

**THE LEGISLATIVE COUNCIL SELECT COMMITTEE ON ORGAN DONATION  
MET IN COMMITTEE ROOM 2, PARLIAMENT HOUSE, HOBART ON MONDAY  
1 OCTOBER 2007.**

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**Dr DAVID REID**, SPECIALIST, RESPIRATORY MEDICINE, ROYAL HOBART HOSPITAL, WAS CALLED, MADE THE STATUTORY DECLARATION AND WAS EXAMINED.

**CHAIR** (Mr Wilkinson) - Thank you, David, for coming along. What the committee is about, as you have probably seen from the terms of reference, is organ donation and looking into the areas as set out in terms of reference 1-5. You have been recommended by Rudi; he said you were the man, so we took his advice and invited you along to give us information on organ donation. Do you have the terms of reference before you?

**Dr REID** - I do.

**CHAIR** - If you could speak to those specifically, that would be more than helpful. Would you like to start with a general overview?

**Dr REID** - My understanding at the moment is that organ donation in Australia is an opt-in process. It is done through Medicare. There is an organ donation consent form on the Medicare web site, or in a paper version at Medicare offices, with which individuals can specify their wishes about organ donation - which organs they wish to donate or do not wish to donate.

**CHAIR** - Do you believe people know how to donate organs, if requested?

**Dr REID** - I suspect not. I think there have been media campaigns to try to increase organ donation. I think the thing that dictates organ donation uptake is very much an educational thing, so the community has to understand the benefits of organ donation and what it involves. I think it is very difficult to discuss this issue with families at the time about an individual who has not registered their wish but who could be an organ donor.

**CHAIR** - As you have said, you did not know these were the types of questions you were going to be asked.

**Dr REID** - No. I spent six years at the Royal Prince Alfred Hospital, between 1996 and 2002, and for the first four years of those years I was mainly involved as a senior registrar or a research fellow in the lung transplant and cystic fibrosis units. The Alfred Hospital has one of the world's busiest lung transplant units, and the adult CF unit is one of the biggest in the world as well. Then I came to Tasmania and took a position as a general respiratory physician but, by default more than anything, I have a responsibility for statewide adult CF services. That is what I do now; I am not actively involved in transplantation at the present time. As to renal and liver transplantation, I would not be the person to talk to.

**CHAIR** - Rather than going through these specifically at the moment, can you give us a general overview of your experience? You know the type of things we are looking at. What things do you believe we should know?

**Dr REID** - I think one of the important things is death on transplant waiting lists. That is what we are talking about, whatever the organ is that we are discussing; how many people die whilst awaiting new organs? That is a very good measure of organ donation rates, I think. My specialty is respiratory so I know about respiratory deaths on transplant waiting lists. There is actually very little data in Australia on this issue, but there is plenty in other countries of the world with a similar health care system.

The most common cause for lung transplantation in Australia would be smoking related - COPD or emphysema. The second most common would be cystic fibrosis, and following that is idiopathic pulmonary fibrosis - a scarring condition of the lung, which is where Rudi is at the moment. Pulmonary fibrosis has the highest death rate on the waiting list and that reflects the aggressiveness of the disease and the fact that people may be referred a bit too late in the process, so they don't get onto the waiting list to give them enough time to get a transplant. About 40 per cent, maybe up to half the people, with IPF will die whilst awaiting a transplant.

**CHAIR** - Am I right in saying that those people who require a transplant are measured - their lungs are measured - but because of the illness their lungs decrease in size and therefore, depending on when they are able to obtain an organ, if they are, their lungs are a different size from what they initially were? Therefore there has to be a continual monitoring of the size of lungs et cetera?

**Dr REID** - No. When they actually match the size of the organs they match it to the pre-disease size of the person's thoracic cavity. Pulmonary fibrosis is a condition where the lungs become scarred and shrink down, but when they match the donor to the recipient they match it on the recipient's predicted lung function. So it is not the measured lung function at the time they are coming to transplant; it is what their lung function should be. We know that over time - one to two years - the chest wall will remodel itself back to what it should have been. It is the opposite with diseases such as cystic fibrosis and emphysema where you get big, hyper-inflated lungs. They are bigger than they should be but you match them to what their predicted size should be, so they usually get smaller lungs when they get transplanted - the ones they have on the day of transplant.

**Ms FORREST** - There was a media report recently about a child needing a lung transplant and having an adult lung cut down to size; can you explain how that would have worked? I come from a medical background so I have a bit of an idea about how lungs work and how it all fits together. Do you take off the bottom lobe and is that a way forward?

**Dr REID** - I'm not sure anatomically which bit of the adult lung they take off. It would be a living, related donor so normally it would be a parent who would be the donor. Depending on the size of the child I assume they trim it down the bit. Often it is a single lung or maybe they take one lobe from one lung of the donor and divide it into two and give the child two lungs, so the size matches. The trouble with that sort of procedure is the potential for very high mortality, so you might not only lose the child, you may lose

the parent at the same time. Living, related donation of lungs is a very hazardous thing I think.

**Ms FORREST** - Would you do that procedure with a cadaver donor to a child?

**Dr REID** - I do not know about paediatric transplantations. Certainly in adult transplantation if you can't quite get the size matching right then they will trim the donor organs down a bit to get them into the thoracic cavity.

**Ms FORREST** - Thank you.

**Dr REID** - Does that answer the question?

**CHAIR** - It does, thanks.

**Dr REID** - With idiopathic pulmonary thrombosis it is more likely for people to die on the waiting list. That may reflect late referral but usually it is a reflection of lack of donors because they do not have quite so long to wait, so the more donors there are the more likely they will be to get the organs.

Cystic fibrosis: probably a quarter of those people will perish on waiting lists. COPD: they can keep going for ages waiting for new organs; maybe 10 or 15 per cent of those people will die whilst waiting transplantation.

Transplantation isn't always to prolong life. For people with pulmonary fibrosis and cystic fibrosis lung transplants will prolong their life; they will live for longer. With COPD it is more to do with quality of life. You may prolong their life but it is more to do with quality. They could sit for years with home oxygen but be miserable, but you can get new lungs and have some quality of life and maybe get back to the work force.

**CHAIR** - Did you have to speak with the families of the people who were going to donate?

**Dr REID** - I never really went on any organ retrieval runs when I was based at the Alfred; the team would go out to wherever it might be. Occasionally we got a donor from within the Alfred intensive care unit but I never had those sorts of discussions with donor families, but I may be able to help you if you have specific questions.

**CHAIR** - In Australia about 1 700 people die and there are around about 2 500 waiting donation.

**Dr REID** - Across all organs.

**CHAIR** - Yes, which is a significant amount. Am I right in saying that if one person is willing to donate they can assist approximately four other people with an enhancement of life or a continuation of life? Are you able to give me a broad overview in relation to all that?

**Dr REID** - There are all sorts of things they can do with donor tissues now. Certainly lungs and heart. Single lung transplants are very effective in people who have emphysema or pulmonary fibrosis, so two of those individuals could benefit from one donor, and the

heart would go to another individual. You have a liver, two kidneys and then all the other potential transplants like corneal transplantation, skin transplants now -

**Ms FORREST** - Bone marrow.

**Dr REID** - Bone marrows, potentially, yes. So if you add it up - two lungs, heart, liver, two kidneys - that is at least six people who live and you may transform their lives.

**CHAIR** - We are talking about being brain dead prior to a donation occurring and not everybody who dies is able to donate. Can you run us through who is able to donate?

**Dr REID** - The usual process is that the donor is brain dead and that is ascertained by a team of clinicians.

**CHAIR** - Brain dead being what?

**Dr REID** - There are lots of tests that they do at the time, such as EEG activity to assess brain death and I think it is a very reliable assessment of brain death. The patient may be on a ventilator but they are actually brain dead with no hope of recovery and the donation is then done in a setting of a beating heart so the patient is I suppose alive but brain dead. One of the things that people are doing now is trying to optimise organ donations to use non-beating heart donors so the patient is actually dead and they are dead at the time that they harvest the organs because the majority of the time the patient has a beating heart when you harvest them. I think advances in science and preservation of fluids and so on can allow retrieval teams to get organs from non-beating heart donors and it seems, from my understanding, that some families are happier to donate organs from a non-beating heart donor. Whatever the reason, they have a lot of angst about donating organs from their loved one when their heart is beating so they are still sort of alive but when they are dead it seems to help relieve some of that anxiety.

**CHAIR** - Can you run me through the process as to what has to happen when a person is, unfortunately, brain dead? He or she is willing to donate their organs, any organ that they believe is able to be used, what happens in the medical sense?

**Dr REID** - I am not quite sure what exactly happens in the unit.

**CHAIR** - Let us say it is a lung transplant.

**Dr REID** - Someone has expressed their desire to be an organ transplant donor and the family are happy with that, they have already signed up to the Medicare consent so we are assuming the consent is fine. Then the intensive care physicians will phone up the various transplant units and notify them that there is a potential organ donor. Each of the transplant units has a coordinator and they then coordinate the whole process, whether it is lungs, liver, heart, and somehow they all communicate with each other, and a number of investigations are done at the time on the potential donor. A lot of them would have been done already, so blood grouping, tissue typing, checking for various latent viruses, and they identify it. Nothing has been taken from the donor so they characterise the donor and talk to the transplant teams. They then go through their database of people who are on the waiting list for organ donation and they match them for things like blood group, size, tissue typing, and they normally have a short list of about five. If it is a lung,

the Alfred Hospital would whittle the list down to about five people and then it becomes an issue of who is most in need of those organs and most appropriate.

**CHAIR** - How do you discover who is most in need?

**Dr REID** - The Alfred team comes down to Tasmania at least twice a year to see all the patients on the transplant waiting list and it is an eyeball test so they know from objective measures how sick they are but they also like to meet patients in clinics to make a physical assessment of how sick they are. If a patient who is on the waiting list has a deterioration in their clinical status, normally the caring physician will notify the transplant team that things have changed and there becomes more of a sense of urgency to transplant the individual.

**CHAIR** - When you look at who is to obtain the organ do you just look at how ill that person is or, alternatively, do you look at other factors as well, maybe a young family of four children under the age of six or something like that?

**Dr REID** - It is very difficult.

**CHAIR** - Are all those things looked at or is it just the illness that is looked at?

**Dr REID** - I think you will have to ask the actual transplant team because it is a very difficult thing. It often happens in the middle of the night and is an incredibly difficult decision, I think. For instance, 65 is generally the cut-off for lung transplantation so someone over the age of 65 would not be a candidate but if you have someone who has lived quite a good life, enjoyed things, they are 60 and they have bad emphysema and you know that they are relatively sick and you have a young person who is 18 with cystic fibrosis who is quite sick and they are both ideal recipients, it is a tough call. All those things come into the equation.

**CHAIR** - So it is not just the illness but it is other things as well, you believe?

**Dr REID** - Yes, it is the illness inasmuch as we know that sufferers of pulmonary fibrosis and CF have a much more rapid decline so in that sense the illness does come into it.

**Ms FORREST** - You made the comment earlier about the Alfred being the busiest unit with lung transplants and any other transplants within Australia. Is it only using Australian organs, organs from within the country, or do you ever get them in from somewhere else, if Singapore, for example, had no-one who was a viable recipient for a lung or a heart that was available there?

**Dr REID** - The limiting thing in Australia is distance and distance for lungs especially is really important because they are fragile organs and they deteriorate very quickly when they have been removed from their natural environment. It is called ischemic time which is low oxygen and low nutrition and damage happens very quickly. So they use a number of preservatives that they fuse the organs with and keep them cool obviously to keep them going for longer. They may have extended ischemic time in the time since I left but about eight hours is the time that you can be fairly confident that when you get the organs they are going to be fairly fresh, fit and healthy for the donor so going further afield, for lungs at least, is not really an option. It is very difficult.

Western Australia has now a lung transplant program, I think - I do not know whether it has started but they certainly have the facility - but prior to that they all came to Victoria because of the distance. You could not live in WA and expect on the night, with an organ becoming available, to get it; it was impossible because of the time it would take so they had to relocate. It was the same with South Australia. Tasmania is quite lucky; they have a good retrieval service. Tasmanians can stay here and wait for the call.

**Ms FORREST** - That brings me to the next point, the non-beating heart donations. The time factor there too is pretty crucial, I imagine. Can you talk a bit about that as opposed to a brain-dead beating-heart donor?

**Dr REID** - I am not sure because it is a fairly recent thing. It has happened since I left the Alfred. It is only in the last one or two years, I think, that they have been looking at non-beating heart donations and they could have only done a few transplants from such donors but you are right, it would have to be done very quickly which I suppose gives the family less time to grieve.

**Ms FORREST** - Thinking through this a bit, a patient generally is in ICU, or DEM anyway, and hooked up to most things. Are we suggesting that we wait until the heart stops bearing in these cases or is this where the heart stops beating and then the clock starts ticking?

**Dr REID** - I think it's where they withdraw treatment.

**Ms FORREST** - If this was made more the norm, I guess, a more common way of retrieving organs - I don't like the word 'harvesting' very much - do you think if there was a publicity campaign saying that the way we intend to look at organ donation now is through non-beating heart donations then it might have greater public acceptance and it might be one way of enhancing the donation rate?

**Dr REID** - I would have to look at the literature on it. I am not sure exactly how much it would increase the donor rate. It would increase it substantially, I would think, if it was that society, the community, was happier with that way of doing things.

You would certainly need a big education program. In the UK they have had success with education programs on kidney donation. It took many, many years with ongoing education at a large financial cost until they were at the point where they saw donation rates going up. So education is critical. You need to really get in there and plug it and support it financially.

**Ms FORREST** - In your opinion, do you think that is one factor that could be making people less likely to donate?

**Dr REID** - It might make families feel more comfortable about it.

**Ms FORREST** - I had a discussion with my 14-year-old about this before coming down. I said to her that even though I might say I want to donate, if I die she might be the one who is called upon to make the decision. I would hope that she would respect my wishes, but a lot of people don't. Whilst talking about being brain dead as opposed to a

non-beating heart, are you aware of any place in the world that has focused more on that sort of donation and the outcomes or is it a bit too early perhaps?

**Dr REID** - I don't know. I suspect there probably are countries where that might be the issue because they have beliefs in the country about live donation versus a cadaveric donation. I would have to go away and have a look and report back.

The other thing about organ donation is that it is not only the media education, it is also what happens on the night of donation. Regarding a family that are hesitant or they are approached in a way that makes them anxious about it, there have been studies that have looked at whether it is a registrar, nurse or whoever goes and discussed transplantation and it makes quite a big difference as to who it is who discusses organ donation with the family. If it is someone who is very well-versed, educated and can communicate, it makes it more successful and you will allay the family's anxieties about it.

**Ms FORREST** - You made the comment that there is a coordinator in each unit you have been involved in, so if the possibility is there that a patient is identified as being a potential donor that person swings into action. In Tasmania we don't have anyone in the State, to my knowledge, in the Department of Health and Human Services who can coordinate this. Do you think that if we had someone - it would probably only take one person in the State to educate all the staff in the DEMs, the ICUs and maybe operating theatres - that would be an important step in trying to make that part of it easier and hopefully impact on the public perception of it?

**Dr REID** - I suspect it would make a difference. I think there is a look in Victorian hospitals at ICU donation rates and how many they were missing that would have been good donors. There is a substantial proportion of cases where the people who should have been considered as potential organ donors just weren't. If you had someone on site who could educate intensivists and physicians, even if it got a few more organs per year, it would make a big difference to individuals. I think it would be a good idea. Educate the health professionals.

**Ms FORREST** - Yes, to have a consistent voice doing it.

**Dr REID** - One person, yes. I assume what happens is that when a potential donor goes into Medicare - the national donor register that exists - that central body coordinates.

**CHAIR** - I've recently become a donor. I have often said I don't mind, but I think I am like a lot of Australians. People say, 'I wouldn't mind donating my organs if something happens to me', but that is as far as they go. In order to go the next step, I had to find out what to do. I had to request a document, the document came, I had to sign it and send it away to get on the register. Years ago, as you know, if it was on your licence then you could be a donor. It is different now. They say it is the education of the family as well to let them know what your wishes are, which is the next step. It is now an opt-in process if you wish to donate your organs. What about if you reverse the process where, unless you opt out, you are opting in? In other words, unless you opt out and say, 'I don't wish to donate my organs', everybody who does not opt out may have their organs donated. What do you think about that and how do you think that would be accepted?

**Dr REID** - It is very difficult because there are so many complex issues with how people perceive these things. I think they can surprise you with how they feel about this. I think it has got the potential if it is backed up with an education program so that it does not become an almost compulsory-type thing. People have asked about compulsory donation it has actually lessened their desire or it has frightened them, so it has had the reverse effect. If you educate the community and you have to opt out, so you have to declare that you do not want to be a donor, then that may be a very successful way of increasing the donor core.

**CHAIR** - Do you know of any other countries that have that process?

**Dr REID** - I don't. Do you know?

**CHAIR** - I heard Spain did but I do not know for sure whether they have or not.

**Ms FORREST** - Austria is another one. Austria has what they call 'a hard option' and Spain has a soft option. With Spain if you do not opt out then you are in but the relatives still have to give consent and often they do not. With Austria they were saying that they have changed the attitude of people to the point where they just accept it and the relatives basically cannot do anything, unless there was some fear for the mental health or otherwise of a family member if a decision to proceed would be detrimental to them. Even with the opt-in and opt-out options there still seem to be a lot of variations so finding the right option may be a challenge. You are not aware of how those systems work?

**Dr REID** - I am not, I am afraid. In all these sorts of things obviously you would have to look at the legality of it concerning the families who object to the donation when the person has obviously not opted out of the donation process. Then there is an ethical debate as well about this sort of thing. I think it would be a sensible thing to do.

**CHAIR** - Is that an issue worth pursuing? As I understand it, Spain is an opt-out country, as is Singapore.

**Dr REID** - It is probably worth seeing how they went about it, whether they actually went to their people and asked them what their feelings were about it and whether there was a very comprehensive education program before they introduced the opt-out system.

**CHAIR** - Do you believe that that would be a good system to follow because of the assistance it can give to lives of suffering people?

**Dr REID** - Yes, I do.

**Ms FORREST** - With the opt-out option, if there were relatives who were reluctant, as a medical practitioner would you be happy operating on the donor without what could be perceived as full consent? There may be a lack of consent from the family. How would that impact on medical professionals, do you think?

**Dr REID** - It would depend on whether they got sued or not, I suppose. I imagine what would happen is that there may be a test case to see whether you can actually litigate



against a surgeon who has retrieved organs from someone who has apparently given consent by not opting out but the family are resistant to that.

**Ms FORREST** - You are not aware of a test case like that?

**Dr REID** - No, I am not. The other thing is like enduring guardianship. If people opt out they may also nominate a guardian, and that might not be a family member, who ensures that their wishes are adhered to. So if they want to be an organ donor and there is a nominated, signed-up guardian, but the family are contrary to the idea, then I think they would think you would be more protected in that setting.

**Ms FORREST** - Are you suggesting then that there may need to be some -

**Dr REID** - Third party.

**Ms FORREST** - legislative framework around that to protect the medical practitioners?

**Dr REID** - Yes, there may need to be another party who is the enduring guardian for somebody. These things do not take very long. It is the same as not-for-resuscitation orders where people nominate an enduring guardian, who is often not a close family member because they know that family would be so upset that they would insist on everything being done but the individual does not want that to happen. Perhaps having a third party involved in the opt-out option, nominated as the person who will police the deceased's wishes, will ensure they are adhered to.

**Ms FORREST** - You believe that there needs to be some sort of protective framework for medical practitioners to avoid being sued?

**Dr REID** - On first thought about it. We are not that litigious a society yet but it is a bit of a concern.

**CHAIR** - On the other hand you have the US, who have the opt-in process and their process is fairly successful. They have 21.4 donors per 1 million people, I think, so that is quite good. You have Spain on the other hand in the 30s with the opt-out clause but that is a soft option. Austria has the hard option, so there are different options in relation to the opt-out clauses. If you had to design what you believe would be the most appropriate plan in relation to organ donation, would you have an opt-in or opt-out clause? If you have an opt-out clause would you have it with certain conditions and, if so, what would those conditions be - or is that something I have to put on notice for you?

**Dr REID** - Probably.

*Laughter.*

**Dr REID** - I think opt in would be the desirable way of doing it because the community would be much happier I think with an opt-in facility, but that will only work if you have an incredibly good education program so that they really understand the issues and can then opt in and see the benefits. That would be the ideal thing because then it is really someone consenting positively to it; they discuss it with their families and everyone

agrees. Opt out would be equally good I think with an educational program. Maybe they are just opposite sides of the same coin and there would not be that much difference.

**CHAIR** - In Sweden the rate of donors has declined as a result of the opt-out clause.

**Dr REID** - Yes. With opt in, people would understand that much more easily than an opt-out option, although you might get there after several years of education. It would take longer to educate the community about that. They would have a sort of knee-jerk response to that way of doing it, I think. I am not saying it is not a good option; I just think it might raise hairs on the back of the neck. So opt in, with a good education program, we have seen works quite well in the States. I am not sure what the Australian donor rate is but it is quite a bit less.

**CHAIR** - Around about 10.

**Dr REID** - I see from the terms of reference that Tasmania is at the bottom of the pile, so it's even less than that.

**CHAIR** - Tasmania is about two - a low number - therefore it is fairly volatile as to how to increase or decrease it.

**Mr HARRISS** - With the ethics of the whole process, at the Alfred did you confront any circumstances where there was real family conflict? What was the outcome of that and who ends up making the decision?

**Dr REID** - I was not directly involved in that acute setting where you would be discussing it with the families. We had skilled counsellors who did that. I am not aware, during the six years I was there, that there was any large conflict. As soon as it becomes apparent that there is going to be some conflict, the people who go and talk to the families are fairly skilled at realising that this is something that is not going to be resolved without causing a lot of anxiety. I think you just leave it, you don't continue trying to get the family to consent to donation, even if the person who has died has consented. I think they would pull away from that and I think the reason for that is that if you continue with these sorts of discussions and a family gets incredibly upset and it may appear in the media, transplanters are very sensitive about this sort of thing because it impacts adversely on organ donation. It would appear that people are being coerced to consent to a member of the family being an organ donor. I think people would tend to pull away quite quickly if it looked as though there was going to be substantial conflict.

**Mrs RATTRAY-WAGNER** - I want to follow on about the organ donation coordinator. It has been in some of our submissions. The Australian Red Cross submission indicated that Tasmania doesn't have a coordinator. It has been mooted a couple of times, obviously by the Red Cross, and the Health department in Tasmania has looked at it but not funded it. Have you had any experiences where that has been brought forward and you have made representation or had talks with the department?

**Dr REID** - No.

**Mrs RATTRAY-WAGNER** - So it has not come across your desk, so to speak?

**Dr REID** - No. I had not realised that the Tasmanian donor rate was so low but two compared to 10 on average in Australia is woeful. Obviously there is an explanation for it - it has to be education of health professions, I think. I have no idea; you would have to ask the intensivists whether they find that Tasmanians are far more resistant to organ donation than people on the mainland. You could find out fairly quickly by looking at Medicare, at the organ data registry, whether fewer Tasmanians have registered their wish to be organ donors than on the mainland.

**Mrs RATTRAY-WAGNER** - I think it is something interesting that we could follow up on. If it has been put forward on a number of occasions but, if nobody seems to know about it, you wonder where it has been put forward.

**Dr REID** - If we have somebody there all the time, repeatedly reminding you about organ donation and they visit intensive care units and talk to clinicians - you could nominate some of the allied health staff in an intensive care unit and they are the ones who keep tabs on things - surely it would increase the donor rate here.

**Mrs RATTRAY-WAGNER** - From your perspective, do you feel that one person for Tasmania would be adequate?

**Dr REID** - I don't know. Having a solitary person is always very difficult. Often these things happen in the middle of the night. You would have to work out what the workload would be, how often potential donors became available.

**Mrs RATTRAY-WAGNER** - So even perhaps a part-time regional person.

**Dr REID** - Two part-time people maybe. It is always better to have two part-time than one full-time person who will be burnt out in a short time.

**Mrs RATTRAY-WAGNER** - They can share the workload.

**CHAIR** - It's always easy for people like me to sit back and assume what must occur in relation to families and loved ones who are going to die unless they obtain an organ. You think it must be terrible but you don't see it at the coalface day in and day out. Certainly if anything happened to, say, one of my four children, grand-daughter or wife, I would be saying, 'Who's willing to donate an organ?' and it becomes far more personal and pressing. Can you give me some type of understanding of what families go through and what the donor and recipient go through? Probably the recipient and the family more so than the donor.

