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How can we improve organ donation rates? Research into the identification of factors which may influence the variation

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EXECUTIVE SUMMARY

1) Transplantation is the most cost-effective treatment for end-stage renal failure, and the only treatment available for end-stage liver or cardiac failure.

2) Nevertheless waiting lists for transplants of all types continue to increase in almost every country, including the United Kingdom, and for kidney transplants now exceed the annual number of transplants fourfold.

3) The only real limitation to increasing the number of organ transplants is the number of organ donors. This has actually *fallen* during the 1990s in the United Kingdom, in part because of a welcome decline in the number of fatal road accidents, and also to changes in the management of patients with fatal brain haemorrhages.

4) The majority of donors are unfortunate people who have suffered fatal brain damage (sometimes called «brain-stem death») but are already maintained with a heartbeat by artificial ventilation. Much evidence suggests that many more such potential donors exist than are currently come to donation.

5) Although in the case of kidneys, living donors and non-heart beating donors can be used and are being encouraged, the central need is to identify and make use of these heart-beating donors, which are the only source of transplantable hearts and livers.

6) The process of organ donation is a complex one, involving organisational, ethical, medical, legal, cultural, social and emotional factors. The chain of donation has many links, and failure of any one results in organs not becoming available.

7) There is wide variation within the UK (and internationally) in rates of organ donation, and the cause of this variation are poorly studied and little understood.

8) If all regions could perform as well as the best, and the UK rate raised to the level already achieved in countries such as Spain and Norway, then the problem would be solved - as it has been in these two countries, whose waiting lists for transplants are static or falling.

9) Despite extensive debate, the quantity of hard data on donation remains small, and what is available is often not readily accessible. Neither has all the information been assembled in one place and correlated, to see which factors already recognised as important might determine the variation within the UK on the one hand, and between nations on the other.

10) The NKRF is interested in promoting and funding both the collection analysis and correlation of existing data, and collection of new data, to help answer these questions. We hope that these urgently needed analyses will lead to a robust base for action at several levels of the donation process.

11) By June 2001 we have:

- Conducted a poll on public attitudes to presumed consent legislation (57% in favour - NB before Alder Hey).
- Convened a group from ethnic minority interests with DoH involvement to explore awareness of renal disease in ethnic minority communities, including the sources of low organ donation rates.
- Set up a working party under the aegis of the Transplant Partnership and directed by Dr Jeremy Wight (Wakefield HA), with the collaboration of the BTS, UKTCA, ICS and UKT, to gather and correlate global donation data (rates of potential donors, numbers of transplant surgeons, ICU factors, numbers and activity of transplant co-ordinators, numbers of RTAs etc.) with the intention of examining (and we hope explaining) variation in donor rates within the UK.
- Invited Professor Rafael Matesanz, lately director of the highly successful Spanish ONT to the UK in April 2001 to meet individuals interested in the «Spanish system» of transplant co-ordination. We are also gathering unpublished information on UK members of the transplant community who have visited Spain and participated in their training programmes.
- Obtained up-to-date information on the performance of various channels of recruitment to the donor card and donor registry programmes, and begun investigation of the reasons for the (low) use of these in practice.

We will also:

- Visit high performing and low performing units to assess factors in relation to Dr Wight's retrospective analysis.
- Send teams to visit Spain and Norway to assess their programmes at first hand.
- Begin a programme of assessment of potential numbers of non-heart beating kidney donors, and the possible role of elective ventilation in this field should this programme be re-considered.
- Consider any other approaches which will help alleviate the shortage of organ donors within the UK.

BACKGROUND

Renal transplantation has established itself as the optimum treatment for irreversible kidney failure in terms of results, rehabilitation and costs, using even the current inadequate technology of immunosuppression rather than induction of tolerance. The scope for renal transplantation now extends from young children to those aged 70 or *75* years of age, since the inevitably poorer survival of the elderly is offset by the lower rate of rejection from an aged immune system. In the case of liver and heart or heart-lung transplants, transplantation offers the only current option for those in terminal heart, liver or pulmonary failure.

The only limitation on the number of grafts performed is a shortage of donors. Because of the inadequate supply of donor organs, many patients who could receive a renal transplant need to remain expensively and often unhappily on some form of regular dialysis. Every week, potential recipients of livers or hearts die, still waiting. Almost everywhere in the world, waiting lists for transplants lengthen whilst the number of transplants has remained static, and in the United Kingdom has even fallen during the 1990s.

