

# **AN ORGAN DONATION STRATEGY FOR SCOTLAND**

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**Scottish Transplant Group  
Report**

JUNE 2002

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### INTRODUCTION

1. There have been dramatic advances in the field of transplantation over the last 20 years. In patients with terminal heart, liver or lung failure, transplantation offers the only current option for survival, and renal transplantation is established as the optimum treatment for irreversible kidney failure. Despite this success, transplantation rates are falling because of the inability of the current system to meet the increasing demands placed upon it. The Scottish Transplant Group (STG) has examined some of the problems surrounding the shortage of donor organs. Each of these was the subject of considerable discussion within meetings of the Group. Outside evidence was sought and experts invited to share their views. As a result, the Group recommends a number of actions, some of which have already been progressed by members of the Group themselves. It is hoped that implementation of these recommendations will benefit those waiting for a transplant either to save their lives or to dramatically improve their quality of life.



## BIRTH OF THE SCOTTISH TRANSPLANT GROUP

2. The Acute Services Review was a process which began in January 1997 and reported in June 1998. The Renal Sub-Group of this review had asked a working group to examine the process of organ donation, retrieval and transplantation. Out of this review came the concept of a Managed Clinical Network. Although not set up as a formal network, the teams involved in the care of transplant patients worked very closely with a high degree of co-operation. Examples of this include:
  - Common waiting list for renal transplant patients in Scotland (and Northern Ireland).
  - Development of a network of transplant co-ordinators across Scotland with the appointment of additional staff (as recommended in the renal sub-group report).
  - Regular meetings of renal services and transplant services staff across Scotland.
  - High quality audit data available for liver transplant, renal transplant and heart transplant services.
  - Peer review of renal units in Scotland led by renal physicians in conjunction with the Clinical Standards Board for Scotland.
  - Development of an information booklet for all potential renal transplant recipients and all potential liver transplant recipients, distributed to all newly-listed transplant patients.
3. In order to maintain the momentum of these developments, the Scottish Executive Health Department had indicated that it would find a new Scottish Transplant Group a useful source of advice on a range of difficult issues surrounding organ donation and transplantation, as this was an area in which the Health Minister took a particular interest.
4. The membership of the Group was chosen to cover the full range of interests in organ and tissue donation and transplantation as well as trying to achieve a good geographical spread. In addition there are three patient representatives on the Group, each representing one of the following groups:
  - Patients who require treatment in the form of transplantation.
  - Members of families who have experienced the tragedy of one of their family members having become an organ donor.

- Members of the public who have no declared interest but maintain concern for the issues under debate.

The STG met nine times, including a meeting in Stirling which was open to the public and at which the Group's draft recommendations were discussed. The Group was then able to finalise its report. The list of those in the Group is to be found at Annex 1, along with each member's affiliation. The list of those supplying evidence either in oral or written form is to be found in Annex 2. Specific documentation available to the Group is also listed at Annex 2.

5. The Department has made it clear that it sees a continuing role for the Scottish Transplant Group in providing advice to the Department on all issues relating to organ donation and transplantation. Some of the recommendations in this report are therefore addressed to the Group itself. Membership of the Group will be kept under review, to ensure that it is as representative as possible of the views of patients, both pre- and post-transplant, of the general public and of all health professionals concerned with organ donation and transplantation.

## DEVELOPMENT OF UK TRANSPLANT (UKT)

6. During 1998-1999 the quinquennial review of UKTSSA (as it was then) took place which confirmed the importance of a newly-constituted authority, UK Transplant (UKT), continuing its core functions but recommending additional responsibilities. These include improving arrangements for transplant co-ordinator services and improving organ donation and procurement rates across the UK.
7. At the time of the formation of UKT, the donor rate per million population was 13, compared with 33 per million in Spain. The UK currently has nearly 6,500 people waiting for an organ transplant of whom 4,800 were maintained on renal dialysis.
8. Transplant services are organised across the whole of the United Kingdom with sharing arrangements between different units depending on the specific organ which is to be transplanted. UKT is a special health authority which is central to this process. It maintains the national waiting list, maintains a 24-hour office to organise the retrieval, allocation and transport of organs and it maintains the national transplant database. Its advisory committees decide on the organ allocation arrangements so that each organ goes to the most suitable recipient, maximising the likelihood of success. With effect from 1 May 2002, UKT provides access to the organ donor register for those staff who are involved in identifying potential donors and eliciting their wishes.
9. UKT has been given new terms of reference enshrined in statute to include:
  - Improving organ donation and transplantation rates.
  - Providing a framework for the employment and work of organ donor transplant co-ordinators.
  - Greater involvement in press and public relations arrangements.
10. A business case outlining the arrangements to meet these new responsibilities was approved and funded in full by all Health administrations. This includes proposals for funding a range of organ donation initiatives: increased use of living donation, non-heartbeating donors and maximising the use of cadaveric donors and funding more transplant co-ordinators.

- 11.** At the Secretary of State for Health's summit in February 2001 the following targets were announced:
  - Doubling the number of people on the organ donation register by 2010.
  - Doubling the number of kidney transplants by 2006.
  - Increasing liver and heart transplants by 10% by 2006.
- 12.** In order to oversee these developments, Sue Sutherland was appointed as the new Chief Executive in Autumn 2000 and Chris Rudge was appointed Medical Director in 2001.
- 13.** In Scotland, the Minister for Health and Community Care agreed that the Scottish contribution to the running costs of UKT would be increased in order to meet Scotland's share of these developments.

## STANDARDS

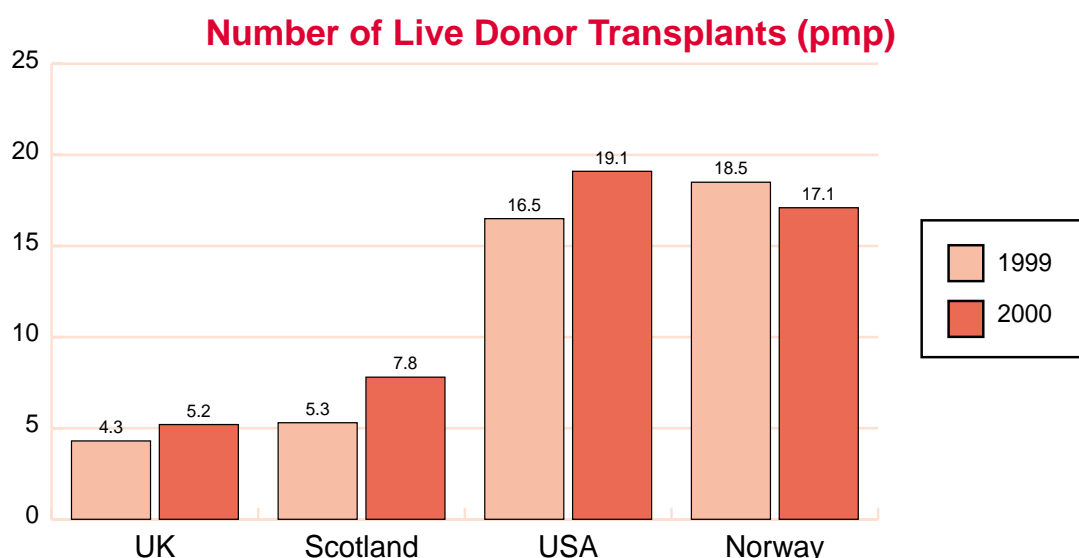
- 14.** The Group is aware of the Scottish Executive's response to the Final Report from the Bristol Royal Infirmary inquiry, and the emphasis it places on patient safety and the quality of services. It is also aware of the report (September 2001) by the Commission for Health Improvement on its investigation into heart and lung transplantation at St George's Healthcare NHS Trust, London.
- 15.** For those transplantation programmes provided on a national basis (heart, liver and combined kidney and pancreas), the standard of service is monitored by National Services Division through its Service Agreements with the units responsible for each programme. NSD has assessed its Service Agreements in the light of the recommendations in both the Bristol and St George's reports. NSD is also involved in the development of standards by the National Specialist Commissioning Advisory Group in England, and will consider with the Clinical Standards Board for Scotland how these standards can be applied to the work of the Scottish Heart Transplant Unit.
- 16.** The Group welcomes the development by the Clinical Standards Board for Scotland of standards for renal services, and has noted that these include standards for renal transplantation, which are mandatory on the renal transplant units in Scotland:

  - Standard 8 - Transplantation 1: Assessment for Transplantation  
Standard Statement: All dialysis patients are assessed for suitability of transplantation within three months of starting dialysis.
  - Standard 9 - Transplantation 2: Kidney Retrieval  
The removal and use of cadaver kidneys for transplantation is carried out to optimise the quality of future renal function.
  - Standard 10 - Transplantation 3: Survival Rates  
Patient and transplant survival rates following kidney transplantation are within acceptable limits.
- 17.** The Group believes that all transplant programmes should be delivered with the highest standards and best possible outcomes as their main aim.



**LIVING DONATION**

- 18.** For renal transplantation rates to be maintained or increased in Scotland, in an era with declining death rates from road traffic accidents and intra-cranial haemorrhage, it is likely that a greater proportion of organs will have to come from living rather than cadaveric donors. The number of living donor renal transplants in Scotland is already increasing and the rate is slightly greater than the UK national rate. However, the donation rate is still very much lower than in the United States or some other European countries.



- 19.** Norway has had a very strong tradition of living donor transplantation, which has arisen because of difficulty for patients accessing dialysis from remote rural areas. In the USA, recognition of the better success rate with living donor renal transplantation, and more recently the potential for living unrelated transplantation, has led to a more rapid increase in the practice. Long-term transplant function is superior in grafts from both living related and unrelated donors compared with cadaveric grafts because of significantly reduced cold ischaemic times with elective implantation, the absence of prejudicial factors associated with brain stem death and rigorous donor evaluation prior to acceptance.
- 20.** Nephrectomy carries a small risk to the donor, but with careful donor assessment and selection, and by confining surgical practice to centres with sufficient specialist experience, the risks can be minimised. In future laparoscopic nephrectomy might reduce donor discomfort and length of recovery and encourage more offers of donation, but the expertise that is

required for this technique is not yet widely available. Recent publication of the United Kingdom Guidelines for Living Donor Kidney Transplantation, which was reviewed and approved by a Scottish Working Party, will assist in promoting good standards of clinical care. This document recommended a target in excess of 10 living donor transplants per million population per year.

### Current Practice

21. In Scotland the perception is that there is scope to increase living donor transplant activity further. Factors that might favourably influence donation rates include positive publicity, first-hand experience of successful donation and, most important, clear information about the process.
22. An informal survey of Scottish Dialysis Units revealed that all patients who are considered suitable for renal transplantation are told about both cadaveric and living transplantation. The way information is imparted varies, but usually a nephrologist introduces the topic and then the patient is referred on to a specialist transplant assessment clinic in either Glasgow or Edinburgh. Here, transplantation of all types is discussed in more detail by a transplant surgeon, sometimes a transplant physician and often also a transplant co-ordinator. Written information is usually given to potential recipients, most commonly in the form of a booklet about all aspects of renal transplantation, compiled by representatives from the transplant centres. In Scotland this is available to every potential recipient on the transplant waiting list. A more specific drug company-sponsored booklet aimed at people contemplating live kidney donation is also widely used. The extent to which relatives and spouses (ie potential live donors) are involved in the counselling process varies and depends to a degree on the local method of delivery. Partners of patients already established on dialysis may be less aware of developments in the area of living unrelated transplantation. **It would be helpful to review the literature available for patients and families relating to live donor transplantation to determine whether there is need to develop information packages for all Scottish potential renal transplant recipients and/or donors.**
23. Although no suitable patients appear to be denied basic details about living transplantation, the timing of approach can differ. In principle, both centres which undertake live donor surgery in Scotland consider pre-emptive transplantation, but discussion is sometimes delayed until after the start of dialysis. Another cause of delay is the time for appropriate investigation and work up of potential donors and occasionally recipients.