**Dr REID** - I am not really sure of the confidentiality and whether I am allowed to discuss the cases in any specifics. Sufferers of cystic fibrosis, if we use that as an example, are people who die at a relatively young age from a disease that affects mainly the lungs. Transplantation is a very good option for them. It gives them a survival advantage. The transplantation program at the Alfred, for instance, started in 1990 or so and people with CF who had transplants in those early years are still going strong when otherwise they would have died many, many years ago. So it can be a fantastically successful procedure.

When you have CF and you are very sick, it is a miserable existence and transplantation offers them hope of longer life and a better life. At the same time you know they are sick and they may not get the transplantation so there are two things and it is a difficult thing for clinicians, I think. Do you involve palliative care at the same time as you engage them in the transplant process? We do both. We get palliative care involved because they may not get a transplant and they also get assessed and listed for transplantation and then we assist them to maintain their health as best they can to allow them to get to transplantation. It may be during that process, whether it is CF or pulmonary fibrosis, that there comes a point where they become so sick that they will not survive the transplant procedure. It is a big undertaking and if you are bed-bound and unable to get up and do anything, your muscles waste and you do not have that reserve anymore, there is a chance you may be removed from the transplant list because you are just too sick and they know that you are not going to make it. What you do not want to do, of course, is give a transplant to somebody who isn't going to make it because there are other people who need organs. It is very difficult. I think it gives them a lot of hope and medical teams do their utmost to make sure they remain well to get to transplantation. When you talk about families and obviously spouses and children, this treatment could offer them longer life or quality of life. I think it is very tough. They have to engage with the health system on a very frequent basis.

It is much more difficult, I think, for parents when you have young people with CF and their parents may be in their 40s or 30s and yet they have children who are dying from their disease and they are waiting for organs. I have children so I know it must be incredibly difficult.

Of course the other thing is, particularly in this State, there are a lot of people with CF who have siblings with cystic fibrosis. They can have a younger sibling so you have the older one who is dying, waiting for a transplant, and a younger sibling who may be quite well, looking at their older sibling who is deteriorating. It would be awful, I think.

**CHAIR** - So the success rate, as you have described, is good because normally with cystic fibrosis, as I understand, you die in your teens, is that correct?

**Dr REID** - It depends which State you live in. Generally now the median life expectancy is the early to mid thirties and if you have CF and you were born in the 1990s, it is expected that most of those people will get to their forties, so they are going to get into middle age and beyond and outlive their parents. In Tasmania probably the mid twenties would be the life expectancy.

**CHAIR** - I know of a young girl who died from cystic fibrosis - her parents were friends. She moved to Western Australia. They had great problems in relation to that. She was not able to get a transplant but what I am endeavouring to get at is if the organ is transplanted, the donor does has an improved standard of living, number one -

**Ms FORREST** - The recipient.

**CHAIR** - That is right, I will not go into a joke about that. The recipient has an improved standard of living; obviously they can live for quite some time - as you are saying, with cystic fibrosis up to another 17 years already and still going.

**Dr REID** - Some of them may. Some of them don't make it that long. The other thing, of course, is that they get on with life. It is not as if they do not have CF anymore; they have all the other organ problems but they do not have the lung issue anymore and they get back into work. You have people here in the State who work full time. They just get on with things. Not only have you given them life, they have also become part of society and are productive. They earn money, pay taxes and have children. We have at least one male in the State who has had transplantation and who has managed to have children. He has done very well for many, many years and will probably see his children reach a reasonable age. It can be very successful. We have people like Rudi Sypkes who needs a lung transplant. I would think that when he gets a transplant, hopefully, he would continue to be a productive member of society.

**Ms FORREST** - Picking up on a comment David made about not realising Tasmanian donation rates were so low, I have talked to people about this issue when it was first raised earlier in the year. I had a few phone calls from constituents in my area really concerned that we are going to be harvesting organs from people and they were feeling bad about that. There is also another perception out there that we do not do it in Tasmania, in that we do not transplant organs so what is the point. When you look at the regionalised population and the time taken to get someone to an ICU and who may be an appropriate donor, that is a challenge in itself because they can often be dead en route, so they have the problem of not having viable organs. When you look at the health service in Tasmania at the moment, and the argy-bargy that is going on, for want of a better word, what do we really need in looking at intensive care services? You cannot keep someone in good condition when they are brain dead unless you have the facilities to actually use their organs, so what do we need in Tasmania? It is a small State with a regionalised population. It is no good saying to people, 'We want you to donate your organs' and then not being able to do anything because the services are not there. In a State of this size, what do you think? Is an ICU in Hobart, an ICU in Launceston and potentially an ICU in Burnie enough? Would that be enough to maintain things if we had all these donors suddenly coming on line? Would we be able to cope in Tasmania if that is all it came down to?

**Dr REID** - There would not be more donors in that ICUs would not be suddenly swamped with lots more sick people.

**Ms FORREST** - No.

**Dr REID** - Some of the questions would be better answered by transplant physicians who do it all the time. With the north-west I am not sure because it may be that retrieving things from the north-west may be a bit more difficult than it is from, say, Launceston or Hobart. I do not know about the logistics of it. You do need to have good intensive care unit facilities because the donor goes through a fairly rigorous assessment. It involves oxygenation and so on. You need people to maintain the circulation very aggressively, so you need very good intensive care personnel to optimise the donor, to maintain the donor in the best state they can whilst the retrieval team comes down. What you do not want is to have the retrieval team coming down and then the donor is actually not appropriate at all because the intensive care team has not managed them appropriately. So you need good intensive care teams that really know what they are doing. Like everything they need to have a critical mass of people to do it, so you need really good

intensivists, good allied health intensive care people and to be close to somewhere where jets can land and pick up organs in a short space of time.

**Ms FORREST** - Can they do helicopter retrievals or do you need a bigger aircraft?

**Dr REID** - Oh, I don't know about a helicopter over Bass Strait. The Royal Hobart Hospital and Launceston have well-supported intensive care units and look after these patients really well. If they are rushing around and under-resourced then their priority will be to the patients who are salvageable in their intensive care units.

**Ms FORREST** - They should transfer the donor to the site where the organs can be retrieved or do you retrieve the organs on site and then transport them?

**Dr REID** - You retrieve the organs on site.

**Ms FORREST** - If you are only taking the organs, you don't necessarily need a big aircraft. You need the team to come, but you don't need a big team. You could have a smaller plane if necessary?

**Dr REID** - Yes.

**Ms FORREST** - You don't need a jet necessarily?

**Dr REID** - No.

**Ms FORREST** - How can we ensure that we do not waste the opportunity there?

**Dr REID** - I don't know. It is the sort of thing where you would have to look through intensive care admissions and see, say, in the North West Regional Hospital, how many people could have been potential organ donors in the past one or two years and how many we are missing.

**Ms FORREST** - You were saying that an audit hasn't been done in Australia; is that right?

**Dr REID** - There are lots of holes in the transplant data in Australia, things like deaths on waiting lists. There would be some information from some States in some diseases but not in others. As far as how many potential organ donors are missed, I do not know that there has been a comprehensive analysis throughout Australia, but I could be wrong. I am aware of ones that have been done in Victoria, where they have gone to the intensive care units. They may have done the same sort of thing in other States.

**Ms FORREST** - Do you think it would be worth looking into that to see whether audits have been done -

**Dr REID** - You can do it retrospectively.

**Ms FORREST** - and maximise the retrieval of organs by ensuring that ones that could be possible donors aren't missed? Is that what you are suggesting?

**Dr REID** - Yes.

**CHAIR** - David, thank you very much for coming, and for coming fairly promptly.

**Dr REID** - I think you would get very good information if you talk to Trevor Williams, who is the head of respiratory medicine there, or Professor Greg Snell, who is the head of the transplant unit. Trevor Williams is the clinician who started the transplant unit, so he would be very good. I am not saying he would agree with everything I have said, but he has a very good handle on organ donation. That is what they do all the time and they are always looking at ways to improve donor rates.

What they have done mainly is to look at the donors and try to optimise them. Six years ago if a patient had pneumonia or something we would not want to use that person as a donor because they were not perfect but now they push the boundaries, they use marginal donors, so they have really gone with marginal donors. They were also the ones in Australia, I think, who started the non-beating heart donations so they are the ones who pushed that envelope, so they would have a very good idea. They provide an excellent service to Tassie; you do quite well out of it. It is not as though Tassie donors' organs go to Tassie recipients so you probably do quite well out of other States as far as donation goes. It is not coming from here so we would be getting a bigger bite of the cherry than others do.

**CHAIR** - Thank you very much. Thanks for coming along and thanks for your evidence.

**Dr REID** - I hope it was helpful.

**CHAIR** - Yes, thank you.

**THE WITNESS WITHDREW.**

**ASSOCIATE PROFESSOR NEIL BOYCE**, EXECUTIVE OFFICER, LIFEGIFT VICTORIA, AUSTRALIAN RED CROSS BLOOD SERVICE WAS CALLED, MADE THE STATUTORY DECLARATION AND WAS EXAMINED.

**CHAIR** - Neil, thank you very much for coming over today from Victoria to address our committee.

**Prof BOYCE** - As a very brief preamble, I really do believe this is a serious public health issue. I am not sure that it has been tackled as a conventional public health problem in the past. It has often been treated as a specialist clinician problem instead of a public health issue.

The reality is that every time we fail to realise a potential donor, three or four people don't get transplanted and for every three such failed realisations someone dies on the waiting list, so it is not a trivial issue. From a health economics point of view, every donor saves more than \$1 million in health system costs. So it is also an expensive thing to get wrong.

To address the terms of reference, I believe that the system, albeit a somewhat rocky one, of the Australian organ donor register is the best way of getting a registered and legally valid consent. I think exploring more options for getting people to access that register is probably the best way of getting consent registers in place.

**CHAIR** - Do you think that is better than what we have in place now, that an opt-in is better than an opt-out situation?

**Prof BOYCE** - For two reasons I believe it is. Firstly, I do not think culturally that Australian health care professionals will ever accept an opt-out system. Even in countries such as Spain that have legislated opt out they still function as opt in with consent for every donor. Secondly, there are significant ethical issues about the necessary level of information that has to be consistently given to the community to get genuine informed opting out. As my hair colour would suggest, I have been in this area for 35 years and we have been talking about opting in and opting out for all 35 of those years. I have been rude enough to suggest it is probably time to stop talking about it because, if anything, I think health systems are going more in the direction of specific informed consent.

In terms of whether Tassie's approach to identifying potential donors is working as well as it can be, as I put in the submission, the simple answer is that we don't know because no-one has looked, at least to my knowledge. I would be a strong advocate for putting in place routine systems to measure the performance of donation systems. As I say, I think missing even one potential donor is a significant matter.

**CHAIR** - What should we be doing to do that?

**Prof BOYCE** - There is a process - I think I copied it for you - which is called the Australian Potential Organ Donor database, a systematic audit of all deaths in hospitals. I think that is the best way of approaching the problem, but it would require engaging local health-



care professionals embedded in these communities to do the audit work and feed back the results.

**Ms FORREST** - This is only in Victoria, though, isn't it?

**Prof BOYCE** - That publication is from Victoria. A version of APOD has been done in South Australia, Western Australia, New South Wales and Queensland but has not been published. In broad terms the results around the country are very similar and I cannot believe they will be any different in Tasmania - that is, there are significant numbers of unrealised potential donors.

**Ms FORREST** - Do you think, if such a study as this was done and an audit conducted, that it would perhaps raise awareness for the medical staff involved and the patients and the public generally? Would it be of benefit to do it as much to find out whether it is the same in other States or as a promotion activity?

**Prof BOYCE** - The short answer is yes. I think the audit is a 'Trojan horse' in that, whilst it provides data, it also engages people in a conversation about the issue. We found in Victoria that initially there was a lot of anxiety about the audit, professionals feeling that people were intruding on their turf and challenging their professionalism. Over time it became obvious that the results of the audit spoke for themselves and those very individuals who were concerned then became committed to fix the problems that were being identified. I also am a strong believer that if you want to improve performance then you have to measure something because there is no good having a lot of rhetoric in the room saying how fantastic we are if no-one has any data to back up the claim. This is by far the best way of doing it. There are other mechanisms of auditing particular aspects of the process but I think you are better off, particularly in a State of your size, to say, 'Let's look at all deaths in hospital and determine where potential donors lie'. That sounds challenging, but we can do it in Victoria with a relatively small oily rag so I think you would find it not a big resource issue. My guesstimate is that it probably would be about \$50 000 per year for Tassie to audit all deaths in hospital, so it is not a huge impost.

**Ms FORREST** - You are suggesting an audit to see whether they would be potential donors or not?

**Prof BOYCE** - It looks at who could be potential donors and then determines what happened to them and why, by both looking at medical records and talking to the clinicians involved. It brings out issues such as, 'We didn't want to approach the family because we thought they were too upset', or 'We didn't have access to nuclear medicine imaging at the weekend so we couldn't determine brain death', or 'We thought they were Jewish so we didn't think it was appropriate', or 'We got the junior staff to do the approach and the family said, "You've got to be joking", or they asked a question that the junior staff couldn't answer and so they said no'. It follows right through to the outcome and provides very valuable information about what is going wrong. Some of it may not be fixable but much of it is. Much of it is just health system belief, attitude and behaviour that can be changed.

Whilst I think many doctors and nurses take donations seriously, there are still a substantial number who would say, 'It's not my responsibility. This isn't my job. I'm

really busy doing other stuff'. They do not articulate whose job it is and, clearly, if it isn't the job of those caring for potential donors, I cannot for the life of me think whose job it is. Some emergency and ICU doctors in particular will argue that it isn't their job, that they are just too busy.

I overheard a question you asked the former witness. We have to get a grip; this is a rare event. In Tasmania, if we were to double your donor rate, we would use perhaps six or eight ICU beds for one day in a year. This is not a resource issue, this is a focus issue. I get the same arguments in Victoria; people say that they do not have the resources. The reality is they do. It is a very small resource charge in terms of ICU requirement or in fact for hospitalisation because these people are dead and are quickly out of the building. They are not like some of the other challenges in acute health care with people in hospital for weeks and months.

**Ms FORREST** - I hear what you say about it not being a resource issue as far as the bed itself goes and the short time that a person occupies that bed. Are you suggesting that it is more about the capacity of the treating staff to deal with that situation and do we need to support those people more?

**Prof BOYCE** - We do.

**Ms FORREST** - How do you suggest that we support them? This goes to one of the other terms of reference about having a coordinator and it could perhaps be that person. What measures would you put in place to ensure that we do not miss opportunities, I guess?

**Prof BOYCE** - We need a continuous education and performance monitoring program. These environments unfortunately are chaotically unstable, they have huge turnovers of junior staff, less so of nursing staff and senior staff. Again I do not know your own circumstances well enough but probably something like the Royal Hobart and Launceston have ICUs and an emergency department with staff numbers approaching 100 or more and each and every one of them has to be ready. It is a bit like a fire drill; they have to be ready for the rare event that a potential donor is there and know what to do because you cannot come back the next day and say, 'Oh, we missed one, that's a shame'. It is over. As a famous character says, 'You're dead dead once you've got down to the morgue' so it becomes just not feasible.

**CHAIR** - He did not stutter, did he?

**Prof BOYCE** - No.

**Ms FORREST** - Regarding the coordinator role, do you think that is where we need to be heading or are there other things that need to be done?

**Prof BOYCE** - Again for Tassie, I think a coordinator who is closer to what I call a liaison nurse and that is their primary credibility is they are an ICU or ED nurse who take on organ donation as a special cause. It might even be two such nurses in Hobart and Launceston, for example, who work half a day a week in this particular role. You have to get the data, you have to feed it back to people but you also need to be upskilling them in identification and management of donors, again eavesdropping on the prior witness, that there is a skill in managing the unstable brain dead or approaching-death donor and it is

something that is a pretty rare event and people do not necessarily have much experience in it as individuals, if that makes sense. Even at a hospital like the Alfred that is our biggest donor centre, we have looked and most health care professionals themselves see only one donor every year or two, so if it is even a less common event it becomes really important to have protocols, procedures and access to support.

Previously we have tried to get this position up and we have been told there just are not enough donors to justify it and it is not actually a role that is primarily about managing the donor events, it is getting people to the point that they can manage those events when they occur.

**CHAIR** - Do you know the number of donors now on the list?

**Prof BOYCE** - How many are on the Australian Organ Donor Register?

**CHAIR** - Yes.

**Prof BOYCE** - I brought that with me because I thought I might be asked. It is quite a large proportion of the Tasmanian population, which is interesting, but I will just quickly check. They tell me that there are 172 728 Tasmanians plus 67 so really let us say 173 000 Tasmanians are on the Australian Organ Donor Register.

**CHAIR** - For a population of 500 000 that is a significant number, I would have thought.

**Prof BOYCE** - It is 42 per cent of your eligible population, they tell me, so it is a significant number. I believe that as a nation we need to get all of those people to tell their families in life that that is what they want to happen because that is still a huge problem. Fully 50 per cent of people in Australia think they want to be an organ donor but have not told anyone about it and I am afraid when you are dead you are not a great conversationalist and so getting those conversations in life so families are strongly supportive of that intention when the opportunity arises is important. But I guess that data says you do not have a community who are not supportive of donation; you have the highest proportion of any State or Territory on the register.

**CHAIR** - Sure, which is good news. What have we to do to put that into practice?

**Prof BOYCE** - Two things. The first general one is to make sure no donor is not recognised and managed to the best of the system's ability. The second is to ensure that this conversation takes place in life so that families know.

We know from data if families do not know their loved one's intention, they are very unlikely to give consent at the time of approach for what is the worst day of their life. Someone may have gone off to work and died suddenly and unexpectedly. They have been dragged into the ICU, they have had a complex discussion about brain death and now someone is saying, 'What about organ donation?' So it is much, much easier for people to know yes, that is what my husband or wife or child wanted to do.

The health system side of it is less easy because it does involve training a whole lot of people. Again, I will be frank because I am getting too old to be other than frank. A lot of health-care professionals are not comfortable with care of dying patients or patients

who have recently died and find engaging in conversations around someone else benefiting from that tragedy quite challenging and they need specific training. I think big hospitals also need support systems. So if you have someone who is really technically a great doctor but is hopeless at talking to families, you do not ask that person to have that conversation; you have people who are supportive and skilled.

We run training programs that staff find very useful in how to go about having those conversations but, as I say given the turnover, I think there is a requirement for continuous education.

**Ms FORREST** - Do you think that generally speaking staff who work in ICU, and choose to work in ICU generally, do not particularly plan to deal with death because ICU do not have dead people there usually. They come in and they are critical or they are salvageable usually, so you treat them and you send them on to the rehab., the medical ward, the surgical ward or wherever so for people in ICU to have a dead person in the unit is a bit of a challenge. Is that something that needs to be looked at more thoroughly?

**Prof BOYCE** - It is, I think. I think increasingly intensive care specialists take on the responsibility for end-of-life care. They see it as part of what they do. That might be, though, a generational thing and there may be generations of ICU specialists who are less comfortable with providing high-quality end of life care. I think, though, one of my ICU colleagues says you pick the wrong people to do this. I like physiology, I like getting people's blood pressure up, I like curing their pneumonia or I like controlling the ventilator; the thing I don't like is having all of these deep, rich and meaningful conversations with people about death, dying and what might subsequently happen.

My experience is many of them can be trained to do that well but I think there are some, as I alluded to earlier, who should not be forced into doing it. I think we are in a transition. When I started this, I used to be a transplant physician, so this used to be secret transplant business. The ICU doctors used to turn away and we used to run in and talk to the families and get the consent and arrange the whole process. Increasingly the ICU community, I believe quite correctly, are taking responsibility for managing this but it is a transition.

In a recent survey of intensivists around Australia about 65 per cent of them are strongly supportive of donation, which is great but it still leaves a fair number of them who are a bit lukewarm. I sometimes use the analogy: donation is extremely difficult, it is extremely complex; if you fall at any hurdle it's off. There is no redundancy in the system. So if you have someone who says, 'This person's cause is hopeless. Let's withdraw active therapy and let them die', you don't have time for the next person who is supportive to come on and say, 'Well, we could have had that person as a donor'.

Again, the cultural in Australia is that doctors are very rarely challenging of their colleagues' behaviours, whereas now in Victoria we are increasingly seeing a culture where the ICU doctors will say, 'Where was your brain? That person was a perfectly reasonable organ donor. What do you mean you just stopped treating them?'

**Ms FORREST** - So this audit helped with that?

**Prof BOYCE** - Absolutely. It has made a huge difference.

**Ms FORREST** - So there is a really strong case for conducting an audit in Tasmania, do you suggest?

**Prof BOYCE** - I believe there is nothing better than data to get through to doctors, basically. Much in all as they love opinion when you present them with data that has been collected using defined methodology and you start then comparing, dare I say it, north with south in Tassie, the little I do know of Tassie, that would work, but also comparing the mainland with Tasmania because this is a performance issue; it is not about numbers. If you are getting all of your donors through to donation, I do not think the number matters. Clearly I would prefer it to be a bigger number because there are 2 000 people on the waiting list but there is a bit of me that says if no-one dies in circumstances where donation is possible, well that is terrific. I always say to my staff, 'We're not there to shroud-wave. We're not there to encourage people to die'. There are countries who shoot one another in the head and drive stupidly and do not take their blood pressure tablets, and they have very high donor rates. I do not think that is the model that we want to go after but we do still have probably a number of donors who, for one reason or another, we are not realising.

It is interesting; through the audit in Victoria, when one challenges clinicians, it is amazing how often the initial response is, 'We just didn't think of it'. Often when you probe there are reasons why they did not just think of it. These are really bright, capable people and they usually manage rare events quite well; they are usually right on top of rare technical things. So I do think this is an unusual aspect of care; you are actually moving from caring for an individual and their family to raising the potential that this person would help other people in the community.

**CHAIR** - Isn't that the big fence between the two, because if I was a clinician my major focus would be on keeping that patient alive?

**Prof BOYCE** - As it must be.

**CHAIR** - If unfortunately I failed at that sometimes, I would imagine, clinicians say, 'I've done my best, I can't do anything more', rather than going that next step -

**Prof BOYCE** - Correct.

**CHAIR** - and saying, 'Is this patient able to donate organs?'

**Prof BOYCE** - There is no doubt there is sometimes in the jargon what is called 'therapeutic failure'. The idea that somehow or other, because the person has died, you have failed as a clinician is a problem. If that is the way you feel then it is very difficult. I did this 30 years ago and I can still remember the families. It is a uniquely intrusive form of discussion. Although now I believe it is of value for families to allow their loved ones to donate at that stage, I did not really know that and I used to think it was incredibly intrusive to be talking to someone about someone else benefiting from their tragedy, particularly if you are ambivalent and think, 'I've somehow or other failed to save this person'. Intensive care doctors have mortality rates of 20, 25 or 30 per cent so they are not uncomfortable with death but we need all of them to feel comfortable or to have access to a colleague who is comfortable with making that transition. I do not have a

problem if people do not want to donate and again some people do not believe in that. I think it is equally wrong to take organs from someone who did not wish to be an organ donor as it is to fail to take them from someone who did.

I do not think that we should not ask families because it is difficult for us health care professionals; I just do not think that is reasonable. We have to do a lot of things in life we would choose not to. Again, another one of my delightful intensive care colleagues, who is my age, tells me he hates doing it every time he does it. There are not many things he can remember doing in his career that each and every time he does it he just hates it. He has to go into his office and psych himself up but he does it, and I know he does it very well because I have actually watched him over the years. I think it is a very special thing to do well. There is no doubt from the data that if you do it well your consent rate is infinitely higher because, as you can imagine, people making difficult decisions pick up on both verbal and non-verbal cues from people talking to them and pick up on a belief that this is a right and reasonable thing to do.

You probably know from surveys that just about every man and their dog in Australia says they are willing to be an organ donor so there is this huge gap between stated support and actual behaviour, which I think we need to understand better because I do not honestly know where the true level of support lies. Consent rates of around 50 per cent, I think, are probably too low.

**CHAIR** - When you look at Tasmania it would appear that it is doing quite well as far as registering their wishes are concerned.