This in turn has led to renewed interest in transplants from species other than man (xenotransplantation). However, even if current doubts about dangers of transmission of retroviruses from donor animals such as pigs can be allayed, formidable immunological problems suggest this approach is still some years away at best. The use of pluripotent stem cells, however derived, promise some relief from this impasse but decades of work are needed in this area before practical results will be visible in organ (as opposed to cell) transplantation.

The result has been an intense examination during the past decade of how the number of donors available might be increased from the current rate in the United Kingdom of some 13 per million population (pmp)/year to at least the 20 or 30 pmp/y which the data suggest can be achieved - and almost certainly exceeded. It must be noted that even these levels remain inadequate fully to satisfy the need for renal transplants, if transplantation of those 65-75 years of age becomes the preferred method of treatment.

Unless attempts to raise organ donation rates are to be a random activity, at least some of the reasons for the variation and inadequacy of organ donation, and their possible interactions, must be identified. At the moment they remain largely unknown, and this brief paper attempts to identify areas where well-designed studies are needed urgently.

ORGAN DONATION

The donation of an organ from one human being to another is a complex act, involving medical, social, cultural, ethical and legal issues discussed in the King's Fund document *A question of give and take* (New et al. 1994) and by the British Medical Association Ethics Committee document *Organ donation and transplantation: the need for a consolidated approach* (BMA 2000). Organ donation rates vary widely, presumably as the result of one or other of these aspects, or interactions between them. It would be naïve to expect that a simple approach is likely to give an immediate answer on how to increase the number of organs donated to that observed in the most successful regions or countries, or beyond. Despite these caveats, much of what has been written and said about the problem takes an unhelpfully simplistic standpoint.

A number of approaches to optimising organ donation have been proposed, discussed and adopted, and are discussed in more detail in New et al. (1994*)* and in the recent document from the British Medical Association (BMA 2000) to which the reader is referred. The latter paper places particular emphasis (which we endorse) on the fact that the question of donor supply, and the factors involved in its variation, must be looked at in broad context and a number of solutions sought simultaneously. Because both living donors and non-heart beating donors can be used for renal transplantation — options not open for liver [1]or heart transplantation— possible strategies for increasing kidney donation exceed those of other organs, as noted in the table.

These options may be summarised, together with the present position in the United Kingdom, as follows (New et al. 1994; Sells 1999; BMA 2000; Hou 2000):

(*) Increasing numbers of transplants of the lobe of a liver from living donors have been performed in recent years, but currently the donor morbidity and even mortality appear to be too high for this to become generally useful; however more data and future technical developments must be awaited.

Tabla I. Some approaches to increasing the supply of transplantable kidneys

APPROACH 1: INCREASE THE SUPPLY AND USE OF TRANSPLANTS FROM LIVING DONORS

(This applies only to increasing the availability of kidneys at the moment [But see footnote 1])

1.1. Encourage related donor transplantation within families.

1.2. Encourage unrelated donor transplantation between concerned but unrelated individuals (Levinsky 2000; Gjertson and Cecka 2000),
- *both these approaches have been exploited in the UK, and numbers of transplants in either category are rising rapidly (13% p.a.) at the time of writing (UKTSSA report July 2000), and exceed 20% and even 30% in a few units. The introduction of laparoscopic nephrectomy has almost certainly reduced the impact of donation on the donor, and may be safer.*

1.3. Encourage «non-directed» living donor transplantation between an altruistic donor and a recipient unknown to the donor (Matas et al. 2000)
- *this approach has been discussed and advocated elsewhere, but has not been practiced in the UK*

1.4 Pay donors cash to donate kidneys to a central organisation, which will then be matched with a suitable donor.
- *this approach has met with complete opposition in developed countries (although such an approach may have advantages over the rampant commercialism in some developing countries).*

APPROACH 2: INCREASE THE SUPPLY AND USE OF TRANSPLANTS FROM CADAVER DONORS

(Multi-organ, heart–beating cadaver donors supply the majority of organ transplants today).

