually transplant a kidney into a child if it has come from an adult more than 20 or 30 years older.

The demand for organs for transplantation

Waiting lists and need

3.17 The extent of the waiting lists for organs is often quoted as a measure of need. However, the size of a list does not reflect the full scale of the situation. If clinicians think that there is no chance of a patient receiving an organ, they are unlikely to put that patient on the waiting list.

Trends in waiting lists and transplantation

3.18 Over the last 5 years, waiting lists have grown and the number of donors has fallen. Table 1 compares the number on the waiting lists and the number of transplants in 1993 and 1998. Table 2 shows the length of time those on the waiting list had been waiting at the end of September 1999.
Table 1 – Waiting lists and number of transplants, 1993 and 1998²

<table>
<thead>
<tr>
<th></th>
<th>Waiting List 31st December</th>
<th>Number of Transplants</th>
</tr>
</thead>
<tbody>
<tr>
<td>Kidney</td>
<td>3,947</td>
<td>5,631</td>
</tr>
<tr>
<td>Liver</td>
<td>111</td>
<td>209</td>
</tr>
<tr>
<td>Cardiothoracic</td>
<td>556</td>
<td>628</td>
</tr>
</tbody>
</table>

Table 2 – Time spent by patients on waiting list as at 29 September 1999

<table>
<thead>
<tr>
<th></th>
<th>Time on Waiting List</th>
<th>Numbers on list</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Up to 1 Year</td>
<td>1 to 5 Years</td>
</tr>
<tr>
<td>Kidneys</td>
<td>37%</td>
<td>49%</td>
</tr>
<tr>
<td>Livers</td>
<td>79%</td>
<td>21%</td>
</tr>
<tr>
<td>Cardiothoracic</td>
<td>53%</td>
<td>40%</td>
</tr>
</tbody>
</table>

3.19 The availability of cadaveric organs for transplantation has fallen in recent years following successful public health programmes in road safety and hypertension. Britain now has one of the lowest road death rates in the OECD. In 1998 there were just over 6 road deaths per 100,000 population, compared with 16 per 100,000 in the USA and 9 per 100,000 in Germany. There was a reduction of over half in the number of deaths from intracerebral haemorrhage between 1976 and 1996.

3.20 Other factors have an impact. About 1 in 4 families object to their relatives’ organs being donated. There are many possible reasons for this, including religious and ethical beliefs. It can be particularly difficult for a family when they do not know the potential donor’s own views.

The organisation and process of transplantation

The system of allocation

3.21 The United Kingdom Transplant Support Service Authority (UKTSSA) maintains the national waiting list of patients awaiting transplantation.

3.22 There are limits on the time that organs for transplants can be safely kept out of the body. It is possible to transplant a kidney successfully after more than 40 hours of such storage, but the shorter the storage time the better the quality of the organ. Liver and cardiothoracic transplants require much

² Transplant Activity Report for 1998 UKTSSA
shorter storage times. For these the geographic proximity of donor and recipient is therefore a relevant factor.

3.23 There is consequently a balance between organs being transplanted locally and being offered nationally. There are well-developed allocation rules that determine which organs go where. Organs that are not accepted through these systems are offered to other European centres, or possibly to the private sector. In practice kidneys rarely get this far.

3.24 Geographic organisation is different for the three main organs.

The system for livers and cardiothoracic organs

3.25 For livers and heart/lungs the UK is split into zones. There are 7 zones for livers and 8 for cardiothoracic transplants. For livers there is a “super-urgent” list of those patients who are in imminent danger of death and an “urgent” category for heart patients (although this did not exist in July 1998).

3.26 “Super-urgent” and “urgent” patients take priority for organs wherever they live in the UK. If there are none of these patients, livers and hearts are offered within the zone where the donor is being maintained, before becoming available to other patients nationally.

The system for allocating kidneys

3.27 In agreement with the transplant community generally, the Kidney Advisory Group of UKTSSA has developed a set of rules to allocate donor kidneys to recipients. These rules determine which recipients’ clinicians receive offers of any particular kidney, and in what order. The current rules were implemented on 1 July 1998 and so were operational at the time of the incident.

3.28 The rules take into account the biological and other factors described earlier, including the donor’s blood group and tissue type.

3.29 A priority-rated list of recipients is created by a points system which takes into account the patient’s tissue type, time on the waiting list, age, and any previous transplants, as well as geographical distance from the donor. Children and highly sensitised patients are given priority.