**Prof BOYCE** - Correct.

**CHAIR** - In terms of reference one we ask whether the present systems established within Tasmania and Australia that enable a person to register a legally valid consent to become an organ donor are adequate. I suppose we are not saying they are adequate because we can always do better, but what do you say in relation to term of reference 1?

**Prof BOYCE** - I think they definitely are adequate - you are winning the State and Territory poll. I think we should be looking at multiple avenues to get people to consider going on the register.

**CHAIR** - We are adequate, we can do better, but how can we do better? We can do better with education; what have we got to do with education?

**Prof BOYCE** - I think in the community education side of it we have to stop talking about knowledge and awareness and get people to change behaviour. The behavioural change is, 'Make a decision and tell your family'. Going on the register is okay; I think there will be a lot of people who do not want to be on a government database, frankly, but the real thing is to tell your family. There is little point keeping it in the privacy of your own mind and there is little point having a piece of paper you carry around in your wallet; you have to tell your loved ones.

**CHAIR** - But you don't even do that, do you? Recently I have signed the form and sent it away and that is all that happened.

**Ms FORREST** - You are given a card to put in your wallet. You will get that.

**CHAIR** - I haven't received that card yet.

**Prof BOYCE** - Unfortunately the Commonwealth system depends on how much money they have as to whether you get a card. One would hope that we can eventually end up with an AODR that has consistent systems, that always gives people cards, for example. The conversation is still key. I can tell you about families where my coordinators say, 'Your loved one's on the register' and they say, 'Don't be stupid, they wouldn't be on the register. How dare you say they're on the register. Prove it'. It is a difficult conversation at 2 o'clock in the morning with a bereaved family. A big policeman came up to me once and said, 'It puts the mozz on to talk about death, Doc', and I had to say, 'I don't think it does'. I think you can simply say, 'Should I ever die, in circumstances where donation is possible, I am happy for that to happen', or 'I don't ever want that to happen'. It is the assumption that we all one day die. Culturally it seems we are a bit hung up about talking about death. My colleagues in funeral and estate planning tell me that internationally we are poor at this sort of thing. I think we need some research to work out how best to do it. If we can get people to stop drinking, driving and smoking, and to have cervical cancer screening and mammograms - all the things we have been world leaders at - surely we can get people to say, 'I do or do not want to be an organ donor'. It does not seem an impossible ask.

**Mrs RATTRAY-WAGNER** - We have been very good at some of those education programs, haven't we?

**Prof BOYCE** - Australia has the best performance in these public-health initiatives. I do not think we have ever dealt with this as a public-health initiative. Let us take it out of the hands of the clever technical people and say to the public health people, 'How do we make this happen?' Some of those other things are quite difficult. I know it wasn't easy to get cervical cancer screening and mammography up, but they did it. They tried and tried and have had great success. It needs to be funded in that way, though; it is not sixpence here and tuppence halfpenny there; these are major slip-slop-slap, 'Don't drink and drive. You're a bloody idiot'-type campaigns that go on continuously because it appears you need that level of reinforcement.

**Mrs RATTRAY-WAGNER** - Neil, in your submission you spoke about the Health department in Tasmania, looking at optimising donation performance in Tasmania, but nothing has happened. Has your organisation, to your knowledge, been involved in any of those failed attempts?

**Prof BOYCE** - Yes. It has always come down to funding. The department has always been in-principle supportive but essentially said, 'We just don't have the money'. I have always thought it doesn't seem like much money -

**Mrs RATTRAY-WAGNER** - The \$50 000 that you quoted to do a study to get a start?

**Prof BOYCE** - Correct.

**Mrs RATTRAY-WAGNER** - And that has been too much money for our Health department?

**Prof BOYCE** - It has. It used to be \$40 000 when we started, but it is now \$50 000. To me it has never been a large lump of money, but to be fair we have good audiences and it wasn't that this is stupid; it was just it is a tight budget.

**Ms FORREST** - Some \$1 million is saved by the Health budget every time a recipient receives a donor organ, but it is not just one person who is saved.

**Prof BOYCE** - It is 3.7 on average.

**Ms FORREST** - And not just one person benefits from a donor; it can be up to 12 or 13 from the last count. Do you think, if those figures were published and out in the media as to how much we could save, that the department would have less of an argument?

**Prof BOYCE** - The short answer is yes, but my experience with budgets is that there is always a global health system budget and everyone says, 'But where in my bottom line does that come out?'

**Ms FORREST** - It doesn't show up on that line, does it?

**Prof BOYCE** - Worse still is the financial year - the \$1 million saved is over a 15- or 20-year period. It usually is the holder of the cost centre who is the problem. People who are willing to take a systems view are hard to find. They won't argue that it is not true, it is just that, 'It's not my budget. It's not my hospital's budget. It's not my department's budget'.

**Ms FORREST** - You can't count saved money on your bottom line. That's the problem, isn't it?

**Prof BOYCE** - It is difficult, but as a system, if we don't have people who take this view then we are spending millions of dollars that we don't need to spend. I hate using the financial argument because to me it is more about the quality of life of people. Transplantation transforms people's lives and the lives of their family, friends, work mates and everything else.

**Mrs RATTRAY-WAGNER** - It has obviously been used in the past, though.

**Prof BOYCE** - It is a no-brainer financially. In fact there is some lovely international literature that says really in terms of spend this is a great area to spend money because the return is so enormous. With most health system changes you do not get that sort of financial payback as quickly as that at all. You are usually talking about 10- and 20-year horizons and saving relatively small bickies, not \$1 million a donor.

I think some of this has to be at the Commonwealth level, with the big purse-string holders who make decisions about particularly national communications campaigns that can make a difference. I think I mentioned that they currently have a consultant who is probably getting paid more than my annual budget to look into what sort of national campaign we need and I hope that that comes to something because we do, I think, need a national public health campaign to convince people to take the action, which is to make a decision and tell their family.



We think there are small numbers of people in the community who have the wrong end of donation. You have probably heard the dinner party conversation, 'You don't want to talk about that because you will be a donor and they won't look after you in the hospital' or various other sillinesses or a confusion between post-mortem and donation and various other things but I think they are rare. I think for most people it is this discomfort with articulating a decision to their family.

**CHAIR** - Some people also appear to think that if they put their name on the register they are going to donate an organ -

**Prof BOYCE** - Correct.

**CHAIR** - but very few of the people who put their name on the register donate, do they?

**Prof BOYCE** - Yes. A number of people say to me, 'I am an organ donor' and my usual response, somewhat flippantly, is, 'You look remarkably well'.

*Laughter.*

**Prof BOYCE** - The reality is that fewer than 1 per cent of people who die in hospitals can donate so that means it is only a tiny fraction of a per cent of the people who are on the register where donation is possible. That means it is more important that everyone knows their position and ideally everyone is on the register because it is a great tool for communication. Because it is such a rare event you cannot afford to have missed opportunities and, as I mentioned earlier, the cost of every lost donor is substantial, both human and financial.

**Ms FORREST** - There has been some concern raised to me from people from various backgrounds about the definition of brain dead and what it means. We heard from our last witness about the beating heart versus the non-beating heart donations. Would you like to give us a few comments in relation to that and maybe public acceptance because some people see it as the brain dead and the body still working.

**Prof BOYCE** - Firstly, I think the general public are still much more comfortable with the concept of cardiac death - that is, they are used to seeing imagery of people whose hearts have stopped and they are cold and pale and whatnot. Certainly the families of donors repeatedly are challenged, knowing the person is dead despite the fact that the machine is keeping them looking warm and pink.

We changed legislation 20 to 25 years ago to make brain death accepted, mainly because of changes in technology that enabled you to keep essentially corpses on machines for very long periods of time. The driving force was in fact well that is tacky; you have to have some definition of death that goes beyond if you can have machines keeping everything going. But we never communicated that to the general public. So most of the knowledge of brain death in fact is acquired by individuals who are facing someone who is brain dead.

Personally, a lot of my colleagues feel very strongly about all of this technical stuff, as I call it. I find that most people in the community either trust the doctor that their loved

one is dead or they don't. You are not going to get donation from someone who does not believe their loved one is dead and nor should you because I think it would be difficult to ethically justify donation and we have sometimes had to knock back potential donors. I remember one lovely Russian family who said, 'You can have one kidney but he will need the other one when he gets better'. We had to say, 'I don't think you really understand the exact circumstance'. Similarly with all the brouhaha about donation after cardiac death in the health-care professions, we have found, dealing with families, they are very happy that their loved one is dead. They are not as obsessed about how the doctors determine death as we health-care professionals are.

There are a small number of people who do not believe in brain death. I think they are nuts. I do not think there is any scientific justification for saying brain death is not dead. The very fact that you cannot breathe without a machine would suggest to me that if you are not dead, you pretty much should be. What is more, we know if you follow these people the heart will stop within a period of hours anyway, so I think that argument is well at the margins. There is a prominent ethicist in Victoria who for my entire career has been challenging brain death but I am sick of listening to Nicholas so he can say what he likes. He is part of a very small radical fringe. There are more controversial concepts in modern health care than whether brain death is death, I think.

**Ms FORREST** - I was informed recently of a person who is awaiting a transplant, I am not sure what organ, and they are an educated person. They have said that because they do not agree with the definition of brain dead, as it stands - and this is from someone with a medical background - they would not accept an organ donation.

**Prof BOYCE** - I have looked after such patients in my career. I think that is a personal choice. Again I think it is nuts but it is a personal choice. If they want to stay on, hopefully they are on dialysis because otherwise they are facing death, but if death or dialysis is their choice as against accepting transplantation, to me it is out there with Jehovah's Witnesses bleeding to death. Sure, they can do that and I do not think we have the right to override that decision but I do not know that it is within the mainstream of community beliefs, and they are very rare patients. Funnily enough, all of the ones that I looked after were health-care professionals so that is interesting.

**Ms FORREST** - It is an interesting concept because those people should better understand brain death than anybody else, you would think.

**Prof BOYCE** - Well, perhaps. Sometimes people who are close to things I think over-intellectualise quite simple concepts. I think it is important perhaps for the committee to appreciate that death is a continuum just like life. You know the debate about when does life begin, well you can have the same philosophical debate about when does life stop but I think all of us agree life begins and life stops and there does need to be some degree of arbitrary decision-making from a medical and legal perspective because otherwise you would go on ad infinitum debating the point. The debate around brain death, I think, is one of where you draw the line. I personally am very comfortable with the line that has been drawn because typically it is drawn three standard deviations away from where it probably occurs so people say, 'Let's leave wiggle room for the possibility of error'. Brain death was a concept and they spent years looking into people. They looked at the criteria, they followed them to see what happened, tens of thousands of them, and they all died and no-one got better and went home.

As I say, I think the brain death thing is the lunatic fringe. It is the sort of 'Don't vaccinate your children because they'll get something'.

**Ms FORREST** - Brain damage.

**Prof BOYCE** - Something. Do not have fluoride in the water or something bad will happen. These people seem to continuously oppose many commonsense public health initiatives. They are obviously passionate about it but most people just shake their heads and go, 'I just don't get it' and I am certainly one of those.

**CHAIR** - Regarding the adequacy of Tasmania's approach in identifying potential donors and facilitating the donation and procurement process, the brief answer am I right in saying is that you have to have an audit and you have to have, say, two people down south, two people up north in order to -

**Prof BOYCE** - Correct. You have to get the data because my experience is that before we did the audit there was a range of opinion and usually the loudest and most strident opinion won out on the day, the 'I've been doing this for 30 years and I can assure you that' argument. I just think you have to look. It may be that every single potential donor is realised.

One of the things that makes me hesitate is that consistently Tassie has the lowest donor age in Australia. I think it is very unlikely that that is just a statistical fluke over the last 18 years; you have always had the youngest donor age. To me, it suggests that there might be a systematic bias toward thinking of it in younger people but not in older. That is an hypothesis but, again to put it in context, when I started my transplant career donors were considered as potential donors up to the age of 40 and we are now talking about 70 to 75 as considerable for the upper age. I was looking through all the Tassie data trying to find anything and I thought, 'Gee, it's really funny, for 18 out of the last 19 years Tassie has had the youngest median donor age' and I just wonder whether there may not be a culture of just not thinking about it in 'older people' who have had strokes in particular and that is something that the audit would quickly bring out. It is the most common cause in our Victorian context of relatively older potential donors where they think that, in their view, donation isn't possible, so they censor it at that point and things stop. We are trying now to get the system to say, 'That isn't your decision'. We need to bring in more expertise to make that decision rather than leaving it in the emergency department or ICU to a relatively junior staff member.

**CHAIR** - What about term of reference 3 - the impediments, if any, causing Tasmanians to have the lowest organ donor rates in the nation?

**Prof BOYCE** - The short answer is we don't know. I would hope it is because Tasmanians are not dying in circumstances where donation is possible. I doubt that it is the distribution of your population. The data I have suggests that in all other States and Territories regional donors reflect the exact proportion of their population. Most health systems are set up to get really sick people to big hospitals. They don't always work, but by and large they do. Distances in Tassie are quite trivial so I would have thought, even with conventional road transport, you are not going to have people in what I would

imagine must be either tiny hospitals or big hospitals who are not able to access intensive-care beds.

**CHAIR** - Again, with an audit the question could be answered much easier.

**Prof BOYCE** - It would be lovely to have the answer instead of continually hypothesising. Even if the initial commitment is to do the audit for certain a period of time - and it can be done retrospectively to get a reasonable number - look at the data and then decide what to do, whether to go forward. I think in big centres continuous audit is a great idea, emphasising that one missed donor is a real tragedy. In smaller centres you might only have to audit every few years to remind people. The smaller centres need support. Again, if Victoria and Tassie are similar, sometimes smaller centres might want to transfer a patient to a bigger centre, if only for the purposes of potentially supporting donation, but the big hospital tells them to rack off, they are too busy and they don't want to take the patient - who clearly is not going to survive - because they are not that supportive of donation. I do not think that is acceptable because it does not take many knockbacks for the small hospital to never approach again.

**Ms FORREST** - That is a big issue in lots of ways because when you are trying to transfer anyone who is critically ill the risk is that they could die any time.

**Prof BOYCE** - By and large I would usually be talking about transferring people who may well already be dead - that is, brain dead - and being ventilated.

**Ms FORREST** - As opposed to treating them in the local ICU.

**Prof BOYCE** - If you have an ICU bed, it is fine. I was assuming there may be some small regional hospitals that may not have them.

**Ms FORREST** - Say, in Queenstown. If they are brain dead there, you are not going to ventilate them in Queenstown. You have to get them to Burnie.

**Prof BOYCE** - And sometimes, at least in Victoria, those transfers are knocked back. People say, 'This person's dead or is about to die, so why are you transferring them?'. The answer has to be, 'With the consent of the family to support donation'.

**Ms FORREST** - Can you effectively ventilate someone in the back of an ambulance between Queenstown and Burnie - it is a three-hour drive on a good day?

**Prof BOYCE** - Yes.

**Ms FORREST** - They would still be in good enough condition when you got them there to be put into ICU?

**Prof BOYCE** - Yes. Essentially you would use the retrieval-team approach. I don't know Tassie but I assume you would have retrieval teams. If you have people who know how to get the blood pressure and oxygenation up -

**Ms FORREST** - I'm not sure that we do have retrieval teams. For neonatals and paediatrics we certainly do,, but I don't know that we do for adults. I think that is a question we need to look at.

**Prof BOYCE** - Even competent ambulance officers can support the physiology.

The biggest thing is the change of mindset. One of the things I harp about is that if people saw organ donation as mainstream hospital activity then we wouldn't have these discussions about whether or not that was a reasonable thing to do. If the person was being transferred for emergency cardiac surgery, you wouldn't have those conversations.

Organ donation sometimes has an element of 'it's an option'. I sometimes flippantly say, 'You do it on a good day when the weather is fine, the wind is blowing the right way and everyone is in the mood'. But if everything is not going right, there is a reason you can't go forward. Usually health-care professionals overcome all sorts of barriers to achieve what they want to happen. I would like to see that be the way we approach donation: the family wants it, the person wanted it, let us make it happen. Let us not say, 'The ambulance is busy' or 'We can't find a ventilator', or 'The nurse has called in sick'. Let us have strategies to say, 'We will make this happen'.

**Ms FORREST** - So having a State coordinator, or a couple of people in those positions, to oversee that so that if the call comes and it says, 'No, sorry, we do not have time. The nurse who does that is off sick' or whatever then if you have those people they can swing into action to achieve it. Do you think that is what we need?

**Prof BOYCE** - Partly it is that person swinging into action but the biggest role for them is education and audit. They also act as a change agent within the facilities. Working with their medical and nursing colleagues over time we have seen units go from either being disinterested to being actively interested. I shouldn't name hospitals but we have had Melbourne hospitals that have gone from a dreadful donation performance to a stellar one. It is about this local ownership and frankly I believe they can do it better than they have. Often these resource people just enable things to happen that would not otherwise happen.

The audit is pretty boring; it is getting a medical record and getting the data out and putting it into a database but if someone does not do that you then do not have the tool to drive change. That is why they need to be part of that local culture. People have sometimes suggested that they should be sitting in an office somewhere with a computer doing stuff, but they need to be in the hospital and they need to be known and credible members of those critical-care communities.

**Mrs RATTRAY-WAGNER** - Or at least a face that people can relate to?

**Prof BOYCE** - Yes. Many of them will continue to work in some shape or form in the rest of the hospital. Sometimes they have roles in quality and safety within hospitals but they are hospital people, they are of the brethren and they are working on a particular aspect of end-of-life care in their hospital. It makes such a difference, as against exporting someone into that environment who goes rah, rah, and everybody asks when they are leaving. It does not have that enduring effect.

**CHAIR** - You have touched on point four and also to some degree five. It seems to be highly important that there is a proper program out there of education and promotion to get over to the public the fact that an individual wishes to donate.

**Prof BOYCE** - Correct.

**CHAIR** - How do think that is best done?

**Prof BOYCE** - Think about the way we have done the slip, slop, slapping or the drinking and driving. Essentially they are thematic programs that run over time and are refreshed periodically. They use mass media and targets for particular demographics, and all of that needs to be worked out by my clever public health colleagues.

I have put this challenge to Victoria Health for example - who have more money than they know what to do with but don't tell them I said that.

**Mrs RATTRAY-WAGNER** - They might read it unfortunately.

**Prof BOYCE** - No, it's all right; I have told them that.

When they have that level of resourcing they have the clever people who need to take on this new challenge. These are the same people who have designed recently the cervical cancer vaccine campaign. We need to say, 'Great job, you have done that so now turn your head to this'. They will need some underpinning research because we have been terrible at not doing appropriate research in this area in Australia. Then they will be able to say, 'Well, let's trial this, let's pilot that, let's do this ad in a focus group'. Some of it will be feel-good stuff; some of it will be shock horror.

Personally I think we need to get through to people that it is a terrible thing to do to your family - to leave this up to them when you are dead. If my staff had any opportunity to spit the dummy it would be to say why don't you people sort yourselves out and have these conversations because it is awful to have to come in and ask about organ donation - 'Organ donation, oh God I don't know what they wanted to do'. It is, I think, one of the worst things you can be doing to someone who is in a terrible place. My staff, I think, are brilliant at what they do but they would much rather hear people say, 'No, no, go away, he didn't want to have anything to do with donation' or 'Yep, that's right, where do I sign?'.  
I have an anecdote that I will share with you. Anyone who says to me that the only thing you need to do to fix organ donation is whatever then I usually say I don't want to listen

**CHAIR** - As a committee, what conclusions do you think we should make?

**Prof BOYCE** - I believe there probably is an opportunity to do better and I think with constancy of purpose and a commitment to changing both health care providers and community behaviours we can get there. We believe we can almost double Australia's donor rate. It is about time we started making progress in that. It is something that goes beyond the political cycle in that you are talking about probably a 10-year program of change in both health system and community behaviours to see that doubling. Some people find that frustrating.

I have an anecdote that I will share with you. Anyone who says to me that the only thing you need to do to fix organ donation is whatever then I usually say I don't want to listen

because it can't just be one thing. If it was only one thing then after 30 years someone would have thought of it. It is a series of interventions, none of them are rocket science, and all of them require a little bit of money and constancy of purpose. All of them require respectful commitment to the primacy of the responsibility for end-of-life care not ever being transgressed, making sure that donation is a by-product of high quality end-of-life care, and a belief that if someone wants to be an organ donor then that is a worthwhile thing to pursue. Again, I work with some people who think it is their decision as to whether that ought to happen, rather than saying, 'Well, that's what they wanted; why don't we make sure it happens'.

**CHAIR** - Are there any other recommendations you believe we should make that you have not touched upon?

**Prof BOYCE** - Whatever DoHA and whatever the ministerial task force come up with, whatever is done locally should dovetail with that. I will not bore you with the number of times in my working life that people have headed off in completely opposite directions at a State and Commonwealth level. It has sometimes made it very difficult in the middle to work out which way to go.

**CHAIR** - So the Commonwealth are coming down with their recommendations, as I understand it, in December?

**Prof BOYCE** - They are, very late in December.

**CHAIR** - I doubt very much whether this committee will finish its deliberations and report by then. You are saying it is best to wait until those Commonwealth deliberations and recommendations have come down?

**Prof BOYCE** - Yes. Without labouring the point, the sector has grown organically, so it is not logical or sensible or particularly effective or efficient in some respects. I think this is an opportunity now to start to put some rigour into it. The head of our liver transplant unit in Victoria calls it a cottage industry - it has grown higgledy-piggledy. When I was a transplant physician I used to do all of this organ donor stuff and now suddenly I have reinvented myself and changed hats and moved offices and organ donation has now become a recognised specialist aspect of care. Once upon a time the intensive care community tolerated it and now they want to own it and I think that is great. This is a national business - I do not mean to use the term flippantly - but organs and patients are shipped around so we need to get it right nationally and to do that in consistent ways. I have heard the Commonwealth, for example, make some suggestions that they are going to directly fund certain things. I am saying to them, 'But you don't directly fund health care in acute hospitals so that model won't work because the governance won't be there'. If you are going to do things in health, and health is still a State responsibility for at least most of the country -

**Mrs RATTRAY-WAGNER** - In part.

**Prof BOYCE** - in most hospitals, then you need to use those natural governance things because this separate line of funding through the back door will not work in the long term.

**Mrs RATTRAY-WAGNER** - With the RPA show on the TV, 10 years ago nobody would have thought of having a program like that in people's lounge rooms so obviously the community has come a long way.

**Prof BOYCE** - Tune in over the next few weeks to a program called *The Gift* which will probably be following RPA, produced by Fremantle Media and focusing on organ donation and transplantation. It is an eight-part series and a second series has just been commissioned.

Popular culture has a big role to play because sometimes we have been a bit preachy in talking to the community about donation. In Australians there is a cynicism and anti-authoritarianism. If you look as if you are preaching to people they switch off. My staff keep saying, 'Oh, you shouldn't have let them say that and you shouldn't have let them do that'. My view is that the community learn about things without even realising they are learning about it. If it is a bit of shock horror and a bit of it is heart-string stuff, they tell me that is what entertains.

**Ms FORREST** - You would not recommend *ER* or *All Saints* then.

**Prof BOYCE** - Yes, it was filmed at the same time as one of those and we occasionally had difficulty working out whose patient was whose. That popular-culture avenue has been under done. Think about the number of ways we have gone about making it unfashionable to smoke - ads about who wants to kiss someone who smells of cigarettes, et cetera. A lot of the purists would have said, 'You should be talking about the risks of particular subsets of cancer, not telling people not to kiss someone who smells bad'. You need different strategies for different demographics. Fremantle Media make *The Gift* and it is not a program that I would even want to watch, but they are good at what they do. They have already had a second series commissioned before the first one has been shown. I think some of us in our health system towers needs to say, 'Let these people do their job. If they can get a whole lot of people talking about donation, even if some of it's a bit silly or gory, that's great'.

**CHAIR** - What do you think about universal registration, making people say yes or no?

**Prof BOYCE** - Australians, as I mentioned, are anti-authoritarian and are likely, in the equivalent of the Australian salute, to say no, in the context of that being, 'No, I don't want you to tell me what to do'. They tried it in Texas. They said everyone had to make a decision and they got an 80 per cent 'no' response. I do not think we are quite the rednecks of Texas, but if you think of the Eureka Stockade and various other things - particularly if it is government saying, 'You must do this' - there will be a whole lot of people saying, 'You're not going to tell me what I'm going to do'.

