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Health and Social Security Scrutiny Panel

Organ Donation

The Minister for Health and Social Services

Monday, 5th March 2018

Panel:
Deputy R.J. Renouf of St. Ouen (Chairman)
Deputy J.A. Hilton of St. Helier
Senator S.C. Ferguson

Witnesses:
Senator A.K.F. Green MBE, Minister for Health and Social Services
Mr. F. Le Gros, Legal Adviser
Ms. K. Stephen-Dalton, Assistant Law Draftsman
Mr. M. Richardson, Assistant Director, Policy, Communications and Ministerial Support
Ms. S. North, Acting Clinical Manager I.C.U. (Intensive Care Unit)/H.D.C. (High Dependency Care)
Mr. R. Sainsbury, Hospital Director
Mr. T. Innes, Communications Manager

[14:03]

Deputy R.J. Renouf of St. Ouen (Chairman):

Thank you for attending upon us. This is a meeting we had hoped to hold last Thursday but we thank you for your assistance in rearranging it so quickly after the weather we had last week. This is a public hearing of the Health and Social Security Scrutiny Panel with the Minister for Health and Social Services concerning the proposed - it has a long title - Human Transplantation and Anatomy (Jersey) Law. But we are talking about it in shorthand as the Organ Donation Law, I think. Because this meeting is recorded, Minister, in the usual way we will introduce ourselves and then I will ask you to introduce yourself and your team, if I may. So I am Deputy Richard Renouf, chairman of the panel.

Deputy J.A. Hilton of St. Helier:

Deputy Jackie Hilton, panel member.

Senator S.C. Ferguson:

Senator Sarah Ferguson, panel member

The Minister for Health and Social Services:

Senator A.K.F. Green, Minister for Health and Social Services.

Legal Adviser:

Frank Le Gros, Legal Adviser, Law Officers' Department.

Assistant Law Draftsman:

Karen Stephen-Dalton, Law Draftsman Department.

Assistant Director, Policy, Communications and Ministerial Support:

Mark Richardson. I am policy lead on this.

Acting Clinical Manager I.C.U./H.D.C.:

Samantha North. I am the lead nurse in terms of care but previously specialist nurse for organ donation.

Hospital Director:

I am Rob Sainsbury. I am the new Hospital Managing Director.

Communications Manager.

I am Tom Innes. I am Communications Manager for Health and Social Services.

The Deputy of St. Ouen:

Thank you. We have apologies from Deputy Terry McDonald, who is not feeling well. I should say Deputy Geoff Southern is not participating in this topic, so we only have a panel of 4 on this. Minister, can you tell us what are your objectives in seeking to move from an opt-in organ donation system to an opt-out system?

The Minister for Health and Social Services:

I think primarily to ensure that as many organs as possible are available for transplant. It does not mean every organ will be taken or used but, as you know, we have a very low uptake of people opting in at the present time and that is primarily, if my information is correct, because people have not got round to it, not because they have got a problem with it. I think if I had a second objective ... so make more organs available; if I had a second objective it is to get people to talk about it when it is less traumatic, so when they are not faced with the loved one at end of life where they are, for the first time, maybe thinking about organ donation; it had never been discussed. I want those conversations to take place years, hopefully, in advance so that people know what their family wants as well as the fact that they can choose. If they do not want to they can choose to opt out, so I want to bring those conversations forward much earlier so people can really discuss it. I have personal experience of that, which I can share with you, if you want to, later. So it is about making organs available, it is about encouraging people to have those conversations years in advance.

The Deputy of St. Ouen:
Do you have any evidence to lead us to believe that the number of organs available will increase if we went for an opt-out system?

The Minister for Health and Social Services:
You do not need to dig too deeply to see that if we have an opt-out system more organs will be available. I guess the important question is how many of those will be useful or could be used. We do not know the answer to that. We have seen an improvement - we have an expert here anyway - but we have seen a small improvement in the number of the organ donations that have taken place. While it is small it is still an improvement. But the fact is that organs are available, then of course a suitable donor has to be found and all the rest of it has to be joined up, but the fact they are available means that opportunity to transplant when it all comes together is more possible than before. I do not know if Sam would like to add to that.

Acting Clinical Manager I.C.U./H.D.C.:
I think the main focus of organ donation should be around the conversation as opposed to what is available, and I think this will naturally generate conversation and hopefully people will come with a definitive view rather than be left in limbo when they are asked in the Intensive Care Unit.

Assistant Director, Policy, Communications and Ministerial Support:
Can I just add that obviously England is doing a consultation on the whole concept of an opting-out arrangement and that finishes, I think, tomorrow? But in that part of the work their scientific adviser advised that on the basis of review of the evidence that they had seen up until now it is possible to say, with moderate certainty, that when introduced as part of a wider communication and logistical package, opt-out systems can be associated with higher donation rates. We cannot, hand on heart, say absolutely this is going to lead to an increase in donor rates, but it appears that it would certainly do no harm and one would hope to think that it would go that way.

Deputy J.A. Hilton:

Can you just remind us what consultation has taken place in Jersey?

Assistant Director, Policy, Communications and Ministerial Support:

Of course. So we put some questions in the Jersey Annual Social Survey, I think it is called J.O.L.S. (Jersey Opinions and Lifestyle Survey) now, is it not? Those questions were seen and, I suppose, approved, if you like, by the Statistics Unit to make sure that we were not asking any loaded questions, or whatever. The survey went to 3,300 households and 1,335 households responded. The response rate was 42 per cent. So when you compare that to, for example, Scotland which did a consultation, with a population of around 5 million, and they had 824 responses; their response rate was very small. I have not done the maths but it is not very much. In our consultation 52 per cent approved moving to this kind of opt-out system. I would argue that because our questions were part of a broad range of other questions in the J.O.L.S., it meant that we were more likely to get people to respond because otherwise if you just do a consultation on organ donation per se there is a danger that you just get the people who are really for it and the people who are really against it. We want to find out what everybody thinks. I think you are more likely to get that in a survey like J.O.L.S. than you are just doing a straight consultation. You saw for yourself, 75 per cent said that they want an organ transplant if they needed one but only 55 per cent said would want their organs to be used to treat others. That is kind of what we are dealing with.

The Deputy of St. Ouen:

I was aware there was some comment in the press over the weekend, but I would like Senator Ferguson to ask a question around that to you, Minister.

Senator S.C. Ferguson:

It was Professor Rudge F.R.C.S. (Fellowship of the Royal College of Surgeons), who is the national clinical director for transplantation between 2008 and 2011. He quotes figures that in the U.K. (United Kingdom) last year over 50 per cent of the donors were not in fact on the register. He claims that improvement is possible without changing to a controversial new law. Have you consulted any of the English clinical directors for transplantation?

The Minister for Health and Social Services:

I will let Sam give you the positions that people hold. When we started this journey over a year ago, it started with me meeting with our own transplant committee and representatives from the U.K. who came along to sit in and advise at that meeting. So the answer is, yes, we have consulted the experts from the field. I cannot remember if you were at that meeting, Sam, or whether you had not started.

Assistant Director, Policy, Communications and Ministerial Support:
This is probably more my area to comment on. We are aware that there are different views on this. Not everybody has signed up to it. Not everybody thinks it is a great idea. I have seen the comments of the person that you are referring to and that does appear in the literature, alongside other people who think it is the best thing. I think the British Medical Association has been saying this should have been happening for some years now. So it just depends. There are contrary views and other people who think it is great, so you take your pick really. Nobody is saying there is going to be an instant panacea but I think my argument would be that nothing has happened for a number of years and we are still not at great numbers, so I think it is worth giving this a go and finding out, hopefully, that it will push up the numbers and, as the Minister says, it is all about making people more aware of what is going on. So I think in itself that would be a good thing, to make sure that people are having those conversations. I think in itself that will make people more likely to come forward and think: "Oh, yes, this is something that we should be doing."

Senator S.C. Ferguson:
In that case, over here, you are saying you want more donors here. How many donors did we have here who were not on any register or had any sort of firm views of donating their organs?

Assistant Director, Policy, Communications and Ministerial Support:
I am not sure we have gone into that depth to find out.

Senator S.C. Ferguson:
Have you got any statistics for Jersey?

Assistant Director, Policy, Communications and Ministerial Support:
We know how many people are on the organ donor register. That was included in the data that is here. We know how many organ donors I think there were ... 8 Islanders in 2017 received an organ and in the year to 31 March 2017 there were 3 organ donors from here who donated 9 organs.

Senator S.C. Ferguson:
So if more than 50 per cent of the donors are not on any sort of register how does that translate to Jersey?