24. The absolute number of living donor transplants performed in Scottish centres is small and it is difficult to draw conclusions about geographical variations. There may be differences, particularly in transplantation rates from unrelated living donors, a practice which until recently was very uncommon.
25. More controversial methods of increasing live kidney donation include 'altruistic' donation, when a member of the public expresses a desire to donate a kidney to the pool of potential recipients. In addition, there is the possibility of paired donation, when two potential pairings, hampered by blood group incompatibility, mutually benefit by kidney exchange between pairings ie; donor A (who is incompatible with recipient A) gives to recipient B and donor B gives to recipient A. At present neither of these types of donation would be approved by the Unrelated Live Transplant Regulatory Authority (ULTRA), although ULTRA is currently reviewing its standpoint on these issues.
26. The donor co-ordinators in the Edinburgh and Glasgow units have responsibility for organisation of the living donation programmes. An essential factor in improving the number of live donor kidney transplants is the availability of live donor co-ordinators. The aims of raising awareness, ensuring equity of access, assessment of potential donors, facilitation of transplant procedure and donor follow-up, all provide an increasing challenge to the current system. Recent initiatives by UKT have acknowledged the requirement of dedicated personnel and applications for funding are being received.

### Recommendations

- **Clear information should be given to all potential transplant recipients about live donor transplantation. If possible, relatives and spouses should be involved in the counselling process when patients are approaching renal replacement therapy.**
- **Efforts should be directed towards updating patients and their partners and families about the scope of living donor transplantation. In particular, all patients should receive the information booklet at the earliest opportunity, so as to allow for pre-emptive donation in as many cases as possible.**
- **Pre-emptive live donor transplantation is not currently available to all Scottish patients, and guidelines on this should be drawn up by the transplant co-ordinators and appended to existing guidelines.**

- **A more uniform approach to transplantation counselling should be agreed across Scottish centres and it is essential that transplant personnel are in close contact with staff at non-transplanting renal units so that all are aware of best practice guidelines in a rapidly-evolving field.**
- **Transplant co-ordinators should develop the concept of link nursing further, ensuring an identified nurse in each area of renal medicine can act as a contact for potential pairings.**

## NON-HEARTBEATING DONATION

- 27.** This form of organ donation is the type of procedure which began cadaveric organ donation in the 1960s. Nowadays the vast majority of organs that are donated are in a setting of death having been confirmed by brain stem death testing and the procedure is carried out as a relatively unrushed procedure in an operating theatre. Although the brain of the patient is irrevocably damaged the heart is still beating.
- 28.** Because of the shortage of organ donors in the last number of years, interest has arisen again in non-heartbeating donation. This procedure has been carried out in a number of different situations but the most common is as follows.
- 29.** A patient is brought into an accident and emergency room and is declared dead. A small catheter is introduced into the main artery in the groin and this is used to perfuse the kidneys and keep them cold until such time as a discussion can be carried out with the relatives. If the relatives refuse to agree to organ donation then the procedure goes no further, the small cannula is removed and the groin is sutured. If, however, the relatives agree to organ donation the kidneys are removed by an operative procedure in a surgical theatre. Transplantation is then carried out in the usual fashion.
- 30.** This form of organ donation has been utilised by a number of centres in the United Kingdom but Leicester and Newcastle have led the way in this topic. The main worries regarding such a donation programme can be summarised as follows:

  - 30.1** The public would react badly to organ donation happening in a rushed atmosphere.
  - 30.2** Placing the catheter in the groin of the patient following death might be regarded as an 'assault'. This possibility was dealt with by the two centres in England using discussion with the public and the coroners of their area. Publicity campaigns were carried out in local newspapers and opinions of the public sought. The general view was supportive and therefore the programmes have carried on. It must be stressed that no organs have ever been removed without explicit permission by relatives.

- 30.3** It was suggested that relatives approached at this emotionally traumatic time in a rushed manner were unlikely to agree to donation. It was felt that approaching relatives at this time might somehow 'backfire' on heart beating donation.
- 30.4** Because the organs were not cooled immediately after the heart stopped beating, it was felt that warm damage may occur to these organs and therefore the survival of the transplant would be inferior to transplants removed from heart beating donors.
- 30.5** Because a surgical team has to be available at very short notice to perform this procedure, resources must be identified over and above those normally present on a transplant unit.
- 31.** In fact a number of centres around the world, including Leicester and Newcastle, have demonstrated that the number of kidney transplants can be increased by up to 20% for their unit. Obviously this would have a significant positive effect on the waiting times for kidney transplantation. Counter arguments to those negatives described above are as follows:
- 31.1** Both successful centres have established a programme of education for co-ordinators, accident and emergency staff and all those who may surround non-heartbeating donation. Those who are well informed carry out the programme successfully and the procedure is not seen as 'rushed', in fact it is felt that it has allowed relatives of a recently deceased person to have the opportunity to allow organ donation when otherwise this would not have been able to happen. UKT in particular is encouraging the development of non-heartbeating programmes around those patients who are urgently admitted to hospital, whose initial diagnosis confirms that their condition is grave and they are going to die. These patients are not taken to ICU because they cannot benefit from treatment and they are therefore transferred to a general ward. In these patients there is a longer time to gather relatives together which gives the opportunity to discuss the possibility of organ donation. Such time is not always available in cases where patients are admitted to accident and emergency at or around the time of death.
- 31.2** After a full discussion in Leicester and Newcastle with the local lay public and with coroners, the placement of a catheter following declaration of death was not felt to be an unreasonable procedure if it allowed organ donation. At all times it was stressed that informed consent from relatives had to be obtained before organ donation proceeded.

- 31.3** It is of great interest that the rate of consent in the situation of non-heartbeating donation is above the rate of consent in heartbeating donation. Co-ordinators are unsure why this may be and various suggestions are offered. However it appears to be a true finding.
- 31.4** The survival of organs removed at non-heartbeating donation appears to be as good, if not even slightly better, than organs removed at heartbeating donation. Again the reason for this is slightly uncertain but it is possible that all of the hormonal and immunological changes that occur when a brain stem-dead patient remains on an intensive care unit could affect the organs once they are transplanted. Such findings would not be present in the non-heartbeating donor situation and therefore the graft survival would be improved. A recent article in *The Lancet* suggested that lungs removed at the time of non-heartbeating donation actually had an improved survival compared with heartbeating donation; again this is against what one might predict.
- 31.5** There is no doubt that significant extra resources are required for a programme to run non-heartbeating donation.
- 32.** In Scotland it is felt that the major barrier to considering non-heartbeating donation further is a legal one. Dr Douglas Briggs, recently retired nephrologist in Glasgow, sought a Scotland-wide medico-legal approach at Crown Office level with a view to a national protocol. Initially this approach was gently discouraged, recommending local liaison with procurator fiscal departments. An approach was made to the Central Legal Office and the Crown Office in order to clarify the legal situation in Scotland. This now has even more urgency given that UKT has launched a three-year programme aimed at encouraging units to develop non-heartbeating donation initiatives.
- 33.** Non-heartbeating donors are a useful source of tissue donation (where tissues may be procured up to 24 hours after death). The Scottish National Blood Transfusion Service has plans to expand its activities in tissue procurement via this route in close co-operation with the transplant community which will be mutually beneficial.
- 34.** The transplant co-ordinators' network has agreed that attention be focused on intensive care unit (ICU) deaths and the potential for asystolic donation. A paper from the Netherlands<sup>1</sup> suggests that a successful non-heartbeating programme should commence in the ICU, in a controlled situation. This paper emphasises the importance of education prior to setting up such a programme, so as not to adversely affect the current donor situation. There has as yet been no such discussion in Scotland, but this is very much needed.

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<sup>1</sup> Koostra, G. *How to start a Non-Heartbeating donor programme and what are the pitfalls?* 3rd International Transplant Co-ordinators' Society; Japan 2001.

## **Recommendations**

- **A non-heartbeating programme should be established in Scotland as soon as possible, preferably under the auspices of the UKT initiative.**
- **The Scottish Transplant Group should clarify the legal position with the Crown Office as a matter of urgency, but the planning of such a programme should not be inhibited by the current lack of a ruling on this point.**
- **There should be a specific debate in Scotland about the proposal that a non-heartbeating donation programme might best be initiated in an Intensive Care Unit setting.**

## TRANSPLANT CO-ORDINATION

35. Transplant co-ordinators are at the heart of all the issues discussed in this report, and their contribution is acknowledged in each section. This section focuses on issues which relate directly to the co-ordinators themselves.
36. Following the Acute Services Review, a transplant co-ordination network, the Scottish Transplant Co-ordinators' Network (SCTN), was set up across Scotland with funding channelled through National Services Division. New appointments have been made in Dundee, Aberdeen and Inverness with an extra appointment made in Glasgow. Grading issues have also been addressed. The co-ordinators meet regularly to identify objectives, audit results and plan developments in co-ordination services. They also co-ordinate publicity and education opportunities. SCTN has agreed a standardised donor medical and behavioural questionnaire for organ and tissue donors which has been used to good effect throughout Scotland. A Transplant Co-ordinator representative is elected for a set term for administrative purposes and to sit on appropriate transplant bodies.
37. The Group consists of donor, recipient and tissue co-ordinators working towards national initiatives to increase donation rates and provide standardised recipient care.
38. It is recognised that Scotland is uniquely placed because of geography and population to optimise co-ordination services. Under the auspices of the National Service Division there are now donor co-ordinators throughout the country, national cardiac co-ordinators based in Glasgow, national liver co-ordinators in Edinburgh. Renal recipient co-ordination is undertaken by donor co-ordinators in Dundee, Edinburgh and Glasgow as a dual role.

### Further Development of Transplant Co-ordination Services in Scotland

39. The continued aim of the transplant co-ordinator network is to increase and improve transplantation in Scotland. Members of the STCN are represented on the UKT Transplant Co-ordinator Advisory Group and sub-groups. It is anticipated that issues such as standards of practice and co-ordinator education will be within the UKT framework. In addition, the new managerial structure proposed by UKT, with the appointment of a regional manager for donor transplant co-ordinators, will be implemented in Scotland.

40. The network will continue to meet on a three-monthly basis. These meetings have recently included invited speakers and feedback from international conferences, with the aim to continue developments in transplant co-ordination.

### **Recommendations**

- **The Scottish Transplant Co-ordinators Network should continue to develop and maintain strong links with UKT. The Network must be managed in a cohesive fashion, and the number of co-ordinators should be assessed continuously to ensure that it matches the levels of donation and transplantation activity.**

## SINGLE ORGAN RETRIEVAL TEAM

### Zonal Organ Retrieval

41. Multi-organ procurement by teams working in zones was introduced in November 1993 and has greatly improved the retrieval process. The whole of Scotland counts as a zone for organ retrieval purposes. Since the UK was divided into zones for the purpose of organ retrieval it is rare for any retrieval team from outwith Scotland to be called to a Scottish donor. An audit carried out by UKTSSA in 1996 analysed six years of retrieval data, three before the introduction of zonal retrieval and three after.
42. The audit found that there had been:
  - An increase in the number of organs offered per donor.
  - An increase in the number of organs transplanted per donor.
  - An increase in the proportion of transplanted organs that were retrieved by another centre.
  - A decrease in the number of different retrieval units visiting each donating hospital.
  - A decrease in the distances travelled by retrieval teams.
  - No apparent change in the number of cadaveric donors available.
43. Despite these clear improvements organ retrieval remains unpopular with consultant surgeons and is frequently delegated to trainees. They may have to learn techniques and procedures from fellow trainees or from visiting fellows. In Scotland, consultant surgeons regularly attend the retrieval process (approximately 30% of donor operations), and this is quite unusual in the context of the rest of the United Kingdom.
44. Organ retrieval is a nocturnal activity. Data from over 50 retrievals performed by the Scottish Liver Transplant Unit show that most retrievals begin in the hours between 1900 hours and midnight. Given that the procedure takes at least four and often six hours, this represents a significant undertaking in the donor hospital, with a large number of staff from the Transplant Unit needed to run the retrieval process.

## Organ Retrieval in Scotland

45. The organisation of the organ retrieval process is co-ordinated by the local transplant co-ordinator.
46. The organisation involves the management of the patient on ICU, discussions with relatives, liaison with UKT and arrangement for access to theatre space and the availability of an anaesthetist. Approximately 80% of retrievals lead to multi-organ donation. In those cases the local transplant co-ordinator must ensure simultaneous arrival of the specific retrieval teams from different parts of the country. The liver team travel from Edinburgh and the intrathoracic team travel from Glasgow. The kidney retrieval team is often drawn from the liver retrieval team but may have input from the local kidney transplant unit. This is particularly the case in Glasgow.

