



## Organ donation: the way forward. Panel discussion

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### PROFESSOR ANDREW REES, CHAIRMAN

I would like to move on to the third element of this morning's meeting which is a panel discussion. It has been clear from the intensity of the questions and also the nature of the questions that there is an overwhelming demand that «something should be done» to improve donor rates in this country. The object here today in the panel discussion is to bring together those people who might perhaps be considered necessary or responsible for effecting the change in the United Kingdom together with Professor Matesanz who has clearly effected such change over the last ten years in Spain.

The format is very simple. I want to retain the great majority of the time for a simple «Question & Answer» session but in order to introduce you to the members of the panel were, I shall ask them just to say a few words to introduce themselves and the organisations they represent. With luck, I am going to stick to my own guidelines by saying that I am the current President of the Renal Association. The Renal Association is the organisation which represents British Kidney doctors who are responsible for all aspects of care of patients with renal disease. It has a purely scientific aspect, the investigation of the underlying basis of renal disease but also, increasingly and now very importantly, it has a role in determining all aspects of the care of renal patients, from standards to manpower, to patient related issues directly. It doesn't have a formal position on what should be done to increase donor rates but it is clearly committed very strongly indeed to a single set of initiatives that I hope will emerge very soon indeed, perhaps which will be obvious by the end of this morning. And without more ado I hand over to Professor Andrew Bradley, President of the British Transplantation Society.

### PROFESSOR ANDREW BRADLEY

The British Transplantation Society represents about four or five hundred transplant surgeons, scientists

and transplant co-ordinators. It was set up initially to disseminate large sections of scientific information and clinical practice between those involved in transplantation. Like the Renal Association, it has increasingly developed a political arm involved in advice to the Department of Health, training of personnel and the creation of guidelines for good practice and in the current context we have recently produced guidelines for living donation and are currently in the process of drawing up guideline on cadaveric donation. I would like to thank Raphael for that excellent talk and, of course, the British Transplantation Society is completely committed to any initiatives which increase organ donation. My only comment is that I do think this will need resources but I do sense that there is now definitely a chance of enacting many of the things I have seen and heard about this morning.

### MS. PAM BUCKLEY, CHAIR OF THE UK TRANSPLANT CO-ORDINATORS ASSOCIATION

I am the Senior Transplant Co-ordinator in Newcastle and also the current Chair of the UKTCA. The UKTCA currently has 130 members which may seem a lot of co-ordinators for the UK but in fact only 50 whole-time equivalents of those people are involved in organ procurement work. The rest of the membership are employed as dual role co-ordinators looking after recipients or as tissue co-ordinators. The UKTCA provides the only formal education for co-ordinators with a training course which has a university accreditation but there is no obligation for any co-ordinators to attend this course although most are encouraged to do so by their employers and the courses are heavily supported, as is all procurement work we undertake, by the pharmaceutical industry. We do have standards of practice and we do have much support given to our service by many others. We currently have no national supervision. We have no performance management or accountability other than to our Unit Directors or the people that we report directly to within our own

Unit. The majority of co-ordinators are nurses who have come from a background in organ failure or intensive care. We are very interested in the Spanish system. We feel that there is gross under-resourcing of transplant co-ordination in this country and we are keen to see what parts of the Spanish system may be transferable to the UK. As a final note, I would say that we do have a very different donor population in the UK, not in terms of the sorts of patients who become donors, but primarily where they die and most of our donors come from District General Hospitals or Neurosurgical Units which are not in the same hospital as a transplant unit. A very small proportion come from within big institutions where there is transplantation and neurology.

#### **MR. CHRIS DENHAM, TRANSPLANT RECIPIENT**

I represent the views of transplant patients. Basically five years ago I received a kidney transplant at the Oxford Transplant Centre, which was then run by Professor Peter Morris—a very fine man indeed! And I am basically here to tell you what it's like and how it is to go through renal failure and then to be fortunate enough to receive a kidney transplant. I can't speak highly enough of the team at Oxford—they are a very highly professional and well co-ordinated team which seems to be the essence of the success of the whole operation. On another subject, organ donation: the people I talk to, e.g. people I work with, are all for donating organs in the event of their untimely demise. When you ask them if they carry a card or are registered the response is «I am thinking of getting around to it». It appears that the availability of these cards is either in a doctors' surgery or in a chemists, if you are lucky. So although it's a part of the whole big picture, maybe if there were some way of making the decision on either the Census form or the driving licence, where people can simply tick Yes or No rather than having to get off their bums to go to a chemists, more would register. At the end of the day, if anything does happen to them they will be approached by the co-ordinators and their next of kin will be asked the question, «do you agree?» I think there is a bit more work to be done on that.