Assistant Director, Policy, Communications and Ministerial Support:
I do not know the answer to be honest, but I think that is part of the "problem", I would say. We need more people to be on the register and publicising it will mean that more people will get on the register. I do not think it is a good thing that people are not on the register, as you are saying. What happens at the moment is if those people are not on the register then obviously their next of kin are

approached when it is deemed appropriate if they are in a position where organ donation should be considered. That approach is happening, organs are being given, but there seems to be a big gap between the people who want to give an organ when asked and what they do about it. So hence the deemed consent approach.

Senator S.C. Ferguson:
Have we had many cases where people have said they want to donate organs and the relatives have said no?

Assistant Director, Policy, Communications and Ministerial Support:
My understanding is ... I mean Sam can talk a bit more, but I think my understanding is that in Jersey we are fortunate that has not happened up until now.

[14:15]

But it could happen tomorrow. We could have a run of 3 people and all the families might say: "Oh, I do not want this to happen." That happens quite a lot in the U.K.

Acting Clinical Manager I.C.U./H.D.C.:
I think that situation is very rare. When I was doing the job I could probably count on one or 2 fingers and that was often down to the fact that people would say: "Oh, he was not in his right mind when he put himself on the register" and that often came down to their own views on organ donation. That was often sorted with a communication with the specialist nurses, which was my role at the time, so it might have been a misconception about process or what would happen. Will it delay funeral arrangements? It was often, once you had given them that information, that they would be able to see that it was the patient's wishes and that they were going to go along with those wishes. It often came from the family's misunderstanding of what the organ donation process was. That all comes down to education.

Senator S.C. Ferguson:
So if they left their body to science have you ...

Acting Clinical Manager I.C.U./H.D.C.:
I have no dealings with leaving bodies to science. That was not part of the organ donation. I was a completely separate part of the anatomy department.

Deputy J.A. Hilton:

So just to clarify, you are saying at the current time in Jersey that all those families that can be approached, because that is our approach, that is the current situation, regardless of whether they are on a register or not ...

Acting Clinical Manager I.C.U./H.D.C.:
Any patient who ... they have to be in the Intensive Care Unit; any patients to become an organ donor have to be in the Intensive Care Unit on a ventilator. There are certain criteria that they have to meet and then if they meet that criteria the doctors will naturally inform the specialist nurses in the U.K. if they meet that criteria. If they are over a certain age they would not because you would not give a family false hope if it was not able to happen. Then the specialist nurses would, if they deem the patient a potential donor, fly over and be in those conversations with the doctor and then they would support the family through the process regardless of whether it was a yes or a no.

Senator S.C. Ferguson:
In looking to move to an opt-out system, what experience have you drawn from other jurisdictions that have already moved to this system? Have you only consulted Wales? Have you consulted other people as well?

Assistant Director, Policy, Communications and Ministerial Support:
No, the main one we have consulted is Wales. We are aware of what has gone on because when you read obviously the Welsh literature on the subject, and obviously Scotland did a major consultation this time last year, within all that literature that surrounds that there is quite a lot of reference to other countries. Spain, I know has got this. Across Europe it is quite common. I was reading the other day I think Germany has got an opt-in system or something and opt out is in Austria, and Austria's got a much better response rate than others. But there is also lots of things like cultural factors you have got to take into account. So all these figures have to be treated with some caution. It is not always as straightforward as it will appear.

Senator S.C. Ferguson:
Is it something then that the E.U. (European Union) is actively encouraging?

Assistant Director, Policy, Communications and Ministerial Support:
I think probably it is but I could not point you to that, I mean in the sense of when you look at European countries. I think the Republic of Ireland, for example, is looking at this, and dare I say, Guernsey is looking at this. England has said it is going to do it. The consultation is not about whether they should do it or not, it is about inviting comments on particular aspects of it. Scotland is doing it. Wales has done it. In the jurisdictions which we would normally compare ourselves with things are moving forward. The Isle of Man as well, for example.

The Minister for Health and Social Services:

But we should not have to wait for the E.U. to rubberstamp something like this. If we, as a community, think this is the right way to go then that is what we should be doing. When I have been questioned on this in the States and by the media I have always said that I would wait to see some results back from Wales because they had already done that, and then we would make up our own mind.

Hospital Director:

I was just going to add, I have worked within the N.H.S. (National Health Service) Wales context, and I think if you look at the timeline of the change coming into place it is still relatively quite a new thing. I think the belief is that this will be an evolving situation, and I have been going back to Sam's point. The thing that is overwhelmingly recognised is that the promotion of the conversation has been the real benefit from what has happened within Wales. So families are able to have a discussion in a much more planned way than when you are in an urgent situation, and from a care and a quality perspective, clinicians really like that part, that is very clear from the experience.

Senator S.C. Ferguson:

You have previously told the Assembly that you will take a watch and learn approach based on the Welsh experience. What has happened in Wales that it triggered you to bring this forward now?

The Minister for Health and Social Services:

Basically that they judged their system to be successful, that while they have not had masses amounts of transplants taking place as a result of it there has been an improvement. The evidence is that these conversations have taken place, and I met with the Minister for Health for Wales, whose name escapes me at the moment, and discussed directly with her face to face the benefits that they have seen over the last year. So I took that watching brief. I waited that year until they came back with their report, and then we went out and did our own survey to see if the community were minded the same way as I was. I would argue that that has come back very clearly that they are.

Senator S.C. Ferguson:

In Wales, has there been an increase in the number of organ donations?

The Minister for Health and Social Services:

I said there has been a very small increase.

Assistant Director, Policy, Communications and Ministerial Support:

They certainly experienced more registered donors. They have experienced fewer family refusals, so when families are asked, you know, people are more likely to say yes, which again comes back down to the education point. I think there has been a small ... yes, actual donors ... the answer to your question is it is probably small but it is still showing some positive effects.

Senator S.C. Ferguson:
What do you call “small”?

Assistant Director, Policy, Communications and Ministerial Support:
I have not got the numbers.

The Minister for Health and Social Services:
It is a different answer to organs being available to organs being used. Because you have to match up both the recipient and the donor. There is no doubt that there are much more ...

Senator S.C. Ferguson:
Yes, you have got to make sure of the blood types.

The Minister for Health and Social Services:
Yes, it is far more complicated. Sam can tell you all about that, if you want to. But the fact is if organs are available then the chances are that the transplant will take place with a suitable recipient. If they are not available, it does not matter how ill that recipient is, they cannot get that organ.

Deputy J.A. Hilton:
Will Jersey continue to be linked to the National Health Service Blood and Transplant Service for the purposes of organ donation?

The Minister for Health and Social Services:
Yes.

Assistant Director, Policy, Communications and Ministerial Support:
Yes, absolutely. There is one register so we need to be. There is one register and everybody is on that register. So it is absolutely imperative that we are.

Deputy J.A. Hilton:
So everybody from within the U.K. is on that register?

The Minister for Health and Social Services:

The last thing you want is a Jersey register and a U.K. register or Welsh register and a Scottish register because that is not efficient and it is highly risky, might I say, because you might miss things.

Deputy J.A. Hilton:
So what changes will there be to how someone notifies their preference on organ donation?

Assistant Director, Policy, Communications and Ministerial Support:
I think that is something that we need to look into going forward, but I mean my understanding is at the moment, for example, you can phone or do it online. I am on the register and I rang them up to check I was. You can also do it online, I understand. The difference will be that obviously under the new arrangement, if it is accepted, that people will also be able to opt out and make sure that is put across and recorded on the register as well.

The Deputy of St. Ouen:
Can I ask you, Minister, that ability for somebody to opt out of the presumed consent is not recorded in the draft law? There is no provision for a system for a method whereby somebody can opt out?

Legal Adviser:
There is no mechanism in the law itself. The law allows the States to bring regulations to provide systems for recording opt in and opt out. The effect of someone opting out is reflected in the law in Article 4(2). The regulations will elaborate, flesh out, the mechanisms for registering that opt out, but the right place for the opt-out elements to be reflected in law is in the impact of an opt out on the consents system. That is in Article 4(2)(a).

Senator S.C. Ferguson:
The regulations; are they made by order?

Legal Adviser:
They are regulations.

Senator S.C. Ferguson:
Yes, are they made by order?

The Deputy of St. Ouen:
No, it would be ...

Senator S.C. Ferguson:
It would be proposition:

The Deputy of St. Ouen:

We have seen the provision to introduce regulations but Article 4(2) does change the law very dramatically in that we are moving from the opt-in system, which is a person's individual choice to, an opt-out system. So consent is now presumed. If somebody does not wish for any reason, ethical, religious, moral, whatever, does not wish to give their organs, we do this law as it is, as you are asking the States to pass it, does not contain any mechanism for them to be able to alert you, Minister, to the fact that they do not wish to give their organs.

The Minister for Health and Social Services:

I certainly hope they will not be alerting me, but I understand the context.

The Deputy of St. Ouen:

The States because the States is presuming a consent.

