THE LEGISLATIVE COUNCIL SELECT COMMITTEE ON ORGAN DONATION MET AT LIFEGIFT OFFICES 538 SWANSTON STREET MELBOURNE ON MONDAY 26 NOVEMBER 2007

DISCUSSION WITH **Associate Professor NEIL BOYCE**, EXECUTIVE OFFICER, LifeGIFT.

CHAIR (Mr Wilkinson) - Probably the first question I would ask you is if you were doing this report and preparing this report, can you run us through what you'd be doing? You are the expert.

Prof BOYCE - I guess there are two principal points for action. The first is in the community of getting, hopefully, every Australian to make a decision about whether they wish to donate organs after death, and communicate that decision to their loved ones, and in an ideal world, register that intention on the Australian Organ Donor Registry.

Certainly the most important thing is to make that decision and communicate with the family, and I think for that change to come about we will need a fairly sustained public health campaign, probably over five to 10 years, using a variety of clever people and different messages to change the existing behaviour, which would appear to be people making a decision in the privacy of their own mind about what they wish to do, and almost half of them not communicating that decision to anyone.

We need, I think, to better understand why there is that reluctance to communicate, and to come up with the sort of slip-slop-slap, or if you drink and drive you're a bloody idiot-type campaign, using social marketing, as it is called, to change that behaviour so that almost all people, when they are confronted in the intensive care unit with the question about organ donation, will know the answer regarding their loved one.

We have never tried to do that before in Australia, it has always been dealt with in a very episodic call to arms-type way. It has usually been entirely opinion-based, that is someone thought I think this is a good way of doing this, whereas with social marketing the approach is that people have an hypothesis of what will work, but they then test it with small groups and see if it does work, and then do a pilot campaign and see if the campaign actually makes a difference.

I was very impressed, we are only about three blocks away from Quit Victoria, and when I went up on a couple of occasions to talk to Todd, who is now head of Vic Health, he went through the history of their campaigns to get people to stop smoking, the campaigns that worked and the ones that didn't work. The graph was initially flat with no change in smoking rates. As I said to him, 'I am very familiar with the flat graph.' But after about three years, again the proportion of people who stopped smoking started to rise, and then it would periodically plateau, and he would say, 'We realise that those messages had got that many people but we needed to change the message to get the rest of them'. There are 40 people up there, and there's a real rigour and science about the way they designs their campaigns.

As he said, some of the campaigns that they liked best did not work, whereas some of the campaigns that they were not all that fond of - such as the gory pictures of legs dropping off and whatever - were much more effective.

So I think we need that investment. Personally, I think that investment will only ever come if the Federal Government is interested and, as the media are largely national now, I think it is going to be a national responsibility.

The second set of things we need to do is to make sure every potential donor who wishes to donate is recognised in hospital, their family are approached, the approach is done in the most professional and competent way possible and the whole process is managed in the most professional and competent way possible. That is going to involve, I think, broadly two interventions. The first is to make those who manage health care accountable for their donation performance. At the moment it is in a grey zone. I doubt that a CEO in any hospital in hospital in Australia has ever been asked to report on their organ donation performance, to be held accountable for why it was apparently high or low by comparison to other similar hospitals.

I have been arguing now for some years that it ought to be part of the accountability for hospitals. It is sometimes seen as what I call an optional extra - if hospitals feel like doing it or if they have the time. It is almost waiting for applause. Occasionally I will get hospital that says, 'We went out of our way to help you do *x*,' and I say, 'It is really not about me and my agency at all; it is about doing the right thing by the community.' But often the hospitals, particularly those that do not have transplant facilities, feel as if they are doing this for some anonymous other group of people. I don't just mean the CEO, but if the CEO were accountable, then they would have mechanisms in place to ensure that they had internal accountability.

The second aspect which I referred to last time I spoke to you is that there have to be mechanisms to measure performance. The ideal measure of performance, I believe, is what proportion of potential donors become actual donors, looking at those who do not discover why. That involves some form of medical record review sometimes. We often use the word 'audit' but increasingly I am trying not to use that word, because it seems to mean different things to different people. But the idea is of reviewing the records of people who would appear to have died in circumstances where donation might be possible and establish what happens. We have been doing that in Victoria for some time. This moves it out of people's strong opinions as to what is going on and focuses discussions on what is actually going on: these are the cases that would appear to have been unrealised potential donors and these would appear to be the reasons for that.

We have found, over time, initially there was the usual cry of 'Oh, the data is wrong,' and 'You don't understand - it is all very difficult and my department of radiology will not work out of hours'. Suddenly, instead of defending why things were not happening, people started to focus on changing some of these things so that they could do better.

The good thing is that, because donation is such a rare event and the opportunity for donation is still a relatively rare event, you can do that without spending a whole lot of money. It is not an impossible ask at all. In fact we think that there are probably only something like 600 potential donors in Australia each year. So it is not as if you have to look at a million medical records or anything. We have done it in Victoria. It is a process that is eminently doable. But once you start that level of measurement of performance and sharing it with the people you need to share it with - clearly the managers and those who pay for the system and, more importantly, those who work in emergency departments and intensive care - one of the challenges is getting ownership.

As I stressed, one of the challenges I think is getting ownership in those groups for wanting to do donation as well as they do a whole lot of other things and for me again that is bringing it into the core of their operations so that an emergency department doctor, for example, feels as passionately about doing potential donors well as they do about resuscitating someone who has had a heart attack or been run over by a bus, and at the minute that is not the case. It has a special categorisation in those professional groups.

I think it is starting to be seen as clearly their responsibility but it is just a little bit peripheral. It is sometimes the case that when I talk to people in these critical care areas people basically use language like, 'It's not my job. I've got other things to do. Do you know how busy I am?', et cetera, and the answer is yes, I do know how busy they are but these are their patients and their families and it clearly cannot be anyone else's job because there is no-one else there. But the challenge is there are so many of these professionals; there are nearly 10 000 doctors and nurses working in emergency medicine. It is slightly less in ICU but it is still several thousand. Because it is a 24-hour-a-day seven-day-a-week high-volume activity there is a huge number of people to get to and I think the only way we will get to them is through their professional associations, and you are meeting with some of them.

CHAIR - And through perhaps universities making it part of the course. I do not know how you would do it but it seems to me that it has to be more than just a fleeting mention of it.

Prof BOYCE - Correct. As an undergraduate it is probably best dealt with in the area of health ethics, in my opinion, and even health economics. I think ideally the nuts and bolts of it are best taught in the postgraduate arena where it means more because medical students tend to be obsessed with trying to get, I guess, the bread-and-butter stuff under their belt. They are much more worried about whether they have the blood pressure cuff up the right way and whether they can remember the seven causes of something and something that seems quite remote and rare to them often does not get a guernsey. But I think the whole area of the ethics of donation and transplantation are quite important. I try not to be rude to my colleagues who say, 'It is not my job'. Regarding a health-care professional and providing high-quality end-of-life care, making sure that the family have the option of donation and that the three or four people who might be transplanted get that option, I think it is a fairly disappointing response if someone wishes to say, 'Well, I'm too busy to do that' because, by comparison with nearly everything else they do, it has a far greater impact on the community.

First of all, if donation is done well I think it is does help the donor family feel that at least some good came out of their catastrophe but to be able to transform the lives of three or four people is not something that we health-care professionals get the opportunity to do very often. Usually we are tinkering at the margins with chronic illnesses that we can make little impact on. I sometimes think that the big-picture issues do get lost in the busyness of day-to-day life. I am very aware that more than 5 million people attend emergency departments across Australia every year and you are sort of thinking, 'This is a speck in an ocean' and getting people to get interested in that speck will involve them having, I guess, a social conscience. Sure, it might be easier just to let the person who has had a massive stroke die quietly in the emergency department and move on because the answer is yes, it is easier for the health-care professionals than doing something that will engage a process and involve a whole lot of people coming down and difficult conversations being held, but it is clearly the right thing to do.

They are the main themes of what I think needs to happen. There is some interesting data that has come out of places like Spain and North America more recently where donor performance has changed but quite a lot of the changes are the cultural and attitudinal change. Whilst the particular programs are important, it is almost the attitude that we can do this and can do it well.

I have reflected on this long and hard over many years and often there are rare things in health that people do exquisitely well and they never miss the opportunity to do it well. They are often procedural things rather than this interesting mix of procedural but also intensely personal. I was listening to Professor Jack Cade - he would not mind me calling him a doyen of intensive care. I think Jack is in his early 70s and still runs the Royal Melbourne intensive care unit. I was at a talk he gave the other day - it was to a lay audience - and he was saying that the intensive care unit is the centre of the hospital, and I wasn't surprised that he said. That's Jack, he thinks it is the centre of the hospital and where they do all the clever things. I was starting to drift off because I thought, 'Here he goes again', but he said, 'This organ donation thing is the hardest thing we do' - and I woke up. He went on to tell people that a lot of people focus on all the machinery, the bells and whistles and technical stuff that they do and think that that is terribly important. He was saying that throughout his lengthy career he has always found organ donation the single most difficult thing they do. He said it is also probably one of the most important because it makes such a huge difference to people.

CHAIR - That could be a good start. That is a good quote.

Prof BOYCE - I found it interesting because if Jack thinks it is the hardest thing they do, he is probably right, but it also might explain why it hasn't been done as well as it can because it is in fact so hard. He also went on to make the observation that perhaps it is particularly hard for the sort of doctors who work in those environments because many of them are drawn to the technical and the doing things to people side of things rather than talking to families about intensely difficult problems. I also am of the view that we probably need some specialisation within intensive care. If people are really hopeless at talking to families, we shouldn't say, 'I don't care, you're going to do it because it is good for you'. In procedural interventions we have specialisation. The person who puts in the big tube or runs the funny machine would be called to do it. I think there is good evidence around the world that having people who are good at requesting results in a better consent rate, which I think is a no-brainer.

CHAIR - Are there any lessons or courses on that? I suppose it is up to the individual because some people are not that way inclined, are they?

Prof BOYCE - Correct. There is a program called Adapt, which is run nationally for intensive care doctors and nurses. I think it is a very good program. It is now a requirement for all intensive care trainees that they go through it.

CHAIR - Is that Australia-wide?

Prof BOYCE - It is, yes, and many ICU nurses do it.

The training is available and it does help people do a better job. The other thing that really is important is this peer valuing of doing it well and an acknowledgment, if someone isn't particularly good at it, 'We ought to get someone who is good at it'.

When I started I used to literally Rambo into ICU and do the requesting because the intensive care unit took the complete hands-off it, as I think I told you last time. I think now they wish to be in charge and some of them are really good at it. Bill Sylvester, who you will meet later, is one example of someone who is a passionate advocate of donation. Again, Bill probably won't mind me saying this, but some of his colleagues think he's nuts because he is a passionate advocate of donation. It is about doing something that is an important part of intensive care well. One of the tricks I think we will have is the balance between making sure donation is offered and is done exceptionally well, but never be looking as if you're only caring about getting the organs - if that makes sense. I have difficulty sometimes when I am talking to people because they assume all I want is organs at any cost and having to say, 'No, if there are no potential donors or there are no potential donors who wish to donate organs then the right number of transplants is zero'. I feel quite strongly that if people do not want to donate that is the game over.

We believe that there are a sufficient number of people who wish to donate but I think we always have to be very cautious. Sometimes the zealotry of we have to get more organs forgets that that is the person who needs transplantations perspective. The perspective of donations, the right number of donors, is the number of people who die in circumstances where donation is possible who wish to donate. I think if the health-care community and the general community were confident that that was the case, some of the silliness that goes on about, 'You'd better not say you're an organ donor or they won't treat you properly in the intensive care' and all of that rubbish would disappear and also some of the discomfort of the health-care professionals who I think sometimes themselves feel a bit of conflict in that they think if they are passionate supporters of donation, people will think that they are not looking after their family members properly. To me donation is just an end-of-life option – that is, your life is ending so it has nothing to do with donation and one of the questions is, 'Your loved one is dying or has died. Do you know whether they wanted to be a donor?'

CHAIR - It is an interesting way of putting it, isn't it? A friend of ours has cancer and is receiving treatment. I was talking to her a couple of weeks ago and she said, 'Not everybody reaches 80. This might be a case where I am one of those who don't reach 80. I can't feel too bad about it because I'm 60. I would love to get to 80 but if I don't, not everybody does'. It seemed to be such a matter of fact conversation, that she accepted that as opposed to saying, 'What do I have to do to keep on?'

Prof BOYCE - 'Fight on'.

CHAIR - Yes. That seems to be, and please tell me if I am wrong, the way that this should be looked at as well. It should be a matter of fact type of comment, a comment which is made as a result of looking into it and looking into it fairly closely and then you make the comment, as you say, 'It is an end-of-life option. This is what I want to occur', rather than having the hysteria that can sometimes occur around it.

Prof BOYCE - Correct. I have found it quite interesting that it is an area of health care that has an incredible histrionic around it on both sides. Sometimes people are quite strangely passionate about donation. The taxi driver who picked me up from my visit to Parliament in Hobart was saying, 'They should just make it a law that you have to donate'. I said, 'I'm not sure that is the answer'. 'Oh no, it is the only way you will fix it'. I said, 'But we do not do that with anything else in health care. We do not pass laws to tell people they have to have a bypass operation or they have to look after their diabetes'. Sometimes people are stridently passionate about doing it.

Other people have really bizarre ideas. I was talking to someone the other day who was being highly critical: 'How could you possibly participate in organ donation? Do you know what it involves?' I said, 'Yes, it is fairly major surgery after death'. 'That is ridiculous'. I said, 'What, as against burning people at high temperatures or burying them in the ground?' 'Don't be silly'. I said, 'I am not really being silly. I do not understand why you are so upset about someone having an operation after they have died as against being incinerated at 2 000 degrees or put in a coffin'.

Mr HARRISS - And yet we will tolerate an autopsy to determine the cause of death.

Prof BOYCE - Yes although some people become hysterical about autopsies. I think we still have something about the whole death thing that gets in the way of, as you say, simple, unemotive decision-making. I believe the no answer is quite okay too, as I think I said to you before. People should have a bit of a think about it and say, 'It is really not for me'. Just as some people cannot get their head around being buried or cremated or don't know what to do with the family silver or whatever, I do not think it is about coercing people into the yes position. I would much rather people think about it and if they can't make a decision say, 'I can't make a decision. Maybe it is not for me'.

We have to do a lot of work to understand why people are so het up about it and remember that the impact is on your family because you are dead. I think that is part of the importance of those discussions with the family because they are the ones that have to tolerate the 16- to 24-hour delay in what would otherwise occur if they were not to be donors. To me, that is not an impossible ask if the family knows that is what their loved one wants and maybe that is part of the message we need to get out to the community that really being an organ donor after death is not just your decision, you really have to involve your family because they are the ones who will live through the process.

CHAIR - It would seem, and I am philosophising a bit I suppose, that it is something religious because people want to believe that there is a God, they want to believe that there is a life after death because that is what we have been taught for time immemorial, if you are a Christian, a church goer or whatever, that there is life after death.

Prof BOYCE - Sure.

CHAIR - People at some stage seem to hold on to that. They do not really know, probably they are more deciding now that there probably is not, but if there is 'I want to be intact to go into this second life'. I do not know. It sounds a bit loopy, I suppose -

Prof BOYCE - I am not sure.

CHAIR - but I think that is a belief of a lot of people.

Prof BOYCE - Whether it is religion or culture, I am not sure. It would appear that some cultures are more comfortable with death than we are, probably many are. Maybe what has happened in our society is that very few people experience death because death is now sort of shunted off to special places for dying rather than people dying at home - I know some people choose to but it is still not a common thing in Australia - but I think we need a better understanding of why people have the hang-ups. Although, to be honest, I would rather work with the people who currently think they want to be donors but are not taking the necessary steps to donate. I have a bit of a problem - I guess I am very comfortable dispelling myths. If people did not say, 'I don't want to be a donor because the ambulance officer won't treat me when I get hit by a bus', you just need to say that is nonsensical rubbish because, firstly they will not know that you want to be a donor and, secondly, you cannot stop ambulance officers treating people even if you have a series of large barriers between you and them.

CHAIR - They seem to forget that they have to be kept alive to some degree to be able to donate anyway.

Prof BOYCE - That is what I always say to them. In fact if there was a bias, they would go the other way, they would try harder and longer because they have to, as you say, keep the circulation and all the rest of it going. If people say, 'I don't want to donate because all the organs go to Kerry Packer' and we have had people say, 'You make money out of it'. I try to get a salary but if I were not doing this I would be doing something else within Red Cross. We are not doing it to make money. I am not sure where you cross over. If people do not want to donate and they do not even know why they do not want to donate, well I am not sure I want to pursue them, if you know what I mean, because I think it is one of these personal health-care life-related decisions that people need to make.

We need to get it on a slightly less emotive, slightly more 'ordinary' footing so that people see it as a reasonable option in what goes on. I would certainly like to get away from the feeling that it is an extraordinary thing to do. I still think it is an extremely generous thing to do but, mind you, I feel like that about blood donors, too. I really enjoy talking - not that I get to do it as much as I used to - to a room full of blood donors who are always really fascinating people. They are just the sorts of people who would go out of their way to try to help other people, but they are not treated as if they are extraordinary members of the community. If you had a little badge on saying 'I'm a blood donor' people would not applaud when you got on the tram or whatever and they certainly would not put it on the front page of the paper as they did when David Hookes died. On the first day, 'God, shock horror he is dead' and then the second day, 'Christ, he's donated his organs' and everyone was saying, 'Isn't that good - all the publicity,' and I was saying, 'No, it is really disappointing, because what is the big deal?' A lot of people donate organs, not nearly enough, but I do not get it just because a 'celebrity' has donated their organs, why are we going on and on about it for seven pages in the *Herald Sun* because it is a kind of a non-story? But it just is a reminder that it still has a special quality about it. Maybe if people better understood what really happens, some of the mythology would disappear.

There was a program on Channel 2, I think, a week or so ago - not that I have seen it - that was talking about all the things that can happen to your body after you have died. Norman Swan is doing something on the health report. I think we need more programs that talk about the factual matters of what happens so that some of the silliness gets out of the conversations and people realise that, whilst transplantation is quite a miracle, it is also just an operation where you take one organ out of somebody and put it into another person and it has a huge benefit. But it is not magic and there is no need to treat it as anything other than a very complex healthcare intervention that is entirely dependent on the generosity of the donors.

Mrs RATTRAY-WAGNER - Since we spoke to you last time, we have had a gentleman, who had been funeral director, come and give evidence to the committee. He gave us some really interesting information - information I had no idea of - about what happens to the body and how it can perfect after it the organs have been taken. I think that is an area that if people had a better understanding they would be less fearful, if that is the right terminology.

Prof BOYCE - Certainly I think, about two thirds of our families view the body after donation. Again, we sometimes have to say to people, it is perfectly possible. In reality, from the point of view of presenting a viewing, you would be better of being an organ donor than being hit by a bus or having a lot of nasty illnesses because you are having sophisticated surgery. Whilst it is major sophisticated surgery, it is not even like an autopsy and I think that is part of educating people. Funnily enough the gift that you are referring to, I have had a number of, I am sure, well-meaning colleagues going on and on about, 'You let them show all that gore.' I said, 'First of all, I did not let them do anything, Fremantle media are an independent production company and they can do whatever they like. But what is the problem? Al that gore, as you call it, is on every second TV program as a matter of course nowadays.'