#### **DR. PETER DOYLE, SENIOR MEDICAL OFFICER AT THE DEPARTMENT OF HEALTH**

I have the privilege of giving medical advice to the Transplant Renal Policy teams there. I also wear a second hat—at the moment I have inherited Raphael's job as Chairman of the Council of the Expert Committee of the Council of Europe on organ transplanta-

tion which Raphael chaired for five years. I have been on it for five years so that gives me the great advantage of hearing from the horses' mouths of some twenty or so European countries what really works in their country, not what people say works. As a result of that experience the current Government has made two major announcements, one in February last year and one in February this year, on reorganisation of the organ transplant services in this country. You may not have seen much happening yet and we understand that because the first priorities following last February's announcement were to reorganise what was the UKTSSA and is now UK Transplant and Sue will tell you more about that. She is the new Chief Executive, we are about to get a new Medical Director. The organisation has completely changed and has been given new responsibilities. The second major plan we started work on last February was the reorganisation of some of the services themselves and we started with the Cardiothoracic Transplant Service and that restructuring is nearing completion. Others will follow. It does mean a big resource increase for those units - the teams of surgeons will grow significantly over the next few years and we have also in parallel discussed with the profession and the college and the SAC on getting new training fellowships so there will be newly trained transplant surgeons coming off the pipeline in the next few years. So there has been a lot of work in the background getting the necessary infrastructure changes to start putting these things in place. The new action plan was announced in February—I am not going to go into detail about it now—it is there for all of you to read and comment on because there is going to be a final chance to submit comment on that over the next few months and a final version will then be agreed, we hope sometime in the summer and that will then be an official NHS plan to take forward the reorganisation of these services.

#### **DR. GILES MORGAN, PRESIDENT OF THE INTENSIVE CARE SOCIETY**

First of all I am a Consultant in Anaesthesia and Intensive Care at the Royal Cornwall Hospital in Truro, which is in the far Southwest of England and we serve a population of 375,000 in a 900 bedded hospital. I look after a combined intensive care/ high dependency unit of about 12 beds, in a fairly hands on way. I have had quite a lot of experience over 18 years as a Consultant in the management of patients who have become organ donors and in the management of their families and so I have got, I think, a fair bit of personal insight into the problems. The Intensive Care Society has almost 2,000 mem-

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bers and the majority of them are consultants but there are also nurse members and members of professions which are allied to medicine and these members look after the 285 to 300 intensive units in the country. There has been a radical change over the last five years in the provision of intensive care medicine in this country. The Audit Commission, when it published its report called «Critical to Success» in 1999, estimated that there were about 1,400 intensive care beds and subsequent to that report the Society worked very closely with the Department of Health through its National Expert Group on critical care to reconfigure critical care services altogether and the document which was the basis of that was called «Comprehensive Critical Care». That was produced in May last year and along with that document came the £150 million investment in critical care services so that the way in which critical care services will work in the country in the future will be a patient led system rather than a system which revolves around numbers of beds. The numbers of beds have in fact gone up from 1,400 to an estimated 2,800 but just as this situation is in Spain those beds are now all «intensive care ventilated beds». They are high dependency service beds for patients who fulfil the criteria or that category of illness. But the principle of the reconfigurations has been to take down the walls of intensive care units and export the expertise that is contained within them to other parts of the hospital. This is particularly important with reference to the retrieval of organs because comprehensive critical care comes in three parts. First of all, every Trust will have, or should have already, a critical care delivery group which is made up not only of the people that provide the intensive care service but also those people who use the intensive care service. So that means that the physicians and surgeons, as well as the 80% of intensive care doctors who happen to be anaesthetists generically, also get a foot in the door of the critical care service and have the opportunity, through that group, to make local reconfigurations and have input into the service which is delivered at Trust level. The second part of the package is outreach care; all hospitals will be expected to take the expertise from this intensive care out to the rest of the hospital, to do ward rounds, look after the patients or have some input into the care of patients who are in the advent of critical illness and also to look after patients who are recovering from critical illness. But, of course, in that advent and in that recovery it is likely that patients will be picked up who are potential organ donors so there will perhaps be a better rate of detection. The third aspect of comprehensive critical care is education and training and

that takes a little longer but the Society together with the intercollegiate Board for Training in intensive care medicine are basically revising SHO training, revising specialist registrar training on a multi-disciplinary basis in anaesthesia in medicine and surgery so that the trainee medical staff, at least in hospitals, on a nation-wide basis will in the future become much more attuned to the problems that face one another. Their education in aspects of acute medicine, which will include the management, the detection and the recognition of patients who are potentially organ donors will be much better. So I think through comprehensive critical care there are great opportunities for the involvement of the critical care service in the management of donors throughout the hospital as a whole. The Society in the past has also worked very closely together with the UKTCA and the British Transplant Surgeons Association to produce a document about the management of the organ donor and that, in due course, will be revised. So I think that the critical care community in this country is well on the ball with regard to the management of potential donors.