**CHAIR** - Do you think there is also a view with registration like that that people will say, 'I really haven't got time to think about this. I've got better things to do', therefore they will tick no, as opposed to making this informed decision?

**Prof BOYCE** - Correct. In New South Wales, where they try to embed it in the driver's licence process, about 40 per cent of the people say no. I think a lot of them use that response, because the rest of the survey data in New South Wales doesn't support that.



I have concerns with the new access card, should it ever come. I was talking to a man from the Office of the Access Card - I found it quite funny that such an office exists - and he was telling me that plan A at the moment is to ask 16.7 million Australians in the post office or wherever whether they want to be on the organ donor registry. I said to him, 'I really think you need to think about that'. We did a trial in Medicare offices in Hobart - I don't know whether you have heard about it - and it was really hysterical because all the Medicare staff had to ask all their clients whether or not they wanted to sign on to the organ donor registry. They forgot that some of these people are sick and they got a bit paranoid about why the Medicare staff were asking them about the organ donor registry. Within 24 hours they had to stop the pilot because staff were going off on stress leave. People were shouting at them because they were being asked all sorts of questions they couldn't answer.

I am very supportive of donation but it is a private health decision. If they are going to ask about organ donation in the access card, what about cervical cancer vaccination and breast cancer screening, slip-slop-slap et cetera? I think it is a funny context: where do you live, what is your rank and serial number, what is your pension number, and do you want to be an organ donor? We have put the suggestion that they go back and think about that. It will also save them 16.7 million times one point something minutes, which I gather is quite a lot. I believe people have to want to do this. I think trying to force them to do it is going to be counterproductive.

**Ms FORREST** - Can you reasonably expect people to sign up without some explanation of what it actually means?

**Prof BOYCE** - No, I don't.

**Ms FORREST** - That's the problem, isn't it?

**Prof BOYCE** - I think it is a huge problem to have some clerk asking, 'Do you want to be on the organ donor register? - yes, no, tick.' It is hardly what I could call 'informed consent'. Perhaps we could take the opportunity to give them a brochure and say, 'Take this away. We would encourage you to read it and fill it in'. Some of my colleagues say, 'They won't fill it in', and I say, 'We haven't won the day then'. It does not seem right to me to having some forcing function that says, 'You can't go on to the next screen that will let you get your Medicare benefits unless you give me an answer'.

**CHAIR** - Thank you very much. That was very helpful, Neil. Thank you for coming across and for your interest. We may get in contact at some later stage after the Commonwealth comes down with its findings.

**THE WITNESS WITHDREW.**

**Dr MATTHEW JOSE**, MBBS, PhD, FRACP, STAFF SPECIALIST NEPHROLOGY, ROYAL HOBART HOSPITAL, WAS CALLED MADE THE STATUTORY DECLARATION AND WAS EXAMINED.

**CHAIR** (Mr Wilkinson) - Matthew, thank you very much for coming along. Sorry we are a quarter of an hour, nearly 20 minutes, over time. Sometimes it does drag on but thanks for coming along and giving us your time. We have your submission before us, again for which we thank you. We have the terms of reference. I will hand those across to you and ask you to give us a broad overview and then obviously some questions will fly from the committee.

**Dr JOSE** - Sure. I'm a kidney specialist by training as a physician. Part of my work over my training and over my lifetime has been as a transplant physician. I was working at Monash Medical Centre as the physician in charge of the kidney and pancreas organ transplant program and I have a PhD in transplant immunology, so that is very much my interest and my career.

I came to Tasmania last year as a result of the Richardson Report, as one of the new medical specialists at the Royal Hobart Hospital, I guess encouraged by my Tasmanian wife of 20 years.

**CHAIR** - We are lucky to have you.

**Dr JOSE** - In addition to that, between Monash and here I worked in the Northern Territory as Director of Renal Services based in Darwin in an area which has the highest rate of kidney disease in Australia and also the worst organ donation and transplantation rates in Australia.

Having come down here, I feel much Tasmanian now with all the in-laws and I can see the same issues happening here.

Some of the data that I have given to the committee really shows some of the work I have done over the last 12 months showing the rate of kidney disease in Tasmania is very high and numbers over the next 10 to 15 years are really set to at least double, if not triple, depending on the growth rate.

One of the other important issues which I did not submit is that really three-quarters of people who have severe kidney disease do not even end up on dialysis; they die beforehand. So with our public health and our increasing health networks, the likelihood is that we will push up the number of people on dialysis needing kidney transplants significantly more than the figures have shown. I guess that is the approach I come from.

In the last six months I have been involved in several organ donation issues around Australia and certainly you would have heard the national process going on at the moment. I believe I am the only active member of the Transplant Patients Society of Australia and New Zealand based in Tasmania. On the last list that came out there were not any other Tasmanians as active members of that. A couple of committees or groups have contacted me recently, including the Zadies Foundation which is looking at using

rainbow shoe laces as organ donor awareness, the ShareLife group which is a corporate push for organ donations, and then Neil Boyce's group from LifeGift looking at all the organ donation systems. I guess I have been in Tasmania long enough to know that a lot of what he is saying is true. We need local things on the ground here and simply talking to another colleague of mine about this recently, we do not want Victorians telling us what to do when we have an organ donor because we have done all the hard work and then the Victorian coordinators want to come in and take over everything. So really I would support him. We need local people with local interest on the ground because, without repeating what Neil has said, it really does impact on things.

**CHAIR** - How many do we need, how do we resource them, what should they be doing?

**Dr JOSE** - I think you do need two people because the critical thing I have seen, especially with the Royal Hobart Hospital, is that you do need a critical number of people. One person is not going to change anything unless they are really dedicated and enthusiastic, with a long-term plan. You do need at least two people in any one centre.

Whilst we do need it spread across the State, the difficulty is that the Royal Hobart is nominally the trauma centre for head injuries in that we have the neurosurgery unit so that if there is a significant road trauma with head injury in the north of the State, that person will be transferred to the Royal. So the historical figures for Tasmania you see on organ donation showing that Hobart has greater numbers are partly because this is where the neurosurgery unit is and therefore most of brain death will often be transferred to a neurosurgical unit but not necessarily so and that is why there are single figures for both Burnie and Launceston. So you certainly do need that here.

I do believe also it would be useful to have the same number in the north because the population thing should not be any different per population basis - again, we have heard that today - but you do need a critical mass and you do need links with the other States and that I think is also critically important because things are changing so quickly. You have heard about non-beating heart donors. I am not sure whether altruistic donation or directed deceased donor donation has come up -

**CHAIR** - No, it has not.

**Dr JOSE** - The actions of organ donation are really changing over the period of time. In fact Neil, who was your previous witness, knocked us back on altruistic donation back in 2002-03. As a transplant physician, I had people coming in off the street wanting to give a kidney to anybody because it was a good thing to do. We tried to do one but in Neil's position we were stopped at that level at the time, and four or five years later we are now doing that in Australia. In Sydney the Legislative Council have a program and RPA is now doing that. Last week I gave a Tasmanian gentleman the address of a doctor in New South Wales to go and see simply so he can be assessed to give a kidney. We do not have that ability down here.

Certainly you may have read in the newspaper about a young lady who has gone overseas and I can tell you that she would not have done it if there were some process locally that we could use.

**CHAIR** - What type of things should the coordinators that you think we need be doing? Should they be getting around the community with an education focus or should they be getting this audit up and running as Neil just mentioned?

**Dr JOSE** - I am a strong believer in audits and data and it comes from the saying 'In God We Trust' but for everybody else we need data. We do need data because we need to know where it has gone and, again, that comes as me being not a Tasmanian long term. I have come into this system and questioned a lot of things where the answer has been 'Because we always do it that way'. It does not mean that it is necessarily right or wrong; it is just trying to get the data for where we are at the moment. So I do agree that we need an audit.

Let us go more than that. Do we know donors from Tasmania have good outcomes? If we do a massive campaign in Tasmania, are we going to change the impact on things? We do not have a transplant service here so therefore the time between when you take an organ out of a deceased person and put it into a transplant recipient has probably increased and the longer those organs are out of a body - it is what is called cold-ischemic time - the less well they do. Certainly from kidneys we know that once it gets over 12 hours between those two points in time then the outcomes are not as good.

So in addition to the audit of looking at are we missing donors I would also look at the outcome of organs that have come from Tasmanian residents in the longer term; are they just as good?

I did the same audit in the Northern Territory because Darwin does not have a transplant unit and we have to fly organs all around the country and we showed that there was a significantly prolonged cold-ischemic time up to 18 hours on average but that the outcomes were equivalent, were okay, not statistically different or clinically different from anywhere else in Australia.

I think we should also do that same audit here because there is no point saying, as the previous speaker said, we need to get all the 75-year-old donors, lots of them, because the older you get, any organ is potentially not as good in the long term and anything that impacts on that could have a significant outcome. I think we need the data for that and it is easily obtained from the Australia-New Zealand Organ Donor Registry in South Australia. That should not be very difficult to do. In fact, when I thought of it, it was a bit late to get that data before this committee. It is certainly something that needs to be looked at.

**CHAIR** - Should the audit look at anything else?

**Dr JOSE** - Certainly it should look at what are the indications that people know? What is the education level of the doctors and nurses within organ donation? If people have been working in Tasmania - as I said, there are no active members of the transplantation society - are the attitudes of people here the same as elsewhere? In a hospital I have worked in before - a very large trauma hospital - the ICU doctor said, 'We're not organ farms. We're involved in saving lives, not harvesting organs', so it very much is an attitudinal aspect.

I think the audit should look at the following areas: are we missing people? What are the outcomes? How much the staff know now and look at how much they know later. It is an important part of change management to really look at how much people understand about organ donation. A number of my recipients have recently formed a little committee, as a peer support group. They have received transplants and they are happy to give back to the community. With anybody who wants to give an organ or receive an organ and is involved at our level, we are quite happy to refer them to this group who can give them informal peer support because there is a lot of lack of understanding.

**Ms FORREST** - You talked a bit about some doctors and nurses saying they are not organ harvesters, that they are in the business of saving lives. If you have a patient and the family is well aware the patient is probably not going to survive, or in fact has already died but is being kept alive, how often does the family actually say, 'Is there a possibility for organ donation here?' If it does happen, is it likely that it will proceed, even with the attitude of the staff, 'We're in the business of saving lives, not taking organs'?

**Dr JOSE** - It comes back to the experience of the health professionals on the ground at the time that that is raised. If you have temporary staff who are filling in and that question is posed to them, it will be very quickly brushed off. If you have experienced people on the ground at the time, it is raised significantly by those staff -

**Ms FORREST** - Rather than the family needing to raise it themselves, you are saying?

**Dr JOSE** - Correct. I trained in Adelaide in South Australia and at the time we were setting up the organ donor system over there, which is on numbers basis the best in Australia. We had a dedicated new consultant and dedicated staff who were deemed to be the organ donor group. You had a senior consultant as well as senior nursing staff and that was their job, so you actually had a critical mass and if there was a donor, that group was brought into the hospital to talk about things.

**Ms FORREST** - Were they working on an on-call basis?

**Dr JOSE** - Yes. It is that critical mass on a local basis that was able to then enhance that. You then didn't need for the family to be wondering about it. I don't believe it should have to wait until the family bring it up; it really should be part of standard care, that care doesn't end at brain death. If someone is heading down that track and is deemed to be brain dead or will predictably become brain dead, it should be brought up by the health professional.

**CHAIR** - In relation to term of reference 1, whether the present systems established within Tasmania and Australia that enable a person to register a legally, valid consent to become an organ donor are adequate, do you believe they are or would you say, 'That's not really my field'.

**Dr JOSE** - Clearly, that is probably not my field from a purely organ donation point of view, but I do have a lot of people, especially relatives, asking, 'How do we do it? I want to be an organ donor. What do I have to do?' Even amongst people who have direct family relatives there are those who are still ignorant of the system, so I think the education of the public is not adequate. You have probably heard today that even though we have a

high rate of people registered on the organ donor registry, the next steps are also stepped down significantly so that the number of donors and the number of ICUs that check the donor registry is very poor. There are, I have forgotten the number, a lot of Tasmanians registered on the -

**CHAIR** - About 173 000.

**Dr JOSE** - Yes, so a significant proportion of the Tasmanian population but it does stop at a few extra steps.

**CHAIR** - Do you think it fails because of this lack of an education program or lack of communication out there between the people who wish to donate their organs and their families?

**Dr JOSE** - I think it does. It is partly for people to understand what it is about but even talking last week to the medical students while lecturing at the university, they are ignorant about what it means to sign up for this and then what it means if a family member was there. So there seems, even amongst medical students, to be ignorance about the whole process and what you are signing up for and what does that really mean. So that is not adequate.

**CHAIR** - There is now the consent form; previously it was the intent, wasn't it?

**Dr JOSE** - Yes.

**CHAIR** - You intended to donate but now you have to sign the consent form. Is that the proper form that you believe we should be signing?

**Dr JOSE** - I do. I think it should be consent but, again, when I changed my address and signed up the other day, to sign a consent form from a medical perspective requires informed consent. It was too easy for me to re-register and re-consent without any proper informed consent process. So I do not believe when I re-did my address and things that it prepares you properly for what you are signing up for. I am not sure whether it stops people at that point because they do not understand really what they are getting into.

**Ms FORREST** - We heard from the last witness that he thought one of the problems with an opt-out method is the difficulty in getting informed consent to opt out of it. You are saying that there are still problems with informed consent with the opt-in process?

**Dr JOSE** - Absolutely. It goes on to what people know about the whole transplant process and organ donation. There is significant ignorance of the whole process. Even though the television shows are coming up a lot better, we had discussions for years about when the RPA kidney unit was to be involved. It was held off and held off and then Richard Allen and his colleagues were allowed to do it and it worked out very well for the organ donation issue through RPA.

So there is significant ignorance on a whole lot of processes, and by having people on a local basis they are a great generator of providing education, community forums and things.

**Ms FORREST** - So you are suggesting that regardless of which model might be adopted into the future, public information and education is probably the most important thing to ensure that informed consent is what is being given, whichever way you go?

**Dr JOSE** - Yes. I don't agree with the opt out as a personal belief partly because we are in the era of hand transplants, face transplants and so on. We were talking about solid organs for many years but if you get into the next phase of transplantation, which is happening around the world but not so much in Australia, suddenly your body potentially belongs to the government and any of its bits, so unless they understand the process they may not opt out of it and their face may appear somewhere else. So that, I guess, is following a radical line of thinking. I do not think the Australian community would agree to having your body belonging to the government. A lot of processes have been tried around the world, especially in living donations, but in deceased donation I think it is very much a grieving time for the family and education is really what will help change that over time.

**CHAIR** - What does the recipient go through prior to receiving an organ? Obviously they are suffering dramatically, their health is decreasing rapidly, their family is becoming anxious.

**Dr JOSE** - Perhaps I can talk from two perspectives which have been my expertise: kidneys and whole-organ pancreas transplants. Whole-organ pancreas transplants we do for type 1 diabetics, so they are juvenile diabetics with childhood diabetes. Usually they have had 20 years of diabetes by the time they consider a pancreas transplant. We have been doing pancreas transplants in Australia for diabetics who have kidney failure, so type 1 diabetics who are usually in their 20s or 30s and have ended up on dialysis. So after 20 years of disease, people who came to me are partially blind, often have blood vessel disease, some have had heart attacks, some have had bypasses. They are often skinny, malnourished, partly due to the diabetes, and a lot of them have had poorer education because of chronic illness throughout childhood and therefore their ability to work isn't as good. We then transplant them. One young man I can remember well. He was blind and walked with a cane; he also had faecal incontinence, which is part of the diabetes because it affects the nerves. Within a month of the transplant he went to a nightclub for the first time in his life, at age 25. Even though he was still blind and it doesn't change any of your other problems immediately, his quality of life was transformed significantly. He has gone on, still with his disabilities, to be a peer supporter of other people coming into transplantation. It is life-changing for everybody.

We had a young man back from Melbourne this morning who had a kidney transplant from his dad. I first met him on a Sunday morning about February this year. He is only 30 and had had high blood pressure and headaches for a year. He turned up because he was very anaemic; his haemoglobin was half of what it was meant to be and he was in total kidney failure. His kidneys never worked again, he was on dialysis for the four months and his dad went on to give him a kidney transplant. Now, seven weeks later, he is back at work with all that to look forward to. What people go through is significant.

The system within Australia, I believe, in terms of organ allocation, is fair for most people most of the time. If you are a Caucasian you will get a kidney that is probably better matched than if you are a minority group. It is reasonably fair for most people

most of the time. We have had a couple of long-term people who have been on dialysis for seven or eight years and who have received kidney transplants this year. One lady, upon discharge from hospital, was out shopping that day, whereas she had been very unwell and not able to do things. So it is life-transforming and for most people it allows them to get back to work and to get on with life and other things.

**Ms FORREST** - You said about the pancreatic transplants, is that primarily for type 1 diabetes? Are they being successful?

**Dr JOSE** - Yes. There are two centres in Australia that do pancreas transplants. One is at Westmead, which is the so-called national pancreas transplant centre, and the other is Monash Medical Centre, which took it up about 25 years ago, through David Scott. It has been doing about half the numbers that Westmead has done, but in the last eight to 10 years has done on average about 10 per year. It is whole-organ. A pancreas comes with two components: one bit is for the digestive juices and another bit is for the cells that make insulin. At the moment we are still doing whole organs and the outcomes are still very good. Five-year survival rates of that organ are greater than 80 per cent, so it is quite good.

**Ms FORREST** - The reason I ask that is that the biggest increases are kidney disease and diabetes. Mostly it is mature-onset diabetes -

**Dr JOSE** - It is.

**Ms FORREST** - but type 1 diabetes has catastrophic outcomes for a lot of these people if not well controlled. These are the sorts of things that perhaps people could be more informed of through the media. I did not realise that pancreas transfers were occurring at such a rate with such success. I know it is only going to help a small number of them, but diabetes does cost an awful lot.

**Dr JOSE** - It does. We do rationalise organs and only give them to people with type 1 diabetes who are on dialysis. The stem cell program or eyelet cell program is certainly up and running. Westmead has done a number of people with eyelet cells. The Federal Government has given quite a lot of money - \$30-40 million - for three different centres: Westmead, Melbourne and Adelaide, to get eyelet cell programs up and running. Certainly in the future my hope for Tasmania is that they can isolate eyelets in the cells in the pancreas that produce insulin and what you can do then is transport those eyelets and we could potentially do the transplant down here in Hobart. That is just a simple infusion, so like a drip into -

**Ms FORREST** - Can you take eyelet cells from a living donor?

**Dr JOSE** - No, it has to be a deceased donor and at the moment the efficiency is not as good. We can put one whole organ into one recipient. For eyelets it usually takes two, sometimes three, pancreases to get enough eyelets to keep for one person. So the efficiency of isolation is not as good, the expense is quite enormous and that is where you may have seen some of the Bernie Tuck's work and others in New South Wales who looked at stem cells or are looking at coating some of the eyelet cells and giving different types; using pig eyelet cells and a whole lot of different techniques for these cells that



produce insulin and putting it into the body. So that is all coming but it takes a long time.

**Ms FORREST** - The difficulty is that you need potentially three pancreases for one person; you need three people to die but people don't at the same time?

**Dr JOSE** - You do, but you can give one at a time and those eyelet cells stay in the component of the liver and they produce a little bit of insulin. The next one produces more insulin and then if they are still not independent of the insulin, you can give a further one which then gives them enough insulin on board separate to needing needles.

**Ms FORREST** - Do you think if it was known more widely that these things are happening, these advances are occurring and that the only way to get these treatments is for people to donate their organs, that would help to improve the donation rate?

**Dr JOSE** - I certainly think it would because, as you have seen in my submission, we have so many people coming on with kidney disease, we have a lot of diabetics. Most of them are type 2 but we still have a lot of type 1. We do have one young lady who is on dialysis at the moment who had her first baby last year whilst on dialysis. She is a type 1 and she has been waiting for a kidney/pancreas transplant for about three years and so there are young people here in Tasmania who are waiting on that. It is a very real issue and I think by showing people the reality, the personal aspect which is what a lot of these television shows do, that does bring it home. Most people I look after are very happy to talk to the media in a controlled fashion or in fact even better, talk to not so much the media but talk to others who are in the same situation.

**Mrs RATTRAY-WAGNER** - Share their experiences.

**Dr JOSE** - Yes, because we doctors and health professionals can tell you one aspect but it's what the doctors don't tell you which is also important.

**CHAIR** - In relation to the adequacy of Tasmania's approach in identifying potential donors, do you have anything to say about that?

**Dr JOSE** - I do not have any data which I can give you except to quote one intensive care doctor who recently told me they feel that they have a very good system for approaching organ donors and they aggressively treat anybody with head injuries and therefore they feel that their brain death rate isn't as high as other places' and therefore it is because of their better management. That is all hearsay and innuendo and you need data. I would find it hard to believe that we were the best neurotrauma hospital in the country. It would be great if we were but if we are, everybody needs to know about that and that should be broadcast to Minister Giddings for her to jump up and down.

I do not think it is adequate. If you take, for example, 2005-06 and look at the variation in the number of organ donors in the State between those two years, I think there were two organ donors in 2005 and eight in 2006. I know that we have small numbers but I cannot believe there is a 400 per cent difference in people coming through the hospitals over that year. So I do not think it is adequate but we do need the audit to look at it.

**CHAIR** - When we are looking at organ donors and the statistics, are we saying donors who donate around the country or donors who donate just to recipients within Tasmania?

**Dr JOSE** - I think we need an audit from two perspectives. One would be everybody who dies within intensive care to see whether they could or could not have been an organ donor. I think I did submit this in my slides, some of the Victorian audits showing the missed opportunities and the variation between the hospitals. With the audit, I think if we have an organ donor here in Hobart, for example, and the Melbourne lung team come down and take that organ and give it to somebody who maybe comes from Perth, for example, we should look at the outcome of all Tasmanian donors because their organs will go to everybody in the country, some of whom will be Tasmanian, and we should just make sure that regarding the organs that are coming from Tasmanians, not because they are Tasmanians but because of the distance and the time, the outcomes are as good.

It may be that the outcomes for people over the age of 60 aren't as good because the time between coming out of the deceased donor and going into the recipient, whether that be a kidney or a heart, is just too much for that slightly older organ to handle. In young people it is probably fine, and it may be that is why Tasmania's median age of organ donor is lower. The clinicians on the ground can tell you exactly that, they don't think the organs of old people do as well, but we need to know that. It is really looking at everybody who has been an organ donor from Tasmania and see what the outcomes are. That is a very easy bit of data because the numbers are so small.

**Ms FORREST** - Do you think that older people who are in ICU and are suitable donors may be rejected because of their age, even though we don't really know? With the absence of the data we don't know whether they would be suitable organs to get to the mainland for transplant.

**Dr JOSE** - I do. If you look at pancreases, for example, we usually accept donors younger than 40 for pancreases simply because as you get older, your eyelet cell numbers are less and also the ischemic time has to be low, preferably less than six hours. If you are taking a pancreas from Hobart to Westmead in Sydney and having a donor come from somewhere else, it takes all that logistics time.

**Ms FORREST** - Do you think they're being stopped in Hobart, they are not even being pursued, because of the perception that it is probably not going to work anyway?

**Dr JOSE** - I suspect so, because you have to contact the organ donor agencies to go the next step. They will usually accept someone, or at least find out more information, if they are young enough. I suspect they are not even getting to that point of contacting the organ donor agency, but we need data to look at that.

**CHAIR** - One of the things that has interested me is the fact that you put your name down, you consent for your organs to be taken if necessary - this time aspect is one of the major criteria as to whether it is going to be successful or not - and yet for people who are willing donors, none of the tests are done before they die and the tests themselves obviously would take some time. I know you can be brain dead but your heart can be kept functioning with appropriate treatment, but is there any need to do a scanning of the people who have given a tick that they are quite willing to donate their organs? Would that assist with the time delay?

**Dr JOSE** - I think it would. Part of the difficulty in the informed consent process is about being an organ donor. I am not an intensive care physician, but the management of someone who is brain dead is a speciality in itself. You get blood pressure all over the place where you don't have the brain regulating things. To institute active organ donor management, you have to have fulfilled all the criteria and then be designated as an organ donor and consented at that point. Legally you should not do any of that beforehand. I think to try to push it back and have that consent as a proactive consent, that the management should continue irrespective of whether you are brain dead or not legally, especially for people who have consented beforehand, so having local people being proactive about organ donation in the intensive care unit, is probably the way to help that.