## Current Composition of Organ Retrieval Teams

### Heart/Lung Team

Senior thoracic surgeon  
 Junior surgeon (possibly in training)  
 Perfusionist  
 Scrub Nurse

### Liver Team

Senior surgeon  
 Junior assistant surgeon (possibly in training)  
 Senior scrub nurse  
 Perfusionist

### Kidney Team

Surgeon  
 Local transplant co-ordinator

47. From the above it can be seen that a large number of staff are on-call for organ retrieval at the different transplant centres. In addition to these resources the transplant co-ordinator has to call on staff and theatre resources from the donor hospital. These include theatre nurses, anaesthetists, theatre space and disposable equipment. This can take an emergency theatre and senior anaesthetist out of action in the donor hospital for many hours, with significant disruption to the donor hospital.

### Proposal for the Future

- 48.** Having considered these problems the Acute Services Review working group on organ donation, retrieval and transplantation recommended strongly that a single organ retrieval team should be designed for Scotland. The advantages would be a reduction in the total number of staff on-call across the whole of Scotland, which should allow for a reduction in the cost of the retrieval process. It would also allow the team to become highly skilled at their task.

### Proposed Changes

- 49.** Two key staff members of the proposed new retrieval team arrangements were identified. The suggestion is that the existing specialty mix should be enhanced by the addition of an anaesthetist travelling with the retrieval team. This will make the team more self sufficient: if they do not require access to the anaesthetic staff at the donating hospital they would require little more than an empty theatre from the donor hospital. This would not preclude local staff participating and learning from the multi-organ procedure, in fact this should be facilitated by a professional and efficient team.
- 50.** The second important member of staff was felt to be the locally-based transplant co-ordinator who has detailed knowledge of the donor hospital ICU and theatre staff. This ensures that the co-ordinator acts as liaison between the visiting team and the local staff.

### Advantages of Proposal

- 51.** Advantages of the proposed new system are many and include the following:
- Avoidance of duplication of staff members of the retrieval team.
  - Easier organisation of the organ retrieval process.
  - A reduction in the number of staff needed to travel to the donor hospital with most of the staff coming from one unit. Often retrieval procedures are held up because of delay in one team arriving at the donor hospital.
  - Significantly less disruption to the donor hospital.
  - Significantly less disruption to the anaesthetic service in the donor hospital. Such a move would be very popular in donor hospitals and may have the benefit of increasing the total number of organ donors.
  - A possibly shorter retrieval operation with increased skills and co-ordination among team members working together.

- A professional team working together will advance the image of transplantation within a donor hospital.
- There is likely to be an improvement in the quality of donor organs with increasing skill and experience of the retrieval team staff. There is very good evidence that careful management of the donor by a skilled and experienced anaesthetist can allow intrathoracic organ donation which otherwise would not be possible.
- A potential to improve recruitment to transplant surgery (the organisation of retrieval services was cited by surgical trainees as one reason why they would not wish to pursue a career in transplant surgery).

### **Recommendation**

- **The Department, acting through National Services Division, and in collaboration with the Scottish Transplant Group, should establish a single Scottish organ retrieval team as soon as possible.**

## PATTERNS OF REFERRAL

- 52.** As with all services provided by NHSScotland, it is essential that there should be equity of access to transplantation programmes. There also needs to be transparency about the effects of age considerations in relation to transplantation services.

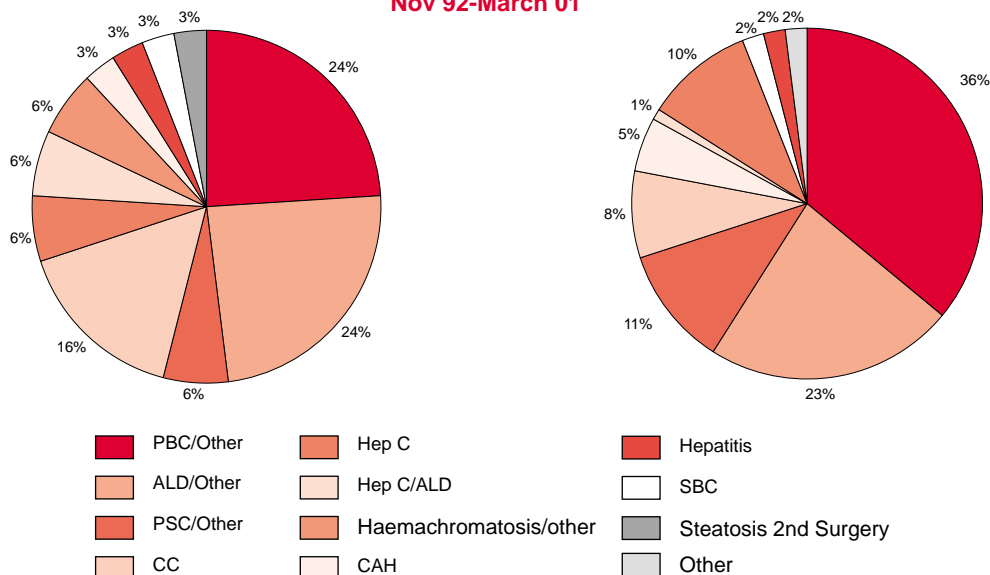
### Liver Transplantation

- 53.** The Scottish Liver Transplantation Unit (SLTU) was opened in November 1992 to provide liver transplantation services to the people of Scotland. Liver transplantation is performed for two major reasons. First, and less commonly, to treat the symptoms of chronic liver disease; for example, a patient with primary biliary cirrhosis who has intractable itch. Secondly, liver transplantation is performed to increase the life span of a patient dying from either acute or chronic liver failure. The indications for liver transplantation in the SLTU are shown in Figure 1. Although Scotland has a reputation for 'hard drinking' and in many people's mind liver disease is synonymous with being an 'alcoholic', for many years the major indication for liver transplantation was the autoimmune disease, primary biliary cirrhosis, which is most prevalent in women. However, analysis of trends over the years has shown increases in the relative frequencies of both alcoholic liver disease and hepatitis C, such that the former is now the most common indication for transplantation (Figure 2). The alcohol-induced liver disease patient group is a highly selected population, and is liable to much pre-SLTU assessment, which may be driven more by prejudices than 'evidence' (Table 1). With potentially 30,000 people infected with hepatitis C in Scotland, 6000 are expected to have liver cirrhosis and 60 hepatitis C liver transplants required per year; there is potential for this particular patient group to completely swamp the requirements for liver transplantation in the future.
- 54.** Since the SLTU opened there has been an increase in the numbers of liver transplants performed. But the numbers have reached a plateau (Figure 3). This is despite a marked increase in the numbers of people either admitted with a main diagnosis of liver disease to Scottish hospitals or patients dying with liver disease in Scotland, since the opening of the SLTU (Table 2). For the purposes of analysis of mortality, if one excludes patients over the age of 70 and those in which alcohol was mentioned on the death certificate, there has been an increase in mortality of 205% in the 'potentially transplantable

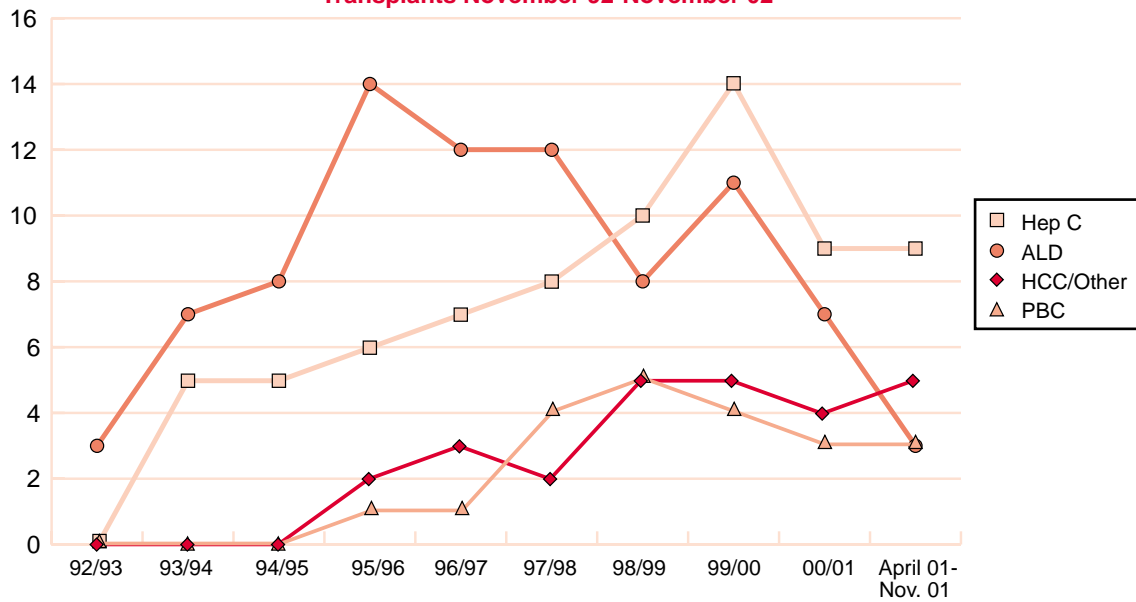
population' between 1992 and 1999. However, the mortality rate for certain liver diseases such as primary biliary cirrhosis is falling in Scotland since the introduction of the SLTU despite apparent increases in the incidence of this disease in other parts of the United Kingdom.

- 55. Referral rates over Scotland are variable for both acute and chronic liver failure. We have considered a 'standardised referral rate' for different aetiologies of chronic liver disease and compared them with the standardised mortality rate (SMR) for chronic liver disease in different health boards (Table 3). These data show that disease 'burden' is still not sufficient to explain the variations in referral rate within Scotland. For example, patients in Lothian are more likely to be referred for liver transplantation than the SMR for chronic liver disease would suggest, compared with patients from certain other NHS Boards, who are less likely to be assessed. These data also show interesting differences between 'standardised referral rates' for alcoholic liver disease compared with primary biliary cirrhosis.
- 56. These data suggest that there is much variation in transplant referral rates throughout Scotland, which are not explained by disease burden alone, and there is great potential for pre-transplant unit assessment of patients.

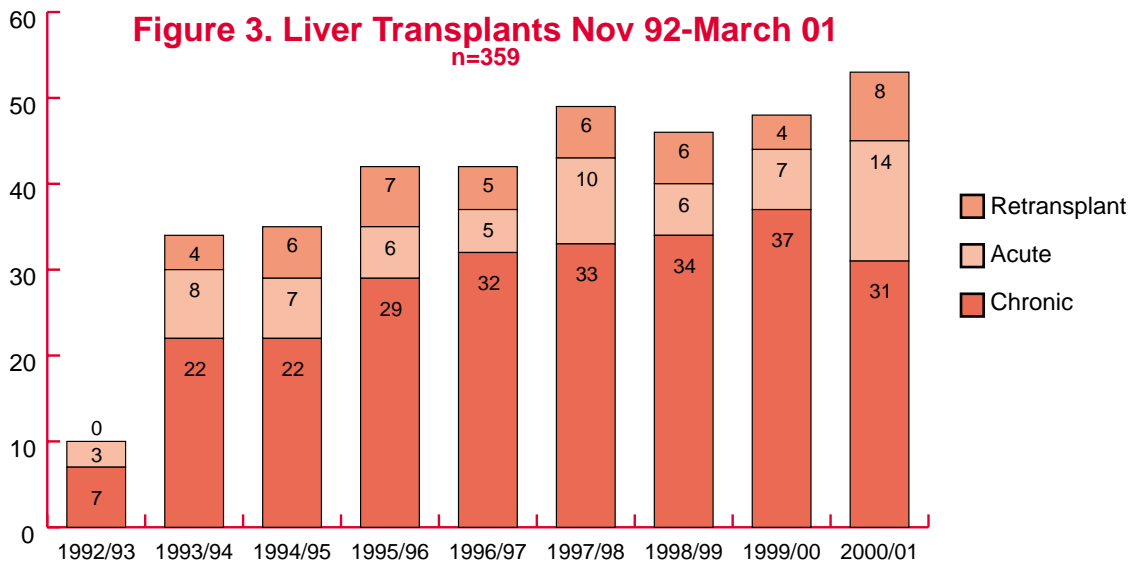
**Figure 1. Scottish Liver Transplant Unit  
Chronic Liver Transplants  
Nov 92-March 01**