The Minister for Health and Social Services:

I think you are making the assumption that if the States pass this, this will become law as soon as it has been to Privy Council, and that is not the case. There is a fairly significant sum of money there available to run a proper campaign, while accepting what Frank says about having to bring the regulations forward. But there will be a proper campaign. So I cannot see the Appointed Day Act being for ... whoever the Minister might be. It might be me, but whoever the Minister might be, I cannot see the Appointed Day Act coming forward for 9 months to a year because that education, that campaign, those systems need to be in place.

Deputy J.A. Hilton:

Can I just ask you a question? There is going to be one register, which is going to be in the U.K., so how would that work if we are out of sync with England because we have an opt out but they do not? How do you think that would work on the register?

The Minister for Health and Social Services:

When you opt out it is the same register so ...

Deputy J.A. Hilton:

But just says that you are opting out?

Assistant Director, Policy, Communications and Ministerial Support:

That is right. Wales is on the same register now and obviously they are operating opt-out and England and Scotland are not. My understanding is if you wanted to you could opt out now, if you wish. The mechanism is there for you to do that. But obviously once, in the year that the Minister is talking about, that is when we need to make sure that people are aware how to opt out and what they need to do.

The Minister for Health and Social Services:
Can I just correct one thing? I know you are the Scrutiny Panel and not the media, but on the media this morning they said people will be wandering around with cards opting out. That is not the case.

The Deputy of St. Ouen:
No, we understand that.

Senator S.C. Ferguson:
We appear to have 2 systems running in parallel. You have got the organ transplant system where you can decide that you want to opt out but your family can decide that you are going to opt in, which is the system that is coming in under this legislation.

Assistant Director, Policy, Communications and Ministerial Support:
With respect, that is not right, no. You are saying you can decide to opt out but your family will opt you back in?

The Minister for Health and Social Services:
Cannot do that.

Assistant Director, Policy, Communications and Ministerial Support:
That cannot happen, no.

Senator S.C. Ferguson:
Well, if we have not got a proper system. Or you can decide to opt in and your family can opt you out.

The Minister for Health and Social Services:
That is correct.

Senator S.C. Ferguson:
So that is one system but, on the other hand, you can leave your body to science ...

The Minister for Health and Social Services:
That is totally different.

Senator S.C. Ferguson:

No, it is not.

The Minister for Health and Social Services:

It is. This is nothing to do with the law that we are looking at today.

Senator S.C. Ferguson:

No, I am saying that the 2 laws are going to conflict if we are not careful.

Assistant Director, Policy, Communications and Ministerial Support:

The mechanism for organ donation will change but only after a year. You will only have one way of doing it once the new law comes in. Nothing happens tomorrow ... if the States passes the draft law on 10th April the existing system prevails for another year.

Senator S.C. Ferguson:

Yes, but as I understand it, forgive me if I am wrong, Chairman, but I understood that if you leave your body to science you put it in your Will.

The Deputy of St. Ouen:

I think, Senator Ferguson, we have not taken any evidence or prepared any questions on that issue so it is a bit difficult to know where we are going once we start down that route. Can we stick to organ donation perhaps? I just want to explore a formal question, the question I asked was: if we are introducing such an important change, which can affect personal lives like this, that we are presuming people give their consent to organ donation, should not also the law, as opposed to regulations, introduce a mechanism for those people who very firmly wish to opt out? Could it not even, say, be a short Article, that: “The Minister shall ensure that there is a mechanism for persons wishing to opt out”? Then by regulation, Minister, you could designate the N.H.S. system as the mechanism by which that is done.

The Minister for Health and Social Services:

I am not uncomfortable with what you are suggesting if you think that makes it clearer, Chairman.

The Deputy of St. Ouen:

Personally I think it would give comfort to those who have a concern about this and comfort to States Members that it truly is a fair change to make because those who are opposed to it ... Mr. Richardson has said that there are different views, sincerely held views, and those who are sincerely against it are not sort of left in a limbo relying on regulations that may or may not come.

[14:30]

The Minister for Health and Social Services:
So you are suggesting an amendment which would say that the Minister will be bringing regulations to explain or to outline the process by which people should opt out or could opt out?

The Deputy of St. Ouen:
I would suggest something that would make it certain that there is going to be that mechanism.

Legal Adviser:
I think the law, as it is drafted, is quite clear on the effect of the opt out. Article 4 talks about consent in the case of adults. Article 4(2) says: “Consent is deemed” unless one of a series of things happens, and the first one is that: “A decision of the adult not to consent to the specified activity was in force immediately before his death.” Then Article 19(2)(d) says that: “The States may bring forward regulations making provision for the registration of express refusal to consent.”

The Minister for Health and Social Services:
It does not say “the Minister” but it says “the States”.

Legal Adviser:
I suppose there is nothing to stop the law binding the Minister to bring forward those regulations but it would just be the case of changing “may” to “shall”, I imagine.

The Deputy of St. Ouen:
I know 4(2)(a) does reference a decision not to consent but that does not mean there is going to be a mechanism whereby that decision not to consent is recorded and accessible to all those who might be involved in the transplantation process.

Legal Adviser:
I imagine if the mechanism was ... my understanding is that the reason why there is going to be a space of a year between passing the law and bringing the law into force, is to enable these mechanisms to be developed. The importance in developing these mechanisms is consulting with people who use them, so clinicians and members of the public who will be organ donors and making sure the systems are in place. That is why it is not appropriate to spell out in the law how those mechanisms could work. But if, for example, you wanted to change that mechanism, you would have to change the law. The law would have to go to Privy Council, it would have to come back and be subject to States debate.

The Deputy of St. Ouen:

You do not want a complex but you could ... there should be an onus on Government to ensure there is a means of recording an opt out.

Assistant Director, Policy, Communications and Ministerial Support:

Which I think we know there is because ...

The Deputy of St. Ouen:

We know that but the law does not say that, that is my only point.

Assistant Director, Policy, Communications and Ministerial Support:

Because there is nothing saying that people who opt in, where is the reference to that, you could argue? I mean there is nothing along those lines either. So people are being treated the same. It is not as though we are trying to be funny about who are opting out. I mean you think there is a need, probably we thought maybe there was not. I mean I think it just comes down to that. But we take your point.

The Minister for Health and Social Services:

But it is in there. Frank read it out: "The States may ..."

Legal Adviser:

As the law stands, it perfectly supports bringing in and putting in place a very detailed system for organ donation for opting in and opting out and registering those decisions and elaborating in finite detail about how those systems will work. If you do not put that in regulations you have to put it in the law. If you have split of provisions in the law and in the regulations about how the system mechanisms and systems work then there is a case to say that the law is not accessible and clear to people who use it because they have to look at 2 different sources. So there is an argument for putting it in regulations but I think that is as much as I can say from a legal perspective. The rest is ultimately a policy decision.

The Deputy of St. Ouen:

Okay. Yes, well, I ...

Senator A.K.F. Green:

So it says: "The State may", we might prefer to see: "The Minister will" but that is as far as it should go.

The Deputy of St. Ouen:

Well, perhaps you will think about that, Minister.

Deputy J.A. Hilton:

How will the current arrangements with organ donation, e.g. notification, assessment, consent and then extraction and transport be affected, if at all, by the new system?

Acting Clinical Manager I.C.U./H.D.C.:

First of all, just from my nursing standpoint, we like to use the word "retrieval" as opposed to extraction.

The Deputy of St. Ouen:

I apologise. That is fine.

Acting Clinical Manager I.C.U./H.D.C.:

Organ retrieval. Though from my point of view ... the notification systems would be the same. The patients are going still to be notified ... the doctors will still be notifying the teams in the U.K. in the same way as we do now. We do not check the register here. So if a patient comes up in the Intensive Care Unit and they are, unfortunately, at the end of their life we then make those telephone calls to the U.K.-based specialist nurses who then check the register. So from a Jersey point of view, I do not think our system could be anything different. The care that the patient will still receive will be the same and if the U.K. nurses deemed that that patient could be a potential donor they would make the necessary arrangements to come over and talk to the family.

Deputy J.A. Hilton:

Okay. So that is all carried out with the next of kin not being aware that that is happening?

Acting Clinical Manager I.C.U./H.D.C.:

Often, yes, because the way that we look at it at the beginning, before you even have those conversations, is you are exploring end of life options. You are not making any decisions based on organ donation and not because you are looking to fulfil what could be their end of life choices. So, yes, that is often done without the relatives knowing, because when the specialist nurses come over they are the ones who are specially trained in that area to have those sensitive conversations with the family at that distressing time.

Deputy J.A. Hilton:

Okay. Has that ever caused any difficulties in the past?

Acting Clinical Manager I.C.U./H.D.C.:

From my experience, no, because, as I said, the specialist nurses are there as end of life care specialists and regardless of the outcome for the family those nurses will stay until the bitter end to support that family through a difficult time. So it is not like they are asked if they say no.