3.30 UKTSSA’s computer produces the ranked list once the information is entered via a standard form. Ethnic origin is captured for monitoring purposes, but it does not feature in the calculation and it does not appear in the output.
3.31 The process is entirely automatic. The computer prints the list in order of priority and the kidneys are offered to the centres in that order by a duty officer at UKTSSA. The only exception to this is that under certain well-defined circumstances the retrieving centre is allowed to keep one of the kidneys for its own patients. If there is no suitable local match, this kidney is offered nationally through the system described above.

3.32 To understand how this works in practice, it helps to follow the passage of an organ from a donor to a recipient.

The process - how an organ gets from a donor to a recipient

Donation

3.33 The process of organ donation starts once a potential donor is identified. Two doctors, independent of the transplant team and at least one of whom must be a consultant, perform at least two sets of tests to verify brainstem death. At some point in this process there is an initial approach to the family where the subject of donation is raised.

3.34 Once the clinicians responsible for the potential donor have certified death, the local transplant procurement co-ordinator is contacted and determines whether the prospective donor is suitable, and if so which organs are potentially satisfactory for transplantation. The family are then approached and agreement is sought to organ donation.

3.35 At this point some families express a desire to attach conditions to the donation, for example that their child’s organs should go to another child. Usual practice is to explain to them that organs cannot be taken with conditions attached, but are used for those in greatest need. However, it is also explained that organs will normally go to a recipient similar to the donor, (that is, in the case of a child donor, another child) although there can be no absolute guarantee. Families usually understand this and withdraw the conditions.

3.36 Once this agreement has been obtained the transplant procurement co-ordinator notifies UKTSSA and the retrieval teams, and the search for a recipient begins.

Finding recipients – which organs go where

3.37 For livers and hearts that cannot be used locally, the duty officer at UKTSSA determines a recipient on the basis of a rota. Zones are offered
the organ in turn. Once they have accepted an organ, that unit goes to the bottom of the list the next time an organ is available.

3.38 For a kidney, the Kidney Advisory Group’s rules are applied. The duty officer enters the kidney donor’s details into the computer, which then produces a list of the potential recipients in rank order, with their location and their basic details. The duty officer then contacts the recipient coordinators in the order given. A key feature of this process is that the duty officer does not exercise discretion over which organ goes where. The allocation is according to a predetermined set of rules.

3.39 The UKTSSA often receives information about the kidney that is not required for the purposes of the computer ranking. This information could for example include clinical statements such as “There is a tear in the renal artery”, or “There is a cyst on the kidney”, or “The donor was a diabetic.” The UKTSSA duty officer passes all this information on to the recipient teams.

3.40 Duty officers are clerical staff, trained only to perform these clerical functions. Two senior duty officers and a duty office manager support them. The duty office procedure manual says clearly that all such information must be passed on. The reason is to ensure that the duty officer does not take any decision about which facts may be clinically relevant, and which are not.

3.41 When they have received all relevant information, the recipient transplant co-ordinator alerts the transplant surgeon and the local units decide whether they will accept the kidney.

Retrieving and transplanting the organs

3.42 Once the donor is in theatre, the retrieval teams remove the organs in order. The organs are perfused with preservation fluid, cooled and transported to the recipient units. If all is well, the transplant or transplants go ahead.

3.43 When a transplant has taken place, the transplant co-ordinator who procured the organs will tell the donor’s family that they have been transplanted, but will not divulge any details about the recipients. Donor details are similarly not revealed to the recipients.

Follow-up

3.44 The UKTSSA co-ordinates a national audit of activity and outcomes as a basis for improved clinical practice.
Transplant co-ordinators

3.45 Transplant co-ordinators are central to the process of transplantation. There are only about 100 transplant co-ordinators in the UK. The transplant co-ordinator community is therefore a small, highly specialised group of health professionals. These individuals, normally nurses by training, are the key links between the donor unit, the surgical teams, the family, the recipients and UKTSSA. They are the individuals with whom UKTSSA communicates when they match donors to recipients.

Transplant procurement co-ordinators

3.46 It must fall to someone to ask grieving families to agree to their relatives’ organs being removed for transplantation. In the UK, as in many other countries, this is normally the responsibility of a transplant procurement co-ordinator. These staff effectively manage the donation process.

3.47 The procurement co-ordinators are typically the first member of the transplant community to get involved with any particular donation and they have a key role in promoting donation. Their task is also technical. For example, they provide expert advice on donor screening to minimise the risk of infection and on management of the potential donor.