2.1. Encourage the population to carry donor cards and register on the national computer donor register («opting in») so that their wishes with respect to transplantation are known.
- *this approach, plus educational programmes, has so far been the foundation of the system in the UK. However only about 8-9 million individuals are now registered as potential organ donors and only 20-25% carry donor cards.*

2.2. Re-organise the medical services so as to give greater prominence, expanded staff, financial support and adequate intensive care beds for organ donation; expand educational programmes within intensive care units, hospitals and the general population.
- *this builds on and improves 2.1.*

2.3. Allow the removal of organs unless the individual has registered opposition to this during life («opting out» or presumed consent) (Kennedy et al. 1998).
- *this approach, which is present in one form or another in more than half of EEC countries, has been much debated but is not present in English or Scottish law at the moment.*

2.4. Expand the criteria for donor suitability.

2.4.1. Make more use of non-heart-beating donors:

(This applies only to increasing the supply of transplantable kidneys)
- *poor results with non-heart beating donors in the 1960s and 1970s resulted in abandonment of their use. Now, with the use of better perfusion techniques such kidneys are again being used in some UK units, and results as good as those employing heart-beating donors have been reported (Nicholson et al. 2000). Such donors arise not in ICUs but in accident and emergency departments or acute general medical wards. It is likely that such programmes can be organised only in hospitals with transplant units, or closely associated with them. The number of potentially usable organs from this source has never been estimated, and in view of likely dependence on this source for some time to come in the UK such an attempt is needed.*
- *Problems remain also because many such kidneys do not function —or function very late— and these cannot be identified reliably. If the recently described tests involving machine pulsatile perfusion and urinary enzyme excretion (Balupuri et al. 2000, Daemen et al. 1997) are confirmed, the procedure may be confined to centres with these facilities. Obtaining permission to cool and preserve the kidneys immediately after death poses practical problems and involves definition of the point of death. Should it be judged by cessation of the heartbeat or the signs of brain stem death? (Vanrenterghem 2000).*

2.4.2. Use of older donors:
- *Donors over 60 years have been used rarely in the past because of the decline in renal function with normal ageing. In other countries such as Norway, however, such donors are used routinely. The use of double renal transplants from older donors has been advocated and performed elsewhere, but is little used in the United Kingdom (Gardielli and Remuzzi 2000). In general, a lower age limit has been applied for cardiac and liver donation. Such «marginal» donors have been used increasingly for older recipients because of the necessarily shorter survival of such patients, and if the upper age limit for transplantation is considered to be fit 70-75 year olds, then this donor source would become increasingly important.*

2.4.3. Ventilate patients solely for purposes of transplantation:
- *This was shown to be feasible in the UK environment in a study in Exeter (Riad and Nicholls 1995) though limited in scope nationally because of a continued lack of intensive care beds. In 1994 the Department of Health declared that they believed this practice to be contrary to English law, as the treatment did not benefit the donor, so it is at present in abeyance although discussion continues. A crucial prerequisite for programmes of elective ventilation is without doubt the availability of sufficient, adequately staffed ICU beds.*

THE ADVANTAGES AND DISADVANTAGES OF A COMBINED APPROACH

The importance and urgency of the problem has led to an overwhelming and understandable desire to try all —or at least the majority— of these approaches simultaneously. Whilst it will be possible to assess separately the contribution of related and unrelated living or cadaver donors in renal donation, it will not similarly be possible to determine to what any success in raising cadaver donor rates may be attributed, and thus where continued effort should be placed.

INCREASING LIVING DONATION FOR RENAL TRANSPLANTATION

Although unresolved ethical issues remain, it is now generally accepted that an increase in living kidney donors is desirable, will be helpful, and can be implemented by widening the scope of such donation and making all those biologically or emotionally close to patients in terminal uraemia aware of the possibility. In the first 6 months of 2000, 17% of kidneys transplanted in the UK came from living donors, the highest rate ever (but only 0.6% in the Republic of Ireland); some units now perform more than one third of their transplants from living donors (UKTSSA monthly report July 2000). That there is some way to go is indicated by the experience in Norway, where living donors form 50% of all renal transplants, even in the older age groups, and waiting lists for grafts are now stable (Albrechtsen et al. 1995).