**CHAIR** - I suppose it is a catch-all question, but if you were sitting where we are sitting and making recommendations in relation to organ donation, what recommendations would you make?

**Dr JOSE** - I think we need to do several things. I don't believe the opt-out system is, at the current time, the best one to do for Tasmania. I am highly aware, as you are, of the national push, federally-funded, for something like an organ donor task force around the country. That is due to report in December, as you aware, and hopefully we can dovetail into that. I think we need to have locals on the ground to help out with organ donation in Tasmania. I think it will only come with locals, it won't work through a Victorian system. Some person did whisper that we should make it competitive between the north and south and that that would get things going. I think that, in the context of the health system where we have one neuro-trauma unit, that would be unfair -

**Ms FORREST** - We're only ever going to have one neuro unit, aren't we?

**Dr JOSE** - Correct. But again you could look at it as many per deaths in that unit, rather than how many overall - as in how many donors per person dying in that unit. That is perhaps another way of looking at it. I think we need to know how good donors are from Tasmania and whether there are any specific things we need to do because in some of the issues you have raised, pushing that informed consent process back earlier and doing all those tests earlier may be input from Tasmania's point of view to look at identifying people earlier. We know of those prolonged times and anything we can do to benefit the outcomes from those organs I think is very important. There is no point everybody feeling good and being an organ donor if, at the end of the day, the person on the end in 10 years' time says, 'Oh, that's a Tasmanian kidney. We don't really want that one'. It is an outcome thing.

In the Northern Territory we were blessed because they were all young males with road trauma who had rolled their car. They were all 25-year-old males and so they were young, healthy organs. In Tasmania, it will be younger than organ donors nationally but it won't be 25, I suspect. They are the things I think we need to do. Education, I think, is critical for people in the community. We have a lot of people who have received transplants who are quite happy to do some peer education, even talk on a more open basis. Each year we have a memorial service in Tasmania to remember organ donors and recipients. We had it at Scots Church earlier this year; next year it will be in Launceston. We alternate north and south and it is a coming together of all people who have been

affected by organ donation, whether it be recipients or donors. It is something which I think we need to have and to make sure people are aware of it.

**Mrs RATTRAY-WAGNER** - Matthew, how do people find out about that service? I am aware of somebody I know who said that they had participated in that service from time to time. I think it was two years ago and they didn't have much notice that it was going to happen. She said, 'I have to psych myself up to even attend and I didn't feel like I had enough time to prepare myself emotionally to get there'.

**Dr JOSE** - It is very hard because Scots Church is a small hall where you walked in and instantly you were seen. In some of the other ones I have been involved in New Zealand or Melbourne you can sneak in at the back of the church. If you were having emotional issues it was very easy to be there and not be the centre of attention, unlike in Tasmania when you walk in and someone says, 'I know you'. It is about the way we do things. Kidney Health Australia is the group that organises that service.

**Mrs RATTRAY-WAGNER** - Is that of recent times?

**Dr JOSE** - Of recent times, yes. Since I have been here in the last year that is who has organised it. I can find out who organised it before that, but Carolyn Mackintosh at Kidney Health Australia has been organising the current ones. Little things like that I think are important.

**Mrs RATTRAY-WAGNER** - I know that this particular person that I am referring to has appreciated it but she indicated that sometimes you need a bit of leeway time to prepare yourself and that hasn't always been the case. That may be something - obviously not that this committee would look at - that we can talk about at another time, that people get some notice about it happening so they can prepare themselves.

**Dr JOSE** - Yes, I think so.

Regarding the complaint about having the Victorians involved, often they refer to Victorian legislation when you are looking at organ donation. Any changes to that legislation here really need to be making sure how they compare to other legislation and also to make sure that people on the ground are dealing with State legislation and not someone else's State legislation.

The reason that is important is that you may be aware that in Victoria earlier this year there was a deceased donor in ICU who was the aunty of someone who was on dialysis and who had wanted to give a kidney to them, but then that person died in intensive care. The family tried to direct that organ to this person who was on dialysis but the legislation would not allow them to do a directed deceased-donor transplant. Under Victorian legislation if they are a deceased donor they have to go into the pool and go along the usual organ allocation rules so that the best-matched person in Australia would get it. This was where the family said, 'Yes, we have such and such who is on dialysis so why can't we give her organ to this person who is a first-degree relative?'.

**Ms FORREST** - It probably would have been a match.

**Dr JOSE** - Probably, but the legislation would not allow that.

**CHAIR** - So that was a lost donation?

**Dr JOSE** - Correct, yes.

**Ms FORREST** - What about the Tasmanian legislation? It would not be done in Tasmania anyway so we are going to have to operate on the Victorian legislation for transplants. Can the decision be made in Tasmania and then the person could go to Victoria and have the operations or do we need legislative change in both?

**Dr JOSE** - I do think we need legislative change in both to look at this. Victoria is looking at that legislation specifically around that case. Transplant is wonderful because it brings up new permutations and combinations all the time and it does require the law to keep up with it. So there are little nuances like that that are important.

**CHAIR** - Which State does it the best do you think?

**Dr JOSE** - I believe that Tasmania did it the best in 2006 but the worst in 2005. In 2006 Tasmania had 41 donors per million population, which is the second highest in the country, but in 2005 only 25 donors per million population, which was the lowest in the country. The South Australian model, where they have dedicated people in their big hospitals who are actively involved and interested in transplantation is really the way to go. So it is all about what happens in intensive care. It is not to say that intensive care doctors are not good at it, but they really need staff on the ground. They can be ICU nurses with a dedicated role to do that but they can also be extra hands to help out with things because I think the local groups do a very good job looking after things. Like any of these things, having somebody else come in and telling you what to do is not fair. So ownership I think is very important.

**CHAIR** - In Victoria do these people on the ground do the same job as in South Australia?

**Dr JOSE** - No.

**CHAIR** - Prince Alfred?

**Dr JOSE** - RPA has a reasonable unit but not as good as South Australia. South Australia has for years had an excellent record. When I was working in South Australia a lot of people would move States if they were on dialysis so they would get a kidney earlier, rather than waiting seven, eight, nine years in Sydney. It is simply because in intensive care everybody is looked at as a potential organ donor. They are on the front foot rather than waiting for the matter to be raised.

**Ms FORREST** - So in our three ICUs we should have dedicated staff. They could be ICU staff already employed within the units -

**Dr JOSE** - Yes.

**Ms FORREST** - but they have, say, eight hours a week dedicated to this role.

**Dr JOSE** - I absolutely agree.

**Ms FORREST** - When we look at costing that it is not a huge impost?

**Dr JOSE** - No, especially if you are providing it within the context of the health system for that intensive care. I think that is where they should be situated. They should have knowledge, not be somebody coming in who has had absolutely no experience in intensive care. They should be within the system, able to help out and if there is a potential organ donor they are able to really facilitate that. It should be done in conjunction with the heads of unit in the ICUs and spread throughout the State.

**Ms FORREST** - Effectively you would not need too many people. You would not need two in Burnie, for example, because Launceston is only two hours away.

**Dr JOSE** - Yes.

**Ms FORREST** - You could support each other. If the nurse who had that role happened to be off sick in Burnie then you would call the Launceston one and vice versa.

**Dr JOSE** - You do need a critical mass of peer support, whereas if you are trying to change management within any of the hospitals and you come in as a loner, as an outsider, you will fail. If it is done in conjunction with the unit that is there and with another offsider who you can help, I think that is the way to go.

The politics of health care across the north at the moment is very difficult but there is not a lot of distance. It is having at least one person in the unit to keep that enthusiasm going and to educate the nursing staff and all the other staff who are there because it then flows onto the rest of the hospital.

**Ms FORREST** - You could manage with one in Burnie, one in Launceston and to support each other. You do not need to have two. Someone else mentioned we should have two in each unit. They are only part-time anyway but you don't necessarily need a lot of people, but you need them to work together - and have one at the coal face in each unit.

**Dr JOSE** - You do. It comes back to the clinical network idea that is proposed in health. Tasmania's health and population is spread out. We need to be able to provide things but from a professional point of view you need to be able to come together and have peer review and data and looking at things. We do not need to re-invent the wheel all the time. We need to look at models from elsewhere. It would be great if we were able to fund one or two groups to go across to South Australia to look at exactly what they are doing and to then bring that back and do it here.

I do not think they need to go to Spain - it is based on the Spanish model - but the South Australian model is something which, if we could do that here, would be wonderful.

**CHAIR** - Matthew, thanks very much for your time and your delivery; that was terrific.

**THE WITNESS WITHDREW.**

**Ms CAROLYN MACKINTOSH**, HEALTH SERVICES MANAGER (TAS), AND **Mr BERNARD FARRELL**, CHAIRMAN KIDNEY HEALTH AUSTRALIA NATIONAL CONSUMER PARTICIPATION, WERE CALLED, MADE THE STATUTORY DECLARATION AND WERE EXAMINED.

**CHAIR** - Thank you, Bernard and Carolyn, for coming along. As you know, we are looking into organ donation and the terms of reference you have seen numbered 1-5. This is an informal process. Perhaps you could give a general overview and then committee members will ask questions.

**Ms MACKINTOSH** - Thank you for inviting Mr Farrell and me to address the committee today. I am here in the capacity of Health Services Manager (Tasmania) for Kidney Health Australia and as a representative of Kidney Health Australia's Tasmanian Consumer Participation Committee. Bernie Farrell is a member of Kidney Health Australia's National Consumer Participation Committee.

I am sure you are aware the process of donating organs is of enormous interest to those people currently suffering end-stage renal failure. At this moment in Tasmania there are 24 people prepared and waiting for a kidney transplant operation. Last year 12 Tasmanians were lucky to receive a kidney, two of which came from deceased donors and the rest were from living relatives. We are here today to support moves to improve the rates of organ donation, from both deceased and living donors. Members of the Tasmanian consumer committee continually raise the issue of organ donation at their meetings. They have some very specific concerns they would like addressed, so I just want to present those to you. There are six of them.

Firstly, they are very concerned that Tasmanians are confused as to whether or not they actually are organ donors. In the past Tasmanians have been urged to indicate their intention to be an organ donor on their licence by ticking a box. Many Tasmanians are still under the impression that, having done that, that is all they need to do. With the new national register, Transport Tasmania transferred their organ donor files to the new register but all the files have been recorded on the new system as intentions to donate. This means that at the time of death family members will be asked if they will consider organ donation and they may refuse so they may override the person's wish. Under the new register, people are asked to complete and sign a formal consent form. So it is a legally binding document that at death cannot be overturned by relatives.

Tasmanians do not actually understand the difference in the systems or the difference in what they are actually signing up to do. The committee suggests the difference between the two systems needs to be explained and promoted. They also suggest mass promotion and distribution of application forms for the new system and ongoing widespread promotion about the need and importance of being an organ donor. They just do not feel that it is being promoted enough.

**Mr WILKINSON** - We were told this morning that 173 000 Tasmanians have actually consented for organ donation.

**Ms MACKINTOSH** - That is right.

**Mr WILKINSON** - That is an interesting figure - one which, I must admit, surprised me. Were you aware of that figure?

**Ms MACKINTOSH** - No. We were aware that Tasmania has the second highest level of being organ donors - 16 donors per million population is the second highest rate in Australia. I think we are outdone only by South Australia with 23 donors per million. So people do like to donate. When we are out in the community we find that people are very keen to be organ donors, but they really do not understand that difference between the past system and the new system and what that means.

**Ms FORREST** - May I clarify a point with the new system? You have said that under the Medicare system consent is given by the person because they sign a legally binding document and the relatives cannot overturn it. Is that it?

**Ms MACKINTOSH** - Yes. In that case if I were on a ventilator right now and the doctors made the call to the register and found out that I was an organ donor, it is still really important that they get the family's support to proceed. Even though they know that I have signed and I am happy to do that, they explain my wishes to the family. They encourage people to discuss that when they are signing the form - to make sure that their family and relatives know because it is really important for the family's social wellbeing that they understand the wishes, they understand the procedure and that they support what is about to happen. So even though it is a legally binding document and they really do not need the family's support, they like to have it. It is better.

**Ms FORREST** - When I signed up, I signed the Medicare form and everything. If I had been killed the next day, at that point I would not have told any of my family of my intentions so they would not have known. It probably would have been some time before I did because it only suggested that you do that - there was no obligation to do so. I have also read in some other submissions that it is expected that consent be obtained from the relatives as well as from the deceased person, and that if there were any concerns that the decision might have an adverse impact on the relative's mental health, for example, that that consent would not be given and the organs would not be taken at that time. I am just a bit confused about what our law is actually saying here because I think there is potentially a bit of a fine line. Also, from a medical practitioner's point of view, I do not think that any medical practitioner would be happy to operate and take a person's organs without consent of the living relatives as well as the dead person.

**Ms MACKINTOSH** - That is right.

**Ms FORREST** - So I would just like your comments on those points.

**Ms MACKINTOSH** - There is the point of law and the point of the clinician being there at the time, but they definitely want the support of the family and the relatives. Bernie, have you heard of any instances where they have proceeded without that support?

**Mr FARRELL** - I am under the impression that the doctor would still make the call and may choose not to enforce the point of law.

**Mr WILKINSON** - That is what we heard this morning.



**Mr FARRELL** - I have heard that said, but it is anecdotal. But it makes sense to me.

**Ms MACKINTOSH** - When I rang Medicare I made up a scenario. I said, 'I am a donor, I haven't discussed this with my family; my husband does not agree with it but I really want to do it and I have signed the document. What would happen in that case?' They said, 'Well, you have signed a legally binding document, so we would take it.' That is what Medicare advised me.

**Mrs RATTRAY-WAGNER** - They are probably not making the call either.

**Ms MACKINTOSH** - No, they are not making the call.

**CHAIR** - Sorry, Carolyn, we probably stopped you midstream - it was my fault I asked the question.

**Ms MACKINTOSH** - It is a very confusing issue and one that needs clarification.

We can go on and say that many Tasmanians who have signed up are under the mistaken impression that relatives can still overturn their wishes, so we do need to talk about this issue more.

Thirdly, one reason why people are unsure about becoming donors in the first place is a fear that their care is going to be compromised in preference for the need for organs. That comes up when you are out in the community so we need to promote Australia's medical ethics, organ procurement procedures, education and training for clinicians and how to discuss this issue with families when it arises. There are people very frightened that their care will be compromised.

Fourthly, promotion of the need to routinely access the register needs to be directed to hospitals and ICU clinicians. Having a large number of registered donors will not guarantee more transplants unless clinicians check the register.

Employing a dedicated Tasmanian donor coordinator would assist, as would Tasmanian hospitals joining the National Collaborative on Organ Donations which is auspiced by Australians Donate.

**CHAIR** - Is Tasmania a party to that?

**Ms MACKINTOSH** - I am unaware that we are. I do not think that we are.

Fifthly, more needs to be done to make live donation more feasible, especially for kidneys. Transplant operations are not performed in Tasmania. Many donors remain out of pocket for expenses associated with their travel, accommodation and time off work. Establishing a live kidney donor travel reimbursement scheme similar to what they have done in WA would assist potential donors on low incomes, as would a subsidy for lost wages when recuperating from surgery.

Having in-hospital haemodialysis costs \$82 000 per person per annum. Transplant recipients cost \$10 000 per annum after their first year of having the operation so they are saving the health system a lot of money and the cost of dialysis in Australia is

presently growing by \$1 million a week. It is a very expensive treatment but organ donations can significantly reduce that cost.

Sixth, non-directed or altruistic live donation is becoming a topic for discussion. At present some hospitals in Western Australia, South Australia and New South Wales have developed their own guidelines and processes for altruistic kidney donations. Under these guidelines donations remain anonymous so that kidneys go to a best matched recipient and there are no costs or payments involved, which is illegal in Australia.

National guidelines and processes need to be developed to ensure that potential donors do not need to go overseas to fulfil their desires and similarly those on waiting lists do not feel they need to look outside Australia for a solution to their problem and that is happening.

Finally, those lucky enough to receive a transplanted kidney remain on medication for the life of the graft kidney. Those on health care benefits pay pensioner rates for these medications. Those who are employed bear heavy costs of approximately \$100 per month for the rest of their lives and we would ask that these costs be subsidised at the pensioner rate also. It is very expensive.

**CHAIR** - But it is a saving. If you are looking solely at figures, which you cannot where health is involved, it is still a saving isn't it?

**Ms MACKINTOSH** - Yes.

**CHAIR** - If the government assisted in relation to that, the \$100 a month would certainly be a saving on the cost of dialysis.

**Ms FORREST** - So they are the rejection drugs?

**Ms MACKINTOSH** - Yes, they are. They need those for their lifetime.

**Mrs RATTRAY-WAGNER** - So they never come off those?

**Ms MACKINTOSH** - No.

**CHAIR** - The first term of reference is whether the present system, as established within Tasmania and Australia to enable a person to register a legally valid consent to become an organ donor, are adequate. Do I take it that you are saying no, because we are not really educated as to what to do and what forms are out there?

**Ms MACKINTOSH** - Yes, Tasmanians are confused. The new system, whilst it has had some promotion, it has not been extensive enough and we would like to see more resources devoted to promotion and discussion about understanding what organ donation is. A lot of people think that they sign up to be a donor and when they die all their organs will be available for donation, but it is only a very small percentage of people who qualify to be a donor. They have to die under certain circumstances, be kept alive on a respirator, be pronounced clinically brain dead, so it only ends up being a very small number of people who become donors. Even that process needs to be explained; people don't understand it.

**CHAIR** - We were told approximately 1 per cent of people who consent to becoming donors actually donate.

**Mr FARRELL** - There is another issue too with the use of the register and that is what happens in the hospital, which I imagine has been raised earlier on today, the relationship of the ED and the ICU.

**CHAIR** - What is the problem there?

**Mr FARRELL** - The ICU is always busy and its major priority is the person with the most chance of living. So if the emergency department has someone who is dying and they are a potential donor, the ICU has to take them on board so there are various potential problems there - I think Tim Matthew referred to a couple of those in his submission - whether it be a logistical problem or sometimes apathy.

**CHAIR** - We were told this morning that what occurs is because the doctor at times can be so focused on keeping a person alive that, if that person is not kept alive for whatever reason, to some degree the doctor feels guilty that he wasn't able to keep that patient alive and therefore he doesn't think to the next step, 'Is this person available for organ donation, if that is his or her wish?' They seem to close the door after the first issue of being unable to keep this person alive, as opposed to going to the next step.

**Mr FARRELL** - It sounds like a reasonable response, doesn't it, from someone who is committed to keeping people alive.

**Ms MACKINTOSH** - A Victorian study looked at how they could increase their donor rates between 2002-04 and they said that identification within the hospital system of potential donors was a key - educating the hospital staff and raising their awareness about organ donation in the processes within their hospital system. It is very important for them to understand how they could better effect an increasing donor rate, and even obtaining consent from relatives, with better training and education for the clinician who have to approach families. If they are more confident and have some experience behind them, they can effect an increase in getting a family's consent.

**Ms FORREST** - In Tasmania we don't conduct any transplants and having a suitable donor in an ICU bed in Tasmania is a very rare event. I worked in ICU for a few years and I came across one young person - the discussion was had but it was deemed inappropriate at the time. Because so few medical staff in those settings get to deal hands-on - it is only a short space of time from the time the person arrives and then leaves the unit, it may be 24 hours but probably likely to be less - only a small number are going to be exposed to this. How do you believe we need to go about informing the ICU medical and nursing staff and the DEM staff to ensure that it comes to mind? If the patient has died and all your best efforts have failed to save the patient, the immediate next step is, 'What can we do now?' What do you think is the way of turning that around?

**Ms MACKINTOSH** - Do you want to talk about the National Collaborative

**Mr FARRELL** - That is the first thing that comes to my mind, too, which you have heard about this morning. I think that offers great potential to interest that issue. I imagine that

coming out of that - but even if it doesn't come out of it - to have a State-based full-time organ coordinator to liaise. I don't know how this ties in but somehow or other I think the DHHS would potentially have some sort of a role here. I am a mug punter in that I am a consumer - my wife has dialysis - but I sit on a couple of DHHS committees in Victoria. Those committees are mainly working on dialysis, not on transplant, but I can see that the Government is very involved. They have the doctors sitting down in this sort of environment and it seems to be working well. I don't how the DHHS would work in with the collaborative because I don't know the workings of the collaborative well enough.

**Ms MACKINTOSH** - Did they talk about the National Collaborative on Organ Donation this morning at all? Have you had Australians Donate?

**CHAIR** - No, not yet.

**Ms MACKINTOSH** - They are the ones for that. In America a few hospitals got together to look at best practice in how they could increase their donor rates within hospitals. Some major hospitals, working together and sharing their ideas, came up with some really useful tools that they could pass on to others. In the space of three years they got their organ donor rate up by 20 per cent. Australians Donate have been funded to start up something similar in Australia. It has been going for just over a year now and several hospitals around Australia were invited to join this trial. They were given the background information from America and the hospitals then shared in these learning sessions. They met regularly; they provided feedback on what worked, how they were improving their rate, what they were doing that worked, what did not work, so then they would go back to the hospital and pinch somebody else's ideas that sounded really good. A bit of trial and error. They found about a 30 per cent increase in donor rates in those hospitals that are participating in Australia. As far as we know Tasmania is not in that trial group but I know Australians Donate are looking to expand that trial now. They said there would be some room for invitations to be made to other hospitals. It would be great if Tasmania put up their hand to be part of that trial because it seems to be having some very positive flow-on effects in getting increased consent from people to be donors, getting hospital staff to think more, making it more top-of-mind to identify them in the first place and then actually obtaining more organs. That would be great for Tasmania to be part of.

**CHAIR** - Why was it not in the first place? It was not asked or they did not put their hand up?

**Ms MACKINTOSH** - I do not know. I am under the impression they were invited.

**CHAIR** - They were invited but did not take it up.

**Ms MACKINTOSH** - I do not know. Australians Donate would know that.

**Ms FORREST** - If the trial is not extended or Tasmania is not involved, is there anything you think needs to be done here that could actually improve the participation and education of the staff?

**Ms MACKINTOSH** - I guess it comes to the Department of Health and Human Services actually committing to some sort of promotion and awareness campaign within the hospital, or even just between ICU and the Emergency Department if they are limited in funding, to put a little awareness program together for those two departments on what the current system is.

**Ms FORREST** - Do you think there needs to be a statewide coordinator to run all that?

**Ms MACKINTOSH** - That would be the best.

**Ms FORREST** - Do you think one person or would you need two part-timers?

**Ms MACKINTOSH** - I would think one person in the State would probably be able to handle it.

**Mr FARRELL** - I think that two successful kidney donations would probably cover their annual cost in a crude sort of a sense. It kind of makes sense.

**Ms MACKINTOSH** - We have a very good relationship with LifeGift Victoria that take on this coordinating role. It is very good but they are in Melbourne and that is where the expertise is. Having somebody locally that could help promote it would be great.

**Ms RATTRAY-WAGER** - Carolyn, we did talk this morning to some previous people who came before us about the terrific national campaigns that have been run. Have you been involved in asking about a national campaign for the donation of organs?

**Ms MACKINTOSH** - I was not under the impression that that was part of the Australians Donate charter. Certainly Kidney Health do not get involved in advertising promotions but we are more of an advocacy for our consumer representation.

**CHAIR** - What would happen if I said I am going to donate, something happens to me, I am in hospital tonight and there are a number of people awaiting kidneys? What is the process, what would happen?

**Ms MACKINTOSH** - We confirmed this morning. It is very confusing when one person is in one State and the other is not. If you are in ICU and the doctor there says he cannot do any more, he could access the national register.

**CHAIR** - How could he do that?

**Ms MACKINTOSH** - Only if he had signed a legally binding confidentiality document that is about 20 pages long with the owners of the register. He would be the contact person - the one and only one - with access and a password to get into the system.

**CHAIR** - So therefore that doctor has to contact the keepers of the register.

**Ms MACKINTOSH** - Yes, they have 24-hour access to the register where they can actually key in and have a look.

**CHAIR** - The person then gives that doctor the authority to access the register and then the doctor accesses the register. How long does that take?