Mrs RATTRAY-WAGNER - All Saints.

Prof BOYCE - People do not seem to be put off by it and it is a bit silly to make out there is not an operation because there is. So, you will put people off and people will not donate if they know there is going to be an operation. If anyone was to tell me that they were willing to donate provided there was not an operation, I would tell them they needed to do something else.

So it is not about hiding things from people to get them across the line. I think it is about changing that community behaviour so that everyone knows and getting healthcare professionals to step up to the mark and see it as a very important part of what they do. I guess they have to realise that every potential donor is a really rare and valuable resource. It is not a case of 'If we miss one today, we will lift our game tomorrow.' Many hospitals will have only a few potential donors a year. That one, single potential donor is, as I say, three or four people at a minimum who would have had their lives changed.

Mr HARRISS - You mentioned earlier the social marketing as a concept and, as you progress the issues of organ donation, that will become more and more a sensitive issue. Do we have the really valuable opportunity with blood donors because they have already made this conscious decision?

Prof BOYCE - We could do more with blood donors; I hesitate, because here is me working for the national blood collector. Increasingly the blood service are incredibly protective of blood donors, because they have such difficulty getting people to come and donate. Any suggestion that you will do anything that might damage that dynamic, I can tell you now, they're fearfully defensive of. Again, my personal view is that that is being unnecessarily silly, but I have had little success in my more than 10 years with the blood service in getting them to do more than token gestures of putting up posters, or making brochures available.

I actually think we miss a big opportunity, just on a broader issue with blood donors, because these are people who you see regularly often for anything up to an hour, and you are in regular communication with them. I do not mind telling you that I frequently told my bosses at the blood service that we ought to be doing much more health promotion with blood donors. Not forcing them to do anything, but providing them with information and opportunities to make other decisions about being healthy, including donation.

My short answer is, yes, I think we should, but I warn you that there has been a lot of resistance. I hear comments such as, 'If you raise that with them we might lose them as blood donors'. I find myself going with an extraordinary leap of logic, but -

Mr HARRISS - I just think of my own experience. I became a blood donor about 30 years ago simply because a mate of mine said, 'Let's go and do it.' But it was probably a year ago when I rocked up and they said, 'Have you ever considered making a plasma donation?' I am thinking, I wonder what that involves.

Prof BOYCE - More time.

Mr HARRISS - I have heard what you've said, and I am still a wuss and I still have the local anaesthetic. You pinch yourself there, that's about the extent of the pain.

Prof BOYCE - Nothing wrong with that.

Mr HARRISS - So I haven't yet ticked the box for plasma, and yet it's no big deal.

Prof BOYCE - Well, it is more time. The blood service isn't great on what I call evidence-based decision-making. There's a lot of opinion about what blood donors will or won't put up with. I certainly don't think you want to tell blood donors that they have to be organ donors, but it would be so easy in the regular letters that go to people, to include the brochure, for example, and we couldn't even get them to do that.

Mr HARRISS - As a blood donor, I'd appreciate that, but then again I'm coming from the standpoint now of a better education through this process.

Prof BOYCE - I think there are ways of making it clear that it's an option for people to consider, although I don't think it should offend anyone. I think if you said, 'We're going to leave the needle in until you sign' -

Laughter.

CHAIR - No more blood left.

Prof BOYCE - I think one of the successes in any social marketing campaign will be to identify the subgroups and the tactic that will work in those subgroups, because some people say this is a very sensitive area and you can't talk about *X*, *Y* and *Z*, but I think in reality if you get the right advice from people who understand communities, they will say, 'You can say what you like to this group of people and they won't be offended, but when you're going to deal with this demographic, you need to be careful with certain messages'.

I know with the smoking campaigns that very different messages got different sectors of the market. They got a lot of teenagers to stop smoking because they suggested if you smelt bad people wouldn't kiss you, sort of stuff. They learned very quickly that the health messages for teenagers were a waste of time because teenagers were immortal and were never going to get sick or die, and it didn't matter what people said, particularly adults. They worked very hard at creating a peer pressure around smoking being sort of icky rather than bad for you, and it was very successful. I watched my kids go through that, and they were very against smoking because it just wasn't cool. Not that it was -

Mrs RATTRAY-WAGNER - It's so last season.

Prof BOYCE - Yes. The thing with the social marketing is that one needs to invest. The funny thing is - and it's not really funny - that the health economics of this is really a no-brainer. Every organ donor saves the health system more than $1 million. There is no way you're going to have to spend huge amounts of money. There are learned papers from Spain that demonstrate that even the huge investment that they put into increasing their donor rate is enormously cost-beneficial to the sector.

CHAIR - Are we able to get a copy of any of those papers?

Prof BOYCE - Sure, I can get those to you.

When I was a kid I think 57 per cent of women and 70 per cent of men smoked, so the challenge for the non-smoking campaign was to change the behaviour of tens of millions of people whereas for the organ and tissue donation side of things we really need an intervention that is changing general behaviour but the impact is only on a very small number of people.

Mr HARRISS - We spoke to you previously, Neil, and we've spoken with others since about appropriately qualified and trained counsellors as part of this process. We have to convince people, as a marketing exercise, to sign up and be available and there is a huge level of trust in all of this. It seems to me, on the surface, that it would need to be an extension of the already highly-qualified medical people. I don't know that you could just throw somebody into this as a counsellor and train them up. The trust level attached to health professionals is very high in our community; people trust their doctor.

Prof BOYCE - I fully agree. This has to be part of people's day jobs. If they were to think of any other thing they do, they would be fiercely offended if you were to say to them, 'Get out of the way. We're going to bring in the A-team now to do this'. Also, people would be quite confused. These are families that are in awful circumstances - a sudden, unexpected death of an often relatively young person. I think it has to be the person they have the existing trust relationship with who, at the very least, brokers the initial conversation. They might then introduce one of my staff, for example, who can essentially give all of the nuts-and-bolts detail. People around the world have tried the idea of the flying squad of the professional requester, but I think the flaw with that is that that person doesn't have a pre-existing relationship with the family. Also, that person runs the risk of looking a little bit like the Grim Reaper, who only appears in the hospital when there is a dead person. It would appear their job is to get it across the line to become a donor. I think the best people are clearly those caring for that particular family and individual, particularly around the issue of what the right decision is for them.

It is a shame a couple of the coordinators aren't here. They could tell you stories about families where they have gone to talk to them and it has become increasingly obvious that this isn't the right decision for that family and that we need to disengage and get them to realise that it isn't the right decision. Just like sometimes people say no very quickly and perhaps without appropriate thought, they sometimes say yes very quickly, without giving appropriate thought. Recently in Victoria we have had a couple of cases where people have wanted to determine the outcome of who received the organs, and have clearly have not understood the game, which is this is a gift for the community, for the best use of the community. It is not some sort of trading or bartering scheme where you decide that the man down the road on dialysis will get the kidney and the other one goes to your sister, for example. If you're not closely involved with the families, I think you can't do that. I have never liked the designated requester model.

It is also a bit of a cop-out. To me, it is the equivalent of saying, 'Why don't we bring someone in every time someone is going to die? We don't want to talk to the family because that's really difficult. Let's bring the chaplain up and he can tell the family that's it's not going very well and they're going to die'. There would be times, I am sure, where all health-care professionals would say, 'Yes, can we have one of those, please?' but it is not fair to the families. I think that that trust is what it is all predicated on and they have to trust the person about the bleakness of the outcome or the fact that their loved one is dead and, as I say, if they cannot broker that initial conversation and get at least preliminary agreement, I do not think anyone else can.

Mr HARRISS - How often is that pursued, when somebody coming close to death or right at the moment of death the health professional has that sensitive conversation with the relatives around? Does that happen without the person having identified themselves as an organ donor?

Prof BOYCE - In Victoria, we think probably 70 or 80 per cent of cases where the conversation should happen it happens but there is still that 20 or so per cent where a variety of reasons led to people not having it. One of the things we have to really work hard at is not second-guessing what families would wish. We sometimes find people say, 'That particular person is of a particular religious belief and so we didn't raise it with the family' or 'They are a particular ethnic group so we didn't raise it at all' or 'They've gone through a terrible time and they're very distressed'. I think, as you alluded to earlier, we need to get a grip and say that if we raise it in a professional, caring, competent fashion, the worst thing that can happen is the family says no.

Mr HARRISS - In an aggressive manner sometimes, though.

Prof BOYCE – Yes. My staff will give you some stories of what they have been called. That is where the argument of the community good comes in. If you are called an uncaring so and so, or told 'How dare you' or 'Don't you know?', I think you just have to wear that because firstly it is not directed at you personally; it is just directed at the fact that the people are angry that they have lost a loved one. It is not just fair to say, 'Well, I might take a few on the chin so I'm not going to risk that happening and I'll just not let those people get the opportunity' because it is amazing how often we are wrong. We follow up families whether they have said yes or no and we did some research on families that were not approached. A number of the families who were not approached the health-care professionals decided would have very happily donated and whilst they were Jewish, they did not care less about the obsession of being in the ground as quickly as possible and they would have happily allowed donation.

So I think health-care professionals need to be willing to take it on the chin on occasions and again my colleagues in ICU will say, 'We need to get the community to the point where they're expecting this question so they won't be upset' and you say, 'Well, maybe it's not a stepwise thing, maybe we need to move together but part of normalising it will be to start making it a routine inquiry'. If someone goes hysterical we should be able to say, 'Well, we ask all families that question. We haven't just picked you because you are in a particular bed on a particular day'. We are very supportive of organ and tissue donation if that is what people wanted. I also think there can be no value judgment, 'Well, you're a bad person for saying no and we're going to go and stick a pin in your loved one'. That line has to be there. It needs to be, I guess, something that we are supportive of but we do not feel people must do. It is, I suppose, the same as saying to someone, 'Do you want to have chemotherapy for your cancer?' and if the person says, 'I've thought about it and I remember my sister had that so no, I don't', you do not say, 'You're a bad person, I've offered you chemotherapy and you've knocked it back'. It is something that people need to elect to do.

I find not approaching people a bit gutless, to be honest. I used to do it and I am not under-estimating how difficult it is for you as a person but you need to get a grip because by comparison to the people you are talking to, you have it easy. The worst thing that can happen is that you can be a bit uncomfortable for a short time, maybe as you are driving home and remember what people said to you.

Mr HARRISS - That can impact in a stressful way on the person.

Prof BOYCE - It does. Some of my staff have had terrible times dissociating what people have said to them and having to say, 'You have to realise that you were doing your job, you were doing it in a professional and competent fashion and the people had every reason to be angry and upset - not at you specifically'. But no you are right. People who work in this area – it is one of the things I talk to my staff about - and it is the same for the intensive care community, need to be professionally supported and they need to have backup systems because one of the hardest things is when people start attacking you, your values and your ethics. This is not like saying you stuck the tube in the wrong place or you couldn't find the vein; they are accusing you of being low, scummy person who is stamping all over their grief just to get bloody organs for someone, and I do not think you can avoid that.

CHAIR – Neil, it seems to me that what you say is correct - and what Paul was saying – that those people who are able to do it properly do it and say, 'This is a question we ask. This is part of our duties'. I would feel more comfortable if there was a form in front of you because then you could show the people this is part of the process that takes place -

Prof BOYCE - Sure.

CHAIR - name, address, date of birth, do you wish to donate organs? If they had that to look at as well then the people cannot say, 'What's all this about?' It is there in front of them. That to me would arm them with something at first to try to get that community understanding that it is just a normal question to be asked.

Prof BOYCE - Some hospitals have gone down that route. It is often linked to the request for autopsy as well to codify it.

I think that can be a tool but it is terribly important that it not replace a professional commitment to doing it well because it is very easy for people to sit there ticking all the boxes.

CHAIR - I realise that.

Prof BOYCE - The autopsies are the classic. All the boxes are ticked as no and yet if you go back and talk to the families, most of them were never asked. It is just the gutless way out; you make out you asked the question.

CHAIR - But it gets rid of that feeling of the person, I would have thought -

Prof BOYCE - It does help and I think part of a community education campaign can be letting the community know that should they die in circumstances where donation is possible, the treating doctors and nurses will raise the possibility of donation so that it is not seen as something that is completely beyond the pale.

It is interesting that with around about a quarter of donor episodes at the moment the family raise it. There are some people who recognise the scenario. It is clearly a very stressful scenario but there are fully a quarter of people who realise that their loved one has died, they wanted to be an organ donor and they raise it with the health-care professional who I can tell you love it because it takes all of that responsibility to initiate a conversation.

What I found when I talked to my colleagues in Spain is that they are in a position now where both the health-care professionals and the community expect this question. Who raises it is not the issue; it is a routine part of the process of dying. And we have to get to that point. It has to be a perfectly normal option. I think we need to do the work to get through all of the silliness that surrounds it to the point that, as you say, it is so routine that it is codified in the usual operational practice.

I think we need some form of record. The part of the task force that is going on at the moment is that people are having rushes of blood to the head about having real-time electronic data entry with everything you are doing and you will instantly know who said what to whom. There is a bit of me that is saying, well just get a grip. If we are going to have anything we might have a paper form because, as I mentioned earlier, you have tens of thousands of people potentially involved. Training them to run to a computer terminal and start entering data whilst they are in the process of talking to a bereaved family all sound a bit far-fetched to me. Anyone who knows health computing knows that no two computers ever talk to one another.

I would like to see, certainly as part of the hospital system, people recording routinely that they have spoken to Mrs So and So about declined consent for donation and at the very least they might say why, because part of it is this accountability. I think every hospital should know, this year we had 12 potential donors, six of them became actual donors and for the reasons following the others did not. If we get to that point, I think it makes a big difference if people know someone is interested. One of the things we have found in our audit process in Victoria is the very fact that people know we are going to audit has changed the way they behave because they know, even if it is not immediate, that at some point in time someone is going to come back and say, why didn't we approach this family? So over time, the proportion of people who are not approached has reduced.

CHAIR - I have been truly surprised, Neil, how many more people are speaking of it. My daughter, who is 29, was saying a couple of days ago, 'I want to be an organ donor, what do I do?' I did not raise the subject with her, she just brought it up. She saw that film 'Life Gift' and she said, 'I don't thing I'd like to give my eyes, though.'

Prof BOYCE - That is interesting. I have a view that popular culture is probably terribly important because letting people see these issues in a context that they might find entertaining and not confronting them, but planting the seed, would appear to be a very effective way. Funnily enough, there is some research out of the United States that sometimes even if what is being portrayed is factually incorrect and even gruesome or silly - such as a story about someone trading in stolen organs or someone receiving a Mercedes Benz for donating their kidney or whatever; and again, some of my purist colleagues say that we have to stop stories like that - it would appear that they are not bad in that people are not stupid, in that they understand that whilst the story might have been entertaining it was in fact just a story but it has raised the issue. We have gone through that with Life Gift. Occasionally some of what has been put forward, while not exactly factually correct, is cool - within the context of the program.

Mrs RATTRAY-WAGNER - You're probably the only one who really knows.

Prof BOYCE - That is what I said. A lot of my colleagues have been hysterical about this apparent linkagem, but I said, 'But it is on purpose; they have apparently linked the stories to make it more interesting, but it is not real so it does not matter. We have not broken the Human Tissue Act and it is good television.' I also said, 'The issues are being planted and raised and discussed.'

In America they have a committee in Hollywood that works to try to place donor and transplant-related stories in the storyline of movies and particularly popular teledramas. Again, often the stories that come out are pretty gory and horrifying, but they have been quite successful in changing the way the community thinks and feels about it. For some reason, donation always occurs in the middle of the night, and maybe it needs to get out of there and be more in the glare of the television cameras.

CHAIR - Even last night we talked about the normality of it now. We were at a barbecue down at Traralgon, and they asked, 'What are you here for?' and I told them. One person said 'Oh, yes, I'm an organ donor.' I said, 'Are you sure you're an organ donor?', and two of them said, 'Yes, I've got my card'. They went to their wallets, and brought out their cards with no prompting at all.

Prof BOYCE - I think we are getting there. All of the surveys would suggest most people in Australia are aware about organ donation and transplantation. The behavioural change needed is that of 'make your own personal decision and communicate it', and ideally record on the register. The health system side of it, I think, is one of the bigger areas where we have to get improvement.

People in intensive care and emergency medicine are working really hard, are really busy, and so on, and they are sensitive to the criticism of not trying hard enough. What I keep saying to them is, 'The data would support the fact that you're missing donors'. They are not missing many, but one is too many. There is no point being defensive about it, it is how can we stop it happening, and accepting that they are hugely complex machines.

It may not be a personal criticism of the person you're talking to, but somehow or another the system has failed, and I think it needs to be elevated on the priority list so that they see it as a sentinel event if they miss a potential organ donor, just as if they had a bloodstream infection from a catheter, or something. It is something they really pay attention to and say, 'How can we make sure that doesn't happen again?'.

Mrs RATTRAY-WAGNER - I did mention that I had registered since we'd spoken last in Hobart. The process was quite lengthy, actually. I filled out the first little form, then I got another form to sign and I sent that, and then only last week I got a confirmation and I had to sign again. So three times I actually had to sign my intent, so I think you're right about the process.

Prof BOYCE - I think the register has got a bit lost. My personal view is they have too many lawyers involved and too many opinions on what they need to do to make it 'legal'. They have created an incredibly complex paper-based system, they won't allow on-line registration in the naïve belief that this is informed consent, and I am still strongly of the view that it's not. It is just a clear statement of intention. Instead of making it as easy as possible for people to register their intention, they have made it really quite difficult, and I think it's a testimony to how stubborn and committed the people who are on the registry are to go through all of those hoops.

I have said to people, 'I think you should make it as simple as possible because at day's end, the family are still going to be asked, and the only way the information will be used will be to say you're loved on is on the Australian Organ Donor Registry as being willing or not willing to donate'. But, no, they have made it incredibly complex.

I was recently at yet another national meeting on the Australian Organ Donor Registry and I gave a presentation to say this was my fifth such meeting, and I wanted to stop coming to them because it was ridiculous that we should keep having whole-day meetings talking about the registry and it was getting more and more complicated. Now we have two colours of the registry, the intent registry and the consent registry, when in reality there's no bloody difference between the two of them, it's just that Tony Abbott had a rush of blood to the head and said he wanted something done and everyone was too gutless to say, 'Minister, there isn't a problem to fix'. He wanted to change the legislation and we had to go back and say, 'Minister, the legislation already says that. There's nothing to change. It's actually a human behaviour and not a legislative problem'. But because he had told everyone he was going to change it we had to 'change the registry'.

CHAIR - Should you have to go to Medicare to get one? That is what happens in Tasmania.

Prof BOYCE - No. I think one of the things we ought to do is have several well-established ways that people can get on to the registry. Things such as going on the Electoral Roll, getting a driver's licence or a driver's licence renewal, getting a passport. Certainly I think the Medicare office is a great option because they have huge transaction numbers and when you renew your Medicare Card. If we come up with five or six standard ways of offering people the opportunity then I think people should be able to register online, and frankly, I would be happy if they SMSd their details in. I think we should stop being so precious about it being anything other than an intention registry because what I always say to them is, 'How do you know. I could sit there with a phone book and I could write someone's name out and scrawl their signature and send it off'. That is why they send you the confirmatory letter because they are hoping that if it is not you that you will let them know, but the suggestion that someone is going to sit there and counterfeit a very large donor registry is a bit far-fetched, to my way of thinking. It is too hard.