Deputy J.A. Hilton:

No. What I meant was, the team coming from the U.K., which is completely separate to the nursing team. So the team coming from the U.K. and family suddenly being faced with a team from the U.K. that they knew nothing about.

Acting Clinical Manager I.C.U./H.D.C.:

So the team as in the surgical team?

Deputy J.A. Hilton:

Yes.

Acting Clinical Manager I.C.U./H.D.C.:

They are much further down the line.

Deputy J.A. Hilton:

No, the nurse that comes from the U.K. to discuss with the family potential donation.

Acting Clinical Manager I.C.U./H.D.C.:

Yes, and that is what I was talking about and the fact that those nurses are introduced to the family as end of life specialists because that is what their ultimate role is. Regardless of whether organ donation goes ahead they are there to support the family through that end of life process.

The Deputy of St. Ouen:

Rather than the local nurses or team?

Acting Clinical Manager I.C.U./H.D.C.:

The nurses at the bedside are there primarily for the nursing care of the patients but they also ... the nurses at the bedside will often ask about chaplaincy at the end of life whereas if organ donation is going to be discussed ... as an I.C.U. nurse I am very lucky in the fact that I have got the background knowledge so I feel comfortable to have those conversations. But what we want to do is make organ donation normal for every end of life conversation, and for some nurses that is not a comfortable subject but that is why we bring in the specialist nurses, to make sure that the family has all the information so that they are able to make an informed choice about the wishes of what their loved one wants at that point.

The Deputy of St. Ouen:
One person we spoke to was surprised and concerned to see the nurse that had come was in wearing an N.H.S. uniform, the N.H.S. badge, and could not understand immediately why that person was there. Is that the usual practice?

Acting Clinical Manager I.C.U./H.D.C.:
Yes, because we do not have specialist nurses who are ... apart from myself, because I am lucky enough to have done that role before, we do not have those specialist nurses in the Channel Islands. We have the U.K.-based ones who cover our remit but no one who is in the Island on a permanent basis.

Senator A.K.F. Green:
But I think it is a very important question, Chairman, because this is really why this campaign of education and information is important, so that people understand that it is one register, therefore the U.K. would be involved. Also, without going into detail, some of the questions that they need to ask the family are very personal and intimate. Well, it is a shock when you hear it for the first time at the bedside of your loved one but if you know those sorts of questions are coming then you are prepared for it. I do not know if you would agree with that, Sam, although the questions are very similar for blood donation.

Acting Clinical Manager I.C.U./H.D.C.:
Yes. It is the questions that have to be asked if the relatives do agree ... if they agree to organ donation the questions are private and invasive but they are handled in a sensitive manner and the reason they are so invasive is because they have to risk assess that patient against the possibility of any blood borne diseases and things like that. The questions are no different. They might be a bit more in depth than if you were to give blood as a member of the public. The problem is you are answering those for yourself whereas in an organ donation situation you are asking those questions of a loved one who may be being ... who is going through, possibly, the worst time of their life. They are asked in a sensitive way.

Assistant Director, Policy, Communications and Ministerial Support:
Certainly in the U.K. the figures show that where there is a specialist nurse involved it is much more likely that the family will say yes to organ donation.

Acting Clinical Manager I.C.U./H.D.C.:

It is 29 per cent for a doctor ... if the doctor was to approach a family about organ donation. It goes up to 76 per cent if a specialist nurse is involved (DBD death) [12% and 64% respectively for DCD] and that is often because they have the skills and the information for that family at that time and often the questions from the family are things like the timeframes involved, what could they donate, will this affect the funeral arrangements, which is where the specialist nurse steps in.

Deputy J.A. Hilton:
If this becomes law do you think that role of the specialist nurse could be filled by somebody in Jersey?

Acting Clinical Manager I.C.U./H.D.C.:
I think it is something that would have to be explored. From working in Intensive Care Unit we have small numbers of donors. We capture every donor that is a potential in the unit, but we do have small numbers. I guess that would have to be a decision based on the resources available and the amount of patients that would, potentially, be able to donate. But, as we said, this is not about necessarily the number of organs to transplant. This is about informing the public and making sure that we are not missing out any one of those end of life choices.

The Deputy of St. Ouen:
Just for the panel, this is question 29. As one alternative to that a family member, who has been the through the process of organ donation, suggested to us as a panel that there should be a liaison officer within the Health Service to guide families through the organ donation process and to work with the N.H.S. specialist nurse and that person would be independent both of the clinical team caring for the loved one and the N.H.S.B.T. (National Health Service Blood and Transplant) Team. Now, do you think that would help in these situations?

Acting Clinical Manager I.C.U./H.D.C.:
From experience, I can only talk from my own experience, the relationship often between the family and the specialist nurses is very strong. The specialist nurses, throughout the process, keep the family updated. Every eventuality ... you know, we do live in an island. We do have logistical problems with regards to surgeons arriving, organs going off-Island. The family do receive a follow up after the procedure has taken place. Then they receive a follow up after 2 to 3 weeks. So I would say that if there were any issues regarding certain cases I would not be able to state that that is a broad representation of the role of the specialist nurse, and I think this current system in place has always seemed to be very robust.

The Deputy of St. Ouen:

Can we ask about follow up because we are on that topic now? So sort of under the 24 to 29 questions?

Senator S.C. Ferguson:
So judging by what is said, what guidance and training is given to persons engaging with families about organ donation? Do we have any over here?

Acting Clinical Manager I.C.U./H.D.C.:
No. Those conversations are carried out by the specialist nurses but from ... I was in the role ... it was 5 years ago now so things may have changed since I was in the role but you go on an intensive training course, which is about 3 to 4 weeks and that is all about the discussion surrounding how to have those sensitive conversations and that, as far as I am aware, is still the same now. The specialist nurses go through a period of supervised practice before they are left on their own to discuss things with the family. I think, broadly speaking, the reason that those specialist nurses got those jobs is based on their communications skills and I would say that, from my experience, that I have never really experienced any bad or insensitive conversations. There is no training on Island for specialist nurses because we do not have someone in that post but nurses in an Intensive Care Unit naturally are equipped to deal with sensitive conversations although some may not feel as comfortable having organ donation conversations and that is often due to the fact that they do not know the full information so they do not want to give the family information that is untrue at that sensitive time.

Senator S.C. Ferguson:
All right, so basically, from what you have said, there are not any plans to have a specialist nurse on Island?

Assistant Director, Policy, Communications and Ministerial Support:
I think that would be something we would have to look at but I mean given, as Sam said, the number of donors we have each year it might be hard to justify, maybe it is something we could look at, but the other argument would be that the system works very well now, I think, so why would you change it? Otherwise we might be accused of, you know, you have got somebody doing this but they are not gainfully employed all the time, which might be a good thing but you get my drift.

Senator S.C. Ferguson:
Well, you could, I suppose, train somebody who is already here.

Assistant Director, Policy, Communications and Ministerial Support:

Well, we could. ... but I think it would just depend on the situation. I mean Jersey is a small place. You could argue that it might be better to have somebody who is not from Jersey at all, given some of things you might be talking about. A complete stranger, for want of a better phrase, might be preferable than having somebody who might be known to the person. So I think there are pros and cons of ...

Senator S.C. Ferguson:
Yes, because, let us face it, I think you will probably find that, like Sam here, women can multi-task.

Senator A.K.F. Green:
I would prefer to have somebody who does this all the time that is current and up to date coming in with the right support locally than somebody who rarely does it, who may not even be in the Island when the event occurred, I would rather have - and that is no disrespect to whoever that person might be - someone who was up to date, does it all the time, understands the situation of today, not 5 weeks ago or 5 months ago.

[14:45]

Senator S.C. Ferguson:
Okay, thank you. What questions are asked by the specialist nurse to the family about their loved one and why?

Acting Clinical Manager I.C.U./H.D.C.:
Okay. So this goes back to basically what we said before. So they go through a series of questions, so from the obvious choice and they say they want to donate and that ... sometimes we know that already because the patient themselves will have specified that in their lifetime. Then you go on to the risk assessment questions and these questions are done and the information is then sent on to ... well, entered into a database and then the surgeons, who are potentially accepting those organs, will look at that data to risk assess the potential patient against their potential recipient. So there are questions that talk about their sexual history. Have they travelled to any countries where things like H.I.V. (Human Immunodeficiency Virus) and A.I.D.S. (acquired immunodeficiency syndrome) are prevalent? Have they ever had any sexual intercourse with someone of the same sex, intravenous drug use? These are questions that you ask to everyone, regardless of their age. These kinds of questions would be asked to a 75 year-old gentleman, to his elderly wife, in a very sensitive and diplomatic manner but they are asked to everyone. You cannot miss one question based on age or what you deem as a low risk patient.