**Ms MACKINTOSH** - If he has already signed the document, he would have immediate access to it.

**CHAIR** - Would he?

**Ms MACKINTOSH** - Yes, but not many doctors do that because they -

**Ms FORREST** - How many in Tasmania would?

**Ms MACKINTOSH** - I do not know. Because it is a 20-page legally binding document, it is easier for them to call LifeGift Victoria - the coordinator there for Tasmania - and say, 'I have somebody, could you check it out'. They will go in and do it on his behalf, so they check the register. They will check your details, see that you are there, check your age, height, weight and all that; then they would look at your blood tissue. If they come back and say, 'Yes, I think he would be good then the doctor gives them the okay and they look at tissue-typing and then the coordinator will either get on the phone and talk to your family and say, 'Were you aware that Jim wanted to be a organ donor', and they would go through the process of counselling them to make sure that they understood.

In some cases they will actually fly here. They will get on the next available plane, come down and take a residence and talk to the family. From here they will coordinate where your organs go. So in the case of kidneys, they will check the register and they will look for the best-matched kidney, matched to you, and they will look in Tasmania first. If they cannot find anyone that is suitable to receive your kidney, they look at Victoria and if they cannot find anyone in Victoria then they take it further and further out.

It is different for different organs but for kidneys, certainly, they look at region - where it comes from first. If they found a Tasmanian that could get your kidney, they would fly the transplant team in so you know they will actually do the surgery here.

If Burnie wanted the kidney in Melbourne - if he had the best match - they get your kidney and they pack it up and take to Melbourne.

**Ms FORREST** - Is it only kidneys we can transplant in Tasmania? Do we do kidney transplants in Tasmania?

**Ms MACKINTOSH** - They would only bring the transplant team from Melbourne here to do that operation if the organ and the recipient were in the same State.

**Ms FORREST** - But you can put kidneys in in Tasmania? That is what I am saying.

**Ms MACKINTOSH** - Not by Tasmanians.

**Ms FORREST** - No, but you can do it in Tasmania.

**Ms MACKINTOSH** - Yes, they will come here.

**Ms FORREST** - They will come and do it, yes.

**CHAIR** - And how long does all that take?

**Ms MACKINTOSH** - It can be very fast. As soon as they get the call and they say you are okay, they will book the next flight.

**Ms FORREST** - There is a period overnight where you cannot get into Tasmania - for about eight hours overnight there are no flights in - and these things always happens in the middle of the night. So do they charter a plane or anything?

**Ms MACKINTOSH** - I suppose they can. I know the transplant team can get a chartered plane that comes straight here. I would need to double-check that with the coordinator, though.

**CHAIR** - So all that is being done. What are major stumbling blocks? Is it the consent then of the living family? They have said, 'Jim has signed the consent form; I don't know whether he's spoken with you about it'. If he hasn't, that is a problem that the coordinators would have to get around.

**Ms MACKINTOSH** - They would probably do that on the phone in Melbourne; they would try to get that address fairly early on while they can.

**CHAIR** - Would communication between the donor and the family be one of the major stumbling blocks to getting that consent because, as we have heard, doctors are not willing to carry out a transplant if the living family do not think it is the way to go?

**Mr FARRELL** - But we also note, don't we, that the senior clinicians are much better at eliciting consent than junior? Once again, they make sense.

**CHAIR** - So has that been a problem, junior people are speaking with the family and as a result they are not able to get the consent as well as the major or senior clinicians?

**Mr FARRELL** - Yes, there is evidence of that. It is referred to in the literature.

**CHAIR** - And the literature says obviously why a senior clinician is better to speak with the family. Do we know why?

**Mr FARRELL** - I haven't read that.

**CHAIR** - Right.

**Ms MACKINTOSH** - We see it as more experience; a senior intensive care doctor would have a lot of experience.

**Ms FORREST** - More likely to have done it before?

**Ms MACKINTOSH** - More likely to have done it before, yes. I remember Dr John Freeman at our thanksgiving service, who said he remembered the very first time he was told to go and ask for the organs. He said he had no training, he just went off and asked. It is trial

by fire, sometimes, for these young doctors. I think it is a 65 per cent consent rate if an ICU doctor does ask the family for consent. It is fairly high.

**Ms FORREST** - You have not been a researcher, you might now know, but if I had someone come to say, 'Your husband is not going to make it' and they wanted to know about his organs, whether he was a donor, if I couldn't get my questions answered about how do you know he's brain dead, how do you know that he's not going to feel this, how do you know all those things that you hear are out there, I would expect a senior intensive specialist would have a better capacity to answer that than a junior one.

**Ms MACKINTOSH** - Yes, definitely.

**Ms FORREST** - Do you think there needs to be some sort of requirement or some sort of structure around who interacts with the family, as opposed to not just leaving it to an ad hoc sort of system, which it seems to be, from what you are saying?

**Ms MACKINTOSH** - Because we don't have a dedicated organ donor coordinator here on standby that can come in in those situations and take on that role -

**Ms FORREST** - So if we did have that person then we would call that person in and let the doctor get on with looking after the other patients in ICU?

**Ms MACKINTOSH** - Yes.

**Mr FARRELL** - Or they might realise that they need to get the senior intensivist in, but at least they have the knowledge and it is much more sophisticated.

**Ms MACKINTOSH** - It becomes more of a team approach.

**Mr FARRELL** - I imagine, also, that the collaborative would be looking at that and facilitating that, too. I am coming from two directions there, but even without the collaborative, I am sure the State facilitator would achieve that end.

**CHAIR** - Why does South Australia seem to do it so well?

**Ms MACKINTOSH** - Because originally they were the only State that did transplant operations, so I think the community culture built up that they had experts in transplants and it flows through to the signing up on the register.

**Mr FARRELL** - It might be out of context but can I say that on behalf of consumers I would like to commend and congratulate and thank you for your interest in this subject. You are in that amazing position of being able to save lives with this. It is awesome, I guess you would say, and I envy you in a way that this initiative will save some people's lives and make a real difference to the wellbeing of hundreds of families.

**CHAIR** - Thank you, Bernie, for that. I understand and you would be well aware that the Commonwealth are already looking into this matter and one of the comments that we have had, which seems to be a wise one was, is that it is best that we wait and see what the Commonwealth recommendations are in order that the Tasmanian committee can



dovetail in with those as opposed to going in opposite directions. Obviously you may or may not agree with that but I would think that you would agree with that.

**Ms MACKINTOSH** - That makes logical sense really. I think even if that is a long way off there are things we can do.

**Ms FORREST** - It will be December this year.

**CHAIR** - Yes.

**Mr FARRELL** - Because of the complexity of the health-care system there will still be things that with your initiative here you may well do better.

**CHAIR** - Health is a State matter as opposed to a Commonwealth matter as far as the legislation is concerned in relation to our hospitals et cetera, apart from the Mersey now.

Therefore the adequacy of Tasmania's approach in identifying potential donors and facilitating the donation and procurement process can be improved and it can be improved by what you have been discussing.

**Ms MACKINTOSH** - Yes, by finding out at least if they are not aware of that national collaborative and if they can get themselves involved in that, it would be a wonderful start, and then looking at having their own dedicated organ donor coordinator for this State would be great and even maybe better promoting to the public about people still rocking up and thinking it is on their licence. Maybe we need to assimilate some of these new organ donor forms through other means.

**CHAIR** - We have been spoken to today about the benefits of an audit to audit not only who is willing to donate their organs but also how many people die that have been able to donate their organs as well. There is not an audit process in place at the moment in Tasmania. Do you believe that is a good start as well in order to get some data on how many we are missing out on and if so, why are we missing out on them?

**Ms MACKINTOSH** - Yes. That would be a great start.

**Mr FARRELL** - Scientifically it makes so much sense, doesn't it? You do not measure accurately where you are starting from and where you are ending.

**CHAIR** - What do you think that audit should contain?

**Ms MACKINTOSH** - It is a national register. They are virtually checking up on themselves, aren't they? They are going to be looking at whom we have missed.

**Ms FORREST** - So if you only need to look at deaths that occur in the DEMs and ICUs of people that -

**Ms MACKINTOSH** - Ones that could have been potential -

**Ms FORREST** - You have to determine whether they were potentials and if they were, what happened to them. Is that what you need to do or do you need to look further than that or not as far as that?

**Mr FARRELL** - I think that is a part of that. And if they were suitable and they did not leave the ED, not only the fact that they did not but why didn't they. And then if they got to the ICU and they were still suitable but it did not progress, then once again why?

**Ms MACKINTOSH** - So the audit can be localised within each hospital.

**Ms FORREST** - Do you think the audit could go a step further to looking at those that were identified as suitable donors and did donate, particularly if we are doing it within Tasmania, the outcomes of those donations, such as when those kidneys got to Victoria and the pancreas got to Sydney and the liver got to wherever that was going, they were successfully transplanted, or don't you think it would need to go that far with an audit?

**Ms MACKINTOSH** - That is actually picked up in the ANS data.

**Ms FORREST** - It is already recorded?

**Ms MACKINTOSH** - Yes, it is recorded nationally and it is pooled and you get the figures by State of how many organ donors in a year were from Tasmania, how many organs.

**Ms FORREST** - So you would not need to go that far with an audit?

**Ms MACKINTOSH** - No, that is already recorded.

**Mr FARRELL** - There are two bodies compiling. There is the Australian New Zealand Organ Donation Registry and there ANZ Data and they both compile variations on the -

**Ms MACKINTOSH** - And it is the ANZODR data that records the number of transplants and the number of organs per State.

**Ms FORREST** - And what the organ outcomes are?

**Ms MACKINTOSH** - No, it would say 12 kidneys from Tasmania. The fact that maybe two of them failed three months down the track would not be recorded.

**Ms FORREST** - No, I am talking about whether they actually get to be transplanted because obviously if the time is too long -

**Ms MACKINTOSH** - These are actual transplants.

**Ms FORREST** - They are not ones that are collected and then not used?

**Ms MACKINTOSH** - No.

**CHAIR** - Would it be worth the audit also following up how the organ from Tasmania coped with the recipient - in other words, is the recipient still living five years on, 10 years on, 15 years on? Is that of benefit?

**Mr FARRELL** - That is accessible information.

**CHAIR** - It is accessible now?

**Mr FARRELL** - Yes, I am sure. Once again, I am a mug punter but I read a lot.

**Ms MACKINTOSH** - I would need to check that with LifeGift, though.

**Mr FARRELL** - But I am sure I read those statistics and they are Australian statistics, not American or European.

**CHAIR** - Because again, one could argue that if the donation was from a person in their late teens, early 20s, it might be a more successful donation than from a person between 50 and 60, for example.

**Mr FARRELL** - Yes, and that stuff is certainly recorded.

**CHAIR** - That is worthwhile data in your belief?

**Mr FARRELL** - Yes.

**Ms MACKINTOSH** - But it is confidential; nobody every really knows whose organ goes where. Certainly when we have these Thanksgiving Services where recipients of organ donors and families of people that have donated come together they like to talk to each other and they get a very different perspective of what each other has had to go through. It is a very moving and healing experience for the people involved.

**Mrs RATTRAY-WAGNER** - Carolyn, I am aware that your organisation convenes these services that you have each year now in Tasmania. I was speaking recently to a person who lives in my electorate and they have had a family member who has donated. They were saying that in the last couple of years, and I am not sure if it was the immediate year or the one before that, they did not have much notice before they became aware of the service and they just did not feel as though they had had enough time to get their emotions intact before they attended. Is that something that you think about when you send out the invitations?

**Ms MACKINTOSH** - Because we do not know who the donors are, LifeGift Victoria send out the invitations to these people so we are not aware of who they are. Perhaps we could give them a bigger lead time as to when they can get their information out.

**Mrs RATTRAY-WAGNER** - I know that is outside the terms of reference but it is just something that was raised with me when we were talking about this particular issue.

**Ms MACKINTOSH** - We can certainly do that.

**Mr FARRELL** - It indicates what a tough area all this is. It is not black and white in so many aspects. This is difficult stuff.

**Mrs RATTRAY-WAGNER** - This was quite some time on - five years plus. Obviously it is still an emotional time for people.

**Ms MACKINTOSH** - Some people come year after year to the annual remembrance.

**CHAIR** - Term of reference 3, Carolyn and Bernie, is the impediments, if any, causing Tasmania to have the lowest organ donor rates in the nation and the net worth to Tasmania of having an organ donor rate equal to the best in the nation. Is that term of reference statistically correct?

**Ms MACKINTOSH** - We actually have the second-highest level of organ donation rates in Australia.

**CHAIR** - In relation to kidneys or everything?

**Ms MACKINTOSH** - In relation to everything.

**Ms FORREST** - Registered donors as opposed to people who actually end up donating. Is that the difference here?

**CHAIR** - Yes.

**Ms FORREST** - We have 173 000, or thereabouts, people registered to donate but the number of Tasmanians who are suitable donors and do donate on their death is small. Is that an accurate representation?

**Mr FARRELL** - Yes.

**Ms FORREST** - Why is the donation rate on death so low in Tasmania? What are the reasons for that, do you think?

**Mr FARRELL** - I know that Tim Matthew travels nationally all the time now. He thinks that part of that is likely to be the lack of a dedicated person.

**Mr HARRISS** - Just to confirm that, that goes to your introductory comments about the processes in hospitals to properly identify rather than simply having names on the register. Dr Matthew addresses that in his paper and that is his contention, clearly?

**Mr FARRELL** - Yes.

**Mr HARRISS** - That seems to be a common thread from the witnesses we have had today about changes that we need to make if we are going to get a higher donor level - actual retrieval.

**Ms MACKINTOSH** - Greater identification of the potential and increased awareness in that clinician group. It makes sense, doesn't it?

**Ms FORREST** - It has been one of the suggestions that with our dispersed regionalised population, even though Tasmania geographically is not large when we look at South Australia, for example, the majority of South Australians living in and around Adelaide

as opposed to more than half of Tasmanians living outside Hobart, which is the only place that has a neurosurgical unit, where people with head injuries are going to go, for example. Do you think that poses problems, having that regionalised population? Is there any way you can see that it could be addressed to increase the likelihood of suitable donors being identified?

**Mr FARRELL** - I'd be only guessing.

**Ms MACKINTOSH** - You wouldn't want to set up an organ donor program in each of the three regions. One centre has to be the main centre, I think, and it would make sense that that would be the Royal with its neurological ward. You can make the other hospitals' ICUs and emergency departments -

**Ms FORREST** - We only have three ICUs in the State.

**Ms MACKINTOSH** - Yes, that is right. Well, here is the potential. Let us stick with Hobart and get them down there fast. Logistically it wouldn't be that hard to do.

**Ms FORREST** - Do we need to maintain the patient appropriately in Burnie or Launceston and get the team to them rather than sending the patient? It is easier for a well person to fly than a brain-dead person on support.

**Mr FARRELL** - My thought there is that it would be interesting to learn this from what has happened in similar circumstances elsewhere. There must be somebody coming in today who has the direct knowledge of that.

**Ms FORREST** - Maybe this is a question that needs to be asked of the South Australian people who run the programs there: percentage-wise, how many of their donators come from the metropolitan area and how many come from regional areas? We did hear that population-wise it was pretty even in one State, but maybe those figures need to be sought. You don't know that offhand?

**Ms MACKINTOSH** - No. We could find out.

**Ms FORREST** - It's a question for other people perhaps.

**CHAIR** - Unfortunately time is running out? What recommendations do you think we should be making?

**Ms MACKINTOSH** - We need to get involved on a national level in the National Collaborative. We need to look at getting a dedicated organ donor coordinator for Tasmania. We need to be asking Australians how they can better promote their new register in Tasmania because they have to undo what Tasmanians have learnt before. I think they need to generate a bit more discussion about the process of organ donation and what it means to people who have to go through it, and promote the awareness that families need to discuss the issue. I think that is one area that they probably have promoted a little bit, but in terms of an overall package it needs to be a big national message and a sustained message.

**CHAIR** - So at the moment we are not part of the national scene, is that what you are saying?

**Ms MACKINTOSH** - We are part of the national scene but not in the National Collaborative.

**CHAIR** - Every other State is part of the National Collaborative?

**Ms MACKINTOSH** - I don't know. I don't think Queensland is.

**Mr FARRELL** - If I could make two points: one is the issue of life kidney compensation, a particularly thorny, complex area of an ethical minefield, but nevertheless one that needs to be looked at closely because I think it can have an impact on non-numbers.

**CHAIR** - These are people who are alive who wish to donate a kidney?

**Mr FARRELL** - Someone who is currently being worked up to be a potential donor to my wife. If I happen to get really sick for three months then we suffer significantly financially and there are other aspects but that may have an impact on my decision to go ahead. It is an ethical minefield.

**Mrs RATTRAY-WAGNER** - It is a catch-22: you need to be well to support your wife but if you donate your kidney you will not be well for a couple of weeks.

**Mr FARRELL** - The ethical minefield of course relates to the fact that almost nobody thinks that we should pay for organs, but compensation payment is the cut-off point and it is not clear; it is difficult stuff.

**Ms FORREST** - You are not asking for people to be paid to be a donor, you are asking to have their costs covered as their income.

**Mr FARRELL** - Discussion is needed to work out what costs are involved. By and large we take a different line to Europe and the USA on this. They have a greater level of compensation but we have a very small level of compensation, so people here can save the state a lot of money but at great personal cost to themselves.

The second point is whether DHHS should set up some sort of advisory committee or clinical network or something.

**CHAIR** - Any final questions at all? Thank you very much for coming along and answering the questions.

**Mrs RATTRAY-WAGNER** - Enjoy Tasmania.

**Mr FARRELL** - That is not hard to do.

**CHAIR** - Thanks a lot.

**THE WITNESSES WITHDREW.**

**Mr GRAHAM HARDING AND Ms MARGARET CLARKE WERE CALLED, MADE THE STATUTORY DECLARATION AND WERE EXAMINED.**

**CHAIR** (Mr Wilkinson) - Margaret and Graham, thank you very much for coming along and thank you also for your submissions, which we have in our file. I would ask you to give us a general overview on your submission, and then we will ask you some questions in relation to it. If you want to sum up at the end, feel free to do so.

**Mr HARDING** - I have an opening statement that I would like to read, if I may. I am attending this hearing as the Christian Science Committee on Publication for Tasmania. My office is part of a worldwide group of representatives of Christian Science who provide accurate information to the Government and media relating to Christian Science. My colleague, Margaret Clarke, represents the Government and media at the national level. It is important to note that Christian Science is not Scientology.

A submission was made by this office with the committee's review into organ donations in which we outlined our position that the law should not presume intent to make organ donations without a valid declaration of intent by the donor. Although the Christian Science Church does not take a position on whether an individual should support organ donation and leaves such decisions entirely up to the individual, those who practise Christian Science generally would not choose to participate in the donation process because of their general preference of turning to spiritual prayer to address physical challenges of all types.

Our submission briefly describes the practice of Christian Science and I am happy to answer further questions on this healing method. However, in terms of the issues raised by the select committee, it is necessary to understand that Christian Scientists approach their health and life decisions from a spiritual standpoint through prayer. That prayer determines one's identity as spiritual rather than merely a body and its organic structure and it is this understanding through prayer that leads to transformation of our human experience, including physical healing.

For this reason the transfer of a body part or organs from one person to another may present a conflict to those who practise the teachings of Christian Science. Organ donation seeks a physical means by which to correct a human condition, which is directly counter to the spiritual means that a Christian Scientist typically chooses to utilise. Therefore, it is paramount that any changes to the law work to preserve and promote the protection of individual choice on this issue.

In this regard it is important that the law not presume consent to donate is given for such a personally invasive procedure where consent is not in fact obtained. Ideally, all individuals would have thought through these issues and clearly stated their desires in advance to remove unnecessary doubt and pressure on those who ultimately bear the responsibility for such decisions. However, the reality is that not all will clearly state their desires. For those individuals the key question to be answered is how to best carry out the intent of the individual. Without a clearly stated intention, the risk of violating an individual's intent is too great when left to the determination of others and such risk

places an unnecessary burden on family members to arrive at decisions that are too complex to bear at such a sensitive time for the family.

One approach to improving the public thought in this area, as well as our experience of achieving certainty with identifying donor intent, may be tied to greater education of the public concerning the importance of formally declaring intent. Regardless, we confirm that the existing options in the law which require an affirmative showing of intent to donate organs or tissue best protects the individual and offers better safeguards for those who desire not to make a donation. We respectfully ask that these protections and safeguards be preserved with any amendments under consideration.

**CHAIR** - Thank you. Margaret, do you want to add to that?

**Ms CLARKE** - No, I do not want to add to it. I have looked at a number of recent reviews of advance health directive laws or discussion papers that have been under consideration in the other States. Because I am working at the national level, I do look at, with my colleagues, what is going on in the other States and I think Graham's statement towards the end there indicates that this is the area that needs to be strengthened and certainly education that that is available.

We are finding many people, not only in our faith community but anywhere, are not aware that they can even make an advance health directive and include such things as organ donations, quite apart from what is going on at the national level with the Medicare option and whatever is going on in other States. I think you mentioned it in the last interview the House of Representatives inquiry into older persons and the many recommendations they have made fairly strongly encouraging that sort of approach - both education and the tidying up of laws to do with making advance health directives. I think that gives more certainty but, however it goes - as Graham's statement says - in the absence of formal consent, our approach would be to maintain the status quo so long as it allowed a person to feel comfortable that they were not going to be assumed to have made consent without doing so. I think that really sums it up.

**CHAIR** - For your information, we have received evidence today that where you either have to say whether you do consent or you do not consent - and some places in America do that - that system does not really work. Then there is the presumed consent if you don't opt out and it would seem from the evidence that we have had that, again, that system does not appear to work. These are just my opinions about the evidence we have heard - not those of the others. Therefore, people are saying that if you wish to donate your organs it should be by a specific consent - a consent which has you sign a document saying that you consent to your organs being donated. That information then should be transferred to your family - you should speak with your family in relation to it.

**Mr HARDING** - Definitely to the family because if the family does not know it could be very difficult and traumatic, I think.

**Mrs CLARKE** - We are a worldwide organisation and we share information, particularly with the United States' law, and I agree with you there is a lot of conversation going on about this over there that we are picking up.



**CHAIR** - In relation to the consent. You would be aware now that if you wish to donate your organs you can do that, you get a form then you fill that form out, you sign it and then send it back to the appropriate authority. Do you have any argument against that?

**Mr HARDING** - No, we don't.

**CHAIR** - Do you believe that is proper consent? Is it fully informed consent?

**Mr HARDING** - I think so, providing the donor tells the family about it.

**Mrs CLARKE** - And they know what they are signing. We do not take a formal position on that we are just speaking fairly generally.

**CHAIR** - Sure.

**Mrs CLARKE** - If you are talking about something like the Medicare form or the drivers' licence.

**Mr HARDING** - The Christian Science Church does not have a view on the subject. It is up to the individual Christian Scientist.

**Ms FORREST** - When you say as long as they know what they are signing, I presume we are getting to the informed consent. The process is that you send away and you get a form sent back which has some information with it. Do you think that information you get is adequate to enable someone to make an informed consent? Informed consent is pretty big in my mind.

**Mr HARDING** - I do not think anybody would sign that form without really thinking it through. It is not the sort of thing where you say, 'Oh, I think I will sign it for fun.' It is not cool; they do not do it for those sorts of reasons. I think people would really think twice about doing it. It is on the Medicare form, isn't it? And it is on applications for drivers' licences -

**CHAIR** - Not now.

**Mr HARDING** - Not any more?

**Mrs CLARKE** - In some States it is.

**CHAIR** - In Tasmania it used to be on the drivers' licences, but I do not believe it is on there.

**Mr HARDING** - Yes, it was when I got mine.

**CHAIR** - I might be wrong, but I do not believe it is now.

**Mr HARDING** - But, of course, not everybody drives and not everybody is sick so they do not fill out Medicare forms.

**Mrs CLARKE** - I think our position is that as long as it provides what you said in the first place - that the individual's signed consent is available if not it is presumed they don't

consent. The issue of whether it is legal is another whole issue and we have not gone into that because you would need to see the forms and know how they were set out and what the information was that was given to the individual.

**Ms FORREST** - That was the point I was making: you have to seek that form, it is not automatically given to you. You have to seek it and you have to return it.

**Mrs CLARKE** - That is right.

**Mr HARDING** - I think, too, if you were a determined donor you might go on to a web site to see what else there was and how you could do it.

**Mrs CLARKE** - In other words you would take steps to find out.

**Mr HARDING** - Yes, and if you went to that extent you would definitely know what you were doing and you would be an informed donor.