Professional background, organisational structures and training

3.48 Transplant co-ordinators are not organised centrally and have no standard employer – some are employed regionally, some by transplant units. Job descriptions and grading, accountability and support systems also vary greatly. Some co-ordinators combine procurement and recipient duties, whereas others are procurement co-ordinators only and there are differences in workload and on-call rotas. There is no standard obligatory training.

3.49 Where transplant co-ordinators encounter ethical problems, they usually turn to their local transplant teams for advice. However, a number of transplant co-ordinators apparently look to UKTSSA, which is not currently set up to provide such advice. Senior medical staff of the Department of Health are also on call out of hours.

3.50 The UK Transplant Co-ordinators’ Association (UKTCA) has been established by the transplant co-ordinators as their professional body. They have set up a training scheme for transplant co-ordinators with the University of Central England. The UKTCA is a voluntary organisation with a voluntary training course partly funded by pharmaceutical companies.
UKTSSA

Functions

3.51 The UK Transplant Support Service Authority was established in 1991 to carry out a range of support functions for transplantation.

3.52 It supports the transplantation service through standardising practice (in part through providing education and training), maintaining waiting lists for transplantation and providing an information service about transplant activity. It also currently provides a range of specialised laboratory services, such as tissue matching. These functions are detailed in regulations as:

“(a) acquiring, recording, updating, keeping and making available information about donors and recipients and organs which are or may be available for transplantation and other related matters;

(b) identifying persons who are potentially suitable recipients for organs, and notifying transplant centres of the availability or potential availability of organs;

(c) giving advice about, or making arrangements for, the transport of organs for transplantation;

(d) generally facilitating the standardisation of practices in respect of storage, transport and transplantation of organs;

(e) providing an organ matching and tissue-typing service;

(f) supplying standardised reagents and sera to transplant centres and laboratories;

(g) providing education and training for persons involved or to be involved with the transplantation of organs, including identifying the need for such education or training.”

3.53 The four UK Health Departments jointly fund UKTSSA. In 1999/2000 it has a revenue budget of £4.8 million and employs around 100 staff.

3.54 In practice it has six key functions:

• maintaining a waiting list for transplantation

3 Regulation 2, The United Kingdom Transplant Support Service Authority Regulations 1991
• organising the allocation of organs to those on the waiting list and co-ordinating the donation process

• maintaining databases of information about donors and recipients, to allow tracing in the event of infections being transmitted and for audit and research purposes

• managing a central contract for organ and transplant retrieval team transport

• providing central support to laboratory services

• arranging and servicing users' advisory groups for the main transplant programmes.

3.55 The UKTSSA also carries out two additional functions related to transplantation, on an agency basis, for the UK Health Departments: it operates the NHS Organ Donor Register and the scheme which reimburses hospitals for some of the expenses of donor patient management.

Structure

3.56 The UKTSSA is a Special Health Authority with a chairman, a chief executive and a board of directors. Organisationally, it is split into divisions, reflecting its various activities. It also services three organ transplant users’ advisory groups, for kidneys, livers and heart/lung transplantation respectively.

The users' advisory groups

3.57 The three advisory groups are chaired by senior transplant surgeons and include both clinicians and co-ordinators. The Chief Executive of the UKTSSA is also in attendance. The chairmen of the three groups meet together two or three times a year. A number of other UKTSSA staff attend the three main groups as observers.

3.58 Observers from the Department of Health and the Scottish Office receive the agenda and papers for the advisory groups and are invited to attend the meetings to pick up any issues that have policy implications. Officials in all the four UK Health Departments receive the minutes of the advisory groups.

3.59 The main work of the advisory groups is to deal with protocols and procedural matters and advise on support service requirements. The kidney group, for example, took the lead in developing the matching criteria for
allocating donor kidneys to recipients. The groups discuss topics such as the appropriateness of allocation rules, retrieval rates, outcomes from transplantation, and so on. They each meet two or three times a year.
Chapter 4 – A detailed account of events

July 1998 – The donation

4.1 The particular case which is the subject of this report involved a man who was admitted unconscious in a critical condition to a general hospital in the north of England in July 1998. Brainstem death testing was undertaken at 11.45 a.m. and 3 p.m. and death was confirmed.

4.2 The local transplant procurement co-ordinator made preliminary clinical enquiries and passed the facts on to the zonal liver and kidney teams. The transplant co-ordinator then went to the donor unit.