INCREASING CADAVER DONATION: THE MARGIN FOR IMPROVEMENT

The simultaneous goals of any programme of enhancing cadaver donation are to increase the number of donors available, and to improve the infrastructure so that use is made of all available donors. As emphasised by Michielsen (1996) and Matesanz (1998), the organ donation process:

«*represents a chain of events, the final result of which will depend upon its weakest link*».

To deal with the many possible causes for failure, a full professionalization of the process of organ donation seems inevitable and desirable.

INCREASING THE SUPPLY OF CADAVER KIDNEYS AVAILABLE

Any attempt to increase donor organ supply from cadaveric sources assumes that there are unused organs available. Although there is indirect evidence that this is so from international and regional comparisons, as discussed below, such comparisons are the result of many variables, some of them not controllable and some to be welcomed, despite the effect on donation rates. For example, two groups of donors have decreased in number during the past decade or two: deaths in road accidents —in which mortality has steadily fallen, and those following cerebrovascular accidents, in which early management has been rendered more precise and ventilation less frequent by imaging technology.

Another approach is to attempt a survey of numbers of potential donors to identify rectifiable causes of non-donation. The majority of cadaver donors —and all heart-beating donors— are identified within intensive care units (ICUs), and the only good UK survey in this field (Gore et al. 1992) was performed almost 10 years ago, using perhaps now outmoded criteria for donation. This suggested substantial under-use of donors and indicated that only one third of potential donors were actually used. Data from the United States, Spain and elsewhere in the same period suggested an even larger number of potential donors (Nathan et al. 1991; Miranda et al. 1999a). Further research is needed urgently on this point. Also, the numbers of potentially useful cadaver kidney donors if non-heart-beating donors are used as well, has never been estimated with any security. These patients usually arise within casualty departments and general medical wards, and not within ICUs.

Obviously it would be very useful if data were available to guide what the emphasis and effort to be given to each approach might be, in what order they might be implemented, or what the likely result of successful implementation would be. It is unfortunate and surprising that despite prolonged debate, such data remain almost completely lacking either within the UK or between countries. This is despite major variations in donation rates within the UK (in 1999, from 5 to 23.5 donors pmp/y) (UKTSSA report 2000), and with donation rates varying between European nations from 5 to 35 donors pmp/y.

Is there *any* evidence bearing on possible factors which might improve the rate of cadaver donation? Some few data are available. First, it is clear that factors outside the control of those concerned with transplantation can operate to influence donation rates. One recognised example is the broad correlation between national donation rates and the death rate through road accidents (New 1994). This may account in part for the consistently superior performance of the Irish republic compared with the UK, which has (along with Sweden) one of the lowest

road death rates in the world; a higher proportion of donations in Ireland comes from road deaths (UKTSSA report 2000), and their donation rate is superior to that in the UK. On the other hand, the low proportion of donors from road traffic accidents in the UK may reflect in part the acknowledged inadequacies in the UK of trauma service at the roadside, with more people involved in severe accidents dying before they reach hospital.

There is a general correlation also between the size of countries and donation rates, small countries having in general the highest donation rates: Spain is now a major exception to this, however. It seems likely also that the pre-eminence within the UK in 1999 of Newcastle (23.5 pmp/y) in overall statistics (UKTSSA report 2000) is in part due to the introduction of a non-heart beating donor programme. However, one must offset against this the consequence that in 1999 only 89% of all donors obtained in that region could be used (compared with a national average of 96%), because subsequent assessment indicated the kidneys might not be viable, or for other reasons.

The low rate of donation from ethnic minority groups in the UK is well-known, which is doubly unfortunate since the rate of terminal renal failure is 3-4 times as high as the UK Caucasian population, and blood group and tissue type differences make it more difficult to obtain good tissue matching from amongst Caucasian donors. Amongst South Asians this must be a cultural and not a religious phenomenon, since all the three major religions of that region —Hindu, Moslem and Sikh— have endorsed organ donation without reserve, as has the Jewish faith. Again, the causes of the low donation rate from Afro-Caribbeans remain unknown, and deserve further research (UK Transplant Coordinators' Association 1995); in the United States, donation from African-Americans is 12%, proportionate to the total population (Young and Gaston 2000).