## **MS. SUE SUTHERLAND, CHIEF EXECUTIVE, UK TRANSPLANT**

UK Transplant, as you have heard is a new organisation, in a sense, in that we have been given new responsibilities from the beginning of last year. Prior to that it was called the UKTSSA. It is based in Bristol and its primary responsibilities until now, which will continue to be the primary responsibilities of UKT, are to maintain the National Waiting List of patients who are waiting for organ transplantation and to match and allocate organs as they arise. So we are open 24 hours a day, 7 days a week, to ensure that organs are matched appropriately and that we ensure that patients who are in the most clinical need, wherever they are in the United Kingdom, receive the organs that are appropriate to them. Since the middle of the 70's the Organisation has been collecting follow up data on all these patients so there is a wealth of data and audit which has been going on, in conjunction with a range of advisory groups so that we have an advisory group for all of the solid organs. We work very closely with all the advisory groups because clearly this is a partnership; we work with everybody to do the best that we can for patients across the whole of the UK. Since the middle of last year we have been given additional responsibilities and that is in recognition of the fact, as we have heard this morning, that we have got rising waiting lists and shortages of organs. So UK Trans-

plant is now responsible for procuring more organs. We are also responsible for ensuring that we have a better co-ordinated system of transplant co-ordination around the country and that is one of the purposes of bringing together the transplant co-ordinators with UK Transplant to work together through the best system we can devise. We have also been given additional responsibilities for communications and public relations and not just with the general public. I think more importantly in the first instance, as I think the Spanish model proves, we must work very closely indeed with all of our colleagues in the NHS because every single person has at some point during their work in the NHS a responsibility and an input to identifying donors. As you heard me say earlier on, we have in the six months since I have been appointed pulled together a business case to deal with the new responsibilities that we have been given. We have heard a lot about resources and I would be the first to say that there is no way that UK Transplant could have met the new responsibilities that we have been given without new resources. Our business case is a five year plan. We have met with the Department of Health and the other health administrations from Scotland, Wales and Northern Ireland this week and our view has been very clear that this is not a short process. It is something that is going to take some time and we have heard from Spain this morning that we will probably need ten years to repeat the success in Spain. But to begin with we are taking a five year approach. It is not cheap, but up till now we have been led to believe (and we trust the Department of Health — maybe that's my first mistake!) that new finance is to be forthcoming and there is no doubt in my mind now that we will be given new resources this year. What we intend to do with that this year as part of our five year plan is target seven intensive care units with new procurement officers who will fit into the transplant co-ordinator structure but will be based in intensive care units. We will be looking to identify and reward medical leadership in those seven intensive care units because I think you need both doctors and nurses in this process. We are going to be looking to fund three new non heart-beating centres in the UK and three centres to improve their living donation rate. We intend to undertake eventually a UK wide death audit and during the course of this year we will be pulling together the audit and validating it and that will be one of the first of many roles for Chris Rudge, my new Medical Director, who I am delighted to have on board. We are also in the process of appointing a new Board —Chris is the first appointment that we have made and it is very welcome indeed to have a doctor of such emi-

nence alongside us. My next appointment is the Director of Communication and that post will come into place, I hope, by the end of June or July— it is already advertised. The Department of Health are also ensuring that we have an appropriate Non-Executive Board and we have already seen the appointment this week, or this month, of the new Chairman to UK Transplant, a lady by the name of Gwyneth Flower, and the Department of Health are in the process of appointing new Non-Executive Directors, one of whom I hope will be somebody from an intensive care background because I think that is very important. We also intend to employ more co-ordinators during the course of this year and to implement the regional structure that the co-ordinators believe is the most appropriate, which will include leadership in the regions of the whole of the UK. So there is quite a lot to do this year but that is only the first part of what we are planning to do for the next five years and, all being well with a fair wind and the resources following us, I think we, in partnership with everybody else can start to make a significant difference to transplantation in the UK.

#### **DR. MICHAEL WILKS, BMA, AND CHAIR OF THE TRANSPLANT PARTNERSHIP**

I have the privilege of chairing the BMA's Medical Ethics Committee but far more importantly I am here to chair the Transplant Partnership which is a coalition of nineteen organisations, patient and charities and co-ordinators but also the bulk of the medical and nursing Royal Colleges. The Partnership is behind a consolidated approach. Our papers have been mentioned so I won't go into them in detail. Rather than pick out what has been stressed this morning —individual areas of potential benefit— it is very important to take all these forward in a co-ordinated and consolidated way. So the issue of say carrying a card has got to be seen alongside the improvement in the infrastructure which would follow from more people coming forward as donors. I was interested in hearing what Rafael said earlier but I didn't hear donor card mentioned once and I wonder where that fits in to the scheme of things if you are looking at the difference between the current consent rules that we have here and the consent rules in other countries. If I take my Transplant Partnership hat off for a minute, and put my BMA one back briefly, I have absolutely no idea how much we would improve donation rates in this country by passing a law on presumed consent. I suspect very little given the weakness of the infrastructure but I have yet to be convinced that it would do any harm