Mrs RATTRAY-WAGNER - I just thought, after talking about it, if you really were committed to this when you filled out your original form you would probably think 'I'm on it, I've already done that' and not read it and thrown it away and not the next follow-up stage.

Prof BOYCE - It is the product of, firstly, a committee and, secondly, the number of legal opinions and of course they ranged widely over what you needed to do. But I find it extraordinary in this day and age that you cannot register online, I really do. If you register online they just send you the form to fill in.

CHAIR - But, as you say, the legal aspect of it seems silly, doesn't it, because all it is, as you say, is an intention.

Prof BOYCE - There are people from the register who will say, 'This is definitely consent' and again one of the many opinions they got is 'You've got to be joking, you can't take this as informed consent by the medical standard of informed consent because it might be 20 years old by the time it is actioned'

CHAIR - That is right.

Prof BOYCE - You have no real way of knowing whether the person has really understood the information that has been given to them. There was this strong belief that we had to make it consent because the strong belief is we then needed to say to the families, 'Who cares what you think, they're on the registry and we're going to take the organs' despite many of us saying right from minute one, 'That will never happen'. You can live in your cloud-cuckoo-land as long as you like, you are never going to get Australian healthcare professionals waving registry forms at families and telling them that we are taking the bits. It is just not going to happen.

CHAIR - It is a bit like your liability clauses where you try to get out of negligence and you cannot get out of it. Once you sign you cannot get out of it, so it is the same type of thing.

Prof BOYCE - I think that, in an intent to make it something that it was never going to be, it has become incredibly rigid and difficult to become a donor. On the web site they only show the new registry data so we have gone from having 5 million people on the registry to 1 million. Fortunately, no-one pays attention but anyone who did would ask, 'Where have all the other people gone? What's happened?' That was a political decision because again it was trying to reinforce the minister's obsession that we have a new registry. I am hoping that commonsense might prevail and we can try to make the registry simple but one of the difficulties when you set up a big bureaucracy that operates in mode *x* to change it seems incredibly difficult.

Mrs RATTRAY-WAGNER - It probably means that you will have to go back to another one of those meetings, too?

Prof BOYCE - I think it does not need a meeting, it needs simple arbitrary decision making. It needs a minister to take advice from his or her department and say, 'Why don't we make it as simple as possible? What's all this rubbish about? Stop making out it is informed consent'. No-one around the world uses them as evidence of informed consent and make it a simple tool because some of my colleagues professionally say it has problems in it. The answer is all databases have problems in them. People make keying errors, occasionally there will be confusion between two people with very similar names and dates of birth and all the rest of it, but to me it is better than the Medicare database which everyone regards as a reasonably good national database.

CHAIR - That did happen, as you probably know, in Tasmania - the same name.

Prof BOYCE - I think you have to live with those imperfections because all big databases will have problems. Women insist on getting married and changing their names, and dead people are on it because again it takes three to six months sometimes for those databases to talk to one another. I see it as a tool.

We have had families to whom we have said, 'Your loved one is on the Australian Organ Donor Register' and people have said, 'No, they are not My staff ring me up and say, 'What are we going to do? They are on the register and the family are denying it'. You have to say, 'You are never going to win that fight. Just move on'.

CHAIR - What about the national task force that has an interim report coming down, you were saying?

Prof BOYCE - No, the interim report is out and the final one is coming in December.

CHAIR - Is the interim one a good one?

Prof BOYCE - It is okay - Boyce's view. The task force has been hijacked by the transplant community. They are trying very hard to get what they want out of it and sometimes their agenda is heavily focused on what we can do to get more organs, instead of focusing on the real issue which is donation and how we can better manage that. There are far too many members of the transplant community on the task force and far too few members of the donation community.

Nothing that they are recommending is silly but some of it is specifically in the area of transplantation and it is going to do nothing for improving donation performance - transplant outcome registries, for example. I was hoping the opportunity would be used to fix the problems we have with donation because that is the problem we have. We do not have a problem with transplantation.

I also think because it is so huge you run the risk, particularly with a transition of government and a new minister and probably new senior bureaucrats, of people saying - and I said this to Jeremy at the last meeting – 'What do you want us to do? There are 78 recommendations'. I have said please in the final report can we try to focus on two, three or four things that we really want to do? But of course there are all the vested interests. They all see a pot of money and say, 'It's a big pot of money, let's go for it', and people are coming up with all sorts of pretty wild ideas.

CHAIR – Regarding the working group meetings from a number of States, there is only one Tasmanian, David Bodle, and he did not attend. It would seem to me that if Tasmania want to be part of the action to understand what is going on, they have to be attending these things to see what the new, up-to-date matters are. I remember when Denis Rogers was in charge of cricket in Tasmania he wanted to be on every board of the ACB so he knew what was going on in Australian cricket, and he was in charge of the ACB for a couple of terms. I said why are you on every committee? 'Well, I want to know what is going on'. So I think Tasmania have to lift their game a bit there.

Prof BOYCE - The task force is very Sydney-centric.

CHAIR - It seems so.

Prof BOYCE - I think the task force in a way has lost an opportunity. We knew there was going to be an election and regardless of anything else, to be providing a report at the end of December to me seems pretty stupid at the best of times but to be providing a report when you knew there was either going to be a re-elected or a new government, I think the task force if they had a half a brain - and again I have told Jeremy this - we should have been reporting in September so that there was an opportunity for consideration.

You probably know that the governance model for the future is this cognate committee. I shake my head. The trouble with this cognate committee is it is going to require consensus for decision-making and, as I have said already to the bureaucrats who are running the process, you cannot get in this nation if you require absolute consensus. The task force has been a classic example. There hasn't been anything that has been considered that everyone has agreed on. If you have a committee structure that can only make decisions by consensus - the lovely people from Canberra said, 'That's the way things happen'. I said to them, 'No, that's the way things don't happen, this federation model where you sit around waiting for everyone to agree to do something and they are adding a whole lot of other people in addition to the jurisdictions'.

I think it could be a difficult time to get decisions on these recommendations made because they will be referred to this cognate committee that will then bat them around. Tasmania will have a guernsey on that committee, at least. Many of us argued that they needed to set up a small authority, such as an organ donation authority, that would be tasked to do something; to be accountable by all means but to get on and make decisions on the basis of consensus? No, on the basis of majority decision making. I have been around for long enough to see a lot of these sorts of mega-task-force reports that end up as mouldy files on someone's desk.

Mrs RATTRAY-WAGNER - Bookends, we call them.

Prof BOYCE - Particularly when they become bigger than *Ben Hur* and start tackling a whole lot of allied areas. It all becomes a bit murky and then everyone sits around and says, 'I don't want to do that. My priority is this'.

Mr HARRISS - An issue then, because this is a national matter of some significance, is what influence can a committee such as ours have on that agenda?

Prof BOYCE - I don't know. Certainly whoever is the Tasmanian representative on the new committee - the new committee is still being formed - I think there could be an argument to at least look at having an executive of that committee that is able to make decisions, for example. We can't rely on the federation model. Tasking them to make timely decisions and act would be great. They got a group of senior government officials together and asked, 'How should we run the sector?' and they said, 'Senior government officials should run it'. I found myself thinking, 'Isn't that a no-brainer if you ask a group of senior government officials who should be in charge?' It is going to be a group of senior government officials. When you say, 'What do you mean by "senior"?', I hope they are senior, but the trouble with senior people is sometimes they are very busy. There is a real body of work that needs to be done. I think they need to employ a small number of people who know the sector for a period of time and get them to do the work. Sometimes nothing happens between these committee meetings because everyone is really busy.

I shouldn't perhaps say this, but a bit of me has decided that nationally it might lose the plot and we need to focus on what we can do in Victoria and Tasmania. Practically, I think in Tasmania we need to start measuring actual donor performance in Launceston and Hobart. That will require engaging the intensive care communities and employing part-time staff in those two centres. I think practically in Tasmania you should look at ways you can have more than the Medicare officers' access to the donor registry. I can see no reason driver's licence applications and renewals, for example, can't be routine.

CHAIR - And then what do you do? With those you would then have that form that is in Medicare, is that what you are saying?

Prof BOYCE - Despite my criticisms of the AODR, we only need one donor registry and there should only be one form. In New South Wales they have a different set of questions. I think you can't assume, if you ask people a different set of questions, that it is the same answer. I think we need to improve the AODR to make it simpler and easier to use, but I think that is the way to get people on it. I think we should provide them with a form. Increasingly, as people move to logging on to web sites to do things, we should provide them with links to the web site. Also there is the electoral roll. I think it would be nice to offer people the opportunity when they sign onto the electoral roll to consider going onto the registry.

The other mechanism that has been quite successful in some States and Territories is major pharmacy chains - I think Amcal for a period of time.

Mrs RATTRAY-WAGNER - We only have two Amcal pharmacies in Tasmania.

Prof BOYCE – Okay. But it is not a big ask for the major pharmacy chains to at least have the brochures prominently displayed, particularly as the PBS prescriptions at the moment have on the cover, 'Have you considered being an organ donor?', and the registry details. So there is a nice link with pharmacists if people are looking at their prescriptions and seeing something about registration, and if the form is immediately accessible that would be good.

The beaut thing about Tasmania is that it is a relatively small medical community. I know that has its problems when you are wanting it to be bigger. But it is a group of people who are manageable in terms of saying, 'Come on, let us really make performance in Tasmania stellar.

CHAIR - To me, the terms of reference have been pretty well answered. When you look through them, I think they are fairly easily answered. You go through them one by one and I do not think it is going to be hard report.

Prof BOYCE - Again, in terms of Tasmania being smaller, we have a really good schools' program, which is for middle secondary school. My more radical colleagues say you should mandate that this be taught. The school curriculum is really iffy. But I think if the Education department makes its availability known and promotes the use of it, that would be a plus as well.

CHAIR - What is that?

Prof BOYCE - It is a middle secondary school program around organ donation and transplantation. It has a number of modules that the teachers can pick from, ranging from the medical, scientific through to the ethical side of things.

Mr HARRISS - With parental consent?

Prof BOYCE - No. We spent some time on that. We kept away from primary because we thought that was a bit sensitive. But part of the work program is for the kids to go home and talk to their parents about their attitudes and so forth. We spent nearly two years in Victoria getting the Education department to agree that that was possible, and it was quite interesting. It turned out to be one bureaucrat who just kept saying, 'You cannot do that' and so I set up a meeting with the then Health minister and said, 'Minister, I heard that we cannot do it many times. I just never heard why we cannot do it, considering these kids are middle secondary school'. The minister just said, 'Of course we can do it'. I thought, 'Two bloody years, if we cannot do, we cannot do it'.

Mr HARRISS - It is easier to say no.

Prof BOYCE - From talking to the lady concerned, she clearly believed it was quite immoral and impossibly irregular to be discussing such things with 'children'. The minister did not share that view. It was clearly a personal belief rather than any matter of law or reasonableness. We find kids are very receptive to it and they ask good questions. To me, it is planting a seed in that secondary environment and then offering the opportunity to reconsider it when they are 18 or so and then periodically reminding people. One of the things that I have learnt from my public health colleagues is that frequently changing behaviour seems to require a series of prompts and people will not always stop smoking on the first reminder, it might be the fifth or sixth or seventh. Even though they want to, they do not actually get across the line. So I think the repeated offers become important as is working locally and trying to make the national sector functional. Prior to 'Australians Donate', which is about to disappear, there was a thing called 'Accord', which essentially was a big national committee and it was completely hopeless. They could never make any decisions and they never did any work between meetings. There is a scathing criticism of their demise back in the late 1980s. I have forwarded it on to the current bureaucrats who are formulating the new committee to say that history seems to be repeating itself, that everyone has forgotten Accord, which was a disaster, and now we have come up with this fantastic term called 'cognate committee'. I thought that was amusing because one of my colleagues was sitting in Canberra and saw the presentation. 'Are there any questions?' asked the secretary of the department and my colleague said, 'What the hell is a cognate committee?'

Laughter.

Prof BOYCE - I am sure everyone else knows.

CHAIR - I know the time is 10 o'clock and today is a busy day with the transplants so -

Prof BOYCE - I am very happy to give you a break. It is a shame Bob could not be here because he is well worth it if you do get the chance to chat to him on another occasion.

CHAIR - We could have a phone chat.

Prof BOYCE - Yes. He is very animated on the phone as well. I guess it must be 20 years or so now I think he has been running the liver transplant program and he is so aware of the impact of literally saving people's lives but he is also very aware of the specialness of donor families. Not all my transplant colleagues have that empathy that Bob has - he really understands that it is a special thing that we need to value.

Mr HARRISS - Has there been a State inquiry in Victoria into this issue?

Prof BOYCE - No. They have had them in New South Wales and Western Australia, to my knowledge. There is a very old one in South Australia that led into the so-called reforms there, but not in Victoria. We had probably the equivalent - it was not actually a formal review - but prior to Life Gift being in existence there was a loose association of hospital-based donor coordinators who were inadequately supported and supervised. There was a bit of an internal departmental review which was never published, but I think it essentially came to the conclusion that this was a shambles and we needed to pull it into some sort of non-hospital body that could act as an interim. They went to tender and we were successful. I would like to say that is because we were fantastic, but I think we were probably the only people who were silly enough to tender! Some governments, particularly New South Wales, are thinking that maybe Red Cross should not run it and I am in the process at the moment of writing a defence, but my reminder to them is 'Who else wants to do it?' It is a classic community service thing; it clearly cannot be profitable because I think there are all sorts of moral and ethical objections to that. The only choices are either government runs it directly, as happens in the rest of Australia, or an agency like us runs it. We tried the experiment in Victoria, and the problem with basing it in hospitals is, firstly, one of appropriate supervision and training of staff but, more particularly, hospitals are quite tribal and people started to have beliefs that, because the coordinator was based at a particular hospital, too many of the transplants were going to that particular hospital and they were not looking after the best interests of other hospitals; they were seen as sort of outsiders. I would imagine that would be the same if we were to revert to a hospital-based for them.

I quite like the idea of having an independent body that tries to balance the best interest of the community without being too close to transplants, that has an independence and is not driven by donor numbers. Because I work in an organisation that is very much judged by how many bags of blood there are in the bank, there is a tendency for people to want to judge my area's performance by how many donors there are. I keep saying to people that this is a silly metric, because I never want to feel a pressure to push staff - 'We need another donor this month or I don't get paid'. You cannot feel that that is your job to get every donor that is appropriate, not ever. I have worked in the American system where people are paid on the basis of donors and sometimes the behaviours there are less than ideal, where there is a sense of 'We have to coerce this donor otherwise we don't meet our performance target'.

CHAIR - So the best system within Tasmania would be the overarching body, then a body that would be an offshoot of this with two employees - one up north and one down south?

Prof BOYCE - I think there has to be a north-south divide. You could argue it is not that long a drive and all the rest of it, but again it is that tribalism.

CHAIR - Yes, it is just the make-up of Tasmania.

Prof BOYCE - For example, the people we would want would be people who were familiar with intensive care - so probably intensive care nurses from Launceston or Hobart. We need to work out how best to do it. It might be better to have, say, two people in either site who work half-a-day a week rather than one person who works a day. It provides a little bit of redundancy. I think we would have to be responsible for their training and professional development. Our staff would still go down periodically and they would come up here occasionally. I think they would need to have an intensive care doctor who was their local mentor, if you like.

CHAIR - So that would be the management role, and then under that would be the hospitals?

Prof BOYCE - Yes. In a way they are embedded within the hospital, in my mind.

CHAIR - I can just see some problems if they were. Some hospitals might be facing more than others, where if you had this independent body - and it would certainly be embedded within the hospital but it would be independent - that then would link with the hospital intensivists and hospital nurses.

Prof BOYCE - You'll probably see it when you go to Adelaide tomorrow. Are you going to Flinders?

Ms McLEOD - No.

Prof BOYCE - In South Australia, because they are bit like you in Tasmania and very small - they only have a couple of significant hospitals - the coordinators are effectively embedded physically within the fabric of the hospital. There is this mini-agency, as you suggesting, but on a day-to-day basis they spend a good bit of their time within the hospital. I think the people would have to be working across the hospitals, public and private, in those jurisdictions. They probably need a line accountability through to a David-Boadle-type person, or at least an 'active interest'.

I think I mentioned previously that people have thought that this role was all about actually managing potential donors. They say, 'There aren't that many of them in Tasmania, so why do you need these people?', instead of seeing it as a performance measurement, education, advocacy, and expert reference person. We have found that the liaison roles that we have in nine of our Melbourne hospitals are really good ways of building relationships, elevating the importance of donation in people's minds and, in particular, providing the data to make judgments on. It works best if they are seen as locals - that is, part of the fabric of the place, and not people who come from outside. But they have a clear role and accountability.

CHAIR - You mentioned Flinders. Would there be some value in paying a visit there, or researching to get an appreciation of the structure?

Prof BOYCE - No. If all the people are somewhere else, it would just look like a big hospital. We are physically here because we have 37 hospitals that we serve. Some people said, 'You should be based at a hospital', and I said, 'We're breaking that nexus deliberately because we want to be seen not to be dependent.' I think a State which has only a couple of major hospitals then it's a different model. You don't have to worry about the 37; you say 'Let's get the ownership in those two'.

I think one of the strengths of South Australia is because they is strong ownership in the two principal hospitals. They perform better than most other States and Territories, and it's that, 'This is something we do and do well' ethos that permeates those two hospitals.

CHAIR - I came into this committee thinking that the numbers were bad, and the best way to deal with it was to say that if you don't opt out, you're in. But I must admit I changed my views as a result of that information.

Prof BOYCE - Good, good. I don't think legislative change will achieve anything. Health care professionals are very poor at responding; most of them don't even know legislation, they just do what they think is a fair thing. In my mind, it is changing what they think is a fair thing, and I believe that the legislative fix would be quite difficult to achieve, there would be all sorts of argy-bargy. The focus would be all on the legislation and the wording, and there would be people marching with placards saying, 'You're not stealing my organs'. I don’t think it would be tackling the real issue, which is a behavioural one both in the community and amongst healthcare professionals.

It is quite interesting, because a lot of people think the Spanish model is about the legislation, and when I say, 'Here's the data of consent in Spain. Every single family is approached and their consent rates a little over 80 per cent'. They completely ignore their legislative framework, despite the fact it was established. People say, 'Well, why do they bother getting consent?', and I reply, 'It's just the way people in health care behave in a particular cultural environment'.

There is nothing in law that drives people to get informed consent for operations because in fact if you get into that legalistic thing of what's enough information, it goes on forever and ever; it is about wanting to do what's a reasonable thing in that culture. That is why sometimes in informed consent forums you will get people carrying on about how do you get informed consent from someone who's been run over by a truck. The answer is that you don't; you get on and try to fix them, and at the earliest available time you try to explain to the nearest available member of their family what's going on. It becomes a tiny bit legalistic to be talking about informed consent for emergency care when you don't have a lot of choices. The person is either going to die in front of you or you're going to treat them, and those two worlds can be quite separate.