Deputy J.A. Hilton:

Is there an age?

Acting Clinical Manager I.C.U./H.D.C.:
Eighty-five.

Deputy J.A. Hilton:
Oh, it is 85, is it? Okay, thank you. I was told it was 65 just the other day. That seemed quite young.

Acting Clinical Manager I.C.U./H.D.C.:
No. The oldest eye donor was 102.

The Deputy of St. Ouen:
Sorry, just for the record because this is being transcribed; that is the age at which ... up to 85 you would still consider somebody able to donate their organs?

Acting Clinical Manager I.C.U./H.D.C.:
I would not personally but then that information would be relayed to the surgeons and they would make an assessment based on who was waiting. If you have a patient who was ... I am trying to think. A 65 year-old gentleman’s heart but you have got a patient who is going to pass away within the next few days you would make that decision based on, is this potentially going to give this gentleman another few years of life?

The Deputy of St. Ouen:
Yes, okay.

Acting Clinical Manager I.C.U./H.D.C.:
So there is different ageing with different organs as well.

Senator S.C. Ferguson:
What communication must take place with families after consent is confirmed?

Acting Clinical Manager I.C.U./H.D.C.:
Okay. So the specialist nurse would stay with the family and the patient all the way up until last offices, which is when we lay the patient out after the surgery has taken place. A specialist nurse goes with that patient into the operating theatre, co-ordinates it and makes sure that the process is done with dignity and respect, as you would expect. They then do the last offices alongside the theatre nurses and dress the patient in anything that the relatives would have wanted. They then

inform the family at that point as to what has successfully been retrieved. That does not necessarily mean it has been successfully transplanted because you have to get it all the way to the U.K. and hopefully by the time it gets there that the organs are still viable for transplantation. Once they have been transplanted the family will often get a phone call or an update within a few days to say that they have been successfully transplanted and then they should receive a letter 2 to 3 weeks after the event to give the basic information, which will be: "Mr. Jones was able to donate his heart to a 50 year-old gentleman who is now doing well and out of the Intensive Care Unit." All anonymous. Then a year after the anniversary of their death the families receive a letter as well just as a mark of respect really and they can opt in or out at that point for any further correspondence.

Senator S.C. Ferguson:
All right but ... sorry.

The Deputy of St. Ouen:
Can I just pick up on something said there? You mentioned in the context of transporting the organs, whether they are viable when they arrive. So is the English Channel a risk that means that the organs that might be retrieved in Jersey are perhaps not always of a sufficient quality when they arrive?

Acting Clinical Manager I.C.U./H.D.C.:
No. It is no different from an organ going from Jersey to London than an organ going from London to Glasgow. You would have been mindful of the fact that these organs have been left with no ... the organ is dead. They are in profusion fluids. So naturally things may happen along the journey. Every effort is taken to ensure that does not happen but then at the other side you could have a patient who has deteriorated, who is unable to accept that transplant in the timeframe of the organ being retrieved.

The Deputy of St. Ouen:
I see.

Acting Clinical Manager I.C.U./H.D.C.:
So it is not to say that there is any mishandling of the organs, they are treated with the utmost respect, but we have to be mindful of the fact ...

The Deputy of St. Ouen:
Jersey is in no worse situation than somewhere else in the U.K.?

Acting Clinical Manager I.C.U./H.D.C.:

No. What we often do when you offer your organs is you offer them to your closest logistical centre. So for us we would naturally offer them up to Harefield rather than offer to Glasgow first due to those travelling times but if ... then you work your way up a series of different hospitals until, hopefully, you find a match.

The Deputy of St. Ouen:
I see. Thank you.

Senator S.C. Ferguson:
We had a family member who has been through the process and they suggested to us that there should be a liaison officer available ...

The Deputy of St. Ouen:
Well, I asked that question. I am sorry I jumped in on you. I apologise.

Senator S.C. Ferguson:
You did. I am sorry.

Deputy J.A. Hilton:
Can you explain to us exactly what happens when a person goes into surgery for organ removal?

Acting Clinical Manager I.C.U./H.D.C.:
Okay. So there are 2 different types of organ donations ... there is one which is when the patient suffers from a brain injury and there is one when the patient suffers from something that they are not going to survive, it could be like a stroke or something. They are never going to have any meaningful recovery and their quality of life would be affected. The general treatment of a patient, regardless of which route of organ donation they go down, is no different. It is just means that certain organs ... you can donate your heart with one kind. If you have a brain injury you can donate your heart and if you have not, you cannot. So the patient, if they go down what we call “the non-heart-beating route”, which is D.C.D. (donation after circulatory death) donation, what happens in these patients, these are the patients who may have had a massive stroke, who are going to make a very poor prognosis and the decision with the family then is, that treatment is withdrawn on the grounds of futility. They will often go to the anaesthetic room and the patient will be with their family and they will have their breathing tube removed and the family will be allowed to stay with that patient for a certain amount of time, often up to 2 hours, and if the patient passes away within that 2-hour timeframe they will then be taken to the operating theatre where the surgeons are there ready to retrieve the organs. That sounds like a very sort of whistle stop tour but it is all in conjunction with the family. The family are aware of the situation; that they have to die within a certain timeframe

because obviously what happens is, once that breathing tube is removed the patient may have a slow decline and that would, ultimately, mean that the organs have been deprived of oxygen for a longer amount of time. The other kind of organ donation is what we call brain stem death, which is when a patient has had such a massive catastrophic ...

Deputy J.A. Hilton:
Can I just stop you just there? So if the person, after having a breathing apparatus removed, passes away within 2 hours their ... so they are dead when organ retrieval takes places.

Acting Clinical Manager I.C.U./H.D.C.:
Oh, yes. Yes. I think this is a misconception that ...

Deputy J.A. Hilton:
That is why I wanted to explore this because people do not know.

Acting Clinical Manager I.C.U./H.D.C.:
So once the breathing tube is removed, the patient would be declared dead by a doctor; they would have their heart listened to in the same way as if they were to die anywhere else within the hospital, or the home. They would be ... what we call asystolic. They would be declared dead and then they would be taken through to the operating theatre. The other one which ...

Deputy J.A. Hilton:
Going to stop you there. So if they have not passed away ...

Acting Clinical Manager I.C.U./H.D.C.:
If they do not die, they come up to the Intensive Care Unit and we look after them as we would any other end of life patient but organ donation cannot happen because the organs have been without oxygen for so long.

Deputy J.A. Hilton:
Okay. Thank you.

Acting Clinical Manager I.C.U./H.D.C.:
The family are all completely aware of this. They are told that there is a certain timeframe and a lot of families will often still push for donation because at that point they really want some kind of good to come out of their situation. The other kind of organ donation is a bit more complex, which is the brainstem dead donors. So these are people who suffered a catastrophic brain injury in which there is no ... there is no brain activity left. In order to declare that, 2 doctors have to do what is called

brainstem testing, which is they test the cranial nerves, 2 separate doctors at 2 separate times, and the time of death is then documented on their death certificate at the time of the first set of tests. So for a relative to come in to see their loved one's heart beating, their chest going up and down, but being told that they are dead is a very difficult complex ... but these patients are legally dead by the term of brainstem death, okay? So they are legally dead. So they would remain with us in the Intensive Care Unit and they would be supported because the family have given consent for organ donation. When the time to go down to the operating theatre comes they would go down to the operating theatre, straight into the operating theatre because they are legally classed as ... they have already passed away based on the time of death when they had those special tests. There was no brain activity left.

Deputy J.A. Hilton:
But they are still on a life support machine?

Acting Clinical Manager I.C.U./H.D.C.:
They are but they are technically ... they are legally dead. They feel no pain. There was no consciousness in their brain anymore. They are dead. Then the operation does take place there and then and a doctor would be ... an anaesthetist would still be with the patient and at the time when they cross-clamp the aorta, which is one of the big vessels from the heart, the anaesthetist would then step back and the team would carry on. But for a lay person, and even for healthcare professionals, to understand brainstem death is a very difficult concept but what it does is a series of tests, which test all neurological criteria. Once they are deemed as "no longer alive" their time of death is put on their death certificate but to someone to walk into an intensive care unit you would presume that they were still alive because you can see their heart tracing and their chest moving up and down but there is nothing neurologically.

Deputy J.A. Hilton:
So at what point do they remove the life support system with brain ...

Acting Clinical Manager I.C.U./H.D.C.:
There is no life support because ... the life support is there purely at that point for the purposes of keeping the organs live or because the family have consented.

Deputy J.A. Hilton:
So do they switch that off in the theatre?

Acting Clinical Manager I.C.U./H.D.C.:

At the point when they do the cross-clamping of the aorta the anaesthetist, who sort of deals with the ventilation, would step back then because the aorta has been clamped.

Deputy J.A. Hilton:
That is it then?