Finally, although repeated surveys (such as those conducted annually by Gallup for the British Kidney Patient Association for many years) have shown nearly three quarters of the UK population to be in favour of their organs and their families' organs being used for transplantation outside their family, in practice today anything up to 30% of requests are met with refusal from relatives. The factors involved are complex, only partly understood, and worthy of further enquiry (UK Transplant Coordinators Association 1995). At the moment there are only about 9 million people registered with the national donor scheme, and only about 20% of the population carry donor cards. The survey alluded to above on intensive care unit deaths (Gore et al. 1992) showed that refusal of the relatives was the cause of only 25% of failure to use potential donors. It is interesting to note that in Spain (despite the presence of «opting-out» legislation —see below) the level of relatives' refusals remains similar to that in the UK, and has declined only slowly in the past decade from 30% to 21% (Miranda et al. 1999b). Two studies in Spain to evaluate possible causes for refusal in 1989-93 and 1993-4 (Miranda et al. 1999a.), and one in Belgium (Roels et al. 1996) together with the unpublished observations of the UK Transplant Coordinators' Association in the UK in 1995 identified a variety of causes, some from failure of information and some based on prior beliefs. That there is a margin here for improvement with education is indicated by repeat surveys showing that most who refused later accepted the idea of donation (Miranda et al. 1999a).

NEW AND OLD SOURCES OF CADAVER DONORS

Use of «marginal» donors for renal transplantation

For renal transplantation, the use of «marginal» donors from the aged, and those already dead by conventional criteria when organs are removed is to be encouraged, but may not have a major impact. A crucial requirement for the exploitation of both sources is some means of assessing the viability of the organs to avoid futile and potentially thus more hazardous transplantation operations. *Ex vivo* perfusion and assessment of urinary enzymes has been promoted (Balupuri et al. 2000) but this is complicated and, takes time and apparatus. This area is another possible target for research support.

Opting out/presumed consent legislation

A number of other factors require assessment. *Opting out/presumed consent legislation* has received the most attention recently, but the debate on this issue has been characterised more by heat than by light. In general, the mainly Catholic countries of Central and Southern Europe, with a legal system strongly based in Roman law, have opting out/presumed consent systems and an emphasis on the citizen's duties to the state; whereas the largely protestant countries of Northern Europe rely more on common law, and place more emphasis on individual rights of determination (Cohen and Wight 1999). However there are exceptions to both these statements, and there is no evidence of a systematic difference in donation rates between these two groups to suggest an over-riding importance for the

style of legislation. In fact, there is very little evidence either to suggest or deny an impact of the style of legislation on organ donor rates (Matesanz 1998).

Sequential and comparative data in relation to introduction of «opting out» legislation have been widely quoted, especially the experience in Belgium (Michielsen 1996). However such studies have major statistical and epidemiological flaws. The lack of correlation between national donation rates and legislation has been mentioned, and *within* almost all countries, even larger local variations exist in donation rates even though there is a common legislative background. In daily practice, in both Belgium and in Spain (but not in Austria) the presence of an «opting out» law makes little or no difference to procedure: in both the former countries relatives are still asked if they are in favour of donation, and their wishes are respected (Vanrenterghem, personal communication 1999; Roels et al. 1997; Matesanz 1998, Miranda 1999a). The difference, of course, lies in the ambience and framework within which such discussions take place, the strong assumption being that the answer will be «yes». Nevertheless refusal rates are similar regardless of legislation, as discussed above.

It seems intrinsically unlikely that an event so complex as donation will be uniquely influenced by a single action such as a legislative act of this type. As Rafael Matesanz, former director of the most successful transplant program in the world in terms of donation rates, and former president of the Council of Europe's transplant committee has written (1998):

«...I am profoundly sceptical whether any change in legislation in and by itself could modify a social reality which is supported by the majority. The sequence of events goes the other way round. Laws are good laws when they conform with that which has been accepted by society and do not try to modify society by coercio…contrary to what one might think (and what is frequently stated) the European transplantation laws have more similarities than differences».

A further major barrier to possible introduction and adoption of «opting out/presumed consent» in the United Kingdom is that almost all the professional groups who would be involved in implementing it appear to be against the introduction of such legislation: after debate, The British Transplantation Society, the Intensive Care Society, and the Transplant Coordinators group have all polled their members within the last 18 months, and found a majority opposed to it (Koffman 2000). Physicians attending the UK Renal Association, after a public debate, again voted against it in March 2000.