One thing that I think is a shame and could be easily fixed if it was not for federation, is that I don't think we should have different human tissue acts in each State and Territory. It is a national trade in organs and tissues, and it seems to me silly to have different rules binding behaviours in different jurisdictions. I give the example in New South Wales. If you are a ward of the State, you can't be an organ donor, and yet you can in every other State and Territory. I said to my colleagues in New South Wales, 'We can ship them down to Victoria and they can donate, and we can send the organs back to you. Would that be all right?'. They said, 'Oh, yes'.

CHAIR - How does Tassie go with the Human Tissue Act?

Prof BOYCE - It's pretty sensible.

CHAIR - So that doesn't need any changing?

Prof BOYCE - I don't believe so, no. On occasions, particularly in trying to fix problems around the retention of specimens for pathology or autopsy or whatever, they have changed the whole human tissue act to try not to look bad in the papers so the idea was in New South Wales they did not want people taking specimens from the wards of the State and using them for research because it would look bad to say 'Wards of State used for tissue farming' or something similar. They forgot in my humble opinion the public good argument. Whilst there is not a lot of public good in all this keeping specimens on the off chance you might want to look at them one day, organ donation has a clear public good so a slightly different standard should apply.

Also, if you are willing to accept the organs what is the point of the law? I think it could create quite interesting test cases and I think it was built up - organ donation used to be the local activity; the time pressure was such you had to do it all locally and I do not think anyone bothered to think how can you possibly have different legislations covering the one activity. I have found it is quite interesting. Every time you talk to someone they say, 'It is easy; you will adopt ours.' We could go back to the original one that was drafted that everyone has changed. I think the legislative stuff is probably too hard. What we really need to focus on is the human behavioural stuff.

CHAIR - That is very good thank you.

Prof BOYCE - That's okay.

CHAIR - Thank you very much for your time; you have been very generous.

Prof BOYCE - It is a pleasure. I hope you have a good day and enjoy tomorrow because one of the things I am encouraged about is that there is interest outside of what has been a tiny little craft group. If we can sustain and focus that interest it will help to get broader community support for what we want to happen. Until that happens, I do not think we are going to move from where we are. I believe that our current performance is the performance you will get from the way we are currently doing things and it will be moving to that next phase of saying, 'Let us broadly discuss it, let us have more television programs, let us have more debate, let us have politicians who are happy to engage in talking about it.'

CHAIR - It seems to be 'Let us endeavour to normalise it', doesn't it?

Prof BOYCE - It is quite interesting. There is a body of opinion that says people can believe in something and want to do something but it is a long way down their list of things to do. Does that make sense?

CHAIR - Yes.

Prof BOYCE - A sort of number 99. So maybe it is not about changing the number of people who are willing to be organ donors, it is about getting some of them to move it up that list to the point that they take the action and tell the person and healthcare professionals the same. Get it away from the old 'it's a nice thing to do if we are not too busy, we have a bed and we are appropriately staffed' and get it up to the point where they do it, regardless of the hurdles that are there. I think it can be done.

CHAIR - With Tassie, if the 174 000 people are out there still, that is not bad. We have to find those 150 000 who just ticked the licence though.

Prof BOYCE - There is quite good evidence - for example, Tasmania is a very high performing blood-donor State. The smaller the community, the stronger sense of connectedness to the community and the willingness to help. It is not easy anywhere, but it will be easier in a place like Tassie or South Australia.

CHAIR - Could we have the statistics for Tasmania's blood donors?

Prof BOYCE - Yes.

CHAIR - I was going to say if you could link it in with that, it is a good link to have, isn't it?

Prof BOYCE - It is quite interesting that for a long time in Tassie we did not have to market blood donation at all. They were sending people away saying no appointments, go away, rack off. It is has become a bit more difficult, but it is still dramatically easier because of that stronger sense of community. We have found that as cities like Melbourne and Sydney get bigger and bigger the donor rate drops because there is that lack of connectedness, someone else will do it.

CHAIR - And a lack of owning it, isn't it? If somebody makes the decision to do it they will defend it to the hilt whereas if somebody tells them what to do they will not defend it nearly as much, will they?

Prof BOYCE - True. I will get the blood donor figures for you.

CHAIR - Thank you very much, Neil.

THE WITNESS WITHDREW.

DISCUSSION WITH **Dr WILLIAM SILVESTER**, JOINT FACULTY OF INTENSIVE CARE MEDICINE.

CHAIR (Mr Wilkinson) - As you would be aware, we have some terms of reference for a select committee to look into organ donation. As a brief summary, when I mentioned it at first my initial views were 'Let's have an opt-out' but I have gone completely away from that. Information we have gathered over the last few meetings has been extremely good in relation to what should and should not occur. Tasmania does fairly well as far as intention is concerned, but it is a matter of doing it properly. All up, there is around 174 000 who have expressed an intention to donate their organs. I think about 150 000 of those have just ticked their licence, thinking that is what you do. They are unaware of the Medicare forms, so obviously there is some work to be done there. What we are looking at is endeavouring to make it more public, normalise the donation of organs within the community and make people aware that, if they can do something. It will not only improve people's lifestyles if the need arises but also save a life.

I will leave it to you to discuss what you think appropriate and then we can ask you some questions as we go along.

Dr SILVESTER - I am here as the Joint Faculty of Intensive Care Medicine-nominated person to come to speak to you, but I am here also in my capacity as a medical director for LifeGift, which obviously covers organ donation for Victoria and Tasmania. I am also the chair of the medical Adapt steering committee, which I have chaired since its inception. It organises the training of intensive care and emergency department trainees and consultants on how to approach families about organ donation and brain death and how to explain it and how to break bad news. In other words, training them with the skills to be able to communicate appropriately, professionally and sensitively. We have been doing that throughout Australia for a number of years now. I am also an intensive care specialist at the Austin Hospital. I have been involved in organ donation since the early 1990s. I organised the first multi-organ retrieval in Western Australia, which is where I trained.

I think in some ways this is very relevant to what we are talking about today, I set up the original audit process that was started here in Victoria - and which is now being established in New South Wales, Queensland, Northern Territory and Western Australia - to audit organ donation activity to help us identify why the rates are low and what we can do about it. If you would like, I am happy to provide a copy of the reports that we have previously submitted to the Victorian Government and copies of the two publications that were published, one internationally and one here in Australia, based on that work. That is work I've done with Helen Optum, who is another intensive care specialists and one of the medical consultants for LifeGift. That started back in 1997 when we were really charged with trying to find out why the rate was low and what we could do about it. We identified a number of things. In summary, we identified that for those patients who had progressed through to brain death there was a low incidence of missed potential donation - we refer to them as 'unrealised potential donors' rather than 'missed potential donors' because we don't want to get medical staff offside in that way. We realised that there was a low proportion being missed that had progressed officially through to brain death. That was good because it meant that most intensive care specialists were prepared to approach families in those cases. We recognised that there was a larger number of people who hadn't progressed to brain death and in whom treatment was being withdrawn prior to proceeding through to formal completion of the brain-death tests and, as importantly, the families weren't being approached. We had situations where intensive care specialists knew that this patient was deteriorating probably to the point of brain death, they weren't doing the formal tests but nor were they going to the families and saying, 'As you know, your family member is very sick and is in the process of dying and we're recommending that we withdraw treatment'. They weren't also saying to them, 'It is part of my job to inform you that if we continue to provide ventilation and other support for the next few hours, or maybe another 24 hours, it's very likely that your family member will progress to brain death. The reason I'm telling you about that is because we need to give you the option of organ donation'. We had a significant number where treatment was being withdrawn without that being broached. We identified that as the investigators doing that research and ANZICS has identified this - ANZICS being the Australian/New Zealand Intensive Care Society - and progressively our fellow intensivists and the Department of Health have identified that that is an important group of patients we are really missing out on. Those are the sorts of patients that they are not missing out in places like Spain, the USA and other European countries because it is an understanding there that the intensive care specialists will make that approach or another nominated person will make that approach and say to the family, 'There is a possibility of organ donation here, what are your views?' or 'What would your family member's views have been before they became so sick?' and if they then say, 'Yes, they would be very keen to support organ donation' we say, 'Under those circumstances we can continue providing the ventilatory support and the cardiac support for the next few hours and if they do progress to brain death then that will be a possibility'.

Currently, as you know, the donation rate in Australia is around about 10 donors per million population. We have seen, through our rigorous research, that we could increase that to pretty close to 20 donors per million population. That is, if we identified all such patients appropriately, if we improved the skill of the doctors approaching the families and if they were able to then convert that to the families saying, 'Yes, we do support donation' we would see that we would get that up to about 18 to 20 donors per million population. We do not believe that it will ever reach the 30 that they have in Spain or the 25 or so that they have in the US because we believe that in Australia we provide a better standard of health care for patients who come in with trauma to the brain or with strokes. We know from the work that we have done in comparing our results with overseas that the number of injuries and deaths from motor vehicles accidents, for example, in Spain and other European countries is higher. We have all driven in Europe and we have seen the lack of helmets and seatbelts and the standard of driving, and that is reflected in a higher fatality rate there compared to here and of course it is also reflected in a lower number of patients with motor vehicle accidents who could be potential donors.

We also know that we have a very low, by comparison with America, incidence of donation from gun-shot wounds, so these causes do have a moderate but significant impact on the availability of organ donation here in Australia but, having said that, we do know that we are missing the cases from the scenarios that I have already described. We also know that we are missing the cases where treatment is withdrawn in the emergency department so the cases I have already told you about are the ones that have come into the intensive care unit, they are getting treatment for their head injury or their hypoxic brain damage from hanging or drowning or asthma attack or injury from a haemorrhage or a stroke in the brain but we also recognise that some of those cases are not even getting to the intensive care unit because they come in with a devastating injury to the emergency department, the neurosurgeons or the neurologists may be consulted by the ED doctors who say, 'There's nothing we can do here, we recommend withdrawal of treatment' and then the ED staff speak to the family and they withdraw treatment.

So through our research we have certainly identified many cases and we are now working with the emergency department staffs in different hospitals to educate them about the importance of again not just withdrawing treatment without presenting to the family the possibility of donation and we have seen some remarkable changes from the number of hospitals where we have gone and presented our audit results with both ICU staff and ED staff attending and saying, 'These are cases we really shouldn't be missing. We have a responsibility to those potential recipients out there to be thinking about this and we also have a responsibility to the donor families to raise this as a possibility'. In the same way as if you were my patient and you came along with a problem you would expect me to fully inform you about all the different treatment options. If you came to me with angina I would say, 'We could give medical treatment or an angiogram or angioplasty or cardiac surgery and I would be derelict in my duty if I was not to inform you about the options and give you the opportunity to make your choice'. Equally, we see it is really important that we give families the option of being able to consider donation. If they say 'No way', that is fine. If they say, 'Yes, we'd like to consider it for at least 24 hours' then that is also appropriate.

CHAIR - It seems to be that some of the difficulties that we have encountered have been the education process of people being able to ask the families. As I understand it, you have been giving some assistance with the asking or the option process, as you call it?

Dr SILVESTER - We have. In running the medical workshops we run them in all States and Territories, apart from Tasmania. We ran one in Tasmania I think about seven years ago. Every year we offer it to the intensive care doctors and the emergency department doctors in Tasmania.

CHAIR - What is their answer?

Dr SILVESTER - There has been, 'Yes, we will see what we can do about it'. But it has not happened. That is not asking them to organise it. We basically organise it. We basically run the whole thing. Its costs us about $300 000 a year to run all the workshops for medical and nursing staff. I have a manager who is based in the Red Cross in New South Wales. She organises it all. She organises the venue, the catering, the registration and the speakers which are two intensive care doctors and a bereavement counsellor. We come down and we run the whole show. We rely on the Tony Bells and the other intensive care doctors and emergency department doctors in Tasmania to help us find people. We have tried to organise them in Hobart, in Launceston and in Devonport. So that has not happened.

CHAIR - How many people normally come to them?

Dr SILVESTER - A maximum of 15 at a time.

CHAIR - So you would think Tasmania should be able to rustle that number of people up?

Dr SILVESTER - Easily.

CHAIR - Are we able to point out in this report how successful those programs are?

Dr SILVESTER - We certainly know from our evaluation that the response rate from the participants is overwhelmingly positive about the skills that they gain, the confidence they gain and the comfort they achieve in having these sort of discussions and being able to broach these things. It is harder to make an immediate direct correlation between that and a change in donation rates, apart from following people up who did it, say, 6 months, 12 months, two years or three years down the track who still say, 'Yes, since then I have felt much more comfortable and I have approached people under circumstances that I would not have in the past'. So we not only teach them the skills but we also that workshop as an opportunity to educate them about the things that I was describing, about the cases we should be considering in the emergency department and in the ICU and how we run our audit process and provide follow-up in that way.

CHAIR - So it would seem that Tasmania, therefore, is missing out because of what may be a lack of knowledge in relation to the matters that you have just been speaking about?

Dr SILVESTER - That is correct. Some of the intensive care specialists have done it in the past - Andrew Turner, for example, and a couple of the others who are now consultants in Hobart, have done the workshop when they were training with us as registrars here in Victoria. But there would also be registrars that are working with them now who have not done it, both in the ICU and also in the emergency department. There are certainly ED consultants who are in Hobart and Launceston, Devonport and Burnie who have not done it who would benefit from having that training.

CHAIR - Then to audit it, what would the audit be? We have advised Jim Wilkinson's family that he is a person who is a potential donor, he is crook and he is on the way to brain death, do they agree or disagree? Is that the type of audit that you need?

Dr SILVESTER - Yes.

CHAIR - So number one was the question asked and number two was whether they agree or disagree?

Dr SILVESTER - Yes, those are two of the 10 or 15 questions that we ask.

CHAIR - Can you supply us with those questions, please?

Dr SILVESTER - Sure, we would be able to give you an indication of how the audit runs. The way we run it here in Victoria and the way we run it elsewhere is that we audit all the deaths in a hospital because we cannot be sure if there is a case that we might not be aware of, so it is better to do it properly. The auditor is usually an ICU nurse who is employed one day a week or one day a fortnight to do the auditing, depending on the size of the hospital, and that auditing means that they get a copy of all the deaths from the previous week from the Medical Records Department. They can quickly eliminate the ones that have come in that would not be appropriate. For example, those who had come in with cancer and died from cancer or those who are over the age of, say, 75 or under the age of two or those who have died from severe infection.

That usually ends up leaving, say, two or three patients. They then call the medical records, they look through it - did this person die in ED or in ICU? Was the cause of death due to a severe head injury that was irreversible and could have possibly lead on to brain death? So they identify these issues through looking through the notes, they fill in a template and then at the end of this auditing process there is a question as to whether this may have been a potential donor. It is then referred back to the central group that is run by Helen and myself where we say yes, this is a potential person; we need to refer this through to our panel of intensive care specialists. We then consider this and then our panel look at the them all and say yes, that one was missed, that one wasn't, that one was and then we collect that data prospectively. Over the last few years we have audited 15 000 deaths here in Victoria. So our data is very reliable. It is scrutinised very carefully.

CHAIR - The percentage of misses is what out of that 15 000?

Dr SILVESTER - Over, say, a 12-month period here in Victoria we would probably identify potentially about 30 to 40 that are missed. As you may know, our donation rate here in Victoria is about 45 to 50 so you can see how that would increase the rate significantly.

CHAIR - Sure. Do you then write to those hospitals and say, 'We have noted this. Are you able to advise why this person wasn't questioned?

Dr SILVESTER - We don't write but in that panel of intensive care specialists that I mentioned we have a representative from each hospital so they are there as the liaison intensivists there. All the data that has been presented where the panel looks at it is de-identified so we do not know that it is Monash Medical Centre that stuffed up there, for example, but we do then have that person there, they hear what the panel is saying and then they take it back to their group and say, 'You remember Mrs Bloggs who died here four weeks ago or three months ago, the panel concluded that in fact she was an unrealised potential donor and they have recommended that we look at the following processes so we do not miss that sort of thing again'.

In terms of the doing a proper audit, as you would know, you need to close the loop by providing appropriate feedback but we do it in a sensitive, professional way so that they do not feel as though we are telling them off and we use it as an opportunity to gain information and help them to take ownership and identify where their problems are and fix them. Through that process we have seen not quite a sea change but a significant change over the last five years from intensivists who were quite anti having people coming along and telling them how they should handle potential donation in a unit to saying, 'Yes, we can see the data speaks for itself, we should be considering these cases and we need to move forward in the process we use'.

We have also spoken in the past about setting up the same process in Tasmania. A number of times in the past we have tried to work with the Health department in Tasmania to employ an auditor in Tasmania who could also serve the position of a coordinator. We thought that you would not need a full-time coordinator and you would not need a full-time auditor but given that they both often come from an intensive care nurse background, you could have a coordinator who is working right around the State, going up to Launceston every now and then and Burnie and Devonport as well as being based in Hobart and could also be prospectively auditing in the same way. It is human nature that when you know your practice is being audited you make sure you cross the t's and dot the i's.

CHAIR - And the Tasmanian Health department has come back with the answer, 'No, we have not got the facilities?

Dr SILVESTER - Haven't got the money. Tony Bell has been a supporter of that in the past. He said, 'Bill, I completely agree. It is what we need to do. Every time we have approached the Health department they have not seen fit to provide the money'.

CHAIR - Am I right in saying, Bill, that in Tasmania with over 170 000 people ticking a box, whether it is the correct one or not in order to become a donor, what we have is pretty well a third of the population agreeing to be donors, which is the higher percentage rate, and yet you have obviously a problem in that a lot of those people are being missed because of the lack of asking the question, the lack of having a coordinator et cetera?

Dr SILVESTER - It is hard for me to know how much that is translated because we know that, for example, intensivists in the Royal Hobart Hospital are very supportive of donation and I am sure that when one of those intensivists is on duty if it is possible they will approach them, but I cannot be more specific about whether there are missed potential donors and whether there are cases where they are withdrawing treatment in the ED or the ICU before the question is asked of the family because we do not have the data. So I would prefer not to speculate without the evidence.

CHAIR - It disturbs me to some degree to think that, first, Tasmania is not wanting to adopt the Adapt Program and, secondly, the Health department are saying that we have not got enough money to put in a coordinator. That disturbs me because it shows that it is not high on the priority list if they are coming back with those answers for the lack of picking up the Adapt Program.

Dr SILVESTER - Yes, and remember it is not just those people who have signed the licence or are on the organ donor registry. Recognising that the registry only has somewhere between 10 and 20 per cent of Australians on it, nevertheless we know that in a lot of cases, when we approach families their 'yes' response will be somewhere between 50 and 70 per cent. Clearly there are a lot of cases where the families say, 'Dad never signed one of those forms but he's always said when he watched the David Hookes stuff, "If I'm ever like that, please donate my organs because they are no use to me any more".' What we do find is that, even more important than the register or the driver's licence, is the fact that people have spoken about it. If I have two families and one of them has no idea what dad would have wanted or their spouse would have wanted, their response rate is about 50 per cent. In the cases where they know that their wishes would have been to be a donor their 'yes' response rate is probably between 90 and 95 per cent.