Acting Clinical Manager I.C.U./H.D.C.:
Yes. Then the specialist nurse would stay with that patient, as they would the other patient group, until that process is finished and help lay that patient out.

The Deputy of St. Ouen:
Thank you for that. That is a very thorough, excellent explanation. Dealing with the family members, we heard of an issue, Minister, where a person had previously been in hospital and had named a girlfriend as a next of kin. They were close but they were not living together but they saw themselves as a couple but it transpired that that person then had a catastrophic episode and was available for organ donation but, of course, the girlfriend was not regarded in that process as the next of kin. It was parents and others.

Senator A.K.F. Green:
There is a ... as you see there, a scenario ...

Legal Adviser:
Is it talking about whose views you may take into account in understanding the needs of the deceased? This is where the question is.

The Deputy of St. Ouen:
Yes, it is in that area.

Legal Adviser:
Yes. Not to pre-empt the question but I mean if you look at Article 1(3) of the law there is a list of people who are regarded as being in a qualifying relationship to the deceased and it gives what might be considered a sort of table, an order, hierarchy, and you have a friend of longstanding included there. So someone like girlfriends or boyfriends their views could be taken into account by clinicians. There is not a definition of what a friend of longstanding means. To do so would be almost impossible in terms of reflecting every case so it is something which would be taken on a case by case basis. These are decisions which clinicians are quite capable of making in terms of understanding whose views are relevant when the time comes.

The Deputy of St. Ouen:

So if the deceased had nominated a friend of longstanding as next of kin in hospital records on a prior occasion, that friend of longstanding would not be the person to whom the N.H.S. team would look to at this stage if there were still parents, for example?

Acting Clinical Manager I.C.U./H.D.C.:

It is not as clear-cut as "this is the hierarchy" because you could have someone who has been your friend for 25 years but you have absolutely no contact with your parents so that almost puts this hierarchy completely out because you are asking the people who know you the least to make decisions about you. If those kind of situations come up it is not a simple case of just thinking of: Who is on this piece of paper?" You would often go to the G.P. (general practitioner) notes, talk to the G.P. "Have they ever said who they want as their next of kin on their notes?" You will often speak to the broader family. It is not just one set of information. If you are getting to the point where you are having to go to a friend of longstanding you have exhausted all other options before you get to that point. There is a huge amount of detective work that goes on to make sure that the person that you are asking is the right person.

Deputy J.A. Hilton:

We just wanted to understand the hierarchy in a sort of legal context. Who ultimately, where you have an unmarried person that is in a relationship with somebody, have they got priority over a parent for instance? We looked at the list and we saw that the spouse and partner or cohabitating partner was at the top but followed by a parent or child.

[15:00]

So it is just trying to understand in that situation, in the law, who has priority over making decisions regarding the ...

Assistant Law Draftsman:

There is no priority.

Deputy J.A. Hilton:

There is not?

Assistant Law Draftsman:

No, it is just the list does not have an order of priority and so the decision would have to be made at the time.

Acting Clinical Manager I.C.U./H.D.C.:

If you have got 2 people who are at completely opposite ends of the spectrum, ... organ donation would not go ahead based on the fact that the family could not come to an agreed decision because what that would do would ultimately leave one part of the family even more bereaved than they would if something was going ahead but it would also have damaged the organ donation procedure because you were taking organs from somebody who did not agree. So that has never ever happened in my role and I would say that that again comes down to the role of the specialist nurses who are able to tackle those often common misconceptions about why the family do not want it to happen. Often by informing, giving them all the information that they need, they are able to actually come to the decision that: "Yes, this what they all want as a family" or: "No, this is not what they all want as a family" and taking account of the thoughts and feelings of the deceased as well.

Senator S.C. Ferguson:

But if you had a situation where the parents and the cohabiting partner were at "daggers drawn" how are you going to sort that one out?

Acting Clinical Manager I.C.U./H.D.C.:

If you cannot come to any kind of common ground you would not go ahead with organ donation. But I have to say that is very rare.

The Deputy of St. Ouen:

But if the family members cannot provide any evidence that their loved one did not want to donate their organs then the law introduces now a presumed consent but what would happen if the family wished to go one way or another and there is just no evidence from the lifetime of the person who is dying?

Assistant Director, Policy, Communications and Ministerial Support:

If the family are not comfortable with it then it is not going to happen.

Acting Clinical Manager I.C.U./H.D.C.:

That would be no different to what we currently do now. If the family cannot come to an agreement about what the correct course is regardless of whether that person is on the register or not, organ donation will not happen.

Assistant Director, Policy, Communications and Ministerial Support:

Our whole argument is by having these discussions in advance that is less likely to happen.

The Deputy of St. Ouen:

Yes. So, Minister, you might know that in the course of the Scrutiny review we have asked people to send in questions to us and we have got one question which I think is pertinent. This gentleman said ... I do not know, it might be a lady: “It is vital families do not have the ability to override or refuse upon death. The donation must happen unless the deceased had opted out.” So how would you respond to that situation?

Senator A.K.F. Green:
I can understand the black and white situation the person is asking about but we are going for what is known as the soft opt out and if the family did wish to go against the wishes of that member then that is what will happen.

Assistant Director, Policy, Communications and Ministerial Support:
There would be no foundation in law for them to override if they have given express consent already. So someone like me, who is on the organ donor register already, and say my parents decided they did not want to go ahead and they made a lot of fuss then, yes, they would be able to override it because of all of the things we have just said. We would not want to cause a big furore and upset people and all the rest of it. On the basis of law there is no right, if you like, in terms of express consent to override my wishes. However, if I had made no decision at all and we were just talking about “deemed consent” again, in law it does say that obviously you have got to ask the next of kin and all the rest of it and it says that in the law. So those people could, if they say: “Well, Mark said to me just the other day that he did not want any of this to happen” then obviously in law you have got to take notice of that. It says that.

The Deputy of St. Ouen:
Yes.

Assistant Director, Policy, Communications and Ministerial Support:
So there is a difference but we would ... even when people have ... and I know this is what has happened in Wales as well, where people give express consent, and there are many people who think like your correspondent has said, that should be the end of it. It should be the right and it go ahead. It does not happen. Even if there are objections from the family it just does not go ahead and we wanted it that way. That is why we were not going to kind of try and do anything different. We are happy with that. It does not work the other way round, just to reassure Senator Ferguson. I think I said earlier that if somebody opts out the family cannot opt them back in again either.

The Deputy of St. Ouen:

Okay. One other comment we had is a lady who says: “I would like to know if a person chose to opt out of the opt-out organ donation system how can they be 100 per cent reassured that their wishes will be adhered to once they have passed away and not just simply ignored?”

Senator A.K.F. Green:
Okay. So we will have a mechanism but they must opt out with the central register.
Assistant Director, Policy, Communications and Ministerial Support:
Tell somebody.

Senator A.K.F. Green:
I was going to say, I would if I felt that way, speak to my G.P. as well and I would also tell my family members. That is what we want; those conversations to take place. Equally, if someone is very keen that their organs be used when they pass away I would argue that they should do the same, have those conversations, make sure their G.P. knows.

The Deputy of St. Ouen:
Yes. Thank you, Minister.

Legal Adviser:
Can I just add also, it is a criminal offence under the law to deal with a deceased body with transplant activity in the absence of consent. So if that adds reassurance to those who are concerned about how their bodies might be dealt with and ensuring that those involved with the system comply with those requirements then the law is supported with specific criminal offences.

The Deputy of St. Ouen:
Fine. Yes, thank you.

Deputy J.A. Hilton:
Are you making provision to protect vulnerable or at-risk groups under the new system?

Senator A.K.F. Green:
By that do you mean people without capacity?

Deputy J.A. Hilton:
Yes, people without capacity and special needs people.

Senator A.K.F. Green:

Well, the law does cover that. It covers children under 18 and those who do not have capacity, for whatever reason, to make the decision for themselves.

Legal Adviser:
So the deemed consent system will not apply to what are considered to be excepted persons. That is Article 5 of the law. So those are people who lack capacity to understand the notion of deemed consent for a significant period before dying. Those adults who have not been an ordinary resident in Jersey for 12 months immediately before dying and then if you look at Article 6 that provides that deemed consent does not apply to young persons. So in each of those cases express consent to the transplant activity is required.

Deputy J.A. Hilton:
So when you are considering people with special needs, varying degrees of special needs, I am just trying to understand ... and we have talked about capacity but I am just trying to understand capacity around special needs people. I mean are all special needs people treated the same regardless of their disability?

Senator A.K.F. Green:
No. It is about whether they have got capacity.

Deputy J.A. Hilton:
Pardon?

Senator A.K.F. Green:
No. As you know, their disability could be a physical disability but they still have full capacity or they may be deemed to have capacity to make that decision but not other decisions. So it all depends on when that last capacity assessment was made and, as you know, it is time relevant; subject relevant. If there was any doubt about that then it would be down to the family.