**Ms FORREST** - If you believe some of the information we have - there is no reason not to - surveys show that 90 per cent of Australians agree with organ donation and support it but we are nowhere near 90 per cent of the population on an organ donor register. Do you believe that the way it is now - registering through Medicare - is adequate to ensure that people know how to go about it? Obviously the diehards - the ones who are really keen - will do it, but most people haven't time or are too busy. If I had to answer a question today from someone, I would say, 'Yes, but the paperwork is a bit hard' - so how do we pick up those people?

**Mr HARDING** - I don't think I could really comment on that.

**Ms CLARKE** - We haven't really got a position on that. I hear what you're saying. We go back to where we are coming from. The individual we are representing would more than likely make a choice not to consent, but that doesn't say a few of them might take another position. We're generally speaking for the majority who would want that choice. Not so much 'thou must or thou mustn't' but they want the choice and they want to be able to think it through and do it properly.

**Mrs RATTRAY-WAGNER** - Also, that could impact from their family situation, too. There might be a need within somebody's family, and all of a sudden it is a priority and it is important.

**Ms CLARKE** - Or the family have a totally different view to the individual, and that's why if it is a proper document, we do really think the advance health directive which includes it, may solve it. But we're not saying that's the only way because it is something they do think about for more than just organ donations. What sort of health care do I want and what sort of end-of-life things I want.

**Mr HARDING** - I think sometimes when the chips are down we sometimes change our view on things as well, but from our perspective we wouldn't support this thrust that you have to presume consent. We would rather do it the other way around.

**Ms CLARKE** - That's right. The individual at a young age might have one opinion and in their later years they take on the views we've discussed from our Christian Science standpoint, and they might have a different view. So they would need to review it and revise it, just like you would your normal will.

**Ms FORREST** - And any advance directive you have.

**Ms CLARKE** - And any advance directive, yes. In Western Australia they're talking about reviewing them every 10 years.

**Ms FORREST** - Medical advances happen very quickly at times, and new treatments might become available in five years' time and we haven't even considered them potentially.

**Ms CLARKE** - Exactly.

**Ms FORREST** - Do you think where that could change people's minds you need a fairly flexible approach that allows regular review? Is that what you're suggesting?

**Mr HARDING** - We're not really suggesting anything of a medical nature; we don't have an opinion on medical advances. We don't come from that standpoint at all, but as far as the select committee is concerned we don't support the idea of presuming consent.

**Ms CLARKE** - I think I was just raising one example in Western Australia because I have been reading the debates. Some people are saying if you make a participatory decision, as some people call them, they should review them every 10 years, and some are saying every five years. All that discussion is going on because, as you say, people's lives change in different ways, or they no longer hold a view which might have been a religious view. Or they may no longer hold a medical view and may now have a different view.

**CHAIR** - Should they be also signing a document - in your belief, and I know you are saying it is for the individual to choose - to say, 'I have discussed this matter with my family and after these discussions my family accept my wish', or something along those lines to not only say, 'Yes, I have consented,' but also 'I have discussed this'? Whether they have actually done it or not, we don't know. Should they be also signing that as well, just to give them the added impetus, I suppose, to discuss it with their family, because it's got to be the family in the end? We have learned that if the family don't really agree, doctors won't go near it.

**Mr HARDING** - I think so. I think if it's a Christian Scientist consenting, that would be doubly important because I think the family probably wouldn't believe it.

**Ms FORREST** - Perhaps the next of kin should be asked to sign.

**Mr HARDING** - I think those who are going to be nearest to the one who passes.

**Ms CLARKE** - I don't think we should take a position on whether they should or shouldn't sign, I think what you're saying is -

**CHAIR** - I'm saying should there be another document, because it would appear to me that one of the problems surrounding consent is whether you've discussed it with your family and whether your family accepts what you've done. If you don't have that, there are complex problems that occur.

**Ms CLARKE** - Sitting in on some of the hearings of the Federal House of Representatives, I heard many stories where families didn't even converse with the individual, so that might not work. That's just a comment, it's not a position.

**Mrs RATTRAY-WAGNER** - Some families are estranged quite often.

**Ms CLARKE** - Exactly, and then when it comes to the crunch they have shown signs of disagreement. So I don't think that would solve it, but again that is not a position, it's just something I picked up recently sitting in on the hearings.

**CHAIR** - And is your experience also that if families don't agree then doctors normally don't continue with the wishes of the deceased?

**Ms CLARKE** - Yes. I have actually heard of that situation with one family member of our own - and it wasn't to do with Christian Science; it was a totally different branch of the family - and they just left it. To not consent is to presume that's your decision.

**CHAIR** - Yes. Therefore I suppose you get to the argument then if the individual wishes to donate and yet the family do not want that individual to donate, who should decide? Should it be the individual's wishes, as you were saying, in relation to consent or should it be a third party?

**Mr HARDING** - This is a difficult one, isn't it?

**Ms CLARKE** - Consent is consent. If the person has consented, you would think that is the end of it.

**Mr HARDING** - It is a bit like a will where maybe the family thinks the will has not been divided equally or fairly, yes. It is difficult, isn't it. But anyway, as I said, our submission is that a consent should be not be presumed. That is the thrust of our submission.

**CHAIR** - So your argument would be if you do not opt in -

**Ms CLARKE** - That is right, you are out.

**Mr HARDING** - You are out, yes.

**CHAIR** - you are out. Not if you do not opt out, you are in?

**Ms CLARKE** - That is right.

**Mr HARDING** - Yes.

**Ms CLARKE** - That was our original objection when we saw this. We thought it takes away that freedom if someone has overlooked it or is not able to make it or whatever.

**Mr HARDING** - Seeing it from outside, perhaps the problem for you is that not enough people have decided to opt in because people never get around to doing it. If it is the other way around, it could be that if people did not opt out because they never got around to doing it, they suddenly find they are in. Well, they could not find they are in of course because they are gone but their families will find that the deceased is in.

**Ms CLARKE** - And then the family might have the same view as them, which was a presumption that this person would not want to do it, if they had not done it, and if there was a coercion to, the family would have the same sort of conflict because they knew they did not want it.

**CHAIR** - We have been told that 173 000 people within Tasmania have consented to be organ donors, which surprises me.

**Mr HARDING** - So I heard, yes. It is amazing.

**Ms CLARKE** - Yes, I was surprised in the terms of the terms of reference here. It seemed to counter that.

**CHAIR** - Yes. I understand what you are saying.

**Mrs RATTRAY-WAGNER** - The awareness seems to be the issue.

**Ms CLARKE** - I think the House of Representatives' extensive recommendations perhaps will go some way towards harmonising these laws and making sure the key elements are there because we had some of our colleagues attend hearings in the different States and the same issues that you are talking about with organ donations were coming up everywhere. It might take a long time but I think it will happen.

**CHAIR** - What about universal registration - that is, as in some states in America, you have to say, yes or no?

**Ms CLARKE** - That is really what you are saying in Tasmania, isn't it?

**CHAIR** - No, in Tasmania you can just consent and if you do not consent, you do not have to say you don't want to be a donor.

**Mr HARDING** - What about those who do not get around to doing it? What is it then?

**Ms CLARKE** - You still have that problem.

**Ms FORREST** - Do they fine them in America? What do they do, do we know?

**CHAIR** - I do not know. I know in America they say it does not appear to be working.

**Ms CLARKE** - That is what I am hearing, yes.

**Mr HARDING** - So our problem is that it would seem people never get around to doing a lot of things, and we all know people like that. In fact we do it ourselves, don't we?

**Ms CLARKE** - And it can take quite a strong opinion about being forced to do anything like that. I think that might be one of the issues.

**Mr HARDING** - If you do not want to make the decision, it is never the right time to think about it - it is human nature.

**Ms FORREST** - Maybe it is when people's lives are touched in some way, when they have a relative who dies suddenly who maybe could have been a donor, or they have a family member who needs dialysis or needs a lung transplant, or a child who is born with cystic fibrosis and you know the path ahead is not very good. Maybe it is only then that people would really be facing it.

**Ms CLARKE** - Possibly. That is how I would have imagined it.

**CHAIR** - Thank you very much for coming along. It was nice to meet you.

**Ms CLARKE** - That is all right, thank you.

**Mr HARDING** - Thank you for asking us.

**Mrs RATTRAY-WAGNER** - Thank you for taking the interest.

**THE WITNESSES WITHDREW.**

**Ms HELEN MULCAHY**, PRINCIPAL POLICY ANALYST, AND **DR DAVID BOADLE**, CHIEF MEDICAL OFFICER, DEPARTMENT OF HEALTH AND HUMAN SERVICES, WERE CALLED, MADE THE STATUTORY DECLARATION AND WERE EXAMINED.

**Dr BOADLE** - I may just give a précis of our submission to kick things off. First and foremost, as we pointed out in our written submission, health ministers around Australia have agreed that there should be a national approach to the issue of organ and tissue donation. Because of the fact of 'rail gauge' issues and that organs and tissues are shared between States and Territories they felt that a nationally consistent approach was appropriate. They mandated that there would be a national reform agenda which would look at the entire organ and tissue donation system right from go to whoa, from the community awareness and registering people's consent or intent to be an organ donor right through to hospital practices and procedures and then into the allocation of organs and tissues and the outcomes for people who receive them. So it is a broad-ranging agenda. We acknowledge that Tasmania is a modest donor of organs. In the last few years we averaged about four donors. Last year we had eight, which can be seen as a good or a bad thing.

**Ms FORREST** - Are they all cadaver donors?

**Dr BOADLE** - Yes, so that equates to a donor rate per million population of 16, which was the second highest in the country last year.

**CHAIR** (Mr Wilkinson) - Second to South Australia, wasn't it?

**Dr BOADLE** - I would have to check that but South Australia is always right up there as the highest. Tassie does its bit to a certain extent but we believe that the nature of our State is a slightly inhibiting factor in that we are very decentralised. Clearly a city State like South Australia, where all the acute hospital services are virtually centralised within the Adelaide precinct and where they have bigger intensive care units and so on, probably lends itself to having a smooth system for organ and tissue donation. They would, quite frankly, see more folk, unfortunately, who could potentially be organ donors. So we feel that that is a contributing factor for Tasmania. In light of the national reform agenda and its breadth and depth, our department's positions has been that we will watch and participate where practicable in that process. Where we believe that the agenda outputs are reasonable we will seek to apply those in Tasmania. We feel that this is important in terms of use of resources and so that we participate in a nationally consistent process so that clinicians, particularly doctors and nurses, who move between jurisdictions do not have to learn an entirely new system when they come to Tasmania from the Royal Melbourne or wherever.

**CHAIR** - So do you believe it should be uniform legislation throughout Australia in relation to organ and tissue donation?

**Dr BOADLE** - I believe that legislation is probably a small part of it. I believe that the other processes are arguably more important, such as the community awareness programs and the methods that you might use in your community to be reminded to sign up to be an organ donor. I think the clinical processes are the more important things to have consistent. I think as far as legislation needing to enable that consistency, yes, that is

fine, but our department's view would be that it is more the nuances of clinical practice and how services are organised that would be the major factors.

**CHAIR** - I understand that and agree with you, although today we heard evidence that a person who died wished to leave an organ to a family member, but was not able to and had to be put onto the register. That meant that the organ could have been left to anybody, therefore that organ was lost. That was as a result of the legislation in Victoria.

**Ms FORREST** - The relative actually needed a transplant.

**CHAIR** - Therefore it would seem to me that there are some areas within the legislation within different States that have to be looked at.

**Dr BOADLE** - Yes. Perhaps that is more the allocation processes than the legislation as such. I have looked at our act again today and it comes up as a constant issue: is it the legislation that is holding it back? I think the legislation basically enables transplantation to take place. It is the processes, the allocation and so on. That is not a process I know about in detail but I know about some of the general issues whereby people try to allocate the organs in a fair and transparent manner according to clinical need, which is the predominant consideration.

The other issue with families and so on is that of course the family member that that person wanted to donate to may not have been compatible from a tissue-typing perspective, although within a family you would expect that to be more likely than not. I would be interested to know what were the other factors in that particular case.

**CHAIR** - They were the wishes of the deceased. The deceased's wishes could not be followed through because they had to be put onto this register and therefore the organ would have been donated to the most needy, for want of another word. The child was not, I suppose, deemed to be the most needy even though the child obviously needed an organ so therefore they missed out on that organ completely.

**Dr BOADLE** - Yes. There is increasing attention being given to directed donations in the Australian scene and there has been some national policy work in the last couple of years to lift the profile of that. The National Health and Medical Research Council has also published an ethical guideline on that. In so doing it published an ethical guideline for health professionals and it also published a companion booklet for the general community about the issues involved in directed donation, particularly to a relative or someone with whom you have an emotional bond.

**Ms FORREST** - Is that more to do with live donors, though?

**Dr BOADLE** - Yes.

**Ms FORREST** - Does that extend to cadaver donors or not?

**Dr BOADLE** - I do not believe it does, no.

**Ms FORREST** - That is where the grey area is.



**Dr BOADLE** - Yes, and the two areas are really considered quite separately in my mind.

Just to finish my preamble, our department would want there to be consistency between Tasmania's approach and the other States, particularly Victoria, as LifeGift Victoria is the State-based organisation in Victoria that coordinates organ donation processes for Tasmania, so we could not afford to get out of step with Victoria in any sense. When looking at the indicator for the success of the organ donation system, we have consistently made the contention that we should be measuring the conversion rate rather than the donor rate per million of population. We feel that the donor rate per million population is a relatively crude indicator and doesn't take into account variances in the members of the community who become eligible to be donors. In other words, if there are more cerebral haemorrhages and car accidents in a particular country or jurisdiction than another, the number of people eligible to be organ donors is going to vary. To some extent your community would desire there to be few people eligible to become organ donors because there would be fewer people becoming brain dead, for whatever reason.

**Ms FORREST** - Could you also take that to the other extent, that in some countries there has been better access to and more advances in medical treatment of certain injuries resulting from accidents and neuro traumas and that sort of thing and that may be why there are fewer organs donated in those countries perhaps? If you can't treat a head injury or a stroke to the extent that some countries can then obviously those people are going to die.

**Dr BOADLE** - Yes. I guess that in the more sophisticated countries or those with the more sophisticated health systems the opportunities are better. I think Australia would be very well placed from that point of view for those people unfortunate enough to have a serious head injury or a major stroke, particularly at a younger age. I am not saying that we prejudice anyone, but people in Tasmania would get a good level of care sufficient to allow them to become potential organ donors.

**Ms FORREST** - Or not become organ donors. I am suggesting that the treatment is much better now and a lot fewer people die from those things.

**Dr BOADLE** - Sure. Again, that is another confounding variable that I hadn't thought of. When we look at the donors per million head of population, the number of people having been in a clinical situation where they might become donors and then the success rates of the treatment are all going to impact on the number of people who become donors. We have fed into the national processes very strongly that we feel it should be the conversion rate - in other words, the people who are found within the health system to be potential organ donors because they have been declared brain dead despite all best efforts - the percentage of those who become organ donors should be the key indicator of the whole system.

**Ms FORREST** - I do not believe that in Tasmania we have conducted audits to see who died in DEMs and ICUs, and whether they were potential donors or not, if they were what happened to them and why weren't they if they could have been. Will it be done? Should it be done?

**Dr BOADLE** - It has been done elsewhere but we haven't done it in Tasmania for a number of reasons. Firstly, the fact that it was done elsewhere and, secondly, with the national

reform agenda coming, one of the elements within that is about better data collection and recording those unfortunate folk as part of the normal data collection process.

**Ms FORREST** - So you are suggesting that this data collection may occur as one of the directives or recommendations from the reform?

**Dr BOADLE** - Absolutely. The National Clinical Task Force, which is the major enabler of the reform agenda is looking at that issue.

**Ms FORREST** - Where do you see the funding coming from to do that?

**Dr BOADLE** - For the data collection?

**Ms FORREST** - Yes.

**Dr BOADLE** - It will just be part of normal hospital business, much as we collect other data when people are discharged or die. It will become part of the routine coding process that will identify that as a discrete interview.

**Ms FORREST** - Is there any suggestion or plan to do some retrospective data collection?

**Dr BOADLE** - No.

**Ms FORREST** - Do you think there would be some benefit in that?

**Dr BOADLE** - Yes, in the purest sense, of course there would be some benefit. My feeling is that we must look at the return on investment for Tasmania of anything we do. In an area that is a relatively small part of our overall acute health system I guess we would be relatively reluctant to do that. When there is a new reform agenda in train we will become part of that and we will collect the data. I agree in the purest sense it would be nice to have a before and after but it is a question of who would do that work and what else would we stop them doing to do that work.

**Ms FORREST** - If a new system is put in place through the recommendations of this review, unless you have got baseline data how can you possibly say you have got some improvement? How are you going to judge the success or otherwise of any reform that is put in place?

**Mr BOADLE** - I agree. We are struggling.

**Ms FORREST** - Are you telling me we need to do some retrospective data collection?

**Mr BOADLE** - Yes, with the caveat I would rather it was part of a national system and that it was funded from outside the Tasmanian health system quite frankly. There is an opportunity cost to all these things and it is something our department and someone in my position has to weigh up every day - where will Tasmania get best bang for its buck in investing in people like me and Helen who - quite frankly we are 'it'. We are the resource for this at a policy level in Tasmania.

We know that there are active clinicians out there beavering away doing their very best and we are very mindful that they have other priorities as well. We try to relieve them as much as we can of the policy-type burden and keep them informed but we know if we take an intensivist or an intensive care nurse or some other highly-trained professional away from doing something else then you know that -

**Ms FORREST** - But is it not a matter of - and I could be wrong - pulling medical records for the last five years, say, from people who have died in DEM and ICU and reviewing the medical records? There would not be that many - there would be a number, of course. All we need to know is these are the ones who have died in those locations, this is what happened to them and yes, they were suitable, or no they were not. There may be some that it would be unclear from the medical record perhaps that they were suitable or not and you might need an expert opinion there but I think some of them would be very clear they were not suitable -

**Mr BOADLE** - Sure.

**Ms FORREST** - Clearly a patient with HIV is not suitable.

**Mr BOADLE** - Yes.

**Ms FORREST** - There would be immediate exclusion criteria there for some.

**Mr BOADLE** - Yes. It would be a relatively straightforward exercise.

**Ms FORREST** - You would not actually need an expert commission to do it?

**Mr BOADLE** - I think you would. I think you would need someone with significant clinical experience to be looking through clinical records and then they would need to have reference to an expert intensivist or emergency medicine specialist. If you are going to do it you should not do it just by best guess.

**Mrs RATTRAY-WAGNER** - A figure of about \$50 000 has been quoted from other jurisdictions. Would you consider that to be a reasonable amount of money to spend to get that type of data?

**Mr BOADLE** - I would like to think you could do it for less than that. You do not like to hear the Health Department saying we could do it for less.

**Ms FORREST** - I do!

**Mr BOADLE** - With an audit of that nature, my recommendation would be that you would consider the methodology very carefully and perhaps do a sample. Not all intensive care units and DEMs would be dealing with those sort of folk because of transfer factors. I would probably want to hone down the scope a little bit - maybe instead of five years look at a year or two - something that gave you a manageable sample and that could be effectively done by a clinical person on a fixed-term basis.

**Mrs RATTRAY-WAGNER** - David, you have convinced me.

**CHAIR** - David, my personal belief is - I do not know about the other committee members - that whatever happens there should not be any recommendations put out until the Commonwealth come out with their recommendations because we do not want to go divergent ways. What should occur is that, if necessary, any recommendations dovetail with the Commonwealth ones. To me that seems the best and most workable way of dealing with this issue.

Can I just touch on a couple of these points we have noted in the terms of reference - whether the present system established within Tasmania and Australia that enables a person to register their legally valid consent to become an organ donor is adequate. Do you believe it is or do you believe it can be smartened up? If it can be smartened up, how do you believe it can be improved?

**Mr BOADLE** - This would be only a personal view, I normally like to have some good research evidence to back up a particular position. I think that the system could always be improved. I was involved at a policy level when we went from the intent-based arrangements to the consent. It is my impression that the consent-based arrangements are still relatively cumbersome and I am not sure that all in the community understand the difference. I think that underpins the reason for that being part of the national reform agenda to see if we can develop a better system.

**CHAIR** - In relation to the intent, did people that intended to become an organ donor immediately go onto the consent file?

**Dr BOADLE** - No.

**CHAIR** - They had to re-register, for the want of another word, and give their consent and sign that special document for them to become an organ donor.

**Dr BOADLE** - Yes.

**CHAIR** - Am I right in saying that in Tasmania there are approximately 173 000 consent donors.

**Dr BOADLE** - Tasmania had 172 278 intent registrations at 30 June 2007.

**CHAIR** - And that is a fair return when you look at other States?

**Dr BOADLE** - Yes.

**CHAIR** - I believe it's 42 per cent approximately. Is that right?

**Dr BOADLE** - To that proportion of our population, yes.

**CHAIR** - That is for 18 years and above.

**Dr BOADLE** - Yes. We contribute 3.63 per cent of the national registration, so that is higher than you would expect pro rata. The intent registrations are part of the Australian Organ Donor Registry but they are listed as just that - intent. They are not consent. I would have thought from a clinician's point of view that is still relatively useful information

because it means that someone has at least registered an intent. The caveat on that, though, is that it was much here done in your driver's licence - do you want to donate organs and you tick, yes, that is all right. That is without the key part of the process - to encourage people to talk it over with their family and friends and significant others. That, I think, has been important change. I think that is the change that the Commonwealth is talking about as a part of the community awareness, seeing what strategies work best in changing community behaviour and how can we get the Australian public talking about a topic which is not necessarily otherwise easy to broach in some circumstances.

**CHAIR** - Have the people who ticked the box with their intent to donate their organs been followed up with a letter and the new registration of changes of details on the organ donation form?

**Dr BOADLE** - I do not know.

**CHAIR** - To me that would be a good first step to do that. Those people have stated before that they intend to do so. If that is the case let us write them a letter, let us get them to sign this consent form so that they can give informed consent.

**Dr BOADLE** - There was a major publicity campaign in the middle of 2005 from memory when we moved to the new consent-based register. A flyer was included I think with people's Medicare renewals at the time, or Medicare cards. That would have caught everyone, including those people who had previously registered their intent. From memory, I think the flyer at the time did make the point that it has changed and that even if you had previously registered your intent that is not the new way of doing things.

**CHAIR** - Here is one of these consent forms that you fill out. What better way do you think you could use to give your consent?

**Dr BOADLE** - If you could do it online, and I am speaking from personal experience, rather than fiddle about with forms and all this sort of caper.

**Ms FORREST** - You can still do it online but you have still got to get the forms signed.

**Dr BOADLE** - That is exactly right, but I am talking about the whole process. You could do it lock, stock and barrel. I can consent to funds such as they are being transferred hither and thither on the Internet, I can consent to all sorts of things.

**CHAIR** - So, therefore, one of the things that could be done is that it could be done on-line and you have your passwords, I suppose, to make sure that it is you agreeing to it as opposed to somebody else?

**Dr BOADLE** - Yes, I am sure the systems exist.

**Ms FORREST** - David, do you think this is an adequate form? I know you get information with it but do you think the information you get with this form constitutes informed consent?

**Dr BOADLE** - That is a very fair question and I guess I would be inclined to say yes. I think it is more important probably to ask some other people who are not tied up or intimately involved in this and who would give a more valid perspective. On one hand I would like to say yes but I am always wary of a process that does not involve a discussion between an informed person and the person who is trying to consent. I still maintain, from years of clinical practice, that that is far and away the best way to do things, sitting down with someone who understands and can answer your questions and you have an exchange of information. No matter what quality of information you provide in written information to go with a consent form I still think it is the exchange between human beings that should give the better understanding and truly informed consent of what it will mean to me. What will happen to my body is an important question.

**Ms FORREST** - That would make it even more onerous, wouldn't it?

**Dr BOADLE** - Absolutely. I think whilst that is an ideal situation I think it would probably be impracticable.

**Mrs RATTRAY-WAGNER** - It is hard to get into a doctor for them to be able to exchange with you about something that is happening to you without something that is perhaps foreseeable in the future.

**Dr BOADLE** - Yes, absolutely. I know general practitioners in particular have so many opportunistic things that they have to do in every consultation.