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and I think that the debate around presumed consent and the debate around the opting in card are all part of the same process of increasing public awareness and debate and I don't think that there is any harm therefore in doing that in whatever way we can. We have heard about the desperate need for an evidenced-based approach from Spain so often that it appears that the vast improvement in donation rate seems to have come from a careful look at the evidence. The crying need is for some evidence here that is up-to-date. We have some ancient evidence, a good ten year old evidence, from the study by Gore which suggested that only one third of the potential donors in an ITU became donors. We really need to have more information about that as well as some understanding of the wide regional differences that have been presented to us today. If we get that information, I suspect it will show that we simply won't improve the number of donations sufficiently to reduce the waiting list simply by using cadaver donors. I suspect that will be case, not only because it may not provide the current need, but also because at the moment there is some selectivity about who goes on the waiting list, so there is a lot of unrecognised need there. So I think we have to look very hard for other means and I welcome the news that non heart-beating donors, and I think very significantly live donors, are being proposed centrally. Certainly I would be very committed to exploring some of the ethical problems that are arising out of the question of what appears to be a more subtle version of the sort of «organs for sale» problem which, of course, is outlawed and rightly so here and in most countries. But the more subtle advantages that can be got from say a paired donation or from joining a pool, do need to be looked at ethically and legally as a matter of some urgency so we have got some answers to those who would actually wish, as I would, to improve the source of donation from live donors. Thank you.

### **DR. CHRIS RUDGE, NEW MEDICAL DIRECTOR OF UK TRANSPLANT**

Twenty-one years ago in May 1976, I did a kidney transplant for the first time on my own. In May 2001, I take up the job of Medical Director of UK Transplant. I shall be very brief because Sue Sutherland has said everything that I am going to, my job is to make it happen. I think it can happen. I think this is without doubt the most exciting time in the organisation of transplantation in the UK for a very long time because I think we have a serious opportunity to invest some money and to invest some time

and to invest some organisation that can really make a difference. What difference it will make, I don't know because I don't think we know the maximum potential that we can reach. But if we can demonstrate that we are reaching that potential, that is the best that we can do and that is what I hope we will be able to do over the next five to ten years.

## **AUDIENCE QUESTIONS**

*Mr. Richard Simpson*

I am a Member of the Scottish Parliament currently a reporter to the Health Committee of that Parliament on the question of organ donation and I will be producing a report in about six weeks time and I am glad to say, from what I have heard today, I seem to be reasonably on cue as to what should be happening.

I have two specific questions. One is about the amount of effort, money etc which has been put into the organ card system, the opt in system which we have at the moment and the cost of that. This question is really to Rafael – do other countries in Europe who have presumed consent, still offer a donor card system to try and promote organ donation? Is that effort actually worthwhile? The second question is, again across Europe: are there rewards to the hospitals for procurement of organs? You hinted at that in Spain, I didn't quite understand what the system was in Spain but it would be interesting to hear what it is.

*Professor Rafael Matesanz.* I think that most European countries with a presumed consent approach try to develop the donor card system. I would say, without much success. My opinion with respect to the donor card and so on is that, of course, they are useful because anything that you do in favour of organ donation should be useful. However, the cost/benefit ratio of such a Registry and such a card is really very high and any effect that you can see with this method would probably be after many, many years. So in fact, as far as I know there is not a single country which has introduced such a system and which as a consequence has really improved the organ donation rates. So the question is why do so many countries introduce such a system? Well, I think that the first answer is that most of the countries realise that they should «do something», to improve organ donation and they don't know how. So they have a Registry, they promote donor cards and so on and so on. Secondly, because it is expensive. For any government, anything which is expensive is

very attractive because it creates a lot of jobs. And in every country there is always some person who says that is really very interesting, so interesting that I want to be the Director! I know that the situation has been repeated in many countries—it is no joke, it is true. That is my opinion. Even in Spain, in Parliament there was a proposal to implement a Basque donor Register. The Basques wanted the Registry although they have 60 donors per million p.a. Fortunately we discussed it in Parliament and we said no, it isn't necessary, we are doing very well as we are so it is not necessary to implement this proposal.

*Dr. Peter Doyle:* The Committee which Rafael and I have been working on for some years has reviewed the evidence for effectiveness for organ donor registers across Europe and I have to say that there is very little evidence of cost effectiveness. There are a number of issues that do need to be considered though. If you have a presumed consent law then you do have to have some system for registering the opt out, for legal and ethical reasons. So you have to have an opt out register at some point to ensure that that happens and many countries introduced their organ donor register really as opt out registers rather than opt in registers. Some, like France and Sweden have made it multi purpose—you can opt in or opt out—you can do both on the same register. In Belgium they have gone one stage further and they have got three options on the Register. One is «yes, I want to be a donor», the second is «no, I don't» and the last is «ask my relatives!» and they send every eighteen year old a birthday card saying «you can now go on the organ donor register and become an official organ donor, here are your options, please fill in the slip and send it back». Again, they are very good at getting publicity and attract public attention, but until some country has got an organ donor register with a large percentage of the population on, it is going to be very difficult to prove that it is cost effective in easing the process of donation. The purpose of having it is to make donation easier and the reason that they make donation easier is that people going to talk to the relatives, and it is the hearts and minds of the people in intensive care and elsewhere that you have got to win. You have got to go in to the relatives feeling that they are doing some good and not making a bad situation worse. There are two reasons why they feel that they are doing good. The first is, if they know beforehand that the person wanted to donate, they feel that they are helping out with the deceased person's last wishes. The second reason is that they feel that donation itself actually does some good. There