Whenever I am on the TV or the radio I always say to people, 'Just make sure you talk about it over dinner. Once your family knows what your views are it makes it much easier for them to say yes when they are in that grieving state and they are being approached in ICU or the emergency department'. The donation register will make a difference, the Adapt Program would make a difference and auditing will also make a difference because then we will identify the pertinent issues in Tasmania.

We have found through the auditing, for example, that at one of the metropolitan hospitals here in Melbourne the radiologists were not supporting doing the imaging that sometimes is necessary when you cannot do the brain death clinical testing. So through our audit process we identified this and we then went back to the hospital and said, 'Do you realise your radiologists are not supporting organ donation because they are saying they don't want to get out of bed in the middle of the night or whatever'. They then fix that and now that is not a problem there any more. At another hospital it may be that the emergency department staff are not onside because there was some stuff-up in the past and they are all anti-donation. So we then go in there and provide a couple of education sessions. As in anything, you cannot fix the problem unless you find out what the problem is.

CHAIR - In Tasmania the only way you can register properly - and it is only an intention of course - is by signing a form at Medicare, and I just picked up a form here. You can only get those from Medicare. They do not come out with a licence, they do not come out with the Electoral Roll and they also do not come out with the pharmacies, et cetera. What is the best way of getting to more people than we are reaching at the moment by just going to Medicare and picking up one of these forms?

Dr SILVESTER - I would recommend that it be sent out whenever anyone receives a receipt or one of those cheques in the mail from the Medicare office. I would also recommend that it be sent out with your drivers licence renewal, whether it be vehicle or personal drivers licence, and I would also recommend that some thought be put towards trying to raise the profile in the media in Tasmania so that it gets into the *Mercury* and the other relevant papers and it runs on the news sometimes. That is again where, if you had a State-based donation agency such as we have here, there is no reason why you could not employ a part-time public relations person who can then pick up the relevant stories, work with the media and make sure that we are using the free media. I would see that that is more cost-effective than running advertisements because advertisements cost a lot of money. Whereas if you employ someone, say, a public relations person part-time who does have the connections with the newspaper, TV and the radio in Tassie, they can bring the stories to their attention. Then perhaps they will run front page or page 3 story about how a donation helped this particular Tasmanian who has just had a kidney transplant and is now free from the constraints of dialysis, or that person who had a corneal transplant. Something once a week, a fortnight or even a month would make a big difference, because it just raises that profile and always finishes off saying, 'Remember you can contact this number', 'You can ring up this office' or you can fill out the form when it comes with your drivers licence renewal notice.

CHAIR - And the best person to do that would be, as you say, a coordinator who could then maybe tick-tack with public relations or whoever it might be.

Dr SILVESTER - Yes. If, for example, the coordinator was based at Royal Hobart, I am sure Royal Hobart have a public relations department. So they could establish a strong liaison in the same way that we have at the Austin Hospital. I am not sure if you have been watching the Gift program. A lot of that work has been done not only based from here, but also working with the public relations department at the Austin Hospital where I am. The upside, from their perspective, is that Austin Hospital has been appearing a lot and, from a donation perspective, the program has been receiving a lot of attention.

CHAIR - Yes, likewise in Tasmania. It's much more normalised now than it was even three or four months ago.

Dr SILVESTER - Can I also mention that in terms of justifying to the health department the costs involved, every time one kidney is transplanted, you are saving your health service $70 000 to $100 000 a year recurrent costs for dialysis, for example. So if you employed a full-time coordinator that costs $70 000, they would only have to achieve one extra donor. Two kidneys have already paid for their job twice over, and that's only once a year.

CHAIR - Not a bad job for a day a week.

Dr SILVESTER - If you actually do the numbers, it so easily pays for itself. As you know, all the kidney recipients come over to Royal Melbourne. With the Tassie donors, those kidneys still come to Victoria primarily, so we'd increase the number of kidneys going to Royal Melbourne Hospital which will feed straight back into Tasmania.

CHAIR - It doesn't specifically feed back into Tasmania, does it, it would feed into Victoria as well? It depends upon where the person is on the list.

Dr SILVESTER - That's true. Of course you want the kidney to be going to the person who is genetically closest to the kidney, but we know that the Royal Melbourne Hospital is the biggest kidney transplant unit in Victoria and all the Tassie ones are linked in there. So Tasmanian recipients aren't being disadvantaged by the Tasmanian kidneys coming to Victoria because they'll get them as quickly as they come up on the allocation system.

I am sure that if Tasmania were to put money towards setting up that sort of thing, there's no reason why we couldn't be talking about ensuring that Tasmanian organs were receiving maybe a higher priority in some way for kidney recipients. I haven't really thought about it in the past, but it's something we could explore.

CHAIR - You can't expect to get them from other places, that's the other side of the thing.

Dr SILVESTER - That's true. I am sure that some Tasmanians have received kidneys from donors from New South Wales or South Australia.

CHAIR - Yes. If you were coming to Tasmania afresh and saying, 'We've got to do more for our organ donation' and you have an open cheque book to do that, firstly, you'd be saying, 'We've got to make sure that the people know how to register correctly'; secondly, ensure that they discuss it with their families; and, thirdly, there has to be a proper audit process in place which is done by getting a coordinator. What else would you say?

Dr SILVESTER - I suppose the only other potential impediment to donation is if the intensive care unit is full and there's a person who is a potential donor down in the emergency department and it's not possible to get that patient admitted. Intensivists quite rightly have the focus or the priority on the living patients. So if they have two patients being presented and there is only one bed, then clearly they are going to give it to the person whom they think has a chance of survival. Having said that, it does not happen that often but it does sometimes happen where the ICU is full and the intensivists simply say to ED, 'I am sorry, we have no room to move. We cannot consider this person' and so treatment is withdrawn. Again, that is something we identify through out audit and if you had an auditing process you would be able to find out how often that is the case. If you then had data it is easy for them to then go to the Department of Health and say, 'One of the benefits of your funding an extra bed in ICU is that we could make sure we do not miss out on those potential donors if you fund it, you could fund it conditional that one particular bed corralled so that if a potential donor is being presented then we make sure that person always gets that bed.' In other words, if we are do an ongoing audit and we, the Health department, fund you, Royal Hobart Hospital, to have an extra bed, we do not want to ever hear that a potential donor has been missed because you did not make that bed available. That is possible.

One of the ways we handle it at the Austin Hospital is that we always have beds, it is whether we have staff to staff the beds but we have ICU nurses who are prepared to come in, who are not on duty, particularly to support donation. So they might normally be having a day off, but they are prepared to come in if there is a potential donor coming into the bed. They will come and look after that patient under those circumstances. There is no reason why that could not be happening at the Royal Hobart Hospital.

Equally, if you gave an extra bed to the Royal Hobart Hospital, then it could be on the condition that if they do not have a bed at Launceston or elsewhere then that person can be transferred down to that Royal Hobart Hospital bed. There are ways around it.

CHAIR - Are you aware, Bill, of the Tasmanian situation in relation to the intensivists and their views? You were saying the majority of the intensivists are sympathetic towards organ donation.

Dr SILVESTER - Yes. I can speak more clearly about the Royal Hobart Hospital because I know that the intensivists there have certainly been supportive in the past. I haven't spoken to them all. I know they have a couple of new intensivists there and I have not spoken to them personally. We have always found that when they refer a case they are supportive. I do not know of any cases that have not been referred. I do not know the situation as clearly at Launceston or Burnie.

CHAIR - How would the system be within Tasmania? We were going through a way of devising a system that could work and it would seem that you have your LifeGift as the governing body. Tell me if I am wrong in any way. Under that you have your Tasmanian coordinator and you may have one or two up in the north and one or two down in the south, working with FTE one day a week and then under that you have the hospitals that we have speaking about. Is that a fair framework?

Dr SILVESTER - I think you could probably do it by having one full-time coordinator based in Hobart whose responsibility, amongst others, is also to do the auditing at all the hospitals in Tasmania. So they might set up their workload so that every second Monday they spend a day auditing potential donors in Hobart and I would not just include the Royal Hobart Hospital but I would also include your private hospital which is?

CHAIR - Calvary.

Dr SILVESTER - Calvary and then maybe once a month they go up to Launceston and spend the day in Launceston on a Monday and go over to Devonport and Burnie on the Tuesday. Not only using it as an opportunity to audit what is going on because they have set up a system so they get all that information sent to them by fax or e-mail and then they identify ahead of time with the Launceston Medical Records Department. 'When I come up on Monday week, I would like to have a look at the records on the following list of patients' and so that is all ready for them. Then they also use it as an opportunity to run an in-service in the Emergency Department in the ICU and in the operating theatres.

They could also be the person who helps to coordinate an Adapt workshop for the nurses in the Launceston hospital, for example. Then on the Tuesday they would go over to Devonport and Burnie. The rest of the time they are coordinating cases. If they are at Launceston and get a phone call from the ICU in Hobart that there's a potential donor, then they hop in their car and drive back to Hobart. They are there an hour-and-a-half or two hours later, they coordinate the whole thing and then they get back up to Launceston the following week.

I think that the ideal is having one full-time person who manages the whole of Tasmania, where they establish a really good rapport with the ICU and ED staff - doctors and nurses and the operating theatre staff. I am sure they wouldn't be sitting around twiddling their thumbs. They could do a fantastic auditing and education process. That is how our coordinators work here. In a number of the bigger hospitals, such as the Austin and so on, we employ an ICU nurse to do the auditing part-time. That is good because they already have a strong connection with all the staff in that ICU and the emergency department. In some of the smaller hospitals we use our coordinators here and one of their jobs is to do the auditing, for example, at Box Hill Hospital or at Maroondah Hospital or down at Frankston Hospital. That way they establish and maintain a rapport with the staff there. That is just part of their normal job. The other thing to consider is how you can increase the sign-up rate through doing advanced-care planning.

CHAIR - What is advanced-care planning?

Dr SILVESTER - It is like advanced directives. I know about that because I am also the director of the National Respecting Patient Choices Program, which is based out of the Austin Hospital. We have received about $6 million funding from the Federal Government and we also receive ongoing funding from the Victorian Department of Human Services. We are running advanced-care planning programs called Respecting Patient Choices in seven health services here in Victoria. We also have it running in a pilot site in every State and Territory, including Royal Hobart Hospital. We have been working closely with Lisa Warner, who is the Public Guardian in Hobart. One of the things we have found through advanced-care planning, where you are going up to patients asking, 'Have you thought about what you want in the future in terms of medical treatment if you were to become very sick? Who would make decisions for you?'. I am saying very briefly what normally takes about 15-20 minutes to discuss.

CHAIR - Lisa is doing that in Hobart, is she?

Dr SILVESTER - Lisa has been very supportive as the Public Guardian, but there has previously been a project officer employed to do advanced-care planning at the Royal Hobart Hospital.

CHAIR - And they're not being employed at the moment?

Dr SILVESTER - No. In each State and Territory, after the Federal Government provided seed funding to run it for 12 months, the expectation was that in each State and Territory the State Government would then carry that on. That has been carried on in New South Wales, Victoria, ACT, South Australia and the Northern Territory. We are still working with Western Australia and Queensland.

CHAIR - What's the cost of that?

Dr SILVESTER - It is about $130 000 a year because you are employing a project officer, who is usually a nurse; you are employing a bit of admin support for that project officer about two days a week; and you are employing a nominated medical specialist in the hospital, who does it one day a week. So lumping all that together, it costs about $130 000 a year. We were very sorry that it stopped in Tasmania. The Royal Hobart Hospital didn't get any funding from your Department of Health and Human Services. They said that it wasn't something they could continue to fund from within their own resources.

CHAIR - They'd be arguing that it's a matter of options; the money is tight and would be better spent elsewhere. Is that an arguable case or, alternatively, have you seen a drop off in donations in Tasmania because there's not this person available?

Dr SILVESTER - I don't think you can link it directly to the organ donation. What we have seen with advanced-care planning is that it improves quality of care. If you want to look at it from a cost perspective, it is justifiable -

CHAIR - Governments do, as you know.

Dr SILVESTER - in having a few advanced-care planning discussions you reduce the number of people who go to ICU. Because they never wanted to go to ICU, they wanted to stay at home and be allowed to die at home or if they came to hospital to be treated with palliative care then, again, it very rapidly pays for itself and we have certainly shown that here.

I am only mentioning that because I know that, as part of doing advanced-care planning, one of the questions that can come up is that if you were to have a sudden serious illness affecting your brain would you be supportive of organ donation and, if that is the case, you will raise the number of potential donors who are signed up.

CHAIR - You are obviously good at speaking with families when the question has to be put to them. How do you go about that?

Dr SILVESTER - You go about it by first establishing a good rapport with the family and that is not just by saying 'hello' to them now, but by having had meetings with them right from the beginning, when the patient was admitted to the ICU. You sit down and talk to them about the circumstances, express your condolences about how sick the person is and keep them informed about the patient's progress - either stability or deterioration. If I sat down with them yesterday and today, then if I then sit down with them tomorrow I can tell them that the situation is worse, the pressure inside the brain has continued to swell, we believe that the blood flow is now being affected and that may well be that your loved one's brain is progressing to the point of dying. Then I explain to them what brain death is all about and how we test for it. I invite them to come into the bedside and witness the test I am doing so it really sinks in for them and they see their family member is not breathing when you take them off the machine, that the pupils are not responding when you shine the torch in the eye, that they are not coughing when you do the suctioning down the tube, then it really sinks into them that their family member is not going to survive.

When I then do the final set of tests and I go and sit down with them and the rest of the family I say I am sorry to inform you that your family member has died because their brain has died and then explain that in detail. Then through the previous communication with me, and with me doing that in a caring and professional and compassionate way, they all have confidence in what I have to say. As much as they do not want to hear it, they trust the information I am giving them and then once I can see that they have come to terms with the fact that their family member has died, they might say to me, 'Bill, where do we go from here?' I say, 'Well, we have two choices. The first choice is that you come in and spend time at the bedside, you contact other family members who want to come in and say their goodbyes, you let us know if you would like a priest to come in and have a prayer at the bedside, inform us as to what you want and then you let us know when you are ready and we will take away the machines because your family member has died and all we are doing is keeping the body connected up to the breathing machine.'

So I explain all that to them and give them time to absorb all that and then I say, 'The other option of what we do from here really depends on what your views are or what your partner's views would have been about organ donation.' I usually pause at that moment so it sinks in what I am talking about and then I say, 'Would you like me to explain what I am talking about? Almost invariably they say, 'Yes, please tell us', which is a very brave thing for them to do because they are in terrible circumstances, having just lost a family member.

So I explain that if we proceed with this we would get a coordinator involved, they would come in and we would see which of your family member's organs could possibly go to help other people who are dying from heart disease or liver disease or needing a transplant. I explain the machinations of what that entails and the fact that we need to do some blood tests and contact the surgeons. I tell them that if the family supports that, the coordinator would come and spend some time talking to them, fully explaining it and getting their consent. It takes about six to 12 hours and then they would coordinate having the surgeons to fly in, the family member's body would be taken through to the operating theatre, they would do the operation in a very careful, respectful way under sterile conditions, just like they do in a normal operation. Once the organs are removed those surgeons take their planes and their organs and they fly back to Melbourne or Sydney or Brisbane wherever the liver, the heart, the lungs or the kidneys are going. They then transplant them, and in the meantime once the wound is closed and everything has been done in a respectful way, the family then have an opportunity to see their family member again, which they usually avail themselves of. That's a quick summary of what obviously takes longer to discuss.

Mrs RATTRAY-WAGNER - Would you approach a family before you assessed a patient, or the person who could potentially be a donor? Would you have some sort of assessment beforehand? What if there weren't any organs that were suitable?

Dr SILVESTER - We would always assess in two ways. Firstly, if they are a realistic potential donor and, secondly, whether the organs are realistically able to be used. So if I said this is a person who is 70, then I know that the heart and the lungs can't be used. They may already have damage to their kidneys from whatever, and so we can't use the kidneys, but it may well be that the liver can be used. So if just the liver can be used and the corneas - the front surface of the eye where the contact lens sits - can be used, then we will still approach that family.

The intensive care specialists would inform them that, 'Yes, organ donation is possible by your family member. Unfortunately it's only the liver, but that liver could still go to help someone else who's dying from liver disease'. In terms of the assessment of a potential donor, we are obviously assessing whether this person is realistically able to progress through to brain death. If that's the case then we would put it to the family in those circumstances, saying, 'Right now your family member's brain hasn't died, but we can see that the pressure is continuing to rise inexorably. We believe it will progress to brain death in the next 12 hours, so that's what we're talking about'.

Or we could be having the conversation in a case where we have seen it already progress to brain death, or it may well be a case where the family are already coming to us and saying, 'Dad would never have wanted it to be like this, we want you to stop treatment or withdraw treatment'. In those circumstances we would then say to them, 'That's fine. The only reason why we've continued treatment at this stage is if your family member would have wanted to be a donor'.

We have the two options: we could support them through to becoming brain dead which may take the next 24 hours, or if you don't want to continue at that stage we could see that they could become what we call a donation after cardiac death donor. That's where we withdraw treatment in the ICU. We wait until the heart has stopped and then we proceed with donation, as compared to brain dead donation where death is declared because their brain has died and then we are able to take the person's body through to the operating theatre while the heart is still beating, while the lungs are still being ventilated and do all the dissection which takes about an hour and a half to two hours. Then proceed with stopping the heart and removing the organs.

Donation after cardiac death is certainly a possibility, there is such a case occurring in a Victorian hospital right now. We have done four donors after cardiac death at the Austin in the last 12 months; in fact, we are leading Australia in that way. Why are we interested in donation after cardiac death? Firstly, we know it raises the donation rate; secondly, we have seen that those organs are certainly very viable and useful for recipients; and, thirdly, I can't count the number of times I have had families contact me directly or through the other hospital who have then come to me for advice saying, 'This tragic situation where our family member is going to die, they are not progressing to brain death. Isn't donation possible?'

It is almost like a double whammy for the families because not only are they losing a family member, but also the possibility of donation that they knew their family member was committed to is also not possible. Conversely, when they can see this person is going to die but donation is going to happen, they say things like, 'This is the only positive thing that's coming out of this tragedy', or 'It gives some meaning to their death', or 'We feel so pleased that in their death this is going to help someone else'. Those sorts of recurring things that you hear which I'm sure you have even seen on the Gift.

CHAIR - That's beaut, thanks, William. That's great.

Mr HARRISS - One area that is more sensitive than the rest, I suppose, is how you discuss with the surviving family members the dignity of the recovery of organs. We have had a funeral director who has given us evidence at one of our hearings. Is that a concern when you are meeting with family members, that they have this great fear that all their bits are going to be removed and then there is going to be a depressed chest when they are viewing it before the funeral?

Dr SILVESTER - It is not particularly frequent but it is frequent enough that we raise it. We do not wait for them to raise it. When I am the intensivist talking to them about it or the coordinator is talking to them about it, I will say things like, 'Doing this will not impede an open-casket funeral. There will not be any visible evidence of having had the donation, apart from a scar. It is sewn up in a very careful way just as if it was a normal operation. There is a bandage put across it just as with a normal operation and, as I say, it does not impede an open-casket funeral. I explain that the surgeons and the theatre staff are very grateful for the unconditional donation from the family. They are very respectful about the way they handle it. The circumstances in the theatre are not handled in an inappropriate jovial or disrespectful way and I just reassure them that those surgeons and nurses in there are handling it in the same way that they would want it to be handled if it was one of their family members.