4.3 After the second brainstem test the transplant co-ordinator discussed organ donation with the patient’s family. Unusually the hospital at that time had a procedure (since discontinued) whereby a duty manager was also present during this discussion. The manager was present to sign the form authorising the retrieval of the organs.

4.4 It was agreed with the family that the deceased’s heart, kidneys, lungs, liver and pancreas could be removed for the treatment of others or for research. The family insisted that this was only on condition that all recipients of the organs were white.

4.5 There was some discussion of this stipulation. The outcome was that the family was not persuaded to abandon it. They were clear that it was what the deceased would have wanted and that they themselves supported it.

4.6 An organ removal consent form was signed by the patient’s family and annotated “family consent is conditional upon recipients being white (i.e. not of ethnic origin)”. It was counter-signed by the hospital’s duty manager.

4.7 There was no formal Department of Health or professional guidance explicitly covering what co-ordinators should do in such circumstances at the time.

The liver surgeon’s dilemma

4.8 The procurement co-ordinator told the local liver team that a donated organ might be available and that the donor’s family had imposed conditions on its use. The most urgent case on the liver unit’s list, a white person dying of liver failure, was a suitable recipient.
4.9 The consultant has told the Panel that if he had turned down the organ, the patient would almost certainly have died within 24 hours. He decided to accept the donation.

4.10 Once the liver team carried out their checks and retrieved the liver, they returned with it to their base and transplanted it.

4.11 The Panel have collected information from the centre receiving the liver. This has satisfied them that the patient who received the liver was the same one who would have received it if there had been no conditions attached. The transplant co-ordinator told the Panel that if this had not been the case they would have gone back to the family and explained that the donation was not possible.

The heart and lungs

4.12 In the meantime, the cardiothoracic team had made an assessment of the heart and lungs and decided on medical grounds not to accept them. The pancreas and lungs were removed for use in research.

The kidneys

4.13 The renal team was the last to retrieve, and took the kidneys and heart valves back to their base. (The heart valves were later discarded as unsuitable for transplantation.) The donated kidneys were suitable for transplant, but there was no suitable recipient within the local area.

4.14 At 4 p.m. that day the transplant co-ordinator telephoned UKTSSA’s duty office to inform them that the kidneys were available. UKTSSA records all telephone conversations in the duty office. This has given the Panel a very reliable source of information. The quotations below are from that recording.

4.15 In the course of a largely clinical conversation with Duty Officer A, the transplant co-ordinator said, “these organs cannot go to anyone who is not white” because the family “are adamant that is what they want”. After some further explanation of the reason for the condition, this part of the conversation concluded:

Co-ordinator: “he doesn’t want the organs to go to someone coloured and if that is their choice…”

Duty Officer A: “You’ve got to respect it I suppose.”

4.16 Duty Officer A then went off duty and Duty Officer B took over. Duty Officer A did, however, subsequently telephone Duty Officer B to talk about the situation. Duty Officer B, also worried about it, called the duty
office manager (who already knew about the condition) at home at 7.15 p.m. At this stage therefore, both the duty officers had recognised this incident as being sufficiently serious to require advice from a senior colleague or manager.

4.17 At the end of the discussion with Duty Officer B, the duty office manager said, “I think if [the transplant procurement co-ordinator] completely guaranteed it to [the family] that that was the stipulation, then I think you have to stick by it. Because [the transplant procurement co-ordinator] is now offering you the kidney under those criteria.”

4.18 The duty office manager had been an experienced transplant co-ordinator and recognised this incident as being extremely unusual. But no advice was sought at this point from any more senior colleagues.

4.19 By this time, a potential recipient had been found for the right kidney in the zone where the organs had been procured, according to the procedures (set out in paragraph 3.31) which allow the retrieving centre to keep one of the kidneys. At 10.30 p.m. Duty Officer B verified with the transplant procurement co-ordinator that the organ had definitely been accepted with the condition attached.

4.20 The duty officer should at this point have followed the standard UKTSSA protocols and, using the priority list produced by the computer, offered the remaining left kidney to each unit in turn. If the duty office manager’s instructions had been followed, the duty officer would have passed on the condition attached as relevant information.

4.21 In practice, Duty Officer B worked down the list, with one important exception. The duty officer did not offer the kidney for two children who were at positions 3 and 4 on the list for that kidney and who had Asian-sounding names. They were being looked after by a unit in an area with a large black and ethnic minority population.