**Figure 2. Scottish Liver Transplant Unit**  
Transplants November 92-November 02



**Figure 3. Liver Transplants Nov 92-March 01**  
n=359



**Table 1. Transplanted Patients with Alcoholic Liver Disease****A Selected Population?**

Transplanted	11	(0.05%)#
Assessed	29	(0.13%)#
Deaths	638	(2.8%)#
Admissions with Alcoholic Liver Disease	3429	(15.5%)#
Alcohol 'Contributed' Admissions to Non Psychiatric Hospitals*	22,078	(100%)

Data refer to 1999

\* = 'At risk' population, # = % of 'at risk' population

**Table 2. Mortality from Liver Disease in Scotland 1991-1999**

	1991	1992	1993	1994	1995	1996*	1997	1998	1999
Acute/Subacute Necrosis	14	27	28	23	22	4	5	10	10
Chronic Liver Disease & Cirrhosis	476	446	494	555	607	723	767	806	896
Alcohol Related Liver Disease	254	248	283	337	378	479	527	565	638
Unspecified not Alcohol	222	198	211	218	229	244	240	241	258
Abscesses and Complications of Chronic Liver Disease	56	56	54	44	55	69	73	59	50
Other	10	11	11	14	9	23	18	22	38
Total All Cases <sup>1</sup>	556	540	587	636	693	819	863	897	994

\* since 1996 Alcohol and Unspecified not Alcohol split in classification

<sup>1</sup> Sum all causes of liver deaths

**Table 3. Ranked Standardised Mortality Ratio for Chronic Liver Disease Compared with Standardised Referral Rates**

	SMR CLD <sup>1</sup>	SRR PBC <sup>2</sup>	SSR ALD <sup>3</sup>
1. Greater Glasgow	165	86 (9=)	126(4)
2. Argyll/Clyde	138	129(2)	177(1)
3. Lanarkshire	117	80(11)	65(10)
4. Ayrshire/Arran	111	86(9=)	69(9)
5. Forth Valley	99	117(3)	46(12)
6. Lothian	82	116(4)	130(3)
7. Highland	71	93(7)	149(2)
8. Fife	64	74(12)	104(5)
9. Tayside	62	92(8)	93(6)
10. Grampian	61	96(6)	39(13)
11. Dumfries/Galloway	39	110(5)	88(7)
12. Borders	38	30(13)	48(11)
13. Islands	24	185(1)	73(8)

<sup>1</sup> = standardised mortality ratio for chronic liver disease (disease burden).

<sup>2</sup> = standardised referral (for transplantation) ratio for primary biliary cirrhosis.

<sup>3</sup> = standardised referral ratio (for transplantation) for alcoholic liver disease.

( )= Relative position

### Cardiac Transplantation

**57.** The following material summarises the referral numbers to the Scottish Cardiopulmonary Transplant Unit over two annual periods: September 1999-August 2000 and September 2000-August 2001. These time points have been chosen as they represent the first two years of involvement in the programme of a cardiologist who is responsible for the assessment process.

**58.** Some caution has to be exercised in the interpretation of the data. Most notably, the actual operative programme ceased in March 2000 and only resumed in September 2001. This may have affected the numbers referred (especially from centres geographically close to Newcastle). Since the relaunch, referral numbers appear to be on the increase. Numbers prior to 1999 are also irrelevant as there were many referrals for surgical therapies for heart failure other than transplantation.

- 59.** The referral numbers are given for each NHS Board and as a referral index based on the estimated population size for the total population in that health board area in June 1999.
- 60.** A breakdown into referral practice per clinician has been avoided as this would provide fairly meaningless data. Clearly the referring physician is the major factor in the referral process. Many referrals are obviously entirely appropriate, but some are clearly referring based on isolation and inexperience and others due to a particular interest in heart failure. Some referrals are inappropriate and the transplant unit is left with the responsibility of telling the patient that not much else can be done. This will hopefully be rectified by current drafting of comprehensive guidelines for referring physicians.

### Referrals for Transplantation by NHS Board

NHS Board	1999-2000	1999-2000	2000-2001	2000-2001
	n	% of Total	n	% of Total
Ayrshire and Arran	11	13.1	7	10.1
Argyll and Clyde	10	11.9	8	11.6
Borders	3	3.6	0	0
Dumfries and Galloway	2	2.4	0	0
Fife	4	4.8	3	4.3
Forth Valley	7	8.3	5	7.2
Greater Glasgow	20	23.8	20	29
Grampian	3	3.6	4	5.8
Highland	3	3.6	3	4.4
Lanarkshire	7	8.3	5	7.3
Lothian	8	9.5	9	13.8
Tayside	6	7.1	5	7.3
Shetland	0	0	0	0
Orkney	0	0	0	0
Western Isles	0	0	2	2.9
<b>Total</b>	<b>84</b>	<b>100</b>	<b>69</b>	<b>100</b>

**Referrals for Transplantation per 100,000 of the Population by NHS Board**

Based on the estimated population size per NHS Board at the midpoint of June 1999

<b>NHS Board</b>	<b>Population n</b>	<b>% of Scottish Population</b>	<b>1999-2000 n/100,000</b>	<b>2000-2001 n/100,000</b>
Ayrshire and Arran	374,600	7.3	2.93	1.86
Argyll and Clyde	425,600	8.3	2.34	1.87
Borders	106,400	2.1	2.81	0
Dumfries and Galloway	146,800	2.9	1.36	0
Fife	349,200	6.8	1.14	0.85
Forth Valley	277,600	5.4	2.52	1.80
Greater Glasgow	906,000	17.7	2.20	2.20
Grampian	525,300	10.2	0.57	0.76
Highland	208,600	4.1	1.43	1.43
Lanarkshire	562,400	11	1.24	0.88
Lothian	778,500	15.2	1.02	1.15
Tayside	388,300	7.6	1.54	1.28
Shetland	22,740	0.5	0	0
Orkney	19,600	0.4	0	0
Western Isles	27,560	0.4	0	7.25
<b>Total</b>	<b>5,119,200</b>	<b>100</b>		

## **Recommendations**

- **Local patterns of referral for transplantation, drawing on data provided by UKT, should be made widely available to NHS Boards, so that they are aware of any equity of access issues revealed by the data.**
- **Clinicians' awareness of transplantation should be raised, through education where appropriate, and by the dissemination by the STCN of information, particularly about new developments in transplantation.**
- **In view of the findings in the report of the Chief Medical Officer's Expert Group on the Healthcare of Older People, patients must be assessed for transplantation on biological, not chronological age.**
- **Each NHS Trust in Scotland should have a policy on organ and tissue donation. The staff of the Trust should be aware of that policy, and understand it.**

**INTENSIVE CARE UNITS IN SCOTLAND**

- 61.** The Group obtained data from the Scottish Intensive Care Society (SICS) for January 1999/December 2000. It was pointed out that this audit did not include the Institute of Neurological Sciences (Southern General Hospital, Glasgow), Hairmyres, Falkirk or Raigmore.

No. of deaths confirmed by brain stem testing	288
No. of relatives approached	170
No. of resulting donations	109

- 62.** There was no information from this audit as to why organ donation was not requested. There was no extra information as to why relatives refused in any particular situation.
- 63.** The Group was aware of concerns about the reduction in the number of referrals to the Institute of Neurological Sciences in the Southern General Hospital in Glasgow over the last three years and decided to investigate. Evidence was therefore heard from Dr Mike Soutar, the then Clinical Director of the INS and Mr Laurence Dunn, a Consultant Neurosurgeon in the Institute.
- 64.** It was estimated that patients with head injuries represented 50% of potential organ donors in the INS. The Scottish Trauma Audit Group (STAG) data, which captured all those with head injuries who would be potential donors, showed very little change in the number of patients transferred to the Institute. Mortality across the rest of Scotland was static at 24%, but had declined from 26% to 19% at the INS. The reasons for this were not clear, as there had been no change in the management of these patients. Mortality amongst patients transferred to the Institute was down from 20% to 15%.
- 65.** Data collected in-house told a similar story. The total number of patients admitted to the Institute with head injuries was static at around 500-600 per year, with the number of deaths around 40-50. The percentage of patients who died having had a brain stem death test performed was less than 10%. 50%-60% of patients who met the brain stem death criteria went on to organ donation. There had been a sharp drop in the number of patients who met the brain stem death criteria, with only 11 last year. The reasons for this were not clear but the percentage of donors had stayed the same.

- 66.** The number of admissions to ICU in the Southern had fallen from just under 1,000 in 1994 to just over 700 last year, a reduction of 25%. There had been a reduction in mortality from 77 deaths from all causes in 1994 to 51 in the year 2000. The main categories of death were the same. The most significant change had been the number of brain stem death tests applied to patients. There had been 11 in 2000, and three out of those 11 had gone on to become donors, whereas in 1994 there had been 17 donors.
- 67.** Both representatives stressed that the Institute took very seriously its responsibility for approaching families about the possibility of organ donation. The reduction in the number of brain stem death tests, in Dr Souter's view, related to the decrease in the number of ICU beds, which was linked to a steep reduction in nursing staff over the previous two or three years. The number of intensive care beds had therefore dropped from 8 to 6, whereas the British Society of Neurologists' guidelines suggested that there should be 11 beds to cover the catchment population. This, in turn, had led to changes of practice. There was greater pressure on beds, and patients who were felt to have a hopeless outlook were moved from the ICU to general wards. As ventilation was not instituted or was discontinued when patients could not benefit they died without brain stem death testing being performed, since the criteria for brain stem death testing cannot be applied in patients breathing on their own.
- 68.** There was an impression that patients who were being given scans in DGHs were not now being transferred to the Institute if the prognosis was dismal, but the Group was told this impression was inaccurate. Patients with abnormal CT scans were usually transferred to the Institute. The essential problem was the gradual loss of senior skilled nursing staff. Beds were available, but not the nurses to staff them. The nearest transplant co-ordinators were in the Western Infirmary. The Institute had identified link nurses, so did not feel isolated from the co-ordinators, and would involve them as soon as anything approaching consent had been obtained.
- 69.** Dr Souter provided further written evidence to the Group as follows:  
 'Our unit, as previously stated, has 8 beds (with one isolation cubicle), but runs on an average of 6 beds open due to nursing staff shortages.  
 We at present are funded for 33.48 whole time equivalent (wte) positions.

Grade	G	F	E	D(S/N)	D(E/N)
Number	5.0	2.0	18.48	5.0	3.0

Based on our 12-hour shift system (the most economical in terms of manpower), we should operate on 6.5 wte per bed opened, which equals 52 wte.

This presents us with a deficit of 18.52 wte.

If we were to employ nurses at E Grade to fill these positions, this would cost in excess of £470,000. This estimate is derived from a midpoint salary scale estimation with 13% employer costs and allowing for weekend and night duty shifts, and was produced by our senior Nurse Manager.

Employing staff at a more junior level ie D Grade is unhelpful in terms of available levels of experience and expertise within the unit and has implications for the retention of skilled trained nurses, who will move when career progression is limited.

The full capacity estimate presents a considerable regular expense - unfunded by the Government's present Critical Care initiative as this does not encompass such specialist regional services as ourselves. The end result is an inability to support desired staffing levels, with limitation of open beds, and the exercise of triage in determining the most suitable candidates for ICU care. We are limited to 6 beds in a population which has been estimated to require 11 critical care beds, by the Society of British Neurosurgeons.

It is not surprising then that the ability to support patients with a hopeless prognosis, whilst awaiting development of brain stem death, is extremely limited. This has resulted in a shift of the locale of dying patients, from the ICU to the general wards, and a concomitant decrease in transplant numbers from our institution.'

- 70.** The Scottish Intensive Care Society is now expanding its audit of organ donation to take on an extended data set. This should allow a more detailed examination of the patterns of organ retrieval and the factors leading to refusal. While this audit data and that of transplant co-ordinators would suggest that many units are already maximising organ retrieval, there is a surprising variation between ICUs in the proportion of brain stem death cases which result in successful donation. This comprehensive data set from all general ICUs in Scotland will also be extended to include the Neurosurgical Intensive Care Units and, hopefully, centres of Cardiothoracic Surgery. The appointment of Donor Liaison Sisters under the auspices of UKT will facilitate the collection of this data. Further fields will be added to the audit to address the following questions:-

- Was brain stem death suspected or treatment not pursued as a result of a clinical diagnosis of irrecoverable brain injury?
- Were brain stem death tests carried out? Yes/No? Outcome?
- Was organ donation requested? If not, why?
- Who made the request e.g. ICU staff, transplant doctors, transplant co-ordinator, others?
- If organ donation was not requested, why e.g. sepsis, malignancy, staffing?
- When was the first approach made? Before or after death was confirmed?
- At what stage was the transplant co-ordinator involved?
- Assessment of patient's wishes - by relatives or donor card?
- Were organs donated? Yes/No. If no, reasons?
- Were donated organs used? If not, why?