All these professional groups felt that more harm than benefit might accrue, from possible forceful misapplication of the law. Data on which these opinions might have been based is lacking, however, and like all the debate on this issue they remain statements of opinion and emotion, and not fact. One major deleterious effect of the prolonged debate on possible «opting-out» legislation in the United Kingdom is that attention may have been diverted from detailed consideration of other approaches.

Nevertheless, a recent (September 2000) survey conducted by the NKRF showed that 57% of the British population were now in support of presumed consent, compared with only 26% in an (unpublished) survey done by the Department of Health prior to the extensive public discussion of the topic.

Improving the infrastructure

Probably within this area lies the greatest possibility for improving organ donation. To quote Matesanz (1998) again.

"for the physician in charge of a potential donor the easiest thing is to find an excuse for not considering him as a donor... this will permit the physician to close the case as quickly as possible, thus avoiding a long, complicated and disagreeable procedure».

The object of any donation programme must be to relieve this burden as far as possible, and further to facilitate identification of potential donors, and to assure that donation actually takes place. It is not clear to what extent the burden of obvious and hidden costs for the donor hospital, such as anaesthetic or surgical time and use of ICU beds, is a disincentive. For the past decade a payment of £1,000 has been available to donor hospitals, but it is not clear how often this sum has been claimed by donor hospitals, especially those whose donation rate is low. The intensive care survey already quoted (Gore et al. 1992) showed that in England more than half the «losses» of potential donors, as judged in retrospect, arose from what could be termed organisational failures; it is interesting to note that the figures from a survey in Spain during 1996 showed similar proportions of causes for «lost» donations, despite the much higher ultimate donation rate (Miranda 1999a,b). The British Transplantation Society (BTS 1995) and the Royal College of Surgeons (2000) have already made a number of suggestions to improve the situation, which the NKRF supports, including an increase in the number of intensive care

beds, especially in neurosurgical units, in which the UK lags behind most other European countries and whose availability appears to be a major factor in limiting donor care[2]. Inadequacies in roadside accident services have been mentioned above.

The object of identifying the crucial areas for possible restructuring within the UK is to allow most or all areas of the country to duplicate the best experience available abroad, and that of the best regions within the UK. If changes are made, it is vital that well-designed audit research projects run in parallel, to assess the impact and evaluate where possible the relative roles of different factors involved in the restructuring.

The success of Spain in raising organ donation rates consistently is well known and the general structure of their programme has been described on a number of occasions (e.g. Matesanz 1997; Miranda et al. 1999a, 1999b). The donor rate in Spain is now above 34 pmp/y, with a fall in numbers of those waiting for a transplanted kidney from just under 6,000 to just over 4,000 during the 1990s, after there had been a steady rise during the 1980s. It seems strange, then, that apparently no report examining in detail what, within the «Spanish system», might be crucial and what might be transferable to the UK has been prepared by any official or professional group concerned with transplantation in this country. That such a transfer may be possible is suggested by experience in Tuscany, where donation rates were doubled to 13.5 donors pmp/y within a year and a half after introduction of a «Spanish» system of transplant co-ordination (Simini 2000). These data, however, are muddied by the fact that a law introducing presumed consent was introduced during the period, but has not yet been implemented fully.

There is an urgent need for a structured analysis of the organisation of organ donation, examining first regional variation within the UK, and then especially the Spanish and now the recent Italian experience. It would be no surprise to find that the quantity and quality of staff may be the crucial factor, and this is incorporated in the suggestions of the Royal College of Surgeons. High donation rates in one particular hospital or area may simply depend upon the involvement of a single active, committed and charismatic individual, or a cadre of similar individuals. In every one of 139 hospitals in Spain licensed (in 1999) to donate organs, there is a dedicated transplant co-ordination team, largely made up of part-time paid doctors and nurses (Matesanz et al. 1997; Miranda et al. 1999a); the whole programme (Organización Nacional de Trasplantes) cost US$3 million in 1999 (approximately £2 million).

Even ignoring the Spanish experiment, organ donation in the UK has grown up in a haphazard and relatively uncoordinated fashion, and numbers, responsibilities, salaries, workload and education of co-ordinators varies greatly within the UK. The United Kingdom Transplant Coordinators Association has produced a plan for a national co-ordination service as part of national transplant service (UKTCS 1999), and we need to professionalise fully this important part of the service along these or similar lines.