is growing evidence that, when there has been a donation, the relatives' grieving process is eased and you actually make a devastating death rather better. So, far from making things worse when you go and ask the question, you potentially make things better for the relative of the deceased person. Now the people who are going to see the relatives have to feel that, have to own it, and have to feel that they are actually doing good. We in this country should have a system of assumed consent not presumed consent. All our polls show that the majority of the people in this country are in favour of organ donation, well over 70% in most polls. So there is a much higher chance of the dead person wanting to be a donor than they didn't. So every co-ordinator in this country should be going in assuming the person wanted to donate and approaching them accordingly. That is not different from presumed consent because what happens in presumed consent is that you go in assuming you have the right to the organs so you have a positive approach to the relatives. But in fact the introduction of some presumed consent laws have been counterproductive and recently in Switzerland where they tried to stiffen the law, donations fell because a lot of health professionals, as well as the public, do not like to feel they are being coerced. As we have seen after Alder Hay, they want to be asked and, if they are asked, they will agree.

*Chairman:* If I can put it bluntly it seems to be treating the symptom not the disease. If we have proper professionally trained transplant co-ordinators you don't need the donor card in the small proportion of the population who carry them to make those co-ordinators feel better, because they know how to do their job anyway. Is that fair?

*A professional transplant co-ordinator:* I am a professional transplant co-ordinator with many years experience, as have many of my colleagues. I think we have come today to hear about Professor Matesanz and the Spanish experience and we have perhaps drifted away from that. Many of the things we have discussed—such as live donation—are already organized. We need to get back to the basics and I think what we need is fundamental change in the hearts and minds of everybody in the NHS about this problem of patients with organ failure. Too long it has been seen as a problem for the transplant units. We as co-ordinators get very good support from our intensive care colleagues but we tread on egg shells; we can't ask to do reviews of notes because it is not seen to be allowable. We beg resources to do retrieval operations because everyone is stretched. Most of the operations are done through the night.

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We have recently, sadly, had reimbursement to our intensive care units stopped, even though it was minor and the whole climate has to change before we can effect any major improvement in organ donation. We also need to do a comprehensive review of the numbers of potential donors because the numbers in intensive care and the numbers who die on medical wards or neurosurgical units who were never considered are unknown and we need the information. So we need to overhaul the system completely and not just look at the fringe.

*Dr. Giles Morgan:* We did come here to listen to what Professor Matesanz has to say and personally I think that the one message that I have certainly taken home is that we have to give the process by which organ donors are managed to the hospitals themselves. They have to have ownership of the system and that struck me as a fundamental difference. With regard to transplant co-ordination, in my mind at least, it is a cumbersome hurdle having a transplant co-ordinator who is distant from where you work. One of the problems is that the family of the potential donor have to be interviewed by the transplant co-ordinator, so the whole arrangement is difficult. I feel that many of the hurdles could be removed if there were a transplant co-ordinator or a team of transplant people in every Trust; they should be part of the critical care delivery group, they should have access to it and they should be part of the way in which the Trust works. That would be terrific because the whole team would then operate in-house. Of course, it would need to relate to the UK Transplant organisation as a whole, but it would speed up the service and it would make life easier. It would give the opportunity for education and revision of education of nursing staff and medical staff, for training and teaching how to talk to and counsel families about donation, to explain the advantages and disadvantages, and to learn the things you can and cannot say. I think that if those things were done much of the debate about whether or not there should be a registry, or whether you should carry a donor card, would pale into insignificance. As someone else has said already, we have to have a change of philosophy not only in the NHS but also in the general population. So I feel personally that there are better ways of educating the general public about the benefits of organ donation than running a registry or investing money in donor cards which are really a waste of time. But please devolve it to the Trusts themselves and put it in their hands through the critical care delivery groups.

*Chairman:* That was a fairly critical comment.

*Professor Rafael Matesanz:* I fully agree with this philosophy and I want to add another thing with respect to a Registry —some kinds of registry are clearly negative. For instance, I remember the registry in Uruguay; whenever a patient came into a hospital for a broken finger or appendicitis, there were some people asking «do you want to become a donor?» And so they obtained 60% of refusals.

*Anthony:* May I extend what Dr. Morgan said. We have a problem of system and finance and Professor Matesanz has already pointed out that if you double the number of kidney transplants you save far more money than you are currently spending on renal replacement therapy so this skinflint attitude should be chucked out of the window.

*Chairman:* Let's hope we hear it has been.