**Mrs RATTRAY-WAGNER** - This is probably not one of them.

**Ms FORREST** - If you were getting a doctor to do it there are some doctors who are not very well informed.

**Dr BOADLE** - That's right.

**Ms FORREST** - It is no slur on them at all -

**Dr BOADLE** - No, no, not at all.

**Ms FORREST** - but that is the reality. If in Tasmania we had a person employed by the department, at minimal cost no doubt, to be the coordinator of the organ donation program would it be reasonable to suggest that people would talk to that person if they had questions, rather than talking to their GP, who may not be all that well informed? People would be talking to someone whose work is surrounding this important issue.

**Dr BOADLE** - Yes. I qualify my term by having a discussion with 'an informed person'. I do not immediately assume that that is all of the medical profession or all of the nursing profession. I think that would be much better done by someone who was appropriately trained and knew the whole system extremely well.

**Ms FORREST** - Do you think it would be a benefit in Tasmania to have such a person employed within a department to be available to the general public who are making inquiries about this? This would be of benefit not only to the people out there wanting to

be donors but also to the medical staff who will be facing this situation perhaps in ICUs and DEMs and other places.

**Dr BOADLE** - That would be ideal, clearly. That has been our hope for some years now. There are two mitigating factors. One is our decentralised population, so you have to have someone who has to be prepared at the drop of a hat to drive to Burnie or to Launceston, whereas organ donor coordinators in other States are usually based in the capital city and they often merely buzz around a few blocks to do that job.

**Ms FORREST** - Could you have two part-time people, one in the north and one in the south of the State, who could support each other?

**Dr BOADLE** - Yes and that is a solution. In fact we tried to incorporate such a role in the new role of blood transfusion nurses in the State because we knew that they would have to be outposted in each of the hospitals. Some of the issues were complementary in terms of tissue types and ethical issues and so on, but that did not grow wings, unfortunately.

**Ms FORREST** - What were the factors that made that not work?

**Dr BOADLE** - I think uncertainty in the new role of blood transfusion nurses. I think people wanted to get that nailed down first and foremost rather than saying, 'By the way, you're in a new job that is potentially challenging and, guess what, we're giving you this other complex bit of work to do off the side of your desk'. I think that was the major factor.

**Ms FORREST** - Will that be looked at again, though?

**Dr BOADLE** - That could be revisited, yes.

**Ms FORREST** - The nurses who are fulfilling this role at the moment, is there capacity within their position to expand it or do we need another position?

**Dr BOADLE** - I do not know.

**Ms FORREST** - If they are flat out doing what they are doing in the transfusion service then obviously they should not be doing the job - unless you put on another one and split their role so that all of them able to do both.

**Dr BOADLE** - Because of the potential quietness of this role - albeit I think that your suggestion of their fulfilling a community information role and a contact point role would add to their scope of activity and probably be a very good addition - I think the notion in Tassie has always been - because of our scale and decentralisation - that if you can dovetail roles, where more than one person is doing a similar sort of thing, then you do so. I agree that if you get 1.5 FTEs doing the blood work maybe or another relevant role then that is the more sustainable way to deliver the service. Far too often in the past I have been privy to creation of a discrete role and someone grows up in the role and retains all the corporate knowledge and then they retire.

**Ms FORREST** - Suck their brain out before they leave.

**Dr BOADLE** - Yes, but it never quite works.

**Ms FORREST** – Sorry, that was probably a bad description.

**Dr BOADLE** - No, that is all right.

*Laughter.*

**CHAIR** - Can I take you back to term of reference 1? We have spoken about it being on-line and that could be an improvement. Any other improvements to make it more adequate?

**Dr BOADLE** - I cannot think of any offhand. Again, I think an important group to ask would be the person in the street.

**CHAIR** - What about 2, the adequacy of Tasmania's approach in identifying potential donors and facilitating the donation and procurement process? We have just spoken about that to some degree in relation to the person up north and the person down here. It would seem in Hobart, because that is the neurological area, if you are brain dead you come to Hobart to be treated –

**Ms FORREST** - So you have to be brain dead to come to Hobart!

*Laughter.*

**Dr BOADLE** - Launceston has an intensive care unit. In Launceston they deal with not just as many necessarily but they deal with a proportion of people who might be eligible as well. Again it would be anecdotal. My impression is that the Tasmanian intensivists in particular are pretty attuned to this possibility. I guess this is demonstrated by the fact that last year they converted eight people - they might have identified more but in fact eight were converted. This signals to me that they are aware of this issue and certainly in all of the contact we have with them it does not come as any surprise. They do not say, 'Oh, I had forgotten about this'. They are pretty switched on. I would like to see the data.

**Mrs RATTRAY-WAGNER** - There were only two the year before, though, and that gives an average of four.

**Dr BOADLE** - Yes, that is right.

**Ms FORREST** - This issue relates to the road crash death rates.

**Dr BOADLE** - It could. You would need to go back and -

**Mrs RATTRAY-WAGNER** - You would need to get some data.

**Ms FORREST** – Yes, retrospective data.

**Dr BOADLE** - Yes, exactly, and you need to look at the cases.

**CHAIR** - As you say, they identified eight last year but could have identified more.



**Dr BOADLE** - Yes.

**CHAIR** - To me, that would be a terrific statistic to have, yes there were another four that were potential organ donors, they did not donate, why did they not donate? To me, that is a good statistic to have.

**Dr BOADLE** - Yes, to understand why.

**CHAIR** - In relation to question 3, the impediments, if any, causing Tasmanians to have the lowest organ donor rates in the nation and the net worth to Tasmania of having an organ donor rate equal to the best in the nation, you are saying that comment is probably wrong?

**Dr BOADLE** -Yes. I do not know that we have the lowest, I think we vary around. Yes, we are below the national average. Over the last six years I think the national average is about 10 donors per million people.

**CHAIR** - In Australia it is 10, I think. Our average is about four and as low as two.

**Dr BOADLE** - Our average is 8 donors per million population so while we might average four per million head of population of course you have got to double that so we get to eight and the Australian figure is 10 over the last six years. So we are marginally below the Australian average. It may be that we have slightly fewer eligible people.

**CHAIR** - Which you would hope.

**Ms FORREST** - Which would suggest that the decentralisation may play a part in that.

**Dr BOADLE** - Yes. I think so. It is a marginal thing to go from eight to 10.

**Ms FORREST** - Only one person.

**Dr BOADLE** - Yes. Say we have the same number of eligible people, the number of brain dead people per annum, you would think that intuitively that if we were running one mega intensive care unit and one neurology unit in Tasmania the overall system would be just more geared I think to identification and conversion. Now that is an intuitive feeling but I think that our decentralisation does not do us any good in this particular instance.

This is a pretty niche area of clinical practice, it is ethically charged. I think in a system, say, in South Australia where they are all clustered together in Adelaide and probably have only one or two big intensive care units, it is a lot easier to be in the swing of these things. That is with the greatest respect to my clinical colleagues in Tassie because these things do not just depend on a doctor or a nurse; this is a team approach and where you have a well-oiled machine where you do it frequently it just becomes easier.

**Ms FORREST** - Do we have an adult retrieval team? We have a submission from someone that if we could effectively ventilate and maintain the blood pressure of someone who is brain dead to get them from Queenstown to Burnie, it would make a difference. I must

say I have wondered about that - I would hate to be in the back of that ambulance. Do we have an adult retrieval team that could do that?

**Dr BOADLE** - I don't know. I am not the right person to ask. The medical retrieval coordinator would be the person to ask.

**Ms FORREST** - We have a NETS transfer team for the neonates where the team come and get the baby and go, but I was not aware of an adult retrieval team.

**Dr BOADLE** - I am sure we do adult retrievals. We send anaesthetic registrars off around the countryside in helicopters to bring people back.

**Ms FORREST** - So potentially that could be used for someone who is identified as being a potential donor in Queenstown, in Scottsdale, down the south somewhere remote in a rural hospital?

**Dr BOADLE** - Yes, but I think they would be flown to the centre anyway for clinical management. I do not think that our rural hospitals would or should be tackling people where they need more clinical management. They would be popped in a truck and taken somewhere quick smart.

**Ms FORREST** - But they have got to be accepted. That is the point that this person was making - that if you get a person that either is about to die, is dying or has just died and you are able to keep their heart pumping and keep them breathing mechanically until you can get them to the ICU, the ICU then has to accept them. If they are not long for this world then the receiving ICU may be reluctant to accept them and that was the point. Do you see that as an issue in Tasmania, being as decentralised as we are?

**Dr BOADLE** - I think there are probably two issues. One is the appropriate clinical management of people in all hospitals including our rural hospitals and quite frankly for someone to have viable salvageable organs they cannot be just about to die in Scottsdale or Queenstown. They have to be clinically viable enough for the clinical decision to be made to retrieve them, bring them to the centre and see what we can do for them.

I think that is one issue. I do not think Tasmania's organ donor rate would be likely to be impaired by that particular scenario. I believe that most of the people who are viable and eligible to be organ donors from catastrophes or road accidents would find their way into the centre and be worked upon. If after a period of time the prognosis is terrible they do the brain-death testing. So I think the people who are likely to die in the more rural areas are going to die and probably will not be organ donors because of the catastrophic nature of what has happened to them.

The second issue, though, about access to ICU is a very valid one. That's not just for Tasmania; I have seen this talked about in the Australian scene. Our intensive care units are bursting at the seams every day of the week. I guess if you are an intensivist with a full house where you'd like always to have one spare bed for the next person that comes into your casualty department, and they are already full, I think the notion of bumping someone out of your intensive care unit to take a potential organ donor is a major ethical dilemma for the clinicians.

**Ms FORREST** - It is, and I agree with you, but it could be argued that that person could potentially save 13 people's lives, or whatever number it might be -

**Dr BOADLE** - Sure, yes.

**Ms FORREST** - and the overall cost to health - not the people in the ICU worry about how much it is costing. Do you think we need a bit of a culture change - attitude is not the right word, but I can't think of another word for it - within these areas to make it acceptable to accept a patient who isn't going to survive. They are not going to be there for a week, they are only going to be there for a day.

**Dr BOADLE** - Sure. I think culture change is part of it, but also the clinicians have to be given permission, because what we as a community do is to foist some very difficult decisions in the middle of the night or at any time of the night or day on to a clinician. They have to weigh up who they take and who they don't take. Then we must provide the system for them to say, 'This is an acceptable use of resources, it's an appropriate thing to do and we would like you to develop a system whereby you could tack on that extra organ donor for a period of time, and we will resource you to do it'.

**Ms FORREST** - That's the question, I guess. Do you think that capacity exists or do we need to address that?

**Dr BOADLE** - No, I don't think it does because that's part of the national reform agenda. That's been identified by the National Clinical Task Force in its mid-term report as an issue that needs to be addressed.

**Ms FORREST** - So in Tasmania you suggest that we need to have better resourcing and, I suppose, encouragement for the intensivist to accept these patients into their units, and resource them appropriately to do it.

**Dr BOADLE** - Yes. I think intuitively the intensivists would be very comfortable with that notion, providing they were absolved, to some extent, from having to make the difficult decision. I think these people would do it, but they say, 'Who's going to back me up?', because if I leave someone's dear aunt or uncle, or son or daughter in the casualty department and bring in someone for whom there's no prospect of recovery into the intensive care unit because they are an organ donor, who is going to absolve me of responsibility?

**Ms FORREST** - Then you get the story on the front page of the newspaper.

**Dr BOADLE** - Absolutely.

**Ms FORREST** - 'My mother had to wait in ICU for six hours'.

**Dr BOADLE** - Quick as a flash, yes. That needs community influence, it needs resourcing. I think the intensivists would be very likely to go it because they do this all the time and they can see the benefits to recipients of organs.

**Ms FORREST** - Do we have figures showing the occupancy rates of our ICUs? We heard from another witness earlier that it's a nonsense to say that we haven't got capacity in our

ICUs, there is room. These people are only there for 12 hours, or whatever, and to say we don't have capacity and room in our ICUs is nonsense. Do you have figures to state otherwise or to support that view?

**Dr BOADLE** - No, I haven't brought data with me on intensive care capacity or occupancy. It is very anecdotal, but part of my role is in emergency and disaster management, and on the occasions when I ring our colleagues to ask, 'How's your ICU capacity?', if there is another Bali bombing or something where we have to fly expat Australians into the country, 'How are you situated at the moment?', I would have to say on the handful of occasions when I have rung up they have all said, 'Sorry, we're strapped, we had to cancel some elective surgery today because we didn't have any room in our intensive care unit'. I appreciate that is anecdotal, but the word I hear from hospitals and intensivists around the country is that intensive care units are usually working at capacity or very near.

**CHAIR** - I suppose a typical example would have been last Saturday week with the fire in Myers. The hospital would have had to be prepared for some major injuries. I don't whether you rang the intensive care unit to see what your capacity was.

**Dr BOADLE** - No, I didn't last Sunday. We were awaiting the call from the police and fires to activate. We were mentally activated. There is a process we go through and they have to push our button to say, 'We're ready to go'. I have two daughters who were evacuated from Myer and they were giving me progress reports.

I think the issue of intensive care capacity is an important one and I think it would need to be worked through with intensivists in terms of what an effective system would be for taking a patient who might effectively be an add-on for a period of time, and how you would staff that. People often look at a hospital bed and think, 'There's a hospital bed'. I say this to the Australian Government all the time, 'Don't count our beds, count our functional units of capacity' - that is, our expert nurses, ventilators and the whole kit and caboodle that goes around a bed. It would be interesting to hear how the intensivists and their nursing staff might approach that creatively.

**CHAIR** - Are there any other areas within term of reference 3 that you believe would be of assistance?

**Dr BOADLE** - No. It would be interesting to know what Tasmanians' attitudes are to this. I guess the only bit of evidence we have is pro rata a good intent rate and a good consent rate so that means that Tasmanians are receptive. I would be interested to know the circumstances where families expressed a very strong wish that it not happen.

**CHAIR** - That is next point, point 4, where it talks about the impact that uncertainty amongst family members regarding an individual's donation wishes has on their decision to allow organ donation and whether there is a reluctance on the part of doctors and family to proceed with donation, even when the wishes of the donor were known to favour donation. What we have heard - and please tell me if it is the same as your evidence - is that, even though there might be a consent from a donor, if the family don't want it to occur it normally won't occur.

**Dr BOADLE** - Yes, I think that is the Australian experience, based on the philosophy that, whilst we would like to respect the wishes of the dead and whilst their consent really does allow us to override any family considerations, I think it is a part of Australian culture that we tend to respect people's wishes where we can talk with them and if they have a strongly-held view. There is evidence, though, that when people have discussed it with their family beforehand and they have had a frank and open discussion, it just happens because they have had that discussion beforehand.

**CHAIR** - I think there is an 80 per cent success rate there. Is that consistent with your statistics?

**Dr BOADLE** - I think it would be consistent with that sort of figure.

**CHAIR** - And 48 per cent if they haven't discussed it.

**Dr BOADLE** - That would make sense, yes.

**Ms FORREST** - Do you think on this form - the one you can do on the Internet - that there should be a section where the senior next of kin acknowledges that they have discussed this with their family?

**Dr BOADLE** - It does for the person themselves. It says that they have discussed it.

**Ms FORREST** - But it doesn't ask that person to make some acknowledgment that they have discussed it. Anyone can tick the box saying that they have; they might tell their husband and their wife and they are killed with them, but they haven't told anybody else. The senior next of kin is still going to be the husband or wife. If our best rates of organ donation occur when the family is aware of the donor's wishes, would that be one way of enhancing the likelihood of that occurring or are there other ways?

**Dr BOADLE** - It could be. It would be interesting to ask some families and see what they would think if the senior next of kin had to contribute to this process. There could be a counter-intuitive response where someone might say, 'If I'm signing this, that means it has to happen'. The senior next of kin might feel they are being locked in to some extent so it would be interesting to test that theory. You would think it would improve things.

**Ms FORREST** - I suppose they could always come back and say, 'Well, we discussed it but I did not agree with them.' There are all sorts of possibilities aren't there?

**Dr BOADLE** - Yes, and whether that would slow down this process as well.

**CHAIR** - Do you know from evidence that you may have obtained already whether there have been people who come under this head - that is, they have consented to donating their organs but because their families disagree with that that has not proceeded? Do you know whether that has occurred in Tasmania over the last three years?

**Dr BOADLE** - No.

**CHAIR** - Would there be any statistics to say whether it has occurred or not?

**Dr BOADLE** - No. We have to include those.

**Ms FORREST** - That sort of thing would be recorded in a patient's history though.

**Dr BOADLE** - Yes.

**Ms FORREST** - So a specific audit will show that.

**Dr BOADLE** - Yes.

**CHAIR** - Would it show that I spoke with Jim Wilkinson and he stated that he did not want his father's organs to be donated or something like that?

**Dr BOADLE** - Yes.

**CHAIR** - It would?

**Dr BOADLE** - Yes. That would be my firm expectation. I would be very disappointed if it wasn't because the people we are dealing with - the intensivists - they are very solid citizens, very protocol-driven and the people who I deal with in Tasmania they are very tuned to the importance of this.

**CHAIR** - That information would be good to get, wouldn't it? Otherwise we might be embarking on a project which we don't need to embark upon because it has not been a problem.

**Dr BOADLE** - Indeed.

**CHAIR** - What about number 5 - whether there is suitable education, promotion and so on?

**Dr BOADLE** - I think that could always be improved and I think that is why the first important point of the national reform agenda is community education. Importantly, the Australian Government have engaged an expert consultant to do some research on this very issue. What are the best tools and techniques for raising community awareness in a contentious area? So I think their approach is laudable. They have invested \$300 000 in the community awareness project to develop a good approach. But, yes, it could always be improved. Unfortunately, I guess, David Hookes was a notable example and his family's endeavours at that time probably did organ and tissue donation awareness no end of good.

**CHAIR** - If you were in our position making recommendations, what recommendations would you make?

One, you would be saying, I would imagine, wait and see what happens with the Commonwealth and then if necessary dovetail in with that because we do not want you going down one path and the Commonwealth going down the other because there has to be some uniformity.

**Dr BOADLE** - Yes.

**CHAIR** – We accept that. What else would you be saying?

**Dr BOADLE** - I would be saying that Tasmania's approach must take into account our population size and the opportunity cost of any additional investment we might make in this area, particularly with finite numbers of health professionals and likely further work force shortages as the eligible population of young people coming through is less, that we would have to be very cautious with the use of resources in an area which is still a relatively small part of the overall health system.

**CHAIR** - If we wanted to be a leader in Australia what would you do?

**Dr BOADLE** - I do not know, I would have to give that some thought. My abiding concern would be the overall return on investment really for a place like Tasmania to be a leader when we have decentralised services. To be a leader I think you would have to reshape the health system more considerably than the current Government has suggested.

**Mrs RATTRAY-WAGNER** - If we could not be a leader but we could step beside other States, would you advocate the appointment of an organ donor coordinator for Tasmania?

**Dr BOADLE** - Yes, or that function encompassed in another relevant role so that we got best use of that resource and less risk of key-person dependency, because in niche areas that always makes Tasmania vulnerable - key-person dependency.

**CHAIR** - Should we be a part of what has been called the National Collaborative? We have been asked to join that but I understand we have not joined it.

**Dr BOADLE** - We canvassed the opinions of our intensive care specialists around the traps and they felt that they could not re-prioritise another part of their duties to be a part of the National Collaborative. Quite frankly we quite simply have to take on a number of issues in Tasmania. For example, my counterparts in other States and Territories have a medical deputy and half a dozen doctors working with them in the office of the chief medical officer. Tasmania has only one, so in these sorts of issues and for a whole lot of other issues we have got to carefully apportion our resources. It is the same for busy clinicians. We made a pragmatic decision, I think - and an appropriate one - to say we won't participate in the National Collaborative but we will keep an eagle eye on it. We will get most, if not all, of the benefits of that process because we are privy to all the outcomes and so on.

**Mrs RATTRAY-WAGNER** - So you are not excluded from any of that information?

**Dr BOADLE** - No, not at all. We participate actively in the intergovernmental committee on organ and tissue donation. Until Helen's appointment I carried that for Tasmania so we are always at the table. That is where all of these things intersect and all the reports intersect. So, in my view, the best bang for our buck is to go to one committee where all the stuff is synthesised and thrashed out between the government departments, rather than necessarily sitting on every working group, otherwise people like Helen or me would never be in the State. The same goes for our busy clinicians. That is the reason we took what is really a pragmatic decision, not through lack of interest. We would love to be at the table for everything but we have to make choices.

**Ms FORREST** - With the position of an organ donation coordinator - and maybe that is more than one person doing more than one job - if that person was able to educate the public and provide ongoing support and education to the medical staff that are dealing with it at the coal face, and potentially promote it and be a resource for anyone in the State who needed it, that could see per capita donation intention and consent increase and actual conversions increase. That would be a leading outcome, wouldn't you suggest?

**Dr BOADLE** - Yes, although other States and Territories have these people.

**Ms FORREST** - They have had quite good increases in their rates?

**Dr BOADLE** - It is hard to apportion cause and effect because organ donor coordinators from my experience have been part of the furniture in most places for years and years. They certainly were in Canberra. Where I worked last at the Canberra Hospital I was involved as the designated officer, and that was back in 2000. So, yes, for Tasmania it would be a bit of catch up.

**Ms FORREST** - Some of the submissions we have read actually attribute increases to the actions of that coordinator. As we have heard from other submissions, the contact with the relatives is, well, less than satisfactory. If that can be basically removed and the only people who approach the relatives are the people who have had educational experience and knowledge to support them, then you could suggest that is one of the reasons that organ donation rates have improved. It is the many ways that person works rather than just the position itself.

**Dr BOADLE** - Sure. Intuitively that certainly seems to be the case. There is a practical challenge for Tasmania and again it relates to our scale. It relates to Bass Strait and the fact that we do not have the population to justify a State-based agency of our own, so we have to rely on the Victorians. The intensivists tell me that that does pose some practical challenges from time to time. As the clinicians involved in a person's care for a period of time in an intensive care unit, and then broaching the issue of organ and tissue donation, they go into the pros and cons and they know the clinical history of the person, whether they are likely to have blood-borne viruses and so on. They find it quite affronting and on occasion for the family quite affronting for someone from outside Tasmania to go through all the stuff again. I am told anecdotally in some cases the intensivists feel that it is not appropriate to put a family through that additional trial, as it were, when it has already been done.

**Ms FORREST** - If the relatives have given consent and they have been through it with someone who does know what they are talking about, then why does the process have to happen again?

**Dr BOADLE** - Because ultimately the Victorian LifeGift take responsibility for the process in a legal sense. In other words, they coordinate the retrieval and the assessment of the donor. They have to verify to people they are allocating the organs to that everything is fair and above board. I guess it is partly big State/small State or the fact that it is happening in someone else's system: if I am not a part of that system I am not going to take responsibility for what they tell me. I am going to do a diligent process and make



sure that I have checked it all out. If you are based in Melbourne and you are working in Melbourne and you know all the clinicians and so on, then it just happens.

**Ms FORREST** - With the national reform this could be overcome, do you think? Clearly we need some sort of partnership agreement here where my word as the intensivist is good enough. Surely, that should be able to be achieved.

**Dr BOADLE** - I agree entirely. You would think that that would be a no-brainer, but unfortunately, human nature being what it is, that has not always been the experience, which is most unfortunate. When I do talk to the clinicians about these issues it is a recurring theme. Sometimes they say it just works like magic. It depends on which organ donor coordinator you get on a particular day; sometimes it is just as smooth as silk and with others it seems to be an impediment.

**Ms FORREST** - That is an area that could be worked on; is that what you are suggesting?

**Dr BOADLE** - It is human nature; how can you work on that? Perhaps - and this is speculation - if Tasmania does have a dedicated organ donor coordinated system that to some extent springs from Victoria or is trained by Victoria and so on, then I think that would be the tactic. Our people would work as part of their system and train in part of their system and then they will say, because again that is human nature, 'Ah, I know that person'.

**Mrs RATTRAY-WAGNER** - LifeGift indicated that they have training modules and sessions, so you would not need to reinvent the wheel.

**Dr BOADLE** - No, we would dovetail into their system wherever possible. We cannot afford to reinvent wheels here.

**CHAIR** - And LifeGift's Neil Boyce seemed terrific.

**Dr BOADLE** - Yes, and our relationship with them, certainly at the strategic and policy level, is very good. They are good folk, there is no doubt about it.

**CHAIR** - Thank you very much for coming along and thanks for giving us your views. It has been very helpful.

**THE WITNESSES WITHDREW.**