**71.** The Group has considered the specific question of whether potential donors are denied the opportunity to donate because it has been argued there are insufficient ICU beds in Scotland. The evidence is unclear, and the Group finds it difficult to quantify the difference which an increase in ICU bed numbers would make.

### **Recommendations**

- **All ICU staff should be made aware of the importance of making every reasonable effort to maximise donation rates from appropriate patients. Donor Liaison Nurses should be actively involved in the Scottish Intensive Care Society national audit.**
- **All Intensive Care Units in Scotland should contribute to the Scottish Intensive Care Society audit.**

## MORTALITY AUDIT

- 72.** The UKT Potential Donor Audit will cover the whole of the UK. The Scottish Intensive Care Society database did not identify patients who did not get into ICU either because of a lack of beds or because of a definite decision not to admit. Since that category of patients could have become non-heartbeating donors, it would not be possible to use current data to answer questions about the adequacy of ICU resources. There was also the issue of the funding of the Scottish Intensive Care Society Audit which at present derived from the Clinical Resource and Audit Group (CRAG). It is hoped the funding of this audit will be taken over by NHS Boards, as happened with the Scottish Renal Registry Audit.
- 73.** The Group agreed, after discussion, that mortality audits in the context of transplantation could be of two basic forms. The first was an in-depth analysis of deaths which occurred in an intensive care setting. The whole process of admission, approach to relatives for consent, cause of death and any data following death was likely to be recorded in considerable detail. The second audit was less detailed but with a breadth which covered many departments of the hospital, including Accident and Emergency, stroke units, medical wards and high dependency units. Such an audit would identify not only patients in whom death was confirmed by brain stem death testing, but also those who died in other circumstances.
- 74.** An example of the latter type of audit was presented by Mr Engeset, one of the members of the Group. He presented an audit which had been carried out in Grampian University Hospitals Trust. A summary of the data from this audit is included in this Report not as a definitive audit of this type, but rather as an example of such an audit.
- 75.** The organ donor rate in the north-east of Scotland has dropped from more than 20 in 1995 to seven in the year 2000. The study in Grampian University Hospitals Trust examined deaths in Aberdeen Royal Infirmary between 1 January 1998 and 31 December 2000 to determine whether there was any change in the number of potential donors. The hospital notes of all patients who died in the study period were examined.

- 76.** The study excluded patients who died in the Maternity and Children Hospitals, subjects who were dead on arrival to the A&E Department and those who died in the A&E Department without referral to a speciality. Included in the study were all patients less than 70 years who died with normal renal and hepatic function on admission and whose diagnosis on admission was head injury, subarachnoid haemorrhage and intra-cranial haemorrhage (potential donors). Some of this group were treated by ventilation and went on to become organ donors. Patients with evidence of malignancy, previous hepatitis, HIV, sepsis and multi-organ dysfunction syndromes were excluded.

**Figure 4**

	1998	1999	2000
Total number of deaths	1054	1300	1337
Number of potential donors (%)	16 (1.5)	27 (2.0)	26 (1.9)
Number of actual donors identified From review (UKTSS figure*)	7 (14)	11 (15)	4 (7)

\* In parenthesis are the number of donors as notified to UKTSSA

Figure 4 shows the total number of deaths in the three years and the number of potential donors for each year in the study group. The number of donors in Grampian for the three years as reported to UKTSSA is shown and it is clear that this form of retrospective study underestimates the number of potential donors. This study suggests that although the number of organ donors is falling steadily the number of potential donors in the hospital population is maintained or even increased in Grampian. Accurate assessment of the true numbers of potential donors would require data on cause and time of death relative to hospital admission.

**Figure 5**

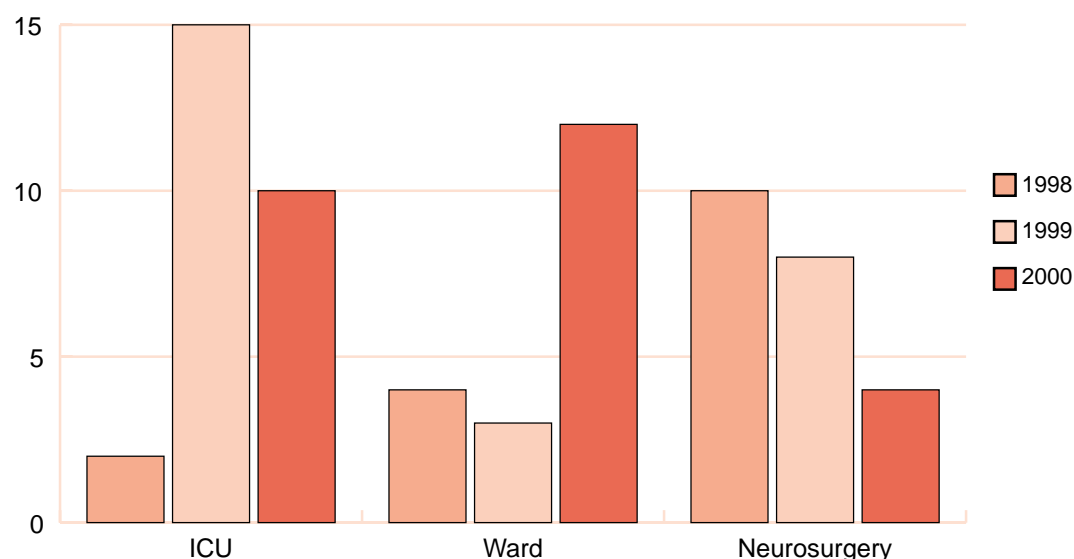


Figure 5 shows the hospital wards in which these patients died in the three years of the study. It is clear that in 1998 most of the potential donors died in the neurosurgical high dependency unit. The trend in 1999 was for these deaths to occur in an ICU and in 2000 on the general medical wards. This change coincided with a policy change that ventilation treatment was only allowed in ICUs.

77. Audits such as this are difficult to carry out because of the work intensity needed to carry out an exhaustive review of medical notes. However, such an audit does indicate that there is potential for an increased number of organ donors either if potential donors were ventilated and proceeded to brain stem death testing or if non-heartbeating donation were possible in these patients.

### Recommendations

- **CRAG should ensure that NHS Boards take over the funding of the Scottish Intensive Care Society audit so that it is put on a secure footing.**
- **The UKT mortality audit should be used to determine whether the number of ICU beds in Scotland is sufficient to allow all potential organ donation, and whether there are other opportunities for donation which are currently being missed. It should be used in particular to illustrate the value of non-heartbeating donor programmes in retrieving organs which would otherwise have been lost.**



## PUBLICITY

- 78.** Each set of transplant co-ordinators across Scotland has tended to work independently to promote education and publicity for all types of transplantation. As indicated in the section on transplant co-ordination there will be increased co-operation through the development of the Scottish Transplant Co-ordinators' Network (STCN).

### Opportunities for Publicity for Organ Donation

- 79.** Evidence was presented to the Group by those responsible within the Scottish Executive Health Department for the organ donation publicity budget, which has been at a constant level for several years, standing at £79,000 per annum. The main call on this budget is usually the purchase of leaflets, booklets and posters promoting organ donation, which are bought from the Department of Health. Other initiatives have taken place in recent years. In 1997 £40,000 was spent on a newspaper advertising campaign. In 1999 a part of the budget was used to sponsor a poster in a Scottish football magazine which associated information about organ donation with large pull-out posters of SPL teams.
- 80.** The Group heard that a TV 'filler' on organ donation had recently been produced. The Minister for Health and Community Care has now approved the use of the filler and it is hoped that screenings of it will start shortly.
- 81.** It has been agreed that there should be future co-operation between the network of transplant co-ordinators and those representing the publicity budget related to organ donation. Regular meetings will be arranged in order to co-ordinate activities across Scotland.
- 82.** The Group is aware that there is strong support at Ministerial level in Scotland for finding effective ways of publicising the benefits of organ donation, and that this has recently led to the amalgamation within the Scottish Executive Health Department of responsibility for the publicity budget along with responsibility for organ donation and transplantation issues generally. The Group welcomes this move.

83. The STCN facilitates an organ donation national symposium on a two-yearly basis. This has proved successful, both by numbers attending and evaluation. It is anticipated this will continue, with rotation of venue. All intensive care units and theatres now have link nurses, who attend both local and national study days.
84. Following a recent billboard and cinema campaign in conjunction with the National Kidney Research Fund (NKRF), the two groups are looking at future initiatives which could form part of the publicity effort across Scotland as a whole.
85. To improve accessibility of information, the STCN are producing a leaflet outlining the history, aims and contact details of the network. In addition, the Network is currently looking at developing a website.
86. The link between publicity such as an emotive appeal on behalf of an individual needing a life-saving transplantation and subsequent increases in organ donation rates is not understood. Such appeals undoubtedly have the ability to increase organ donation rates in a temporary fashion. Further research on this issue would be worthwhile.

### **Recommendation**

- **The Scottish Executive Health Department should work with all interests, including UKT and the transplant co-ordinators, to develop a major national publicity campaign to increase public awareness of the issues surrounding organ donation and transplantation. The campaign should be based on rigorous research in order to determine the most effective approach, target audience and messages. The start of the campaign should follow on as closely as possible after the publication of this Report, and should be capable of generating associated initiatives at local level. This publicity work must be on-going.**

**EDUCATION – TEACHING RESOURCE  
PACK**

- 87.** The Group was struck by the value of a teaching pack dealing with key concepts in transplantation and imparting information about case studies. Such packs could also touch on potential future developments as well as the ethical dilemmas which are often faced by the teams caring for patients who require transplantation. The packs could include video material and a pupil activity component. There might be a separate pack setting the religious context for Higher Still religious and moral studies, and there might also be a scientific component. The pack could be geared to different years across secondary school, especially for children of 16 and over who could be involved in decision-making about organ donation.
- 88.** To produce this pack and make sure it was as effective as possible, it would be necessary to involve those such as guidance co-ordinators who were responsible for curriculum development as well as teachers and transplant co-ordinators. The Group understands that this sort of pack would be very welcome by teachers in this field, since suitable subjects with this potential breadth of discussion are difficult to identify.
- 89.** Apart from its intrinsic value as a teaching resource, the development of this proposal has the potential to bring about, albeit over time, a fundamental shift in public attitudes towards organ donation. At present, one in three of the relatives who are faced with the choice of whether or not to allow retrieval of organs for transplantation refuses to consent. The Scottish Transplant Group is convinced that this number could be reduced, and the number of organs for transplantation increased, if the public were more aware of the general issues relating to organ donation and transplantation, and did not have to think about them for the first time while in the throes of imminent bereavement. Many adults find this a difficult subject to discuss, but children of school age seem to have less difficulty in doing so. Introducing the subject in schools would mean that young people could discuss with their peers or their parents topics such as the benefits of organ donation. The profile of the issue, as well as the speed of possible benefit, would certainly be enhanced if this were to happen on any significant scale.
- 90.** UKT has offered to help with the costs of producing the resource pack, provided it can be developed in a format which would allow it to be used in other parts of the UK.

91. The Minister for Health and Community Care announced on 22 January 2002 that both he and the Minister for Education and Young People had accepted this recommendation. The Group welcomes this announcement.
92. The work which has already been undertaken on the Teaching Resource Pack suggests that it would be helpful if it consists of written material for both teachers and pupils as well as a video. A working group is exploring these possibilities. From the attempts which have been made to gather suitable material, it would seem that such a resource does not exist anywhere at the moment, and the pack may therefore be the first of its kind.