*Dr. Robert Ginsburg:* I have been, for the last 13 years, the Transplant Anaesthetist on the liver programme at Kings and for the last 6 years I have run a training programme for anaesthetists in South East Thames. So I am wearing two hats. I have a very pragmatic question: most organ retrieval teams comprise a surgeon in the appropriate specialty and usually a scrub nurse. There is never an anaesthetist. Giles Morgan may confirm that most donor patients have anaesthetic services of some kind until the heart stops beating, if only to provide physiological support. Those services are provided by the donor's hospital not by the retrieval team. That self-same anaesthetist who provides the donor services is also running the intensive care unit at night there as well. So a hard pressed group of people who barely have the time to run the emergency work, also have to provide services for the organ retrieval surgical team that comes in. So my question is, why does this historical curiosity persist? If there can be surgeons and scrub nurses, why can't there be an anaesthetist on the team as well? There are a number of added benefits therein.

*Mr. John Forsythe:* I have touched on it very briefly but I didn't have time to go into it in much detail, but I would fully agree with that. Part of making it easy for the donor hospital is not taking the anaesthetist off their usual work in a small hospital where the Consultant Anaesthetist will be up for many hours supervising a multi-organ retrieval, when they could be doing other things if there were an anaesthetist on the retrieval team. One of the things that we are looking at in Scotland is a single organ retrieval team. We must say that zonal retrieval is a considerable improvement on what used to happen.

However, we should be looking further along the line —we often have two nurses going out on the team, one a scrub nurse for the cardiac side and one for the abdominal side when one person would probably do. So we can make reductions in the total number of people who are going and focus better on the vital members who should be there. On another point, there is evidence that if you put an experienced anaesthetist on the retrieval team that may increase the number of organs that are donated, particularly intrathoracic organs.

*Dr. Peter Doyle:* That has been taken on board. We are going to be working with UKT on pilot projects for new revised retrieval arrangements. Papworth have always sent an anaesthetist out and they have demonstrated the benefits so we are well aware of the need to get standardised retrieval systems in every zone.

*Dr. Giles Morgan:* Could I just say from the point of view of the Intensive Care Society, being an anaesthetist myself, that 80% of all intensive care units in this country are managed by doctors who are generically qualified in anaesthesia. They may have done a lot of other things besides, but that is the way it is in this country. I would be delighted if I found an anaesthetist coming out with the retrieval team, that is for certain. But the role of the anaesthetist in the donor hospital is not only to provide anaesthesia but to provide intensive care as well. As time goes by, that should change because anaesthetists ought not to be covering intensive care and operating theatres at the same time. But when a retrieval team arrives at a hospital, which is largely alien to them, where they may never have been before, somebody has to meet them, show them round, be an ambassador for the donor hospital and to organise hospitality and a welcome. That is all part of the package, and a very important one, I believe. It is one of the reasons why in my hospital, the donor team and the retrieval team do end up at my place though I live on the far Western approaches in Truro, they actually like coming to my place because we give them a good service. I also feel that the anaesthetist who goes to theatre from our department and escorts the patient is in some respects a spiritual guardian of the patient, he is someone who is there to see fair play, to make sure that there are no divergences of opinion perhaps between the visiting team and the team of theatre staff who are providing the donor environment. So the anaesthetist, I feel, is singularly important in a number of respects.

*Ms. Gemma Benoliel* from the National Kidney Federation and representative from the Churchill Hospital.

It seemed a fundamental point of the Spanish system, to be able to say out loud that we are under detecting, we are wasting potential donors. Are we actually saying that? Maybe I missed it. Has that been accepted and are we going to audit that as the Spanish system does?

*Ms. Sue Sutherland:* Can I respond to that. I am sorry if I didn't make it clear but one of the things that we are going to do this year is to bring together a death audit tool, validate it and push it out to the whole of the UK. It will identify what potential there is out there that we are missing. We have a feeling at the moment that we are missing donors. We think we must be because Spain can achieve what they are achieving, which is a huge difference. Whether we can ever achieve what Spain is achieving, we don't know. But we need the death audit tool in place across the whole of the UK to prove to us what the potential is and what we are missing.

*Professor Rafael Matesanz:* I have read the plan that Peter has just commented on and I welcome the implementation of the UK Transplant plan and this brain death audit, which has just been announced. I think that the first step in solving any problem is to realise that the problem is there. The only way to know that this problem really exists is the brain death audit. Of course, if you compare data in the UK, for instance with the Spanish data with respect to age, number of donors, number of ICU beds and so on, you are likely to conclude that you are losing donors but you cannot say *where* you are losing them. So I think this is the right way to go: I am sure that the death audits should be performed but there should be an external evaluation. Probably the best evaluator would be a transplant coordinator from another country or another region. When you find that your hospital is losing donors you probably won't believe it at first but when it is confirmed by someone from another country who comes and reads all the histories and says you are losing donors you will realise it is true. We are still losing donors in Spain..