I am not sure if you have heard accounts from other people but certainly from all my experience, and I have been running this show for a number of years now, we are very careful about it and indeed if we hear of any people who are inappropriate, we jump on it very quickly and indicate to them that this is something to be taken very seriously and if they are not prepared to then they should move on. We do not want them to be part of it.

Mr HARRISS - We have not heard evidence from other people along those lines at all, just from the funeral director who indicated that his experience was that people were fearful of the dignity with which the organs are recovered.

CHAIR - Bill, your aim obviously is to, in the best possible way, increase the number of donors. You believe that there is every opportunity of increasing those 10 as it now stands within Australia of a million population to 18 to 20?

Dr SILVESTER - Yes.

CHAIR - And the matters that you have spoken to us about are ways that you are going about doing that, is that correct?

Dr SILVESTER - Correct. You are probably aware of the ministerial task force - have you heard of the National Ministerial Task Force? I have certainly been working closely with them and in fact one of the pleasing things is that it looks as though one of their strongest recommendations is that the audit process that we set up in Victoria, which is running in a number of places, be unified across Australia and be standardised so that it runs the way we recommend it be run. We are working closely now with ANZICS - the Australia New Zealand Intensive Care Society - to set that up. It looks as though that recommendation is going to be followed through by the Federal Government so that would mean that Tasmania would be included then as well but it would still need the work to be done by an auditor and in every place we have recommended, this is how we would see that it would run seamlessly and in a collaborative way.

CHAIR - Have we missed anything today in matters that you want to raise with us?

Dr SILVESTER - No. I think I said I would send you those two publications; I would send you a copy of our most recent report so you get a sense of how that audit process runs and I said I would send you a copy of the questions that are covered in the audit.

CHAIR - Yes.

Dr SILVESTER - And, if you like, I can also send you some information about Medical Adapt.

CHAIR - Yes, please.

Dr SILVESTER - I will just write that down and then I can make sure I tick those off.

CHAIR - That is great, and we will send you a copy of the report

Dr SILVESTER - Great.

CHAIR - Thank you very much for your generous time. Obviously you are busy and thanks for taking an hour out of your day to speak with us this morning.

Dr SILVESTER - When do you foresee your report?

CHAIR - I would have thought maybe February/March. We have already noted down what we think should be there. There will be recommendations made. Whether the Government takes them up or not, we do not know. But certainly we, as members of the upper House within Tasmania, can keep pressuring to ensure that if they do not take them up, they have to have good reasons and we will keep asking those questions.

Dr SILVESTER - Have you had an opportunity to interview Tony Bell?

CHAIR - Not yet.

Dr SILVESTER - I strongly recommend it. He would be a good person to speak to. We did previously have a coordinator here in Victoria who is now based in Hobart. That person had approached us at one stage a couple of years ago to ask us whether there was any progress in getting funding.

CHAIR - What was his name?

Dr SILVESTER - I am trying to remember her name. If you want me to look into that, I can find out the name of that person, if that is helpful. If it is not helpful then that is fine.

CHAIR - It will be thank you because we will track Tony Bell down. We are probably looking at around March/April because there is not going to be much done over Christmas. Thank you very much for your time.

Dr SILVESTER - You are welcome.

DISCUSSION WITH **Dr MARK BUCKLAND**, AUSTRALIA AND NEW ZEALAND COLLEGE OF ANAESTHETISTS.

CHAIR (Mr Wilkinson) - Thanks for coming along. As you are probably aware, we are a select committee of the upper House in Tasmania looking into organ donation and how we can improve Tasmania's efforts in relation to organ donation. We have taken evidence over a few days from a number of different people and hopefully we can come back with some worthwhile recommendations at the end of it which will probably be early in the new year, next year.

Have you seen our terms of reference?

Dr BUCKLAND - No, I have not looked at them for a while.

CHAIR - What we are really looking at is improving Tasmania's organ donation record. As far as intention is concerned, Tasmania seems to be doing fairly well. About a third of the population are registered with the intention but the great majority of those have registered incorrectly because they did it through the old licence system. They think they are registered but they are not because there has to be the Medicare form which is a form that you can pick up from Medicare which is the only place you can get it. There are about 20 000 of those that have been signed. But, all up, 150 000 have ticked the box on the licence and they think they are registered. So we have to retrieve those 150 000 and make sure that the intention is done properly.

Dr BUCKLAND - Does that not count, if you express to your family and you indicate on your licence that you are interested in it and you are willing?

CHAIR - No, that is the way it is taken in Tasmania at the moment.

Dr BUCKLAND - Here, my understanding is - and I may be wrong because I am coming at this from a slightly different angle to your previously speaker - that you are able to approach more freely if you know that the person is willing and the simplest way I thought was on the licence.

CHAIR - It is obviously an intention but it is not the intention that is as wholesome, let us say, as the form you fill out which is this one and we can only pick that one up -

Dr BUCKLAND - But even if you do that you still have to get the consent. Simplistically, I would have thought they were interchangeable, but obviously it is not a binding contract. If you make your wishes known and you indicate it on your licence or you fill out that, it is all part of the same spectrum, isn't it?

CHAIR - I suppose it gets back - and I do not know; it is one thing that we have to look at - to the hospitals. If they are aware that this person is on the register then it is far easier for that person to speak with the family. With the licence ones, as I understand, they are not properly registered or not in the same way registered as they are and therefore there might not be that information passed on to the hospitals if those people are in a situation where they are able to donate their organs. That is my thinking of it. I do not know whether that is the correct or not.

Dr BUCKLAND - It strikes me that given that the significant number of our potential donors come from trauma, motor vehicle accidents et cetera, their licences are all part of it and that is part of the bundling and they extract it from wherever they are extracted. I guess that is one of the first places that I would have looked.

I know in our institutional practices, I am from the Alfred, that if there is an indication that the potential donor was willing and/or the family are aware of that then that is an easy avenue of initiating the process. But I may stand corrected on that. As I said, it strikes me as being part of the same thing.

CHAIR - Sure.

I think what Tasmania has to do is to endeavour to find out who those 150 000 are, and there are obviously problems surrounding that, and then obviously send one of these forms out to them if they can or alternatively send out these forms with a licence or refer to the electoral roll or through some other method to have those people sign up in a way which the Tasmanians feel more comfortable with.

Dr BUCKLAND - Sure.

Ms MCLEOD - Giving them more detail and making people discussion it with their families.

CHAIR - That is the general background. How can we do it in the best way possible?

Dr BUCKLAND - I don't know.

CHAIR - Thanks very much for your evidence.

Laughter.

Dr BUCKLAND - Apart from doing what the European countries do and having to have an opt out thing - and that is a big process and it is going to take a long time for any government to get organised with - the notion would be to make intensive cares and parent medical units of potential donors aware of the responsibility and the issue. Certainly if everyone who is willing carries one of those it might make it a bit easier but the whole issue is getting potential donors into the process to be considered and I think that is the problem.

You often hear of patients who could have been in intensive care circumstances because that is where they are all going to be. It does not happen because someone has not thought about it or the practitioners or the staff involved in their care have an ideological issue, which is less of a problem but it has been in the past. Getting around that is possibly one of the things. I know, for example, in Spain, which has the highest donor rate in the Western world, I think they have an opt-out policy like France but each hospital that has any sort of sized intensive care unit has someone in that institution responsible for keeping an eye on potential donors, independent of the treating unit so there is no conflict and all that sort of stuff.

CHAIR - Are you saying, Mark, that you mainly come in after the decision has been made?

Dr BUCKLAND - Absolutely. I am an anaesthetist by craft and trade and I am not involved in intensive care - I used to be in the past - but we would be charged with provision of care of the donor during the procurement procedure and/or care of the recipients during the implantation procedure.

CHAIR - Because some of the evidence that we have had is that there is a concern about the dignity when it is done, that people are not properly informed and that it is not the same procedure as what would happen if the person were alive.

Dr BUCKLAND - I could only try to aggressively dispel that.

CHAIR - Can you go through the process, so that we have it on *Hansard* and we can put it in the report maybe.

Dr BUCKLAND - Okay. What invariably happens, one of us will be notified by our donor coordinators or someone from the Victorian-wide people, depending on which role we are playing. If we are in charge of the procurement process and care of the donor during that time we will be asked by the Victorian donor coordinators when we can be available and, in liaison with our operating theatre staff, when is it suitable. Then when the paper work is all sorted and everything is done and dusted, the donor is transferred to the operating theatre and the standard care that would be given to any patient coming from intensive care is accorded. The emphasis is slightly different because once the decision has been made that the person is deceased the focus shifts to providing care of the organs with a view to the future, the holders of the organs as opposed to treating them optimally to optimise outcome if they were to survive. Once it is deemed they are unsurvivable and they are deceased then the emphasis slightly changes.

From our point of view, they come into the operating theatre, they are connected to the ventilator and all the monitoring is attached, the intravenous and monitoring lines are connected and attended and they are prepped and draped in a normal manner and the various procurement surgical teams will come in and do their business. It usually starts with the abdominal organ group because they have the greater amount of pre-preparation and dissection to go through and that is usually the liver surgeons and they invariably take livers and kidneys together; then the cardiotheracic people will come in and that is the other area that we are involved in. If we travel with our procurement team, one of us will go particularly if lungs are involved and help the local anaesthetic providers to do everything right.

Once they get to a certain point the aorta, the main vessel coming out of the heart, is cross-clamped and a preservative solution is put in to stop the heart and the heart is preserved. Once the heart has stopped and the lungs are infused with a preserving fluid - and they are gently ventilated to optimise the distribution of that fluid in the lung vessels - then the heart and lung team take those organs out and then the liver et cetera team do their bit. The time pressures are more critical on the heart, particularly. The longer it is out of the body and deprived of oxygen supply, the worse it is. It is the most time-pressured thing. They start infusing their preservative solutions at the same time, but then they take their bits out. Once it is all done, the donor is sewn up and laid out in the normal way - just as if someone had died inadvertently on the operating table -

CHAIR - My uneducated medical mind would say, as an anaesthetist for the donor, why are you there?

Dr BUCKLAND - Yes, you are right, and that is a common thought. We still have to make sure that the air is going in and out of the lungs, that the blood pressure and temperature is maintained and that the wee is coming out. We will give drugs that maybe anaesthetic drugs but in essence we give drugs to optimise the conditions for the surgeons procuring the organs. In this circumstance in any anaesthetic drugs that are given are just to control blood pressure. We give muscle relaxants to facilitate the surgical exposure. Even though the brain is dead, there are still muscle reflexes et cetera that are intact. If they incise someone who's brain dead but has those reflexes intact, they're not paralysed, but with the muscle relaxant drug they'll twitch and it is quite disconcerting for people who think, 'Oh my God, they're alive', but in actual fact they're not. That is why we are there. Of the group that are around, we are the best qualified to do that. It is the transition intensive care, the same style but a slightly different thing.

It is done with dignity and respect and all the care is afforded that we would give to someone who was having an operation or any major surgery. If you've not seen it before, it is a fairly confronting process because at the end of it everything is removed more or less. Some junior trainees sometimes find it a bit of a shock the first time but, looking forward and looking at the benefit, they come to accept that.

CHAIR - So people shouldn't feel as though the body is dealt with in any other way other than with dignity, respect and the knowledge that this person is offering -

Dr BUCKLAND - And gratitude for the enormous gift that they make. That is the overwhelming feeling. I have been in it for a very long time and you can get cynical but often you look at the history of the donor and what's happened and invariably it touches you at different times. It might be their age or you might associate them with someone you know, or 'My God, they're my age' or 'They're the same age as my children'. People are very aware of that. It is all very sobering but everyone is very grateful of the gift and the benefit it is going to attribute to upward of six or seven other people. I think that is the overwhelming response that people have.

CHAIR - As an anaesthetist, do you do the work also on the patient?

Dr BUCKLAND - Which patient?

CHAIR - The recipient.

Dr BUCKLAND - Yes, we will be involved in that. If I am involved in the donor procedure, we try to separate being involved in that and -

CHAIR - Why's that?

Dr BUCKLAND - It just makes it cleaner. Often it is just a timing issue. Occasionally we'll have to do it because we are short of staff because people are on leave et cetera. If the Alfred heart and lung transplant unit gets offered a set of organs, it could mean four operations. There is the procurement procedure - and it may be local or it may be interstate, Tasmania or anywhere else; someone doing a heart transplant and maybe either a double one or two single lung transplants. So you need to mobilise four anaesthetists to do that, so there is always two of us available and on weekends a third. You might have to double up a little bit if things go like that. It is just cleaner, I think.

CHAIR - The other reason I ask is that obviously, if you are speaking to a recipient after the recipient has received the organs, are you able to give us some assistance or good quotes as to what they say to you and how grateful they are?

Dr BUCKLAND - It is often in the middle of the night, and it is all a bit of a rush because of timing, and stuff, but they are just grateful and a lot of them have been on the waiting list for a long time. They are as anxious as all get out, as you can imagine, but they are very relieved, very grateful. Afterwards, I think they are just so happy. Whilst I haven't had the direct thank you for the gift, sort of thing, to me, everyone in the system knows that that is the case. They will express it to other people that spend more time with them.

After we have done with our part of it, we hand them over to intensive care, and are involved intermittently in looking after their pain management, depending on what sort of procedure they have had. Heaven forbid they have to come back to theatre for any other procedures as a result of the initial thing, but predominantly they become cared for by the transplant physicians and nursing staff, and so on. They are the ones, because they have woken up and they are clear of all the business, they get all those sorts of comments predominantly. It is a very challenging, very rewarding game.

CHAIR - How long have you been involved?

Dr BUCKLAND - Since I was a boy, basically, because we have always had organ donations since I started my anaesthetics and intensive care time, so that's a long time. Since the Alfred started its transplant program I've been involved. That was in1989, so it's 18 years. It's a long time.

CHAIR - That's helpful, thanks.

Dr BUCKLAND - It is hard to do the public awareness battle. I was just reading a thing about David Hookes, and things like that improve things for a bit and it keeps it in the public mind. If people were to receive one of those with their licence renewal, or something like that, it might motivate them to do something about it. The other things are to avoid any negative press - you are in politics, you know what the press are like. We have just had months of them harping and carrying on. If they think there's something untoward happening, they love it. We spend our lives trying to avoid being misconstrued, and that's one of the problems. It only takes someone to feel slightly uncomfortable and miffed, and that can snowball into a lot of negative press.

Victoria has been troubled over the years with accusations of wrong things happening, and all that sort of stuff, but in essence I think our process is as robust as it can be, and we are continually trying to make it clearer, cleaner and transparent. But it just takes someone to get a little bit off-line and that will snowball into bad publicity and accusations. Even if they are unfounded, that can send a shudder of negativity through the whole process, and that will knock back or reduce donation rates for the next little time.

There is an ethicist at St Vincents called Tonti Filippini. I don't know if you're going to interview him or not, but he has renal failure and should have a transplant, but he refuses to have it. He is a bit of an anti-transplant person who is involved in ethics and all of that sort of stuff. In the 1990s he would be someone that the press would go to, to make a comment and when he did so, everyone would groan and say, 'Oh, my God, he said that! That is going to set us back a bit.' So I guess avoiding that sort of stuff is another good thing.

CHAIR - Did you want that in camera?

Dr BUCKLAND - No.

CHAIR - Have we missed anything at all do you think? Or did you want to say anything to us that you have not had the opportunity to say?

Dr BUCKLAND - I do not necessarily think so. I think it is a big club in Australia and I think there is a good spirit of cooperation. We are somewhat unencumbered by the organ distribution processes that they have in the United States. I think everyone works flat out to try to make it work and optimise benefit for everybody and that is a good thing. Really the only negative thing is the donor rate - we are, as a country, I think we have one of the lowest per head of population -

CHAIR - Donor rates?

Dr BUCKLAND - Yes and it is well acknowledged. I am not quite sure why that is.

CHAIR - We are under the rates of other developed countries?

Dr BUCKLAND - Absolutely. We are a long way behind the United Kingdom and the United States and equivalent places. As I said, the Europeans have a much higher rate. I do not quite know how that has evolved.

CHAIR - Some argue it is because our health system is good and our legislation to stop people from riding bikes without helmets, et cetera, seems to help!

Dr BUCKLAND - I think that helps a bit, but I think Europeans have a legislated helmet process. The United States does not, although it is changing.

CHAIR - The United States has the gun lobby!

Dr BUCKLAND - Yes, they have an alternative source of injury. But I think we have had in the past some new resurgence, for example, of those who have been against it and that means that your donor rate at a particular centre, which could potentially offer a lot to the pool, is impaired. But that has changed and it has evolved.

CHAIR - Has it changed to the extent where hospitals are now finding it more difficult to meet budgets, especially your public hospitals? There is not a lot of money out there to do the things they would like to do. Therefore, as you say, your neurosurgeons might think, we need more money in the neurosurgical area as opposed to the retrieval area?

Dr BUCKLAND - No, I do not think that is the case. That was an ideological set that some neurosurgeons had in my institution in the early 1980s. I think it is an intensive care phenomenon and the neurosurgeon will treat as much as possible and they will make the call that we have come to the end of the road here and there is nothing else to offer. If they suffer a brain death or they come to be considered for donation after cardiac death, which we are just starting to use as a pathway, then I do not think it is a budget issue, to be honest.

CHAIR - Mark, thank you very much for giving up your time and coming to speak with us.

Dr BUCKLAND - I am sorry I do not have the golden bullet answer.

CHAIR - If everybody did, it would be fixed like that wouldn't it?

Dr BUCKLAND - It would. Good luck with that.

CHAIR - Thanks for your time and thanks for your generosity.

<u>THE WITNESS WITHDREW.</u>

DISCUSSION WITH **Mr ASHLEY ECCLES**, SENIOR PROGRAM ADVISER, BLOOD AND PHARMACEUTICAL PROGRAMS, VICTORIAN HEALTH DEPARTMENT.

CHAIR (Mr Wilkinson) - Ashley, you know what we are here for. We have a select committee on organ donation. Originally we heard that Tasmania wasn't faring too well and we are looking into why that was so and whether there are any better ways. I understand you have read the terms of reference. We are trying to get our system as good, if not better, than most and see what we can do to improve the organ donation program in Tasmania. I will just open it up to you to say what you want and then we will ask some questions.

Mr ECCLES - Sure. At the risk of wanting to repeat a lot of what you have heard before, you probably already have heard a lot of what I am going to say anyway. It is timely that Tasmania is in the state it is in at the moment because it seems that around the nation people are beginning to wake up to the idea of wanting to do something about increasing the rates of organ donation. Western Australia has been making quite a few noises and putting up quite a few proposals over the last 18 months to two years as to how they think can make things better - mainly through community awareness campaigns. One in particular is called Project Ford, which the Tasmanian minister would be very aware of because it was presented to ministers some time ago for consideration as a national initiative.

South Australia, as you will become even more aware when you see them tomorrow, is also very much involved in trying to make some inroads at the moment, the Health minister having recently been to Spain and met with the organisation that runs the Spanish model. South Australia has some interesting initiatives which appear to be making a difference to the donor rate per million of population. Queensland, on the other hand, have had some of those initiatives in place as well and they have not seen their donor rates change - certainly not upwards; in fact, I think they have dipped down this year. So it remains to be seen what South Australia may be doing, or what is unique about that State - that is probably a better way of putting it - that is having a positive impact on their organ donation rates.