4.22 The reasons the duty officer gave the Panel for the breach of the normal rules were:

- even if the unit had accepted the kidney the duty officer would then have had to say that they could not have it because of the condition

- it was racist and embarrassing to make the condition known to a surgeon who the duty officer believed came from an ethnic minority

- the duty officer worried that the surgeon would complain to UKTSSA management, which would lead to the duty officer being held responsible and disciplined.
4.23 The duty officer then offered the kidney to the next names on the list, some of whom also had apparently Asian names, but without passing on the condition. The duty officer explained this inconsistency by saying that they were certain that that centre’s protocol would lead them to refuse the kidney as soon as they heard the donor’s age (they did not know this about the first unit). They therefore saw no reason to pass the condition on. The recording of the conversation shows that that centre did refuse the kidney as soon as they heard the donor’s age.

4.24 The kidney was eventually accepted for an adult recipient, with the condition attached. The duty officer at UKTSSA told the transplant coordinator at the recipient hospital about the condition.

4.25 In the meantime, the original recipient for the right kidney was found to be unsuitable. A new recipient was found following the standard protocol for a second kidney: that is, it was offered to the next names on the waiting list, not to the units which had previously refused the left kidney. This kidney was also accepted with the condition attached. The final recipients for both the kidneys were white and both kidneys were transplanted successfully.

4.26 In the course of the investigation, the Panel asked the centre omitted by the duty officer what they would have done if they had been offered the kidney and in particular if they would have taken it for either of those two children identified by the UKTSSA computer list. The consultant on duty that day has told us that the application of the clinical criteria that the centre uses would have meant that the kidneys would not have been accepted.

4.27 It follows that, although it was against UKTSSA procedures for the kidneys not to have been offered to these children, it made no difference to the outcome. The kidneys were in practice received by exactly the same people who would have received them if normal arrangements had been followed and if no condition had been attached to them.

4.28 Shortly afterwards the duty office manager reported the incident to UKTSSA’s Chief Executive. There is no record of precisely when this happened or what was said.

**September 1998**

4.29 On 7 September 1998 a physician, a surgeon and three transplant coordinators from one of the recipient units wrote to the Chief Executive of UKTSSA. They expressed concern about the condition attached to the kidney they had accepted, and asked for a view. The Chief Executive of UKTSSA replied on 23 September with an undertaking to get advice from UKTSSA’s advisory groups.
March-May 1999

4.30 The question raised was taken to the Kidney Advisory Group on 25 March 1999 and the Liver Advisory Group on 11 May 1999, 8 and 10 months respectively after the incident. There is no record of the issue having been taken to the Cardiothoracic Advisory Group.

4.31 The referral to the Kidney Advisory Group was agenda item 4 of 8, under the heading “Donor considerations” and a reference to one paragraph on the 96th page of a 162 page set of papers. The complete paragraph reads,

“A recent situation has occurred in which a kidney was accepted in good faith by a renal transplant unit, however, the accompanying donor information form contained the statement ‘this organ is not to go to anyone who is not white’. Although the kidney was successfully transplanted, the receiving unit were placed in an invidious position and were uneasy about receiving a kidney with the conditions attached. Members are reminded that no pre-conditions are acceptable when organs are offered for donation.”

4.32 A reference was included in the briefing notes sent to the chairman ahead of the meeting in the following terms, “Members are reminded that pre-conditions are unacceptable when organs are offered.”

4.33 The chairman of the Kidney Advisory Group does not remember the issue being discussed. The minutes of the meeting contain no reference to it.

4.34 The case appeared in the briefing notes for the Liver Advisory Group chairman in the following terms,

“Following a case in which a kidney (sic) was offered with an accompanying statement that ‘this organ is not allowed to go to anyone who is not white’, all Advisory Groups are being reminded that no pre-conditions are acceptable when organs are offered for donation.”

4.35 It was taken to the group as the fourth item in the appendix to the agenda, under the heading “Conditions set at donation”. The three paragraph paper explaining the item was the last of a 94 page set of papers sent to the Group. Members were asked to “advise what, if any, further action should be taken if similar cases arise again in the future”. The group’s response, recorded in the minutes of the meeting, was, “it was unacceptable for such conditions to be set at donation”.

4.36 There is no reference to this incident in any of the papers of the Cardiothoracic Group or at the Advisory Group Chairmen’s meeting nor any record of it being discussed at either of these meetings.
4.37 There is also no record of its being discussed at any Board meeting of UKTSSA, although all but two of the Board members receive copies of the Advisory Group minutes.