*Dr. Chris Dudley, Nephrologist from Bristol:*

Perhaps one relatively easy way of integrating some elements of the Spanish model into our system quickly would be to have the system of required request with required orders rather than changing to a presumed consent if we are going to change legislation. I think many of us were disap-

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pointed that it didn't go down that route rather than a presumed consent route. Under this scheme, people looking after the potential donors would be required to ask for donation, assuming (as you have said, and I think you are absolutely right) that most of the general public are pro donation.

*Dr. Peter Doyle:* The problem with required request is that in several places where it has been introduced, it has been counter productive because the people who have got to ask the question, avoid it. As Raphael has said, in the most important point he made in his talk, the easiest thing in the world is for the physician in charge of the patient to find an excuse for that person not being a donor. And what has happened in the States and other places is that donation rates have often gone down after these countries introduced what were seen as coercive systems. We are introducing a required audit of every patient dying in hospital to see which of those patients should have been donors and there will eventually be a single person with responsibility for all procurement in every hospital in the NHS. It will be part of the clinical governance system and it will be a continuous audit, not a one-off. It will be there in perpetuity so that we are doing the maximum we can to procure donors, live, non heart-beating and heart-beating, in this country to whatever the resources will allow. We know less younger people are dying year by year in our hospitals so it is going to be a continuous battle to maintain «our share of the donor market». That is all that we are intending to introduce.

*Dr. Giles Morgan:*

Can I add some information on this topic. The Intensive Care National Audit and Research Centre, or ICNARC, which is the Intensive Care Society's sister organisation, already audits this as part of the Case Mix Programme that we run. The Case Mix Programme now operates in 65% of the intensive care units in the country. It will eventually, be collected in 100% because the Government have now made it mandatory that it be collected in intensive care units in England. Wales and Scotland are out of their jurisdiction because they have separate political organisation. Among the data that will be collected on each patient are whether the patient was «brain stem dead», whether they were a potential donor, whether the request was made and what was the outcome.

*Chairman:* So there will be an audit in intensive care units. I guess one of the critical issues is whether many of the potential donors ever get to intensive care units.

*Dr. Giles Morgan:*

One of the essences of comprehensive critical care and the reconfiguration of the critical care service and the importance of the Trust critical care delivery groups is that the whole of the reconfiguration of the critical care services in this country, and the concept of outreach, has to be underpinned by information management and data collection. That was one of the stipulations that the National Expert Group made to the Department of Health when we put together the Comprehensive Critical Care document and so it is imperative on your Trust to make damn sure that they are actually implementing a proper critical care data collection system because that has been funded and the money is supposed to be there as part of comprehensive critical care. So this is the very sort of data that can be made available immediately.

*Ms. Alison Crombie.* We have looked through the report of the British Transplantation Society working party which set out to investigate the variation in rates around the country. That report shows there are some areas with potential for increased donation rates. I welcome the news that UKT and the Department of Health are putting in place a new death audit. But I want to put a question to Peter Doyle about ownership of donors within the local sector. Will there be much information going out to the Chief Executives about their responsibility and about what we have recently been doing in policy setting. As yet nothing has come out of the Department to the Chief Executives and I wonder if that is going to be done shortly?

*Dr. Peter Doyle:* Very briefly, two things. One: there will be the NHS Action Fund completed during the course of the year. That will be incumbent on all of the Trusts and the whole NHS. Two: there is also in parallel the National Service Framework for renal disease which will include renal transplantation. Both of those will be priorities for Chief Executive to deliver.

*Professor David Kerr.* As John showed us, one of the main reasons why we have lagged behind Spain is that we make very little use of older donors. Is that because older people do not get into the ITU in Britain, or is it a policy and, if so, why we are not campaigning for much more use of older donors?

*Dr. Giles Morgan:* It is a matter of education. In this country there are two problems. One is ageism. In Spain they have a much higher age cut off limit

of 75. In this country it is 65 but I have very rarely managed to sell a donor aged over 60 to the Transplant Organisation Service. [Gasps from audience.] You may be aghast. But one of the questions I would like to ask is what is the proportion of donors in Spain aged between 60 and 75 years of age, because I suspect that it is a substantial proportion but in this country it is this top end of age group that we are missing when they are at large around the hospital and I suspect that it is one large cohort of donors we are missing.

*Professor Rafael Matesanz:* In the early 90's we had only about 10% of donors over 60 but the acceptance criteria of the transplant teams are changing all the time and, while there are only one or two teams who have accepted livers from donors more than 60 or 65 years old, livers from people who are 71 or 72 are now used and in Italy we have recently transplanted the liver of a 92 years old and it is working very well. 33% of organ donors in Spain are now over 60. So I think that it is the responsibility of the co-ordinator in intensive care to be aware that people over 70 and even over 80 should be considered as organ donors and also the transplant team should agree the criteria for accepting such a candidate for transplant donation.