Deputy J.A. Hilton:
Right, okay. So basically if there was somebody with learning disabilities who wanted to be on the organ donation register as long as a relevant medical person said they had capacity to understand the decision they were making that would be all right and the same with an opt out decision as well.

Legal Adviser:
All right. If they have capacity to make the decision to become an organ donor then that decision would be respected. What cannot happen is that you cannot presume consent in the case of somebody who lacks capacity to understand the concept that there is a system of presumed consent

because they would not understand the ability to opt out so they would be swept into the system without understanding what the consequences of that system are.

Deputy J.A. Hilton:
Okay. Who has access to the Organ Donation Register?

Acting Clinical Manager I.C.U./H.D.C.:
The specialist nurses check the Organ Donation Register.

Deputy J.A. Hilton:
So that is the specialist nurses in the U.K. ...

Acting Clinical Manager I.C.U./H.D.C.:
In the U.K.

Deputy J.A. Hilton:
... after they have been contacted by somebody here? Okay, thank you.

The Deputy of St. Ouen:
Nobody in Jersey, therefore? Okay.

Acting Clinical Manager I.C.U./H.D.C.:
I do not know. No.

The Deputy of St. Ouen:
Well, not that you know of?

Acting Clinical Manager I.C.U./H.D.C.:
When you ring to find out if someone is on the register you have to go through to the central hub for organ donation. I have not done it for many years but I am sure there must be safeguards in place but I guess members of the public can call up and find out but from our current practice in Jersey we would use the specialist nurses as our go-between to check that.

The Deputy of St. Ouen:
Okay.

Acting Clinical Manager I.C.U./H.D.C.:

Then often if they are on the register a paper copy will be sent or brought over with the specialist nurses as some kind of ... not proof for the family but just to show them: "This is when they did it and this is their signature from their Boots card in 2002."

The Deputy of St. Ouen:
So when I noted how easy it was to go on to the register, because I have done the same online, and if I changed address in the next few years, and there are a number of Richard Renoufs on the register, how can there be any certainty that it is me that it is talking about?

Acting Clinical Manager I.C.U./H.D.C.:
Because what they would often do is confirm with your family as to what your previous address was from the one that is registered on the system.

The Deputy of St. Ouen:
I see.

Senator A.K.F. Green:
Your date of birth is also ...

The Deputy of St. Ouen:
Date of birth.

Assistant Director, Policy, Communications and Ministerial Support:
I think that is what it is because I changed addresses and it asked me various questions to establish I was who I said I was.

The Deputy of St. Ouen:
Yes, of course. Date of birth as well would be a very easy one to check against. Yes, thank you for that. Minister, you have spoken about the sort of lead-in period for the new law during which you will conduct a campaign of the department's work. So what date is it proposed that the law will come into effect, assuming the States pass it?

Senator A.K.F. Green:
I cannot remember. October, I think, next year. October this year?

Assistant Director, Policy, Communications and Ministerial Support:

No. What we would hope is, if I may, is we would be looking at a date for the law to come in and it would be something like 1st July 2019. So obviously it has got to get through the States in April then we give a bit of time. So that is what we will be looking at. About 1st July 2019.

The Deputy of St. Ouen:
Yes, and in the meanwhile can you give us some details of the sort of information campaign you were hoping to put out there?

Assistant Director, Policy, Communications and Ministerial Support:
I think Tom can probably talk about that. There are things that we have got to do. One of the main ones we are going to talk about is a mail drop to all households making them aware of it but I will stop there and let Tom ...

Communications Officer:
Yes, I think it was mentioned earlier about the onus being on Government to ensure this. It is not a question of doing a public notice and having a website that people need to look out and find out about this. The Government needs to be more proactive in making sure the information is not forced upon people but it is very apparent to them and a leaflet drop to all households is very much part of that. The leaflet that will be printed would also be available in appropriate places, libraries, G.P. surgeries, Parish Halls; those sorts of things, where people would expect to find them. We would also use the media. The media are interested in this. It has been covered quite extensively since the Minister first put it forward. Social media; which can also be boosted with a small financial sponsorship. There are also other advertising routes and maybe some routes less travelled such as refuse trucks, branded buses, banners on roadsides. Anything that will alert people to this and direct them towards information and how to opt out or in.

Senator A.K.F. Green:
Yes, we have a lot of correspondence with our patients and so there is no reason why the second leaflet could not be in a letter or some mention to it on the footer of the letter or whatever.

Assistant Director, Policy, Communications and Ministerial Support:
You could imagine some kind of slogan like “Time to Talk” or “Time to Choose”. We could put that somewhere, in all sorts of different places, to make sure people have this. There are free Parish magazines, we will get in those. There are lots of avenues I think we can use.

Hospital Director:
I think it is fair to say that the experience in Wales was very media intensive. It became part of a national debate. So there is a formal approach in terms of getting the messages and the information

out there. There is something about an intuitive debate as well so that people can ask the questions, so they have to think about those options in terms of being able to have an interactive discussion about questions that people might have. This is very important.

Senator A.K.F. Green:
Chairman, before you go on, just in case you have got a lot of questions you would like to ask ...

The Deputy of St. Ouen:
We are coming to an end.

Senator A.K.F. Green:
... Sam does have to be away by 3.30 sharp. So if you wanted to focus those questions and keep the rest of us a couple of minutes later, fine.

[15:15]

Deputy J.A. Hilton:
Can you tell us what happens to organs which are not used and how relatives are told?

Acting Clinical Manager I.C.U./H.D.C.:
Okay. So when a relative is asked about organ donation they consent to research. If they want to consent to research they can. The overarching principle of organ donations is organs are only ever taken for the purposes of donation but, for the reason I spoke about before, you may have an organ that is not viable by the time it gets to the recipient or the recipient is too unwell to receive that organ the organ would be then ... obviously it cannot be put back in so it would be disposed of as per the hospital policy from where it lands, unless the family have consented to research, and it would be entered into a research pool. The family would typically have consented to the research and are told all this during the process that in the event that they cannot be donated this is what the options are and many families will go for research as opposed to disposal. The families are then told on the day or even by the time it gets to the other side that the organ unfortunately was not able to be transplanted.

Deputy J.A. Hilton:
So they are told that more or less straightaway?

Acting Clinical Manager I.C.U./H.D.C.:
Pretty much straightaway, yes.

Deputy J.A. Hilton:

Okay. Can you remember there was a scandal involved in the Bristol Children's Hospital, the heart scandal, where they ...

Acting Clinical Manager I.C.U./H.D.C.:

That was to do with storage, was it? The storage of organs.

Deputy J.A. Hilton:

Yes. So are you saying that organs that are not used are basically incinerated?

Acting Clinical Manager I.C.U./H.D.C.:

Incinerated, yes.

Deputy J.A. Hilton:

So that is ...

Acting Clinical Manager I.C.U./H.D.C.:

They will be disposed of as per hospital policy.

Deputy J.A. Hilton:

All right, okay. That brings us to Article 2 in the law. I just wanted some clarification around Article 2 because ... I was looking at the explanatory notes on page 28 and so you have Article 2, which defines the term "transplantation activities mean" then it gives 5 different explanations. So underneath it says: "By Article 2 the term 'specified activity' is defined to mean a transplantation activity will ... of the body of the deceased person for use in teach of anatomy, medical education and research, therapeutic purposes or any other activity as may be specified in regulations made by the States." I just wanted some clarification around that. Does that mean that somebody who has opted in and they have agreed to their organs being used that the State can also use their body for medical purposes?

Legal Adviser:

No. So you would opt in for specific purposes. So you would opt in for transplantation to, I guess, a family member or you could say: "I give my body to science." I think that is how the opt-in organ system would work. You are specific when you are asked to opt in to specify how your body is to be ... the material is to be used. I understand. I mean I am not sure how it works in practice.

Deputy J.A. Hilton:

Right, okay. It is just that Sam did mention that if the organ was not used for transplantation that the family might be asked, could it be used for medical research, and Sam said that ...

Senator A.K.F. Green:
Sam did say that. That question is asked at the same time as agreement to organ donation.

Deputy J.A. Hilton:
Yes, that is right. But I am just trying to understand what this means.

Legal Adviser:
Well, Article 2 defines these various activities for the purposes of the law so that is for tying the concepts of a plan for a consent; how a deemed consent might be used. I suppose it is a construction mechanism in the drafting by saying that if you are doing any of these activities, whether you are doing transplantation for medical purposes or whatever, it is a specified activity and to undertake the specified activity you need consent under Article 4. If it is an accepted person then this is what you need to do in order to undertake the specified activity. So it is more a mechanism for tying the provisions in the law to the activity rather than specifying necessarily what happens in the occasion of each particular type of donation.