The present «opting-in system» has never reached its full potential, perhaps because it has never been promoted with sufficient energy, staff commitment and finance, unlike the system in Spain. The UK system has been criticised because only 9 million names are registered on the national computer out of a potential of over 40 million adults. It is also commonly said that because only a quarter of potential donors are on the register, staff involved in seeking permission for donation often do not bother to consult the Registry. Both are remediable faults. Studies of the possible bottlenecks that prevent this system from operating at full efficiency are urgently needed. It is an essential preliminary to any national campaign, supported by NKRF and other organisations to increase registration.

CONCLUSION

Although preliminary results from the year 2000 suggest that, at last, organ donation rates in the UK may be on the rise again, the gap between what is possible and what is achieved remains huge. More information on cultural and organizational factors critical to the donation process is needed urgently. The NKRF is eager to play a part in supporting well-designed studies in these important areas of operational clinical research.

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Appendix. Areas in which information is lacking and where research could be useful

This list is by no means final or inclusive, but contains what the NKRF perceives as the areas most urgently in need of information.

(1) Public attitudes to organ donation and legislation governing it. In particular:
(a) Has the recent public debate affected attitudes toward «opting out» legislation (Action: survey conducted by NKRF September 2000 – results available).
(b) The reasons for the low donation rates amongst ethnic minorities (Action: meeting October 2000 attended by renal physicians, patient groups as well as the DoH, to examine the general issue of awareness of the high renal failure and low organ donation rate in ethnic communities; further meeting December 7th 2000).

(2) Why is there such a wide variation in donors/million population within different regions of the United Kingdom?
Can differences in local organisation / staff numbers/intensive care beds/ attitudes / education be related to outcome, and the critical parameters identified?
This study would be done in collaboration with the BTS, the ICU Society, the UKTCA and the DoH.
(Action: draft data base enquiry (outlined immediately below); local questionnaires/on-site visits planned)

Appendix. Areas in which information is lacking and where research could be useful *(cont.)*

The current data base

The BTS and UKTCA reports of 1995 contain valuable data, but before any action to gather additional data is taken we need urgently to gather together *all* available relevant information, to provide a detailed «geography» of donation throughout the UK at the moment. These data, surprisingly, have never been assembled *together and correlated* to see whether or not they might explain all or part of the variation in regional donation rates. When these data have been gathered, analysed and correlated, useful questions to ask locally in both highly —and poorly performing areas will be needed. For each region, the required sets include *at least*:

(i) the site and number of transplant units (source: BTS, DoH),
(ii) the number and sessional commitment of transplant surgeons (source: BTS, DoH),
(iii) the number and sessional commitment of transplant coordinators (source: UKTCA). In addition the framework of operation of coordinators (not standardised at the moment) needs analysis (source: UKTCA). To how many ICUs does each co-ordinator/co-ordination team relate?),
(iv) the number and type of ICUs (including a separate inventory of Neurosurgical ICUs) and the numbers of ICU beds (Source: Intensive Care Society, DoH),
(v) the number of (multi-organ or single organ) donors generated through each ICU for 1998 and 1999 (or 1999 and 2000). A separate audit of non heart beating kidney donors will be needed [UKT(SS)A annual reports] (NB: data on non heart beating donors not separated nationally or by retrieval centre) and
(vi) the numbers of transplants actually performed.

All data will need to be standardised to (e.g.) /million total population covered. Some data (such as number of ICU beds) are changing rapidly and we may need data at different recent time points.

(3) Potential donors in Intensive Care Units:

What are the numbers of potential donors and what are the reasons for organs not becoming available, in 2001?
(Action: new audit in planning with Intensive Care Society. In general the information sought would repeat that of Dr Sheila Gore's survey of ICUs a decade ago, with new audit data gathered currently by Trusts)

(4) What can we learn from the experience of other countries in achieving —or failing to achieve- high donation rates?:

What might be translatable into the UK context with advantage from this experience?
This study will again be done in collaboration with the BTS and the ICU, and also the International Forum for Transplantation Ethics (IFTE), who plan a parallel study in a number of countries, to start next year. (Our contact with the IFTE is Mr Robert Sells, a member of the Transplant Partnership as an individual.)
In view of the outstanding and sustained success of the Spanish ONT (now generating 34 donors/pmp /y in 1999), we propose to concentrate our initial efforts on practice in that country. It is a source of considerable surprise to us that, although a number of individuals and organisations have made visits to Spain, and the structure of the Spanish ONT (now in place for more than a decade) is readily available, as far as we can find nothing has appeared or been circulated in print analysing the Spanish experience in relation to UK needs and practice, and suggesting what could be transferred.
It is well known that the Spanish system includes a number of features with which we would have difficulty, e.g. individuals acting with responsibility for patients within the ICU, who also seek organ donation simultaneously; and individual remuneration based upon the number of donors generated. However there are many features of the ONT capable of application within the UK (such as a national organ procurement scheme with standardised employment and responsibility for co-ordinators, and the presence in every suitable ICU of an individuals who is member of the local team, even if funded centrally).
(Action: Our first task therefore is to access information gathered by individual members of the BTS, the UKTCA and the UKT(SS)A on visits to Spain in the past. «In house» reports may exist which require wider perusal.)
Professor Rafael Matesanz attended the UK on 20th April to meet members of a combined team. We are particularly interested to gather his recent personal involvement of introducing a «Spanish system» into the Piedmont region of Italy, and into South Australia, with subsequent doubling of donation rates- albeit from low initial levels.
Third, we plan a carefully structured visit to Spain, and (depending upon the information gathered locally and from Professor Matesanz), perhaps to Italy.
The IFTE plan to study organ donation in Belgium (follow up on the changes of the 1980s), in France (where despite a presumed consent law, donation rates remain low), in Czechoslovakia (where donation rates have changed dramatically in recent years both up and down, apparently in response to definable events). We in the NKRF are interested to learn also from the Norwegian experience of renal donation, which has both a consistently high living donor rate (about 50% of all transplants at all ages) and a high cadaver donation rate, such that for some years the transplant waiting list in Norway had been static or falling, with renal transplantation freely available to recipients of all ages up to 75 years or so.

(5) What can be done to identify «good» kidneys from non-heart beating cadaver donations without using elaborate and expensive perfusion systems?:

The NKRF will actively seek research projects to support in this area, assessed and funded through its normal grant programmes.

(6) What are the reasons behind the relatively poor uptake of organ cards and the national organ register?:

A number of channels were suggested by the government to increase uptake of donor cards and registry membership, but not all seem to be functioning well. The following are preliminary suggestions to examine some of these:

(i) Are Passport offices sending out invitations to become a donor with each renewed passport? Preliminary enquiry suggests the answer is no. What uptake does this approach generate? Can the UKT identify applications generated through this channel? How could it be made more effective?

Appendix. Areas in which information is lacking and where research could be useful *(cont.)*

(ii) For some years applications have been issued with driving licences. How effective has this been in generating applications? How could the uptake be improved? Is the presentation ideal?

(iii) GP surgeries, as part of their public health role, are supposed to display posters advertising organ donation and donor cards. Preliminary data suggest this practice is not widespread. A survey to determine how common defaulting on this is needed, and an enquiry to determine why the message has not been displayed. Who should be targeted in practices to be responsible for this?

(Action: Graham Brown of the DoH contacted by David Kerr and replied with detailed answers to above questions. Vehicle licence working but Passport Office inactive – perhaps because of last year's chaos. Currently 9.6 million people on register).

New approaches could be explored: the recent initiative with Boots the chemists is one such.

A test of direct mailing to individuals not registered on the national organ donor scheme could be undertaken: a random sample would be mailed for views on donation. Those who say they do not carry a card and are not on the register could be sent one with a suggestion they register, and the uptake monitored with or without reinforcement mailings.

(7) What is the potential number of usable non-heart beating donors?:

As a first step this could his involve identification of patients who might be suitable for kidney donation, admitted to accident and emergency departments or arising in acute medical wards, of hospitals groups which have a transplant unit. As examples (a) patients coming to the A&E department after cardiac arrest in whom resuscitation attempts fail (b) patients who have intracerebral bleeds who have CAT scans and are then judged not suitable for ventilation in an ICU (this latter group are of course patients suitable for elective ventilation if such a programme were contemplated).