4.38 An official from the Department of Health attended the liver group meeting but not the kidney group meeting. A representative of the Scottish Department of Health was present at both these meetings.

May-June 1999

4.39 On 30 May 1999 the UKTSSA’s duty office manager sent a Duty Officer Change of Procedure/Instruction Notice entitled “Conditions Set at Donation” to all UKTSSA duty officers. It said,

“1. You will no doubt recall that some months ago the Duty Office were asked to refer a kidney where the donor family had expressly asked that the kidney could only go to ‘a white recipient’.

2. This naturally caused great concern amongst all involved. Following this all the Advisory Group members have endorsed the fact that this is unacceptable.

3. In the light of this I have sought confirmation from [the Chief Executive] as to the Duty Office role in these circumstances should a similar situation arise again.

4. “[The Chief Executive] has stated that the Duty Office must offer all organs that they are asked to by the transplant community. If that also entails conditions being set then this information must be passed on when offering. If the Duty Office then come in for complaint you must make it clear that any complaints must be addressed to the Transplant Co-ordinator responsible for the donor not the Duty Office. In addition you can suggest to the complainant that they write to [the Chief Executive] or if necessary speak to [the Chief Executive] at the time.

If you have any queries or problems, please let me know as soon as possible so that I may take appropriate action.”

4.40 This was the only formal instruction made in response to the incident.

4.41 It is clear that at least some of the recipient duty officers felt that they were being asked to put themselves in an invidious position and the matter was raised at an unrelated meeting with their branch of UNISON. When members of the duty office showed their Regional Officer the Instruction Notice, he wrote to the Chief Executive of UKTSSA in protest in a letter
dated 24 June 1999. The key point in the Chief Executive’s reply, dated 30 June, was that the UKTSSA was simply the “message handling bureau”. “We are merely passing on an expressed view of a family member.”

**July 1999**

4.42 On 5 July 1999, the Department of Health press office became aware of the incident in the context of enquiries about organ donation from the BBC Newsnight programme.

4.43 At the same time the UKTSSA contacted Department of Health officials and said that the programme might be linked to the incident in question. It had not previously registered in the Department. It had not been picked up either from the advisory group papers nor (surprisingly) by the officials attending the 25 March meeting.

4.44 Newsnight broadcast the story on 6 July and followed it up with another item the next day.

4.45 On the same day as the first broadcast the then Secretary of State, Frank Dobson, issued a press statement. He said that he found conditional donation completely unacceptable and that he had asked his Permanent Secretary to carry out this investigation. On 8 July a second press statement was issued containing a policy statement made by the Secretary of State and the President of the British Transplant Society. This stated that “organs must not be accepted if conditions about the recipient are attached”.
Chapter 5 - Law and guidance

Introduction

5.1 The Panel were asked to consider whether the offer and acceptance of organs with conditions of this type attached was in breach either of the law or of any guidance issued to the NHS.

Guidance

5.2 There was no guidance explicitly addressing this point in 1998, possibly because no one thought it to be necessary. The former Secretary of State and the British Transplant Society have since issued a press notice making clear that conditions of any kind are unacceptable.

The law

5.3 The Panel have taken advice about the general application of the law in this area. The key points of the advice they have received seem to be as follows:-

i. removal and use of parts of bodies for medical purposes are regulated by section 1 of the Human Tissue Act 1961. The Act does not envisage conditional agreement. Either the donor (or their relative) agrees to a part of his or her body being used for donation after death, or they do not;

ii. it is open to a potential donor (or their relative) to decide not to agree to a donation because a racist condition cannot be imposed. Neither the Race Relations Act 1976 nor the European Convention on Human Rights impose a duty on a potential donor to agree to the use of their organs after death, however offensive or irrational the reasons for refusing to do so;

iii. if, despite this, organs are wrongly accepted by the NHS with racist conditions attached, it is almost certainly a breach of the Race Relations Act 1976\(^4\) to comply with such conditions and to do anything other than use the organ for the most suitable recipient, irrespective of race;

iv. anyone who seeks to impose racist conditions on the donation of organs may be acting in breach of the 1976 Act. It is unlawful for

\(^4\) Race Relations Act 1976, section 20(1) and section 31(1)
anyone to induce, or attempt to induce, another person to do anything which contravenes the Act;

v. if an organ has been inadvertently accepted with a racist condition attached, the fact that the condition cannot be put into effect does not invalidate the agreement to donate for the purposes of the 1961 Act. The organ can still be used.