The Deputy of St. Ouen:
Is your ultimate fear, Deputy Hilton, that the authorities might take an organ for use in medical research in one of the teaching hospitals?

Assistant Law Draftsman:
They would not be able to do that. They would only be able to do it if the person consented to the specific activity.

Deputy J.A. Hilton:
Okay, that’s fine.

Senator A.K.F. Green:
If you are worried about something like what happened with the Bristol Children’s Hospital ...

Deputy J.A. Hilton:
I just really wanted to completely understand what that meant and I understand if you are opting out or opting in you are sending something off and that is giving consent, as long as the family agree, the soft option, that is giving consent for the organs to be removed but that was talking about medical educational research or the teaching of anatomy. So that is ...

Assistant Director, Policy, Communications and Ministerial Support:

When you fill in the form for an organ donation card, it says: “I consent to my organs being used for transplant research if they are not suitable for transplantation” and you would put a tick so that would link in back to that.

Acting Clinical Manager I.C.U./H.D.C.:

The family would be asked that as well on their consent form.

Deputy J.A. Hilton:

Okay, thank you. There was just one other question I just put down here. When you have somebody in intensive care what happens if you cannot find next of kin and how much time do you allow before you decide, I presume, to sort of abandon the idea?

Acting Clinical Manager I.C.U./H.D.C.:

Yes. I think, again, that is extremely rare. You would always find someone who meant something to that ... you know, the last case scenario.

Deputy J.A. Hilton:

Even if it was a friend?

Acting Clinical Manager I.C.U./H.D.C.:

Even if it is a friend. So I think that is extremely rare and I do not think I have ever come across that in 12 years of working in the critical care that we have never been able to find someone. I guess if you were talking about organ donations, they were not actively on the register or had not actively opted out; in/out, you would not go ahead with organ donation if you did not have a definite answer. So no.

Deputy J.A. Hilton:

Okay. All right, thank you.

Assistant Director, Policy, Communications and Ministerial Support:

Because remember the other reason for asking family and friends is because you need to ask some of these personal questions, if you like, about their history. So you would not go ahead if you could not find someone.

Deputy J.A. Hilton:

No. Okay, thank you.

The Deputy of St. Ouen:

Sarah, have any questions for Sam?

Senator S.C. Ferguson:

Probably I think for the legal gentleman but I am ...

The Deputy of St. Ouen:

But just before Sam needs to go. Do you need any around the process?

Senator S.C. Ferguson:

No, I do not think so.

The Deputy of St. Ouen:

I do not so please feel free and thank you for your assistance and it has been very helpful to hear from you.

Senator A.K.F. Green:

It is very useful to have someone who has done it.

The Deputy of St. Ouen:

It has been, yes, that is right. Sorry, we were talking just before about intuitive questioning and we have had one person who has spoken to us who was very concerned that families should not just think it is ... the organ donation process is easy and they just need to say yes. They want people to understand about this very difficult questioning that has to go on because they found that difficult. So, therefore, in the course of the educational campaign that will go on, can we just go beyond the idea that “is this not a great thing to happen” and try and educate people sensitively about the traumatic time, the extent of the questions they will need to be involved in, just so that that does not come as a surprise to people should it ever happen. I know it will be rare. But should it happen that there might be some understanding of what they will be asked. Can we achieve that in some way?

Assistant Director, Policy, Communications and Ministerial Support:

It is a bit like blood donation, is it not, when people give blood? It is similar type of questions that are asked.

The Deputy of St. Ouen:

Yes, but it is not the traumatic situation that people are facing.

Senator A.K.F. Green:
They will also be answering about life activities or health or whatever rather than somebody else. So I think you make a really good point, Chairman, that it becomes less shocking if people are expecting those questions to be asked.

The Deputy of St. Ouen:
Yes, that is right. That is important. We also had another email from a gentleman of Portuguese origin who was concerned about the fact that many Portuguese speakers in the Island, and Polish I suppose, will not be able to access this information so can we address that?

Senator A.K.F. Green:
As part of the campaign they will.

Assistant Director, Policy, Communications and Ministerial Support:
We intend to translate it into the relevant languages, yes.

The Deputy of St. Ouen:
That is good. That is encouraging to know. Senator Ferguson, you indicated you had some more questions.

Senator S.C. Ferguson:
Really it is this parallel procedure, leaving the body to science, where the consent cannot be changed after you are dead and the organ transplant set up. I just wonder if you could just check the rules governing leaving a body to science compared to organ transplant just to make sure that the ... because you are the legal gentleman, are you not?

Legal Adviser:
I am.

Senator S.C. Ferguson:
Yes. If you could just check to make sure that we have not got 2 laws that are ... or 2 processes ...

Legal Adviser:
Well, this will be law.

Senator S.C. Ferguson:
Yes, but obviously when I read things like: “If you leave your body to science nobody, including your family, can change the decision after you are dead.”

The Deputy of St. Ouen:

Can we just ask if that would be the case under this law?

Legal Adviser:

No. Well, I do not know what ... sorry, forgive my ignorance. These rules which you are talking about, Senator.

Senator S.C. Ferguson:

Well, I am talking the human tissue authority, talking about, how do I go about my leaving my body to science; not that I think anyone would want mine but that is another story.

Senator A.K.F. Green:

I was not going to say anything, Chairman, but ... **[Laughter]**.

Senator S.C. Ferguson:

I beat you to it. No, but if there is variance between the rules can we just make sure, please, that they do not contradict each other?

Senator A.K.F. Green:

If it puts your mind at rest we will have a look at it but it is not relevant to what we are doing today.

Senator S.C. Ferguson:

Yes, please.

The Deputy of St. Ouen:

No. So is it relevant that this law repeals the Anatomy and Human Tissue Law of 1994?

Senator S.C. Ferguson:

No, I did not see that bit.

The Deputy of St. Ouen:

So that is right at the end of this law because it has all been brought forward into this, is it not?

Legal Adviser:

This law, like the 1984 law ...

The Deputy of St. Ouen:

Article 23.

Legal Adviser:
... is the current law and it will remain the current law until next year and that provides for organ transplantation for medical purposes and also for anatomy and teaching purposes. That will be all repealed and those provisions will be re-enacted but what this law is doing; it is bringing in the presumed consent, a system of provisions around presumed consent, so you have a system for expressing consent to organ transplantation and we are bringing in a system for presumed consent. So we are bringing forward existing provisions and existing concepts around donation and making sure you are on the register for organ donation by bringing forward this new system of presumed consent which is where the consultation and interaction is and looking at how it worked in Wales and develop a policy. So the 1984 law will be repealed but there are elements of that law which are being brought forward in this new piece of legislation so it is a more comprehensive system of legal provisions around organ donation for both express consent and/or circumstances where you can deem consent to be given.

Senator S.C. Ferguson:
That covers leaving your body to science as well?

Legal Adviser:
Yes.

Senator S.C. Ferguson:
Thank you.

The Deputy of St. Ouen:
Have you got any more questions?

Senator S.C. Ferguson:
No, not from me.

The Deputy of St. Ouen:
So, Minister is there anything more you would like to tell us about the law or what is your proposal? I have got one question. Right at the beginning you mentioned that you had consulted with a local transplant committee.

Senator A.K.F. Green:
Yes, a hospital transplant committee ...

The Deputy of St. Ouen:
Can you explain that?

Senator A.K.F. Green:
... which is made up of hospital consultants, the hospital director and Sam and they meet regularly. I do not want to say this wrongly, they meet regularly anyway and they also meet with their Colleagues from the NHS Blood and Transplant Service also attend. When I was first minded to follow closely what Wales was doing I met with the committee.

The Deputy of St. Ouen:
Again, what is the role of the committee?

Acting Clinical Manager I.C.U./H.D.C.:
So the committee is something that exists in every N.H.S. trust within the U.K. and the aim of the committee is to basically look at recent practices within our own unit. As the Minister said, it is made up of myself with our chair and we have lay members who have an interest in organ donation. We have consultants who work on the ... who may be renal physicians who have an interest in donation and we also have the specialist nurse affiliated with our area who comes over for this meeting. They are held every 6 months. The aim of the meeting is to discuss organ donation issues and look at things to do with things like memorials in our own hospital, looking at; how can we commemorate these people who make this decision. Looking at recent cases, is there anything we could have done better, and if it went really well?

[15:30]

So it is just like a general forum to discuss organ donation and we do discuss things obviously about the reason we are here today and looking at how we can increase our numbers within the Island and this is something that happens in every other N.H.S. trust ... well, every N.H.S. trust in the U.K.

The Deputy of St. Ouen:
Yes, I see. Always striving to improve. That is good to see. Thank you very much, Minister. It has been a very informative meeting and I am grateful to you and your team for coming along. Thank you and that brings an end to this public hearing. Thank you.

[15:31]