### **Recommendations**

- **The Teaching Resource Pack should be developed as a matter of urgency, drawing on educational materials already prepared by, for example, transplant co-ordinators. Arrangements should also be made for the effectiveness of the pack to be evaluated.**

## ISSUES OF CONSENT

- 93.** Oral and written evidence was available to the Group from Ms Gill Haddow, a final year postgraduate student at Edinburgh University, researching issues around the question of consent to organ donation. A copy of Ms Haddow's slides is included as Annex 6. The findings of the study underline many of the issues surrounding the sensitivity of the consent process.
- The importance of a sensitive and informed approach by a health professional, preferably a transplant co-ordinator.
  - The need to encourage people to make their wishes known to family members.
  - The fact that relatives would have accepted organ donor cards being given the force of law (and indeed the families who refused indicated that they would have accepted a donor card overruling such a refusal).
  - The fact that donation decisions were related to socio-economic and education levels.
  - If the family felt donation was not a good thing then positive messages from health professionals were regarded as self-serving.
- 94.** The Group felt that this evidence confirmed the need to define the process of obtaining consent, both in terms of who should perform this difficult task as well as the manner in which this should be carried out.

### Potential Change to the Legal Process Surrounding Organ Donation

- 95.** Much publicity has centred on the process of consent needed to remove organs for transplantation after death. Some countries such as the UK have an 'opt-in' system where individuals are asked while they are alive to place their names on a register if they wish to be a donor. The opposite system is called 'opt-out' or 'presumed consent', whereby following confirmation of death in an individual, it is assumed that organ donation will take place unless that person had registered an objection during their life. 'Hard opt-out' is a system where the family views are not taken into account. Practice of this form of opt-out is very rare across the world. Most countries prefer a soft opt-out system which allows the relatives to veto the retrieval of organs.

- 96.** In the UK, the removal of organs for transplantation after death is governed by the Human Tissue Act 1961 (covering England, Scotland and Wales) and the Human Tissue Act (Northern Ireland) 1962. In practice this Act requires that there is ‘no reason to believe that the deceased had expressed an objection to his body being so dealt with after his death and had not withdrawn it, or that the surviving spouse or any surviving relative of the deceased objects to the body being so dealt with’.
- 97.** However, by common practice this lack of objection has come to mean informed consent which must be obtained at a time of tragedy. Many supporters of an ‘opt-out’ system feel that this would make it easier for relatives to cope by relieving them of a difficult decision at such a time.

### **Evidence for Improved Donor Rates in an ‘Opt-out’ System**

- 98.** Comparison of the rate of donation between countries has shown a general tendency towards higher rates in those countries with a presumed consent system. However, the evidence is not strong. Supporters of presumed consent often quote the organ donor rates at two centres in Belgium (Antwerp and Leuven) at the time when Antwerp retained an ‘opt-in’ system while Leuven adopted a new law. Leuven rates rose while those in Antwerp remained the same. However, cause and effect relationship between the new law and the organ donor rates was never proven.
- 99.** The most successful country in Europe as regards organ donation rates is Spain. Professor Rafael Matesanz, who masterminded the ‘Spanish Model’ states:
- ‘the idea that some proposed changes in legislation could resolve the scarcity of available organs is a recurrent topic of numerous meetings. Presumed consent seems to be effective only in specific countries such as Austria where there is an old tradition, well accepted by the society, that disposal of the body is the responsibility of state or Belgium, where a significant but transient increase in organ donation was obtained after the introduction of a presumed consent law’.
- 100.** The Group received evidence from Dr Richard Simpson, MSP, concerning potential changes to the law in Scotland. Dr Simpson explained that he had been asked to report to the Health and Community Care Committee of the Scottish Parliament on the whole issue of organ donation. Through discussions with patients, the public and medical professionals, Dr Simpson concluded that to introduce legislation embodying a hard ‘opt-out’ bill would be culturally unacceptable at present. As the current donor register

was not properly consulted or used, he was proposing to replace it with two new registers, one for opting in and one for opting out. He felt such a move was in line with the Adults with Incapacity (Scotland) Act 2000 and respect for the wishes of the individual. In both cases the relatives would be consulted in case the deceased had indicated a change to their wishes. In the absence of any donor registration families would be consulted, as now, to find out if the deceased had expressed a wish with regard to organ donation. It was hoped that these arrangements would help promote a more positive attitude towards organ donation in Scotland. It was felt that it might be easier if families did not have to make a positive decision in favour of donation at such a difficult time and it was hoped the changes could lead to a 10% improvement in the rate of relative agreement.

- 101.** This was only one element of the changes needed. Dr Simpson went on to describe changes that he felt were needed concerning the link nurse system which could be expanded to learn from the experience learned in Spain. Dr Simpson felt that these changes were required in acute Trusts in order to provide support to families early in the process of seeking consent for organ donation. This would ensure that the approach was performed in a professional and sensitive manner. Dr Simpson stressed that he felt any change in the legislation would simply unlock the gate rather than provide a quick solution to all problems.

### Human Tissue Act 1961

- 102.** During the time that the Scottish Transplant Group were meeting and considering its report, there was much publicity surrounding the events at Alder Hey Hospital and significant public concern regarding consent for retention of organs. Many members of the Group were involved in publicity to stress the differences between the good practice involved in transplantation (where no organ is removed without consent) and the events in a number of hospitals across the United Kingdom (where organ retention following post mortem had been carried out without relatives' knowledge).
- 103.** The serious shortcomings and inadequacies of the 1961 Act are set out in detail in the final report of the Review Group on the Retention of Organs at Post-Mortem (November 2001). The Introduction to the report contains the following passage:
19. 'We know that many parents have been distressed at the thought that the publicity, sometimes sensational and inaccurate, which the issue of organ retention has attracted, may have had an adverse effect on the number of organs becoming available for transplantation. We

too have been concerned at the apparent confusion between the issues of organ retention at post-mortem examination and organ donation for transplantation purposes. We have therefore been encouraged to discover from UKT that the adverse publicity appears, so far, to have had no damaging effect on organ donor numbers. In framing our recommendations for amendments to the existing legislation, we have been very mindful of the fact that the 1961 Act also forms the legal basis for the donation of organs for transplantation. We would be extremely concerned were the implementation of any of our recommendations to impact adversely on organ transplantation programmes, in particular the work of transplant co-ordinators who approach relatives about the possibility of donation taking place. Some of the issues we touch on, particularly the weight to be given to the wishes of the deceased, as opposed to their surviving relatives, are central to the process of seeking agreement to organ donation. Organ donation is outwith our remit, but we suggest that the Scottish Executive, in implementing any changes to existing legislation as a result of this report, will need to think very carefully about whether it should also be looking at the legislative basis for organ donation, and suggest this is something the Scottish Transplant Group could be asked to investigate. Any revision of the 1961 Act must take this into account and ensure that a clear structure also exists in respect of organ transplantation, either by way of a clarified combined Act or by way of a stand-alone statute dealing with transplantation...'

- 104.** Section 1(1) of the Human Tissue Act 1961 provides that if the deceased expressed a request in recognised form that his body, or any specified part of it, should be used after his death for therapeutic purposes, the person lawfully in possession of the body (generally understood as being the hospital administrator) can authorise the removal from the body of any part, or such part as was specified by the deceased. The hospital needs to have evidence of the deceased's wishes, and these have to be either in writing, which can be done at any time, or orally in the presence of at least two witnesses during the deceased's last illness. The power given to the person lawfully in possession of the body is discretionary, and the decision whether to exercise the power, and the factors to be taken into account in reaching that decision, rests with the person lawfully in possession of the body.

- 105.** In practice, however, hospitals have developed a system which has concentrated on establishing whether there is an absence of objection on the part of relatives. In strict legal terms, this is not in accordance with the provisions of section 1(1) of the 1961 Act. It could well be argued that the signing of an organ donor card, or the registration of one's name on the UK Organ Donor Register, meet the requirements of section 1(1) of the 1961 Act and that the wishes of the deceased should not be thwarted by any surviving relatives. The attitude of the relatives would, however, probably be one of the factors which the person lawfully in charge of the body would want to take into account before authorising the retrieval of organs for transplantation.
- 106.** The Final Report of the Review Group takes a robust line on this point and recommends (paragraph 42) that 'the expressed wishes of the individual adult, competently made before death, should take priority over the wishes of surviving relatives. The current legal requirement to discover whether or not this agreement has been withdrawn should remain but it must be clear that the relatives have no legal role in circumstances where the deceased has made known, and not retracted, his or her wishes.' The report goes on to say 'We recognise this might seem harsh, but we regard an important concomitant of this recommendation to be a campaign directed at those who may wish to make such a declaration to encourage them to discuss their wishes freely and fully with those who will ultimately be asked about the deceased's intentions... In this way, we would trust that any potential distress to surviving relatives would be obviated, or at least minimised'.
- 107.** Section 1(2) of the 1961 Act provides that the person lawfully in possession of the body may authorise the removal of any part for therapeutic purposes if, after making such reasonable enquiries as may be practicable, he has no reason to believe (a) that the deceased expressed an objection to his body being so dealt with after death, or (b) that the surviving spouse or any surviving relative of the deceased objects to the body being so dealt with. It is this situation which the current arrangements, under which transplant co-ordinators approach the relatives, are really designed to address. In strict legal terms, this subsection of the 1961 Act should only be invoked where the deceased left no formal indication of his or her wishes.
- 108.** Section 1(4) of the 1961 Act states that removal of all tissues/organs (with the exception of eyes or parts thereof) must be performed by medical practitioners. In the context of tissue donations (which can be removed up to 24 hours after death) this requirement poses significant practical problems. The target donor population is often different from multi-organ donors and there is currently no infrastructure for medical removal of tissues.

**109.** The Human Tissue Act 1961 is not reserved to Westminster, so in theory the Scottish Parliament could amend or repeal it unilaterally. The Group is aware, however, of Ministerial concern to maintain broad consistency across the UK on matters relating to organ retention and organ donation. It is also aware that the Department of Health in London is undertaking a general review of issues relating to the removal, retention and use of human organs and tissue.

### **Elective Ventilation**

**110.** Elective ventilation is the use of artificial ventilation in a selected group of deeply comatose patients close to death in order to preserve the patient's organs for transplantation after the patient's death. It is a principle of common law that patients have the right to give or withhold consent to treatment, but such consent extends only to treatment intended to benefit the patient. If the patient is unconscious, treatment may be given in the absence of consent, but only to the extent necessary to save the patient's life, and provided it is not against the patient's known wishes. To do otherwise could be judged as an assault on the patient. The accepted practice is that only once the patient has been declared brain stem dead should they be ventilated while discussion can take place with the relatives about the possibility of organ donation.

**111.** The Group is aware that the Scottish Intensive Care Society feels this is not the time to introduce elective ventilation since the care of the patient should have absolute priority. The protocol developed in Exeter, where elective ventilation was briefly undertaken, was based on a study of nine patients, in 40% of whom there had been a breach of the protocol.

**112.** The Group believes that, under present circumstances, elective ventilation is not feasible. Greater efforts should be directed towards the process of non-heartbeating donation in order to examine whether successful programmes could be set up within Scotland.

## **Recommendations**

- **The process of approaching relatives at the time of potential organ donation, both in terms of who should perform this task as well as the manner in which it should be carried out, should be clarified and defined.**
- **A protocol should be developed, for use in each Trust, by the Scottish Transplant Group, Intensive Care staff and transplant co-ordinators. The protocol should make clear that while discussion of organ donation intentions should be possible at any time with any member of staff, formal approaches must include the transplant co-ordinator, who should be involved at the earliest opportunity.**
- **So as to strengthen the system of opting-in, the emphasis in discussions with relatives must be on determining what wishes, if any, the deceased might have expressed. Until the law can be changed, ‘relatives’ should be understood as meaning those closest to the potential donor in life.**
- **The carrying of an organ donor card and/or registering on the NHS Organ Donor Register should be regarded as an advance directive, that is the wishes of the deceased should be fulfilled wherever possible.**
- **The forthcoming review of the legislation should include consideration of the power of advance directives in relation to elective ventilation. The potential of the Adults with Incapacity (Scotland) Act 2000, in particular the power to appoint welfare attorneys, should be explored in this context.**
- **Consideration should be given to establishing the best way of tissue-only retrievals. This may include the establishment of specifically trained retrieval teams.**
- **The Group endorses the recommendation of the Review Group on the Retention of Organs at Post-Mortem that the Human Tissue 1961 should be replaced by separate legislation governing organ retention and organ donation/transplantation.**



## RECOMMENDATIONS

- 1** Clear information should be given to all potential transplant recipients about live donor transplantation. If possible, relatives and spouses should be involved in the counselling process when patients are approaching renal replacement therapy.
- 2** Efforts should be directed towards updating patients and their partners and families about the scope for living donor transplantation. In particular, all patients should receive the information booklet at the earliest opportunity, so as to allow for pre-emptive donation in as many cases as possible.
- 3** Pre-emptive live donor transplantation is not currently available to all Scottish patients, and guidelines on this should be drawn up by the transplant co-ordinators and appended to existing guidelines.
- 4** A more uniform approach to transplantation counselling should be agreed across Scottish centres and it is essential that transplant personnel are in close contact with staff at non-transplanting renal units so that all are aware of best practice guidelines in a rapidly evolving field.
- 5** Transplant co-ordinators should develop the concept of link nursing further, ensuring an identified nurse in each area of renal medicine can act as a contact for potential pairings.
- 6** A non-heartbeating programme should be established in Scotland as soon as possible, preferably under the auspices of the UKT initiative.
- 7** The Scottish Transplant Group should clarify the legal position on non-heartbeating donation with the Crown Office as a matter of urgency, but the planning of such a programme should not be inhibited by the current lack of a ruling on this point.
- 8** There should be a specific debate in Scotland about the proposal that a non-heartbeating donation programme might best be initiated in an Intensive Care Unit setting.
- 9** The Scottish Transplant Co-ordinators Network should continue to develop and maintain strong links with UKT. The Network must be managed in a cohesive fashion, and the number of co-ordinators should be assessed continuously to ensure that it matches the levels of donation and transplantation activity.