5.4 The Panel also asked whether there would be any legal liability on the part of the NHS if, having refused to accept organs with racist or other conditions attached, particular organs were not then donated with the consequence that someone on the waiting list did not receive an organ as quickly as they would otherwise, or not at all. The advice is that there would be no such liability.
Chapter 6 Conclusions and Recommendations

6.1 This was a very unfortunate incident. It should not have happened. In the Panel’s view to attach any condition to a donation is unacceptable, because it offends against the fundamental principle that organs are donated altruistically and should go to patients in the greatest need. The Panel consider that racist conditions are completely abhorrent, as well as being unacceptable under the Race Relations Act. As far as the Panel have been able to ascertain, such conditions have never been accepted before. None of those who gave information to the Panel was aware of any precedents.

6.2 In the event, the organs went to the patients who would have received them anyway. In practice, therefore, no one was disadvantaged, and at least one life was saved. But it is disturbing that organs were accepted and distributed around the system with racist conditions attached without anyone calling a halt, despite a number of expressions of unease.

6.3 The impression gained by the Panel is that almost everyone involved was concerned about what was happening, but no one stopped it.

6.4 In saying this, the Panel are conscious that one consequence of a decision not to accept organs might be that seriously ill potential recipients might die before other organs become available. This is therefore a hard judgement to make. The Panel are, however, convinced that it is the right one, morally as well as legally. The Panel have been interested to discover that the vast majority of those they have talked to in the course of their investigation, patient groups as well as clinicians, take the same view.

6.5 This is not true of everyone, however. Some very strongly believe that the overriding principle should be the saving of lives. In their view any conditions should be accepted if the consequence is that more organs become available than would otherwise be the case. The Panel do not accept this argument.

6.6 In the Panel’s view, the point at which the incident should have been stopped was right at the beginning. Co-ordinators are in the key position in this respect because they are the people who talk to the relatives of the potential donor and who alert the rest of the system to the availability of organs. In this case, having tried and failed to get the conditions removed, the co-ordinator should have refused to accept the offered organs. The matter should have stopped there.

6.7 It is hard to have to refuse an organ in any circumstances, with consequences which could literally be life or death for someone else.
Transplant co-ordinators need therefore to be supported by clear guidance that this is the right thing to do. This policy was made explicit by Frank Dobson, the former Secretary of State for Health, and the President of the British Transplant Society in the press notice issued on 8 July.

6.8 It is equally hard for recipient surgeons to have to refuse an organ on a point of principle, especially if they believe that the condition would have had no effect in practice. They should not be put in the position of having to make such a decision.

6.9 The Panel recommend that the policy set out in the 8 July press notice should now be formalised by the Department of Health, that the guidance should make clear that it applies to all conditions and not just those of a racist kind, and that the opportunity should also be taken to set out what the law requires in this area along the lines set out in this report. The Health Departments in Scotland, Wales and Northern Ireland may wish to consider issuing similar guidance.

6.10 In the light of the advice that the Panel have received, they see no need to propose a change in the legislation.

6.11 The Panel have two observations about the fact that, having been wrongly accepted, the condition was equally wrongly passed round the system with no-one stopping it:

i. A number of witnesses told the Panel that they had assumed that the UKTSSA would have stopped the process if it were not acceptable. The UKTSSA, on the other hand, took the view that their role was simply to match and track organs, not to pass judgement on issues like this. This view was consistent with the UKTSSA’s interpretation of their functions as set out in the regulations. But the picture is confused by the fact that clinical guidance is also issued in the name of the UKTSSA as a result of the activities of the advisory groups.

ii. The episode reveals inadequate recognition by almost everyone concerned of their obligations under the Race Relations Act 1976.

6.12 This last point seems to be particularly important. Programmes of work are currently being developed to embed race equality into mainstream structures, systems and processes and make it part of everyone’s professional responsibility, at all levels in the NHS from senior managers to clinical staff. The Panel recommend that:

- these programmes should be reviewed to make sure that they include an in depth understanding at all levels of equal
opportunities, racism, racial discrimination, and the
requirements of managing a diverse workforce and providing
effective services to diverse communities

- the requirements of the Race Relations Act 1976 should be
integrated into all NHS training programmes as they are
developed

The UKTSSA

6.13 Of the people who might have stopped the process, the Panel do not think
blame should be attached to the UKTSSA duty officers. They are not
trained to deal with clinical and ethical issues, and they have been
explicitly instructed to pass on all information which comes to them about
a particular organ. The Panel do not condone the failure of one of them to
offer one of the kidneys involved in this case to all those with a claim on it
in the order prescribed by the computer ranking. But they understand the
reasons for doing this, in the absence of what in retrospect should have
been better, clearer guidance from their senior managers.