*Dr. Peter Doyle:* Giles Morgan's comment about donors over 60 and the response from those of us involved in transplantation in the audience shows that there is a problem. Another part of what UK transplant and I want to achieve over the next year or two is to agree and introduce much more even assessment criteria for managing donors and referring donors and accepting donors. It really is absurd if Giles refers a 60-something year old in his part of the country who is turned down whereas John, myself and Andrew would happily accept that donor if that donor happened to be in another part of the country. We have to use standard criteria.

*Ms. Helen Manderfield, South Thames:*

I have a particular interest in education, having run the UK TCA courses for the last 6 years, and I am very interested to know if in Spain you regularly reaccredit the transplant co-ordinators after they have undertaken the initial intensive training?

*Professor Rafael Matesanz:* Yes.

*Ms. Helen Manderfield:* Is that done every year?

*Professor Rafael Matesanz:* There are many courses for transplant co-ordinators throughout the year.

We have specific courses on approaching the family for transplantation, handling the mass media, donor management, donor protection and so on. I think that in every region there is one hospital which specialises in developing such courses and there are some groups, for instance in Barcelona or Alicante, who have run such courses in Latin America or in Italy, in Tuscany where I am working now. We have even conducted such courses in English for people from Eastern Europe and for all co-ordinators. These training courses have been really important in Spain and have been supported by the Spanish Government and the Spanish Ministry. They have made a great investment during the last decade and I think it has been one of the most important ways of developing transplant co-ordination at work. And now having the transplant co-ordinators fully involved in the training and education of co-ordinators from another country has had a very positive effect.

*Ms. Helen Manderfield:* Is that all centrally funded and is everybody obliged to take part?

*Professor Rafael Matesanz:* It's centrally funded but is redistributed every year. There is a central budget which is distributed to all the hospitals in the region which present some initiative, some project for a training course in Barcelona, Madrid, Andalucia and so forth. The funds are distributed before the courses are conducted.

*Ms. Helen Manderfield:* Thank you very much I hope that we can move towards something like that in the UK, where currently there are no mandatory requirements for any co-ordinator to be funded to attend any ongoing education.

*Chairman:* Pam do you want a very quick response?

*Ms. Pam Buckley:* Can I put a question to Professor Matesanz: in the UK 91% of the Kidneys that are retrieved are actually transplanted and if I have got the data right, only 79% are transplanted in Spain. Why do you have such a large discard rate of the kidneys? The procurement rate is obviously skewed by the fact that many organs are not being utilised.

*Professor Rafael Matesanz:* There are several explanations for this, first of all, the number of marginal organ donors is much greater in Spain than in the United Kingdom. The philosophy of our transplant co-ordinators is to obtain as many organs as possible even from old people. So we get many more

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donors over 65 or 70; from some of these we can retrieve the liver but not the kidneys. From small children we may retrieve the heart, perhaps the liver but not the kidneys and so the number of organs that is discarded is much greater in Spain than in the UK. Furthermore, I have to say that it is very curious that when we are trying to build a unified Europe the transplant organisation has not been able to agree a unified concept of what is a suitable organ donor, something which should be as clear as the concept of an organ donor.

In Spain this concept is closely linked to the concept of reimbursement. The problem here is that when you try to obtain a valid organ, you should first dedicate an operating room, you should dedicate surgeons and you should dedicate co-ordinators and so it costs money. In Spain about 5-8% of «donors», do not in fact donate. We call them «white donors». You start to take the organs, you take the liver, you take the kidneys, you take the heart, then you discover some medical complication which prevents the use of the organs, and discard them. In some countries that would not be counted as a valid organ donor. There should be some mechanism for the Spanish Health System to investigate these «white donors» so that the difference between «white» and conventional donors can be agreed. In my opinion the most specific criterion for separating 'white' and conventional donors is cadaveric renal transplant. Cadaveric transplant, together with liver transplant, is the best statistic to compare the donation rate in different countries.

*Ms. Deirdre Cunningham*, transplant co-ordinator from Nottingham. Does the Panel believe that Bri-

tish transplant co-ordinators should be put to rest after 2-4 years in the post?

*Chairman:* Well who are we going to get to answer that one —what about a transplant co-ordinator?

*Ms. Pam Buckley:* Well I have done nearly 16 years now and I have no less motivation today than I had 16 years ago. I think that one of the positive things about the British system is that many of us do work with the recipients and that is the thing that keeps us going, I go to work to be with the people I know in our Unit and whom I have become very fond of; if we don't have that we may limit the time people can do the job because doing just the donation work is very exhausting. But certainly most of us are not burnt out after 2 or 3 years.

*Chairman:* It is only fitting and appropriate that we have the last word, or the last question, from a patient.

*Mr. Gordon Nicholas:* Yes thank you very much for that. It's on behalf of patients that we are here today and we have heard a lot of people talking about the infrastructures going to be put right, but as somebody who represents 17 - 20,000 kidney patients out there, I can only emphasize the fact that there are patients now dying for a transplant. We've seen and heard a lot of fine words but what we need now is action and we need it quickly. You have got your future plans, but we need them now —people out there are dying. Please, please let's get more donors in this country.