- 10** The Department, acting through National Services Division, and in collaboration with the Scottish Transplant Group, should establish a single Scottish organ retrieval team as soon as possible.
- 11** Local patterns of referral for transplantation, drawing on data provided by UKT, should be made widely available to NHS Boards, so that they are aware of any equity of access issues revealed by the data.
- 12** Clinicians' awareness of transplantation should be raised, through education where appropriate, and by the dissemination by the STCN of information, particularly about new developments in transplantation.
- 13** In view of the findings in the report of the Chief Medical Officer's Expert Group on the Healthcare of Older People, patients must be assessed for transplantation on biological, not chronological, age.
- 14** Each NHS Trust in Scotland should have a policy on organ and tissue donation. The staff of the Trust should be aware of that policy, and understand it.
- 15** All ICU staff should be made aware of the importance of making every reasonable effort to maximise donation rates from appropriate patients. Donor Liaison Nurses should be actively involved in the Scottish Intensive Care Society audit.
- 16** All Intensive Care Units in Scotland should contribute to the Scottish Intensive Care Society audit.
- 17** CRAG should ensure that NHS Boards take over the funding of the Scottish Intensive Care Society audit so that it is put on a secure footing.
- 18** The UKT mortality audit should be used to determine whether the number of ICU beds in Scotland is sufficient to allow all potential organ donation, and whether there are other opportunities for donation which are currently being missed. It should be used in particular to illustrate the value of non-heartbeating donor programmes in retrieving organs which would otherwise have been lost.
- 19** The Scottish Executive Health Department should work with all interests, including UKT and the transplant co-ordinators, to develop a major national publicity campaign to increase public awareness of the issues surrounding organ donation and transplantation. The campaign should be based on rigorous research in order to determine the most effective approach, target audience and messages. The start of the campaign should follow on as closely as possible after the publication of this Report, and should be capable of generating associated initiatives at local level. This publicity work must be on-going.

- 20** The Teaching Resource Pack should be developed as a matter of urgency, drawing on educational materials already prepared by, for example, transplant co-ordinators. Arrangements should also be made for the effectiveness of the pack to be evaluated.
- 21** The process of approaching relatives at the time of potential organ donation, both in terms of who should perform the task as well as the manner in which it should be carried out, should be clarified and defined.
- 22** A protocol should be developed, for use in each Trust, by the Scottish Transplant Group, Intensive Care staff and transplant co-ordinators. The protocol should make clear that while discussion of organ donation intentions should be possible at any time with any member of staff, formal approaches must include the transplant co-ordinator, who should be involved at the earliest opportunity.
- 23** So as to strengthen the system of opting-in, the emphasis in discussions with relatives must be on determining what wishes, if any, the deceased might have expressed. Until the law can be changed, 'relatives' should be understood as meaning those closest to the potential donor in life.
- 24** The carrying of an organ donor card and/or registering on the NHS Organ Donor Register should be regarded as an advance directive, that is the wishes of the deceased should be fulfilled where ever possible.
- 25** The forthcoming review of the legislation should include consideration of the power of advance directives in relation to elective ventilation. The potential of the Adults with Incapacity (Scotland) Act 2000, in particular the power to appoint welfare attorneys, should be explored in this context.
- 26** Consideration should be given to establishing the best way of tissue only retrieval. This may include the establishment of specifically trained retrieval teams.
- 27** The Group endorses the recommendation of the Review Group on the Retention of Organs at Post-Mortem that the Human Tissue Act 1961 should be replaced by separate legislation governing organ retention and organ donation/transplantation.



**ANNEX 1**

**Membership of the Scottish Transplant Group**

**Chairman**

Mr John Forsythe, Consultant Transplant Surgeon, Royal Infirmary of Edinburgh

**Members**

Mr Ian Anthony, Transplant Patient

Dr Adam Bryson, Medical Director, National Services Division

Dr Mike Cornbleet, Senior Medical Officer, Scottish Executive Health Department

Dr James Dougall, Consultant Anaesthetist, Western Infirmary, Glasgow

Mr Jetmund Engeset, Consultant Surgeon, Aberdeen Royal Infirmary

Dr George Galea, Director of Tissue Services, Scottish National Blood Transfusion Service

Ms Jen Lumsdaine, Lead Transplant Co-Ordinator

Dr Theresa McDonagh, Consultant Cardiologist, Glasgow Royal Infirmary

Dr Ellon McGregor, Consultant Nephrologist, Ninewells Hospital

Mr Andrew Murday, Consultant Transplant Surgeon, Glasgow Royal Infirmary

Mrs Rosa Murray, Donor Families Representative

Mr Hishan Osman, Transplant Surgeon, Western Infirmary, Glasgow

Mr Chris Rudge, Medical Director, United Kingdom Transplant

Mr Will Scott, Scottish Executive Health Department

Dr Ken Simpson, Consultant Hepatologist, Royal Infirmary of Edinburgh

Mrs Sue Sutherland, Chief Executive, United Kingdom Transplant

Ms Irene Walker, Local Health Councils

**Secretariat**

Ms Jan McIntosh, Scottish Executive Health Department

Mr David Cowan, Scottish Executive Health Department



**ANNEX 2**

**Specific Documentation Available to the Group**

**Those supplying evidence to the Group**

Mr Laurence Dunn, Consultant Neurosurgeon, Institute of Neurological Sciences, Glasgow

Ms Gill Haddow, Post Graduate student, University of Edinburgh

Mr Nigel Lindsay, Scottish Executive Health Department

Mr Jon Roper, Scottish Executive Media and Communications Group

Dr Richard Simpson, MSP

Dr Mike Souter, Clinical Director, Institute of Neurological Sciences

**Specific documentation available to the Group**

- BMA Report on *Organ Donation in the 21st Century*
- Department of Health News Release on the Alder Hey Report
- Report of the Renal Sub-Group of the Acute Services Review and the report of its working group on renal transplantation
- UKT Business Plan
- Final Report of the Review Group on the Retention of Organs at Post-Mortem



**ANNEX 3**

**UKT DATA**

**1.** Current (13.1.02) solid organ waiting list at Scottish centres

<i>Organ</i>	<i>Active</i>	<i>susp.</i>	<i>total</i>
Kidney	442	114	556
Pancreas	-	1	1
K/p	7	-	7
Heart	7	2	9
Liver	18	-	18

**2.** Cadaveric solid organs retrieved for transplantation from hospitals in Scotland

	<i>1992</i>	<i>1993</i>	<i>1994</i>	<i>1995</i>	<i>1996</i>	<i>1997</i>	<i>1998</i>	<i>1999</i>	<i>2000</i>	<i>2001</i>
Kidney	200	161	164	162	132	126	126	142	118	125
Pancreas	0	0	0	0	1	3	4	3	10	18
Heart	48	28	38	33	28	20	33	42	12	12
Lung	31	24	28	14	15	10	23	35	18	23
Liver	69	47	61	60	48	50	52	67	54	60
<b>Total</b>	<b>348</b>	<b>260</b>	<b>291</b>	<b>269</b>	<b>224</b>	<b>209</b>	<b>238</b>	<b>289</b>	<b>212</b>	<b>238</b>

**3.** Cadaveric solid organs retrieved for transplantation from hospitals in the UK

	<i>1992</i>	<i>1993</i>	<i>1994</i>	<i>1995</i>	<i>1996</i>	<i>1997</i>	<i>1998</i>	<i>1999</i>	<i>2000</i>	<i>2001</i>
Kidney	1696	1651	1666	1691	1602	1576	1462	1409	1454	1472
Pancreas	91	104	93	106	112	99	115	87	113	172
Heart	358	335	380	345	326	288	287	251	211	204
Lung	242	221	291	284	296	272	280	272	235	256
Liver	505	543	627	663	645	658	653	651	664	665
<b>Total</b>	<b>2892</b>	<b>2854</b>	<b>3057</b>	<b>3089</b>	<b>2981</b>	<b>2893</b>	<b>2797</b>	<b>2670</b>	<b>2677</b>	<b>2769</b>



**ANNEX 4**

**Location of Retrieval Operations undertaken by Scottish Liver Transplant Unit (1 April 2000 - 31 March 2001)**

**SCOTLAND**

Lothian	Western General	11	+(1)
	RIE	3	
	St John's	2	
	RHSC	1	
Borders	BGH	1	+(1)
Fife	Queen Margaret	1	
	Victoria Infirmary	1	
Tayside	Ninewells	4	
Greater Glasgow	Southern General	2	
	Western Infirmary	2	+(1)
	Glasgow Royal	1	
	Stobhill	1	
Argyll & Clyde	Royal Alexandria	1	
Ayrshire & Arran	Ayr Hospital	1	
Lanarkshire	Crosshouse	1	
	Hairmyres	1	
	Law	0	+(1)
Dumfries & Galloway	Dumfries Royal	1	
Grampian	Aberdeen Royal	7	
Highlands	Raigmore	2	
Forth	Falkirk	1	
	Stirling	1	
<b>SOUTHERN IRELAND</b>		<b>3</b>	
<b>NORTHERN IRELAND</b>		<b>3</b>	
<b>ENGLAND</b>		<b>2</b>	

( ) indicates retrievals where donor liver was not retrieved



**ANNEX 5**

**Kidney Donation and Retrieval Rates  
1 January - 31 December 2000, by Centre**

Retrieval Centre	Total solid organ donors (pmp)		Kidneys retrieved (pmp)		Kidneys used (%)	
Newcastle	75	25.5	138	46.9	119	86
Leeds	40	10.6	65	17.3	60	92
Leicester	28	13.1	54	25.2	41	76
Nottingham	21	15.1	38	27.3	37	97
Sheffield	21	11.2	40	21.3	39	98
Cambridge	21	8.8	41	17.2	41	100
N Thames	63	8.8	123	17.1	117	95
S Thames	107	15.9	202	30.0	188	93
Portsmouth	31	13.5	61	26.6	61	100
Oxford	43	14.4	82	27.4	78	95
Bristol	13	6.6	24	12.2	22	92
Plymouth	26	14.6	52	29.2	49	94
Birmingham	39	8.6	70	15.5	69	99
Coventry	20	25.0	40	50.0	39	98
Liverpool	48	14.5	85	25.8	81	95
Manchester	73	18.0	125	30.9	120	96
Cardiff	25	11.0	46	20.3	45	98
Glasgow	25	9.2	50	18.4	48	96
Aberdeen	10	12.8	16	20.5	14	88
Edinburgh	27	16.9	52	32.5	51	98
Belfast	21	12.7	39	23.5	39	100
Dublin	68	18.2	128	34.2	127	99
<b>TOTAL</b>	<b>845</b>	<b>13.4</b>	<b>1571</b>	<b>25.0</b>	<b>1485</b>	<b>95</b>



ANNEX 6

**Presentation on Issues of Consent**

**Donor Relatives' Accounts of Organ Donation**

As part of my doctorate research I have been examining the experiences, attitudes and belief systems of donor and non-donor relatives. The presentation is in two parts. The first part covers the obstacles and issues to donation and the second some of the reasons why donation occurred.