6.14 The Panel have less sympathy with the senior management of the
UKTSSA. They are puzzled that they did not act more energetically to
address the point of principle raised by the incident after the event or after
being prompted by one of the recipient units. The issue was taken to two
of the three advisory groups, but not until some time after it had happened,
and then not in a very high profile way. The chairs of the groups appear not
to have recognised the gravity of the issue.

6.15 Nor did the UKTSSA explicitly bring the issue to the attention of the
Department of Health until it was raised by the media. The only action
taken after the discussion in the advisory groups was the instruction quoted
in paragraph 4.39 to the effect that, although racist conditions were
unacceptable, if made they had to be passed on.

6.16 The line the UKTSSA adopted on this issue was entirely consistent with
their understanding of their role as described earlier (paragraph 6.11).
They are not responsible for matters of transplantation policy, but they
should have referred it to those who do have this responsibility, the
Departments of Health. They should not have relied on the advisory
papers as a way of doing this. They could also have sought advice from the
Commission for Racial Equality.

6.17 The UKTSSA is currently under review. It is possible that this may result
in some changes of function. Whatever decisions are taken about that, the
Panel recommend that the opportunity should be taken to clear up any
confusion which exists about their current role and to make clear their responsibility to draw attention to important issues.

6.18 The relevant officials at the Department of Health could have noted the issue in March 1999 if they had read the advisory group papers assiduously and it is puzzling that it was not picked up by officials attending advisory meetings. The failure of the UKTSSA to bring the issue to the Department’s attention explicitly is even more puzzling and may imply something about the nature of the relationship between the Authority and the Department which should be addressed.

6.19 Though not directly relevant to this report, the Panel have noted the variability in the way in which transplant co-ordinators are employed, in the precise functions they undertake, and in their line management arrangements. It would go beyond the Panel’s terms of reference to make recommendations in this area. But they see considerable advantage in a more standardised approach which:

i. makes a clear separation between the function of procurement co-ordinator and recipient co-ordinator;

ii. leaves the line management arrangements with NHS trusts, but does not mean that co-ordinators are accountable to surgical teams;

iii. has clear arrangements for training

iv. leaves no-one in any doubt as to where they should go for guidance on policy or legal issues or when new issues raising policy questions arise.

6.20 All those in the transplantation field should understand how to obtain advice on difficult issues, whether in an emergency or not. The Panel recommend that the Department of Health should ensure that its arrangements for developing policy and providing urgent advice are clear and widely understood.
Annex – List of those from whom information was received

Charles Lister, blood transfusion policy, Department of Health, England
Alexia Michaelides, a transplant co-ordinator from South Africa
Felicia Serenato, transplantation official, South African Ministry of Health
Dr Stephen Rose, transplantation official, U.S. National Institutes of Health
British Heart Foundation
British Liver Trust
British Organ Donor Society
Dr Peter Doyle, Senior Medical Officer, NHS Executive
Dr Sheila Adam, Health Services Director, NHS Executive
Kidney Donor Patient Association
Mr Andrew Cash, ex-Chief Executive, Northern General Hospital
Mr John Evans, Chairman, British Organ Donor Society
Mr John Shaw, Chair, UKTSSA
Mr John Wallwork, Chair of UKTSSA Cardiothoracic Advisory Group
Mr Philip Hatton, Chairman, Transplant Support Network
Mr Philip Taylor, Acting Chief Executive, Northern General Hospital
Ms Judy Wilson, Director, Long-term Medical Conditions Alliance
Ms Robina Balderson, Chief Executive, UKTSSA
Ms Veronica Lennon, Chair, UKTCA
Professor Andrew Bradley, Chair, British Transplant Society
Professor Paul McMaster, Chair of UKTSSA Liver Advisory Group
Professor Sir Peter Morris, Chair of UKTSSA Kidney Advisory Group
The Israeli Ministry of Health via the British Embassy in Tel Aviv
The Medical Director of the hospital that was not offered the kidney
The Medical Director of the recipient hospital for the liver
The Northern Ireland Office
The recipient liver surgeon
The recipient transplant co-ordinator for the liver
The Scottish Office
The UKTSSA duty office manager and duty officers
The Welsh Office
UKTSSA officials
Transplant co-ordinators and members of the transplantation teams involved in the incident