Tasmania is the next cab off the rank by the sound of things. It would be interesting to know some of the background as to how this committee came into being.

CHAIR - It was a proposal put forward in the upper House as a result of an idea to have a look at organ donation after realising that, per head of population, we were not doing as well as we thought. When we looked at it, we found that the intentions on licences was a good result - 174-odd thousand. Some 24 000 have signed the appropriate document through Medicare, therefore there is 150 000 out there who have not done what they are now supposed to do - sign that Medicare form. A third of the population has said they want to be involved. We have said that if that is the case, why haven't they been involved? What is happening? That is basically the question behind the formation of this committee.

Mr ECCLES - And that question isn't unique to Tasmania. I know it is the same question that bureaucrats and stakeholders around the nation have been asking themselves over the past 12 months with the National Clinical Taskforce on Organ Donation, which Neil may have mentioned this morning. He has taken over form Patrick Coghlan as the representative for the State agencies on that committee at the moment, and I have had the good fortune to sit on it as the jurisdictional representative over the past 12 months.

I do not want to backtrack over stuff you already know, so please stop me if I am. The picture is quite a large one and goes back some time. People have probably spoken to you about the origins of the whole organ donation phenomenon in the nation and how it came out of transplantation initially. Transplanters initially had to get organs from somewhere and there was no such thing as an organ donation agency, or the phenomenon of organised organ donation in the nation. Over time, as the idea of transplantation began to catch on it became ethically questionable, for want of a better term, whether the person who intended to use the live should be out there trying to find it. It was decided that that probably wasn't the best message for the Australian public to receive -and rightly so. There was a real opportunity for the perception of a conflict of interest there. With the best will in the world, governments and stakeholders decided to try to separate the functions - to actually come up with an organ donation sector whose primary role was to get the organs for transplantation and then hand them over to the transplanters. Since then, that is what we have been endeavouring to run nationally. There have been three incarnations of a national organisation that has had responsibility in some way, shape or form for moving that forward and I will not dwell on that any longer except to say that, as you would be fully aware, the third and final incarnation was found to be ineffective and will be more than likely no longer functioning by the end of this financial year.

CHAIR - What's that?

Mr ECCLES - The Australians Donate - that is in camera because you are meeting Australians Donate tomorrow. However, certainly the feeling out there in the sector is that Australians Donate have not met the objectives that were set out for them for a raft of reasons some of which AD is seen to be responsible for, some they could not be held responsible for. It is the ones they could not be held responsible for that are the big challenge.

At the same time as this process has been moving forward and the review has now found that we need a new world and there will be a new world announced by ministers, hopefully, in early March. The Federal Health minister, who has a very close relationship with Australians Donate, decided that he would do what he could do from a national point of view in order to improve things 18 months ago and he initiated a national organ and tissue donation reform agenda and announced in the Budget, as I am sure you are fully aware, $28 million over four years to be used. We are in early days as far as that is concerned, even though we are 18 months down the track.

The most significant initiative that has been put in place and is reaping rewards is the National Clinical Taskforce. The National Clinical Taskforce has representatives from around the nation from all of the groups of stakeholders fundamentally brought together to be a think-tank - and I am telling you this for a reason incidentally, I am not telling it to you just for a historical point of view. The National Clinical Taskforce reported to the then Health minister in June of this year with an interim report making 15 recommendations for change. I am not sure whether you have seen the report.

The taskforce is due to finish at the end of December and we are in the process of drafting the final report now. Out of that final report will come a blueprint for change, the best blueprint that I can anticipate for change that has been put up by the key stakeholders in this sector from around the nation representing their various interest groups. I look forward to it with great anticipation. I see that that work plan will more than likely guide us through the next three years of the work that we need to do as a nation. You will decide what to do with the comments that I make today, of course, that is your role. I am a great one for centralist thinking. I do not see yet - and I have been in my role for two years and before that I worked for the Red Cross - with the exception of whatever it is that is going on in South Australia and until we know what that is I have to put that to one side, any positive impact upon organ donation rates in the nation through jurisdictions going it alone for want of a better term and then saying, 'I have a great idea, I want you all to adopt it.' You all know what generally happens when that goes on: people tend to think that they might look elsewhere.

The recommendations that will come out of the National Clinical Taskforce and the recommendations for structural change that will come out of the senior officials committee, which is going to report to ARMAC on the new structure of the sector, will, I feel, provide a very good skeleton for us to move forward as nation.

The senior officials committee is pulling together the recommendations for the sort of organisational structure that the sector needs to move forward post Australians Donate. Their final paper is on its way to the ARMAC secretariat now to be considered by ministers when they meet next, be that next Thursday or, more than likely, early January.

In that paper there is a recommendation for how the work of the National Clinical Taskforce can be picked up and moved forward with in a cohesive, united national way with representation from all of the key stakeholders that matter, which is not something that has happened yet in the history of organ donation, despite what you may hear, particularly tomorrow. We haven't had everybody in the boat before and I think that is pivotal to whatever it is you're going to try to do in Tasmania. There are a lot of brilliant people involved in the both the organ and transplantation sectors who have wonderful ideas but they have not necessarily been given the appropriate forum within which to express their opinions and a forum that then means that those opinions are not just opinion but can be picked up, discussed and become policy. The shape of the new world that is coming post-March I think will make a big difference to giving all of those people the appropriate drivers to move things forward.

The reason I say that is that whatever initiatives you come up with, I think they need to be considered within the national context. I think our problem has been that we have been all trying to do our best, which is only human nature, but not necessarily doing it together. That would be okay if the initiative we were working on was a jurisdictionally-specific initiative but it is not; it is a national process. The best parallel that I can draw is the process that we now have in place with the management of our national blood supply. I'm not sure how familiar you are with that.

CHAIR - It would seem, Ashley, that what we have said is that we wouldn't want to be doing anything that would be contrary to what the national picture would be. We thought that was going to come out in December and then we thought we could tailor this to be consistent with that.

Mr ECCLES - That would work.

CHAIR - But we understand from what you are saying that it won't come out in December but it will now be March.

Mr ECCLES - In December the report will go to the minister but of course we have changed governments now so we have to get a new minister. The national clinical task force is still planning to hand its report down on time, so it will get to the minister at the end of December, as originally scheduled. When do you have to present your findings?

CHAIR - We don't, there's no time limit.

Mr ECCLES - That is highly valuable then. If I am in Hobart next Thursday the other piece will fall into place as well, which is the public revelation of the senior officials committee's opinions on how we should move forward from a structural point of view. Once those two things are in the public domain, I think it will help then for all of the jurisdictional initiatives that are coming up to then see how they will fit into and enhance that picture. Does that make sense?

CHAIR - Yes, it does. In relation to Tasmania then, have you any knowledge as to why the intentions haven't been transferred across to actual donations?

Mr ECCLES - The little that I know about the process of organ donation in Tasmania would say to me, 'Let's put the public aside'. I don't think you have a problem with the public; I think the public are becoming progressively more aware of the desire to do it. The problems with registration that you have just described and I have been through will get sorted in this new structure. Medicare Australia has been given notice, writ large upon the wall, that, as you will know from the report in June, one of the major things that has already come out of the national clinical task force is that the process of getting onto the Australian Organ Donor Register has to be streamlined so that people are not mucking around. You have had three letters now, Tania, which is ridiculous. You are going to give up.

Some States - and it seems that Tasmania is one of them - still have the driver's licence process. From a central point of view, we're not really concerned about what happens out there for the public. If you want to have a driver's licence process in Tasmania, that is all well and good. What has to happen behind the scenes is that the Tasmanian Government needs to ensure that that information gets from the road traffic authority in Tasmania dumped into AODR. The public may well be quite used to the licence idea in Tasmania. We dumped it here quite a few years ago because we went with all having one way in. One way in has not necessarily proven to be that successful. As long as all the punter has to do is write it down once, stuff it in a hole, press enter, we should be pretty right but what happens behind the scenes is more the challenge.

Tasmania, for example, does not have an organ donation agency and has not really needed one up until now because the number of donations has been quite few. I think you only have about four per annum or something like that.

CHAIR - Yes.

Mr ECCLES - Therefore there has been the hands-across-the-sea arrangement with Victoria, as happens, for example, with ARCBS and blood as well. Maybe some form of State-based agency in Tasmania with an education arm, the same way there is an education arm here at LifeGift in Victoria, may help, and with having someone in Tasmania, from the horse's mouth, getting out around the State and providing that information to the community directly. I cannot brag; Victoria' donation rates are not brilliant either per head of population. They are better than New South Wales and Queensland but they are not as good as South Australia's or Western Australia's either.

Perhaps the other thing that I am beginning to think about more and more and it is still floating around in my mind, South Australia have the medical donor coordinator model, for want of a better term, which is an identified individual within hospitals who has responsibility for ensuring that any potential donations, as much as is practicable, are not missed and facilitating the process. Queensland has a couple of them as well. If they are having a positive effect upon donation rates, one would expect that there should be the same upward trend and there is not.

I would argue that South Australia are doing so well because their network is so small and their population is so concentrated they are able to speak to each other much more easily. All the major hospitals in South Australia are in Adelaide. You have Launceston up the other side of the country. The ability for them perhaps to have medical donor coordinators or a designated officer who has a role within their normal role of being a champion would make a huge difference.

The organ donor collaborative is happening in Tasmania. Have you spoken to who was involved in the collaborative in Tasmania?

CHAIR - David Boadle.

Mr ECCLES - He was running it from way up high. Did you manage to talk to anybody on the ground with regard to that? Queensland was the only jurisdiction that did not buy in, so the Royal Hobart should probably have had someone involved.

Mrs RATTRAY-WAGNER - Was that Tony Bell?

CHAIR - No, Tony Bell is an intensivist.

Mr ECCLES - Okay, so if the collaborative was happening at the Royal Hobart, Tony Bell ought to have known about it.

CHAIR - We have not been able to speak to him as yet.

Mr ECCLES - It would be interesting to have a chat to him because that medical donor coordinator role puts a human face on donation at the place where we are really going to make the difference, and that is in the hospital. I do not think the man in the street is going to make the difference to translation from intent into actual donations, it is going to be what we do in our hospitals at the bedside, with the family, with the clinicians involved in intensive care at the appropriate time. That is why I am beginning to, in my mind, think for Victoria that maybe we need to start looking at some sort of a model where we have that kind of a role. At the moment we have designated officers in the hospital, the same way you would in Tasmania where, in the absence of any next of kin, they are able to begin to drive a process forward.

The designated officers are also involved in the death audit that we have been carrying on in Victoria for quite some years now, looking retrospectively at whether or not we have missed any donations.

Mrs RATTRAY-WAGNER - Is this the medical review of records?

Mr ECCLES - That is correct, yes. You are not involved in that in Tasmania at the moment, I do think, are you? However, there is also an opportunity there potentially for this model if we were to build it and say, 'Okay, do you have a little mini-donor agency?' Maybe. 'Do you have a medical donor coordinator at your biggest hospital?' which is the Royal Hobart and Launceston General. They are the two biggest, aren't they?

CHAIR - Yes.

Mr ECCLES - 'Do you have a 0.2 FTE in each of those hospitals who is maybe already an existing intensive care specialist?' That would be perhaps a second option, and a third option would be, okay, then do we look at having a person again - 0.2, or whatever it would need to be - to take part in the audit (*inaudible*), and the follow-up meetings that happen with intensivists. Those meetings happen every quarter. Each of the deaths are looked at, each of the potential missed deaths are looked at and any potential actions that may be able to be taken out of that in order to move forward are looked at.

I might just add a codicil there that the National Clinical Task Force has as one of its tasks trying to identify a more real-time method of identifying potential donors without wanting to be a ghoul hanging over the bed. In Spain, medical donor coordinators have a bonus scheme - the more you find, the more money you get.

CHAIR - For the hospital?

Mr ECCLES - For the donor coordinator. You get a bonus. I can't imagine the Australian public taking that on, and I am not necessarily sure that I agree with it anyway. Those three things would, I think, in the first instance make a difference in Tasmania without a lot of expenditure or a lot of effort in the first instance. The other thing is, that would plug Tassie more really into the mainland network than it currently is, and when I say the mainland network, Tassie already has a bit of a relationship with Victoria, but most of Victoria's time is spent on Victoria, as it should be. We do need to get our rates up. If there was someone with whom Victoria could have an affiliation in Tassie, I think that would make a difference.

CHAIR - So we're looking at the donor agency, if you want to call it that, then under that you have the coordinator who drives that. Then you have your 0.2 of an FTE within the hospitals, and in your other 0.2 of an FTE -

Mr ECCLES - It could also be that same person or it could be a member of the donation agency.

CHAIR - Yes, and they would be doing the audits with the intensivists.

Mr ECCLES - Yes, and buying into our system. That system, as I say, may change and become more prospective. Tassie has been in a bit of a vacuum from the point of view of at the bedside - not the desire to donate. Let's face it, if you are an intensivist at a bedside you're not there to do organ donation, you're there to try to save life. If you are not saving life, you are trying to deliver the best end-of-life care you can.

The collaborative approach hasn't been without its difficulties in the hospitals that have been involved but they have a least started to get the clinicians speaking to one another, so that at least if there is somebody in ICU who is brain dead, there is someone floating around there now who will go, 'Ah, brain death'. Second test is done, this person may be eligible for organ donation, and the process has at least begun to happen.

It has not necessarily translated - despite what AD will tell you tomorrow - into a sustainable increase in organ donation, but I see it as probably the best outcome that the collaborative has produced thus far, because at least people are talking to each other. These suggestions that I have made for you thus far all have to do with building basic communication networks with the rest of the nation.

CHAIR - I agree with you. We were trying this morning to work out what type of framework would be best, and what you say has been pretty well the conclusion of each one.

Mr ECCLES - Good. I am glad that I'm not totally alien.

CHAIR - No, no.

Mr ECCLES - Fundamentally, the collaborative is all about getting people to do things together, which we always think we do but we don't necessarily do when we just scratch the surface. This group of protagonists is famous for having its own opinions on how things should be done, so bringing people together with the sense of moving forward is great. You will meet Gerry O'Callaghan, who is running the collaborative, in South Australia tomorrow. Have a chat to him. Ask him about how he has seen that communication change in the Intensive Care Unit and between the Intensive Care Unit and the donor agencies as a result of the collaborative.

One of the other things the National Clinical Task Force is seriously looking at because it is, again, where we see a major stumbling block, is once the idea of organ donation however it manages to get raised in the Intensive Care Unit, has been raised, who then will carry it forward and how will they carry it forward? There are a couple of serious questions that require further fleshing out there.

Within the clinical community as there is in most communities, people tend to operate according to what they think is 'best'. However, we are finding, through studies that we have done, that if you wanted to get a consent rate that was getting consistently higher, the best person to approach a family when it comes to the question of organ donation is the senior intensivist. That does not happen. So certainly we should push that recommendation from whatever angle we can.

Mrs RATTRAY-WAGNER - Do you know why it does not happen very often?

Mr ECCLES - We all use the same excuses, such as 'I am too busy'. The other one is, 'I will stand on the other side of the room and know they will not donate, I can tell by looking at them'. Also, 'it is too much effort, we are short-staffed' - all of those realities that exist in our health system that are there. But we have found that when the senior person has engaged - and this is why South Australia in the past has had such a good track record; they had a senior intensivist who was very interested - people respond better. You know yourself, if you see an expert or an expert is talking to you about something you pay more attention than you do if you have someone who is in their first year out of medical school, who is probably more terrified than you are at having to do what they have to do. That certainly made a huge difference.

I think the sooner a donor organ agency is involved in the process the better chance you stand, and this is why for Tasmania I think it would be highly valuable to have someone on the ground there as opposed to having to whiz them across Bass Strait. The sooner you can get an experienced person in there, then it takes the pressure off the intensive care staff and they can get on doing their real job because you now have somebody in there who is going to run the show for you. It makes a big difference.

I would also suggest, and I would be really interested to see how it works in Hobart and Launceston, that the intensivists check this register that we spend all of our time getting people to put their names on because, again, we have a very idiosyncratic approach to the register. I will not look at the register because I do not want it to taint my decision before I go to speak to someone. I will not look at the register because I know better than the register. There are a whole raft of reasons, despite the fact the ARMAC put out a public communique and agreed in 2005 that before any potential organ donor is approached an intensivist much first check the register so that they know what it is they are doing when they approach the family. They are not approaching the family to ask permission, they are approaching the family with the knowledge of what is on the register to consider or to give feedback to them that the person who was on the register may have changed their mind. So you are ratifying the information that I, as an individual, signed and gave my consent to doing in my lifetime; you are actually ratifying that decision. Unfortunately the language is still all around, 'I am going to ask the family if they will donate the organs', and that is not what they are supposed to be doing. How do you fix that? Again, I think you need people on the ground reiterating the message over and over.

CHAIR - It is probably a bit of both, do you think, Ashley. In other words, they can check the register and if the register says yes, their intension is to donate, then that is a good starting point to speak with the family. If there is nothing there at all, we will still -

Mr ECCLES - That is when you start from scratch.

CHAIR - Yes.

Mr ECCLES - But the register is there and the register has five million names on it. In whatever way, shape or form they have bundled in, 25 per cent of the Australian population has gone to the effort. Why not look at it? I can't understand it myself. Also, the system that exists would help us out. In Tasmania it could be just as easily done with a phone call to Victoria, which may be what happens now. You don't have to physically do it yourself, you can just phone the organ donor agency 24 hours a day and say, 'Can you just check your register for Joe Bloggs? Is he on it?'

Mrs RATTRAY-WAGNER - I think that's what happens at this point in time.

Mr ECCLES - So in your new world - mind you, they still have to drive up the road to Launceston if Launceston happens to be the place where the donations take place - there is at least that sense of proximity.

Mrs RATTRAY-WAGNER - It has even been suggested that there be a coordinator in that position in the north and the south just for logistics. Then you don't have one person doing a job, it spreads the load. That has been suggested, given that there is a bit of a north-south divide.

Mr ECCLES - You said it first, and I am glad you said it because it was in my mind. When I was with the Red Cross I had a fair bit to do with the blood service in Launceston and Hobart and there often used to be that challenge, just to get over that hump in the middle. And you have that big landmass to the north of you that keeps on getting in the way, too.

Laughter.

CHAIR - As you say, there's probably going to be something out soon, the national collaborative, as to how to make sure that you do the best you can in finding the donors. Paul has mentioned blood transfusions, that most people who donate blood have been donating for some time and they're obviously doing it because they want to help the community in some way. They seem to be ripe for the picking for organ donation as well. A lot of the blood people say, 'No, we don't want to do that. That might scare them off donating their blood. You have to treat that fairly sympathetically'. What do you think of that suggestion?