**OBSTACLES TO DONATION**

**SLIDE Initial Concerns**

Because the donor suffered from some form of head trauma they were usually transferred from the local hospital to the closest neurological centres for specialist care. Two respondents said they were concerned about why their relative was transferred:

**SLIDE** *'Well, to be perfectly honest about it eh, there was a wee nagging doubt in my mind that she only went through for her body parts. That's the only thing I find a wee bit alarming. Well it's what she wanted anyway.'* [Donor, husband, 172-174].

Here there is a suspicion about whether transference to the hospital is choice of treatment or whether it was undertaken in order to utilise the body for prospective donation.

**SLIDE** Once transferred the potential donor is usually attached to the ventilator. Previous studies have suggested maintenance on a ventilator in intensive care cause some relatives concern. Three parents did had varying levels of difficulties:

**SLIDE** *'When it's something you can't see. It's much worse. Cos he's lying there, breathing, everything's fine. Not a mark on his body. And you just think that this can't happen.'* [Donor, mother 223-226].

**SLIDE** However the majority of donor respondents (n=16) suggested the ventilator and the person's apparent breathing caused them little or no distress.

## **SLIDE Respondents' Understanding of Brain Stem Death and Tests**

Whilst the donor is maintained on the ventilator a series of clinical tests are carried out to ascertain whether brain stem death has occurred.

**SLIDE** Most respondents, claimed to be unaware of the procedures involved (n=14).

**SLIDE** Four said they had some understanding although one thought injecting icy water in the ear *'a bit unusual, it's not awfully scientific, drip a wee drop water in your ear. A bit medieval.'* [Donor, husband: 235].

**SLIDE** The majority of respondents said brain stem death was mentioned to them by health professionals (n=16).

**SLIDE** However, due to the stressful nature of events, clear and lucid communication about the donor and their condition was stated as crucial in relatives' interactions with health professionals.

For instance, although initially having some difficulty with the concept of the brain stem tests one husband came to understand the seriousness of his wife's condition:

**SLIDE** *'They were showing me sketches and we're doing this and that. The best way that one of the doctors said to me was like you've got a jigsaw and one piece of the jigsaw is missing and you take it away and all the rest of the pieces are trying to, it doesn't work. It's like that with the brain; it's a very, very difficult thing to explain.'* [449-450].

## **SLIDE Communicating a Diagnosis of Brain Stem Death**

**SLIDE** Donor relatives said that they was a requirement for the language to be understandable to the lay person, free from medical jargon and based in concepts familiar to the respondent (ie a jigsaw).

Although the respondents claimed they had the term brain stem death mentioned to them some felt they needed more time to comprehend it.

**SLIDE** One relative put it as *'I was all mixed up you see and my head was spinning round.'* [Donor, husband 219-220].

Other studies have found that brain stem death can pose obstacles to donation. In this research due to the provision of time and lucid and clear communication the majority of respondents suggested they did understand the diagnosis.

**SLIDE** In fact the confirmation of brain stem death reaffirmed the health professionals' prognosis and also the next-of-kin's.

**SLIDE** This is evidenced by fourteen of the nineteen respondents stating their relative died *prior* to the brain stem tests. For instance, one husband said his wife did not die on Tuesday after the results *‘To me Monday, that’s when she died, if she hadn’t been on a ventilator she would have died.’* [326].

### **SLIDE Concerns about Death**

Essentially the tests were then viewed as a formality, confirming the relatives’ belief death had occurred.

However, although the majority of the relatives suggested their next-of-kin had died prior to the brain stem **SLIDE** death tests, not being with their relative at death or immediately after, was reported as difficult for some (n=4).

**SLIDE** *‘Do you know the worst thing about saying “yes” to a transplant? The worst thing happens, you know how when you’re in the hospital and someone is on life support and they die and the machine and all the lines go flat. When you say yes to a transplant they take your dying person away. You’re not there when he dies. You leave the room with him alive. There’s no end.’* [Donor, mother 270-278].

**SLIDE** A few respondents were also concerned about whether the donor might feel pain during organ removal:

**SLIDE** *‘They just said that they would give him a sedative when they removed his kidneys [crying] and I said that “if he’s dead why are they giving him a sedative?” and they said “we’re not sure that they don’t experience some pain and it’s just to safeguard that he wouldn’t feel anything” And I said “he can’t be dead if he feels pain”.’* [Donor, wife 440-450].

It would appear that although brain stem death was said to be understood, cardiac cessation as the moment of death appears to persist.

### **SLIDE Disposal and Mutilation**

Just as there were concerns about death, there were also concerns about the organ donation procedures.

**SLIDE** Two-thirds of donor respondents reported concerns about the organ removal procedures and four initially refused because of such concerns. One husband initially refused to donate his wife’s organs and will refuse to donate his own in the future liken it to a BUTCHER’S SHOP:

**SLIDE** *‘Let’s have half a pound of heart, three-quarters of a pound of liver. Eh I’m afraid that’s in me / I’m just trying to be as honest as I can and that’s the way I feel about it. I could change my mind but I can’t see me changing my mind in the next*

*couple of years or so. Until I'm maybe certain that it's what I want and / I would hope that my next-of-kin whoever it would be at that time would eh, respect my wishes in it as I did for my wife's.'* [Donor, husband: 717-723].

It became apparent for some donor families there was tension between donating the organs and the procedures involved in organ removal. In part this seems to stem from a belief that the procedures involved in organ transplantation are disrespectful to the body. I would argue this is because the dead body continues to represent the person and is imbued with an emotional and cultural significance.

Insofar as the dead body is attached with emotional and cultural significance as an embodiment of the person, so too were its parts.

**SLIDE** In this sample, the eyes were the main organs restricted:

*'But eh, I did not want them to take his eyes. I had visions of seeing him afterwards with hollows.'* [Donor, mother 533-534].

The visual element of being able to see a person's eyes was thought important. Further in everyday interactions the eyes play a significant role in communication and other reasons for not donating the eyes **SLIDE** was that they were the 'windows of the soul'.

### **SLIDE Reassurances**

**SLIDE** Because of such beliefs and concerns attached to death and the body, relatives said reassurances needed to be offered regarding the procedures of removal:

**SLIDE** *'I really had, although it was just a short acquaintanceship if you like, I could trust her. I felt / she said that she was there to represent the patient and make sure that everything was open and above board and there was no "ransacking of the body" if you like. It was a clinical operation and everything would go according to any other operations as if he [husband] was still alive.'* [Donor, wife: 398-401].

**SLIDE** The majority of families asked (n=16) said they were happy with the role the transplant co-ordinators played. One feature mentioned to be important was they did not wear a uniform and then it was easier to speak to them.

**SLIDE** Most respondents suggested they were generally pleased with the support offered by health professionals (n=14).

Yet several (n=5) also reported some degree of misunderstanding or concern.

Tensions tended to occur outwith the intensive care unit, either at a local hospital or another unit within the main neurological centre.

**SLIDE** *'I ended up shouting, as I say, on the day before he died. I asked for a scan or if they would do something, and I went up on the Friday night and they told me that they sent him for a scan. But I don't believe them cos they also told me that he had sat up and ate his tea that night. But I mean the man just could not move. They told me that he had sat up and ate his tea. I thought, "you bloody liar" so I don't think that they sent him for a scan either.'* [Donor, wife: 162-184].

### **SLIDE Organ Request**

In most cases once the donor was declared dead, a request for organs was made. Most respondents reported they were given enough time to consider the request and said that it had been made in a sensitive manner. Issues arose regarding the request:

#### **SLIDE**

- (1) One respondent was upset it had been made in a public area in the hospital.
- (2) Some had difficulties if the request came before the outcome of the tests or too soon after.
- (3) Inappropriate usage of a word like 'harvesting' can cause the next-of-kin some anxiety.
- (4) Another felt her husband was treated as a resource for organs:

*'They had taken his wallet out of his pocket and they had taken out the kidney donor card and it was propped in front of his wallet. I mean when I think about this I really feel very, very angry. We were there. They had no, I don't feel they had any right to take that wallet out, to go in it, and take his card.'* [Donor, wife: 339-343].

## WHY THEY DONATED

### **SLIDE Obligated Donation - Carrying out the Deceased's Wishes**

Given these concerns why did the donor families donate?

**SLIDE** There was a strong pro-donation attitude in the sample for both deceased and respondent and approximately half of respondents and donors had donor cards.

**SLIDE** All respondents asked, thought recipients benefited from having a transplant and would be willing to accept a transplant themselves.

**SLIDE** Approximately half said their immediate reaction to the mention of organ donation was positive and some made the decision immediately.

**SLIDE** Agreement was strongly related to the presence of a donor card and knowledge of the deceased's wishes: three respondents who initially refused agreed because they knew the deceased carried a card or there had been previous discussion about donation in the family:

**SLIDE** *'As I say it was my mum's wishes so if I went against it I'd probably feel worse, not doing it would have been against her wishes, but this was what she expressly said she wanted to do.'* [Donor, son 661-663].

### **SLIDE Self-Interested Donation/Reciprocated Donation**

In some cases, the donation act considered an obligation by relatives to carry out the deceased's wishes but also stemmed from self-interested reasons, such as the donor families' potential need:

**SLIDE** *'It's also, you know if the roles had been reversed and say Laura had been lying there, or whatever it is, kidney or liver, and we had got one from somebody else and Laura was fighting fit again, you know that's great. So we could easily have been on the other side of the fence.'* [Donor, father: 445-448].

Fifteen respondents asked said they had received some form of emotional benefit from knowing they had helped others and/or carried out the wishes of the deceased:

*'I think that the fact that people have lived because of her, you know? I think that that is a very small consolation you know? If you can call it that. It is a very small consolation, but it is a consolation.'* [Donor, mother 692-698].

**SLIDE** The emotional benefit was not felt to be a sufficient compensation for their loss. Further such an emotional benefit was neither an expected or a desirable outcome.

### Elements of Altruism in Donor Family Accounts

**SLIDE** In the absence of a donor card and/or previous discussion, relatives framed the decision to donate, in terms of the charitable characteristics of the deceased.

**SLIDE** Despite her son initially refusing to donate his father's organs, his mother suggested to him his father *'wasn't a selfish person. He would help you so he was helping other people.'* [Donor, mother 474- 476], her son subsequently agreed.

**SLIDE** There was also recognition and a desire to alleviate the suffering of another's condition discernible in at least half of the donor family accounts:

**SLIDE** *'Just to help others. That's all. Just to help others. To give them a chance in life. They are so ill and they might never get another chance again.'* [Donor, husband: 657-658].

### The Need for Follow-up Care

**SLIDE** As stated, communication may be an integral part of negotiating organ donation, however, can it also play a role post donation?

A question regarding the need for follow-up care was introduced in Phase 2 of the recruitment process in

**SLIDE** A third of respondents asked agreed follow-up care might be beneficial. This tended to be articulated only by respondents who had received a home visit however. It was found to be beneficial as it allowed the opportunity to ask questions and made the donation seem more sincere and personal.

**SLIDE** Conversely common responses from other respondents who had not received a home visit suggested, *'it's done and dusted'* (Mr and Mrs J: 457), and *'I can't really think what I would gain from it'* (Mrs C 688).

## Conclusion

The majority of respondents asked reported were positive about the donation experience and they would make the same decision again.

Any difficulties for donor relatives tended to revolve around 'traditional death' and the procedures involved in organ removal.

Most said they did not know what the BSD tests involved, yet the majority said they understood the diagnosis after clear and repeated communication and time.

Distrust and heightened emotion seemed more likely to result at local hospitals.

For those who initially refused donation the presence of the donor card and knowledge of the deceased's wishes was found to be significant as was framing the decision to donate in terms of the deceased's characteristics.

For those who had received follow-up care post donation they said it allowed the opportunity to ask more questions and made the donation seem more sincere. Those who had not received follow-up care could not see a benefit from it.

## NON-DONORS: Preliminary Analysis

Four interviews carried out with five respondents agreeing to take part. Impressionistic findings as analysis not yet complete:

- (1) Son maintained too long on ventilator (9 days).
- (2) Desire to switch off ventilator.
- (3) Inter-family objections.
- (4) Organ Removal Procedures.
- (5) Organ Donation not mentioned earlier.
- (6) Negative beliefs about Organ Donation and Transplantation.
- (7) No Donor Card/lack of knowledge.
- (8) Deceased wouldn't have wanted it.
- (9) Deceased too old.







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**Astron** B25370 6/02

ISBN 0-7559-0471-0



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