Mr ECCLES - It is interesting that ARCBS's feedback has been that. Your idea at first blush looks like a really good one, Paul. I can also see ARCBS's position. They face some gigantic challenges in the next five to 10 years in order for them to endeavour to reach self-sufficiency in fresh blood products for Australia and also to reach self-sufficiency in plasma production, which has been a stated preference by the populace and therefore an agreed preference by the Health ministers. In order for them to do that, most of their game is going to be focused upon trying to increase their donor numbers by some tens of thousands over the next six years. Anything that they think might scare the horses - and they are a very risk-averse organisation - may not necessarily be welcome with a great deal of enthusiasm. They may feel that they are overburdening a donor population of whom they already make great demands. On the other side of the coin, we are not speaking about you having to do this while you're alive. It is not going to take up any more of your time while you are this side of the grave, therefore it would seem like an initiative well worth pursuing.

The other issue there is that they would seriously have to think about how they did it. The average blood donor in the streets gets so much paperwork through the mail and so many phone calls reminding them of appointment times that a lot of people just dump the lot and don't even open it. So if they were to consider this initiative, they would have to think very carefully about how they went about doing it. It may simply be as basic as giving them a form to take away with them when they leave.

Mrs RATTRAY-WAGNER - And then they can say no at the time or, 'I'm on it' or 'I'm not on it'. It's a good point.

Mr ECCLES - Also, it is not ARCBS's core business from the point of view of their blood service. Even though, as you will be aware, we contract with national transplantation services through ARCBS to provide blood services to Victoria and Tassie at the moment as well as New South Wales and tissue typing services to South Australia.

Mr HARRISS - Ashley, what sort of dollars are allocated in your health budget specifically, if at all, to donor programs?

Mr ECCLES - This is probably not for publication but just for your interest we could talk in round figures, the current budget for National Transplantation Services in Victoria is around about $3.5 million per annum. When we talk about National Transplantation Services there are three aspects to it. There is the Australian Bone Marrow Register, which represents a very small component of it. You would also make a contribution to the Australian Bone Marrow Register from Tasmania but how you do it, anybody could know. The funds for the Bone Marrow Register come from various places, depending upon which government you happen to be with.

Regarding the two main chunks of money, the lesser of which goes to LifeGift itself, the larger part goes to the Victorian Tissue Typing and Immunogenic Service which does all the tissue typing for donation in Victoria and Tasmania. One cannot exist without the other. If you cannot tissue type you cannot transplant so we fund both. LifeGift itself this year will get about $1.2 million to run a staff of six donor coordinators and to pay nearly all of the senior management salary. You may or may not be aware at the moment that the Australian Red Cross Blood Service and the National Blood Authority in conjunction with one another are undertaking a business study which is being run by KPMG to look at qualifying and quantifying all of the cost that ARCBS expects the Government to meet and separating out what has been a fairly tangled ball of string in the past into separate strands.

What will happen in that process is that we will be able to identify which parts of the National Transplantation Service are not currently funded by my separate State grant and there will be some. So the ask will only increase.

Regarding that money that I give LifeGift, which is $1.2 million for this year, LifeGift fund the cost of the APOD audit, so the death audit. There are nine hospitals involved in that at the moment. Each of the large hospitals gets $15 000 a year; the small hospitals get $7 500 a year towards doing the work. They also recompense hospitals the cost of organ retrieval. So you get $3 000 back for the retrieval of a multi-organ donation and you get $1 250 back for the retrieval of a kidney. Those costs are built into the $1.2 million. At the moment this year we have had 40 donations of which most of them have been multi-organ. Multiply that by $3 000 and that is part of it.

The rest of it is simply to run the business, move the organs around, move the staff around and fund the education campaign, and vitally, to employ a communications person, who is Joanna, who will become progressively more and more important as the outcomes of the national clinical task force start to get enacted. One of the really important ones that is going to come out of that is that we need one centralised and agreed message that every jurisdiction and every body involved will sign up to communicate to the public. At the moment we are funding a piece of work through the funding that Tony Abbott gave us for a social marketing campaign to be planned and there has been quite a lot of background work done by an agency already; 12 months' work has been done so far to try to identify what it is we need to tell the public to make a change.

We know 95 per cent of the public think it is brilliant but we certainly do not see that translating as far as rates are concerned. When that strategy is finally put together - and there is probably another 12 months' work to be done on it, including some fairly intensive focus group testing - what we are endeavouring to do for the first time with organ donation is to do something along the lines of the Quit campaign. It is going to be interesting to try to sell something that is so closely related to death to people but the Quit campaign has had successes. What they did in building the Quit campaign, which took the Commonwealth an inordinate amount of work over an inordinate number of years, was to really look at what messages they needed to get out there. A centralised message coming from whatever agencies happened to be involved in the process as we move forward will be vital and that is where Joanna comes in.

I do not know how big an ask it is to ask the Tasmanian Government to put on a full-time donor coordinator but you will need at least one-and-a-half people because a donor coordinator needs to be available 24 hours a day but then if you work that out over the number of donations, you have a year that might not necessarily be a problem in the first instance. You may want to share a COMS person with Victoria for the time being. One of the problems we had with the Australians Donate, which is what is going on in Tasmania as we speak, was Australians Donate did not have the ability to bring together people to make this central community message and often went off on a tangent which is exactly what happened with the Have You Got The Right Card Campaign? that has been running in Tasmania, which was not run across the rest of the nation. It leaks through to the rest of the nation and starts to send confusing messages to people.

We have had problems with this happening, and not just with Australians Donate. There are various lobby groups which understandably, because they are lobby groups, have wanted to push their own barrow as well and the plan as far as the new world is concerned is that all of those lobby groups will be at the table as opposed to knocking to get in – it is sensible, isn't it, really. A centralised message carries uniformity across the nation and should have the best return for us.

Mrs RATTRAY-WAGNER - So if it is a card that you have, then everyone has a card?

Mr ECCLES - Everyone has it.

Mrs RATTRAY-WAGNER - If they are registered and they are on the register, they have a card to show just like a Medicare card. Everyone has the same.

Mr ECCLES - The access card proposal is up at the moment as well, as you are fully aware, and it will be interesting to see what happens now the Government has changed but the access card idea did not strike me as a very good idea from the point of view of how they were planning to capture organ donation information on it anyway. They were planning to capture it in the chip and not on the card so I could not see much point in having it really. We do not have people access the organ donor register by picking up a phone at the moment so there is little chance of them actually going to a machine, stuffing a card in and reading the information, which would have only told them 'Go to the OADR, this person is a donor and is registered'; it would not have told you whether they are a donor or not. You would have still had to go to the OADR to find out whether they were saying yes or no. It just appeared to be counterproductive.

Mrs RATTRAY-WAGNER - Just something easily identified.

Mr ECCLES - The card - people love the card.

Mrs RATTRAY-WAGNER - It is the one to add to your wallet.

Mr ECCLES – Yes. Not that people rifle through your wallet in intensive care but from the stakeholder's point of view there is a sense, 'Okay, I have done it. It's acknowledged. Here's my official receipt that is done. I'm set'.

What is that brochure? *You Don't Have to be a Doctor to Save a Life*? How old is that? What is the copyright on that? The AMA put it out?

Mrs RATTRAY-WAGNER - Yes.

Mr ECCLES - I rest my case.

Mrs RATTRAY-WAGNER - I just picked that up.

Mr ECCLES - This is a perfect example of what I have just been talking about because branding-wise it is a totally different document. There is no continuity of theme. We all know that if we are dealing with Medicare it is going to be green and yellow, something as basic as that. Officially, if you are dealing with that AODR you have got that teal-green colour. If you change that you lose your continuity. It is those sorts of things that we would be looking at trying to standardise across the nation. The AMA are trying to do a good job.

Mrs RATTRAY-WAGNER - But they are not together.

Mr ECCLES - It is a conflicting message, yes.

Mrs RATTRAY-WAGNER - There was also one for tissue, wasn't there?

Mr ECCLES - Which is a real surprise. The tissue one is this South Australian initiative. That is an info brochure. This one, unfortunately, does not have a call to action. So you get the brochure, look at it and you say, 'That is lovely, but it does not tell me what the next step is'. So it is those things that we are trying to look at standardising. It would make a huge difference.

Mr HARRISS - Ashley, where does the matter of bone marrow donations and then transplants fit within the term 'organ donation'?

Mr ECCLES - We fund that under the Australian Bone Marrow Donor Registry. Bone marrow donors are funded under the Australian Bone Marrow Donor Registry. However, they generally sit, while here in Victoria, with the Blood Service. So they are housed within the Blood Service. It is one of those classic examples of shared benefits which we are going to have to cough up more for down the track. Certainly those in the know with regard to bone marrow donation are beginning now to identify it as older technology. A number of new bone marrow donors that the Australian Red Cross Blood Service, who run it for the nation, are looking at recruiting now has virtually disappeared. They are looking at maintaining their donor base. They are not looking at recruiting any more, simply because the progress that has been made with cord blood transplantation now is superseding bone marrow donation for many reasons. The haemopoetic stem cells in cord blood, being much younger, are much better at developing into the cells that are needed.

In the past, cord blood transplants have only been used for children. But now we are looking at adult transplants where two cords are transplanted into an adult and they are having great success. Therefore, from a bone marrow point of view we will see that, I think, dwindle to a maintenance level and sit there into the future. Regarding cord blood, on the other hand - and Tasmania might like to think about this because it is a tissue that is being donated - at the moment the cord blood network in the nation is already funded to an extent by Tasmania. We have three cord blood collection centres, collection processing, storage and release centres in the nation. One is in Melbourne at the children's hospital, one is in Sydney and one is in Queensland. The Cord Blood Collection Network is funded on a cost-shared formula. All of the nation pays for it and at the moment we are endeavouring to maintain the inventory at 20 000 cords, which is where we were able to get to last year. However, the Cord Blood Collection Network are saying, and we have to start listening, that because the demand for adult cords now is two into one person and because the results that are beginning to be shown in journals around the world are proving that it is working, we are probably going to have to fund it more over time to collect more, which may mean that cord collection expands into other jurisdictions or it may mean simply that it stays in the jurisdictions it is in and we collect from more hospitals.

You will also probably find that the public are beginning to ask for private cord collection. Has that phenomenon hit Tasmania yet?

Mrs RATTRAY-WAGNER - I am unaware of it. I have heard of it but I am not aware of anyone asking for that.

Mr ECCLES - We are beginning to have to deal with that now in most of the eastern seaboard States. We have had to issue guiding policy for our public facilities as far as that is concerned.

CHAIR - But with organ donation you can donate to your brother, can't you. What is the situation in Victoria? I know there were two police officers, one of whom donated a kidney to his brother.

Mr ECCLES - That is a directed live donation. You can do that and if we did not have it, God, we would be totally buggered. There are about 1 800 people waiting for kidneys. Live donation accounts for about 500 of the transplants that take place out of the 700 or so transplants a year. Within this context, generally when we speak of organ donation we only speak of cataveric organ and tissue donation and not live donation. We treat that as a clinical process within a hospital because it simply involves live people and moving bits of one to another. So it is funded under our system here and we do not fund that out of LifeGift at all and indeed, LifeGift has no involvement with live organ donation at all and at this point in time, nor should it.

There is only one time when an organ donation agency here became involved in a live donation and that was when a woman had to have a kidney removed. Her condition was irreparable and rather than have the kidney thrown away to waste, she wanted to donate it to donor pool. Then LifeGift became involved in helping to search for a suitable donor. Other than that though, live donation stays in the realm of the transplanters and the clinical facilities, and should stay there. That is where it belongs I think.

Mrs RATTRAY-WAGNER - We had some evidence where a Tasmanian lady had donated overseas because she said that she could not get any -

Mr ECCLES - Yes, I saw the show.

Mrs RATTRAY-WAGNER - could not get any acceptance around Australia. Was that something that came past your desk at all?

Mr ECCLES - We have treated the entire issue of what one would call altruistic donation with a substantial degree of caution, the obvious reason being that all of our human tissue acts to all intents and purposes do not permit a trade in organs in any way, shape or form. You could argue that this woman did not trade; she went across and out of the goodness of her heart gave this man an organ and she still got the altruistic feel-good element out of it. In order for us to be sure that we are not exposing a potential donor to risk down the track, we have been very clear in saying to our clinicians that if they intend to proceed down this path they have to be very clear on the process that they follow within their institution. In Victoria we have devolved responsibility to our hospitals, that there is a clearly written procedure for the process of altruistic donation and that that procedure includes in it not one psychiatric assessment but two from two different psychiatrists over a differing period of time. Then there has to be a substantial cooling-off period of three to six months.

As a result of that process being fairly explicit within our hospitals, we have not yet had an altruistic donation in Victoria. I do not see altruism as the way of solving our problem, just as I do not see live donation as a way of solving our problem. It has simply been the best thing that we have been able to do thus far in order to keep up with the demand for kidneys, because you cannot transplant anything else out of a live person. We need to sort out our cadaveric issue; that is where we are going to make the difference.

Mrs RATTRAY-WAGNER - Yes, but what about the liver?

Mr ECCLES - We have only just now begun to be able to do partial liver transplants. It is still in its infancy, still with a very high risk of death. The risk of death in a live kidney donation is much less than now; it is quite a safe procedure. For a living liver donation the risk of death is still well and truly there.

Mrs RATTRAY-WAGNER - For both the donor and recipient?

Mr ECCLES - For both the donor and the recipient. The recipient is always at a substantial degree of risk simply because they are always in fairly dire straits when it comes to the time that they receive their transplant. Post transplant the risks are always huge but with liver for a living donor there is also that challenge.

We would prefer that our citizens were not involved in the process of altruism. We do not see it as good for the citizen who is doing the donating; we think that it could potentially comprise them.

CHAIR - Ashley, have you looked at suitable education and promotional programs? One we were told about this morning was a module for secondary schools. What has happened there?

Mr ECCLES - I know I sound like a broken record, but there should be a standard approach to this rather than us all wanting to fix it. LifeGift, yes, has a secondary school module that they teach to kids in secondary school It is absolutely valuable to get them while they are young. The same applies with blood donation. ARCBS do the same thing. If you can inculcate that practice into people when they are young they are going to do it all their lives.

Unfortunately we also had a problem with the peak body devising its own education program. 'Oh, but it was different', because it was aimed at primary schoolchildren. Well, in the end it never went anywhere so a whole heap of money was spent on a program that did not last. Yes, I would strongly say that whatever we do that needs to go out there into hospitals needs to be centrally coordinated and centrally sustained. We have a model for that in that we have the ADAPT program which you have probably already heard of, which works the health professionals and is beginning to work more and more, as more intensivists - some pushed kicking and screaming, some happily involved - take part in the ADAPT program. There could be a natural fit there for ADAPT to devise a standardised module for schools.

Mrs RATTRAY-WAGNER - Just lower it down to meet the people you're trying to engage with.

Mr ECCLES - Yes. My key point there would be we don't need six different donor agencies all working on their own package.

The donor agencies around the nation have a fairly good relationship with one another. Unfortunately the peak body that was supposedly representing them didn't. As a result, the communication between the agencies was stifled. We are back to communication, we're back to where I began.

CHAIR - That's good, thanks, Ashley. Did you want to tell us anything that you haven't told us as yet?

Mr ECCLES - I think I've said enough. Just to confirm that those dates are more than likely happening, ARMAC, whenever it happens could be as late as late January. But at least it will be there for you to have a look at, and certainly the draft National Clinical Task Force report is still due out in December.

CHAIR - As you know, what can happen is that the report goes out, goes to government. The Government, maybe because of financial restraints, take on part of it, not all of it, and says, 'No, we're doing this okay'. Can we still get a copy of the report?

Mr ECCLES - Oh, yes. The report will certainly be sent out. In its final form this report will become a public document, I have no doubt. Too many ministers have now put their name to this initiative in the public arena for it to be swept under the carpet. The drivers for change are so great at the moment, and so many stakeholders are now so aware of what is going on, everyone is waiting for a report. The interim report is on the DoHA web site, and that will be where the final report will end up as well for full transparency so that everybody knows these were the recommendations that were made from the task force. Then the new committee, if that's the right term to use, should that be what ARMAC decide upon - he said, making sure he qualifies everything he says - would be tasked with carrying this body of work forward.

CHAIR - The task force seems to be the New South Wales centre.

Mr ECCLES - It depends if you speak to Neil or not. New South Wales is where it has been held, New South Wales has a large number of transplanting hospitals. If you look at the representation from Victoria on the National Clinical Task Force, it actually has the grandfather of organ transplantation in the entire nation in Napier-Thompson on it. He is a renal physician at the Alfred, so he is there with various hats - first, 'I invented transplantation in the nation', second, he's been a board member of AD, and third, he still currently works as a transplant physician. So he is there from Victoria.

Patrick is there - or Neil, depending on who you want to talk to - and that is a very important one from Victoria's point of view simply because that meant that the organ donation agency representation came from this State, which I was pleased about. Marcia Coleman from Australians Donate is based in Victoria, but of course she has a national hat. I would say that the State balance is not necessarily a problem. New South Wales is the biggest State as well demographically. Some jurisdictions don't have representation at all, and certainly representation was more based upon which college, professional body, organisation it was that you represented.

CHAIR - Often these committees want to come in with what some would describe as way out ideas. Do you know what's been happening when committees say, 'Yes, look -

Mr ECCLES - Oh, no, the committee has been everywhere. The recommendations have ranged from the French Revolution to everything else heading back. A lot of the things that you would have suggested yourselves with the knowledge that you had when you began and the knowledge that you have now, will be the things that are recommendations from the task force. A lot of it is basic commonsense. You don't need to know about organs and tissue to know that if you've got one message coming from one place that is consistent you might stand a better chance. There will probably be about 30 recommendations from the group and they are all doable; some of them are easier to do than others. Having said that, though, some of the work has already begun and began as long ago as a year ago, particularly with the community awareness campaign, for example. That was something that the task force looked at very early on.

The role of the task force in the first six months was really to throw everything up in the air, throw anything in, just make it up and tell us how you think the world should be. The second half of the year has been a refinement process. Out of all of that, how do we think we could move forward. A lot of it will be doable and the expectation will be that it gets done. From a funding point of view, that means there is going to be an ask of governments to continue to fund in some way, shape or form in much the same way as they have currently funded organ donation from the point of view of the contribution that governments have made. At the same time, we still have a substantial amount of Tony Abbott's $20 million sitting around waiting to be spent. So there is money, political will in a lot or jurisdictions, including Tasmania - various specific jurisdictional initiatives that they have got up and running. The planets have never been so much in alignment.

CHAIR - Thank you very much for your time.

Mr ECCLES - My pleasure, I hope it has been of some help.

For the Australian Organ Donor Awareness Week last year we had a young guy cycle from Queensland to Melbourne. His mother had had a liver transplant. He was only 15 and he was an amazing boy. She'd had a liver transplant and it worked for three years and she is on the list again for a second one. He was so inspirational. That is when you are reminded about what it is -

CHAIR - I think that is something we could do down in Tasmania. We do a bike ride for diabetes once a year and it keeps that yearly focus on diabetes.

Mr ECCLES - Can you call to mind anything that has happened in Tasmania to raise public awareness with regard to organs donation?

Mrs RATTRAY-WAGNER - I had not even known there was an organ donation awareness week, let alone a day.

Mr ECCLES - Your Government is so much smaller from the number of people point of view and yet you still have to carry all those portfolios. I feel so sorry for David Bartlett sometimes; the poor man has so much on his plate. It must be very difficult to keep abreast of absolutely everything that's going on when you have a limited number of people to do it.

CHAIR - Yes, but something different would be good for that.

<u>THE WITNESS WITHDREW</u>.