



Northern Ireland
Assembly

Committee for Health, Social Services and
Public Safety

OFFICIAL REPORT (Hansard)

Human Transplantation Bill:
Consultant Surgeons

2 December 2015

NORTHERN IRELAND ASSEMBLY

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Members present for all or part of the proceedings:

Ms Maeve McLaughlin (Chairperson)
Mr Alex Easton (Deputy Chairperson)
Mr Thomas Buchanan
Mrs Pam Cameron
Mrs Jo-Anne Dobson
Mr Kieran McCarthy
Ms Rosaleen McCorley
Mr Michael McGimpsey
Mr Daithí McKay
Mr Fearghal McKinney
Mr Gary Middleton

Witnesses:

Mr Tim Brown	Belfast Health and Social Care Trust
Mr John Connolly	Belfast Health and Social Care Trust
Dr James Douglas	Belfast Health and Social Care Trust
Mr James McDaid	Belfast Health and Social Care Trust

The Chairperson (Ms Maeve McLaughlin): Jo-Anne Dobson has declared an interest: do any other Committee members have an interest to declare? No one. OK. While she is on this side of the table, Mrs Dobson will be treated the same as any other Committee member. Only when at the other end of the table will she be treated as a witness, as would any private Member. Should any issues come to the fore out of this or the next briefing that need to be followed up on by the Bill sponsor, they will be followed up in writing. I just wish to make that clear.

I welcome our guests. We have Mr John Connolly and Mr James McDaid, both consultant surgeons at the Belfast Health and Social Care Trust, and retired consultant Dr James Douglas. I have been informed that we have another guest: Mr Tim Brown will also join us to give evidence. You are very welcome.

Mr Tim Brown (Belfast Health and Social Care Trust): Thank you very much.

The Chairperson (Ms Maeve McLaughlin): The normal practice is to ask you to make an opening presentation, after which we will open up the meeting to questions or comments from members. Is it you to begin, Mr Connolly?

Mr John Connolly (Belfast Health and Social Care Trust): Yes. The Belfast Health and Social Care Trust, as providers of the only solid organ transplant service in Northern Ireland, has an obvious

interest in the proposed legislation on organ donation. Although fully supportive of the principle of increasing the number of deceased donor organs available to provide life-saving transplantation, we are cautious about any change that, although well-meaning, will potentially have a detrimental impact on the public's willingness to donate.

There are differing opinions in the medical profession and society at large on the acceptability or utility of an opt-out system. The perception that it effectively means acquisition by the state of body parts and the removal of the altruistic aspect of donation is of concern. Those and other ethical issues have prevented the global adoption of presumed consent legislation.

A Public Health Agency (PHA) survey in 2013 demonstrated a general support in Northern Ireland for organ donation but also considerable misunderstanding of the issue of consent. Another worrying feature, from our point of view, is that 10% of the people surveyed considered that the medical profession may compromise the treatment of patients purely to promote organ donation.

Does the opt-out system work in other countries? The comparator of donor rates between countries is one measure of the success of any system. The gold standard that is the Spanish system is often quoted but often misrepresented. As recently as yesterday, Rafael Matesanz reiterated that the success of the Spanish system is due to the development of organisational structures, education and training.

Following the UK Organ Donation Taskforce report in 2008, organisational change was implemented, with the separation of donation services and transplant services. Clinical leads and specialist nurses were attached to specific intensive care units (ICUs), and there was a resultant 60% increase in organ donors. That dedicated clinical expertise has seen, in the most recent figures, a rise in the consent rates for donation after brain death (DBD) to 80% in the Belfast Trust, a figure that is already comparable to the Spanish rate. From the transplant clinician's perspective, the end point is the number of transplants performed, not the number of donors. In Northern Ireland, we have taken a different approach by emphasising the benefits of living donor transplantation. This has distinct advantages in the quality of organs and therefore the long-term outcomes for patients, more particularly in the ability to help those who would have no prospect of a transplant from the deceased donor pool.

In the past year, we have transplanted 35 out of the 37 longest-waiting patients on dialysis, the longest-waiting of whom had been on dialysis for 21 years. The innovative approach of the Belfast team has become an intense source of interest and, I dare say, excitement to the transplant world. Above all, it is a reflection of the generosity of our community. Notably, we have the highest rate of altruistic donors in the UK; that is, people who are willing to donate a kidney simply to help someone whom they do not know.

I will put that achievement into international context. Spain last year had an overall kidney transplant rate of 54.2 per million population, and Northern Ireland had a rate of 54.1 per million population. This year, as it stands, if we do no more deceased donor transplants, the transplantation rate in Northern Ireland will be 64.4 per million population. That should be highlighted as an international success. It has been made possible only by the motivation of people in the clinical sphere who are pioneering change and by the foresight of those in the public service, such as the Health and Social Care Board (HSCB) and the Belfast Trust, who have invested in the personnel and infrastructure required for the programme. Obviously, we are supportive of every measure that will provide more transplant opportunities for the people of Northern Ireland — indeed, I hope that I have made it clear that we are in favour of innovative thinking — but anything that we embark on must be made with a clear indication of support from the Northern Ireland community.

We have currently a hugely successful transplant programme and, therefore, a lot to lose if we get it wrong. That is why we as a clinical group have expressed some hesitation at adopting legislation that is as yet unproven in its benefit. The instigation of the Human Transplantation (Wales) Act 2013 gives us an ideal pilot study to determine the consequences of a change in the law of consent. We suggest therefore that hesitation may be appropriate at this time. First, deferring any change would allow for continued public education and re-evaluation of the impact of the Public Health Agency's campaign. Secondly, it would allow assessment of the effect of the change in Welsh legislation, which we hope will be very positive.

I thank the Chairperson and the Committee for their attention.

The Chairperson (Ms Maeve McLaughlin): Thank you, Mr Connolly. We will open it up the meeting to members' questions and comments. I will start. I think that you are right that the numbers on live kidney donor rates are impressive, but I hear from your evidence that you are recommending caution on legislation. That caution seems to be around the potential to damage public support.

Mr Connolly: Yes, I think that that is our concern. What came out of the Public Health Agency's original survey was some confusion on the part of the general public about what deemed consent — presumed consent, as it was called — really amounts to. Our concern is that that may backfire on us if it gets into the realm of a conflict between donor families and the medical profession, literally at the point of deciding whether or not donation should go ahead. That is where our concern comes from.

The Chairperson (Ms Maeve McLaughlin): It is in and around public support, and then, obviously, you suggest that legislation should come in after an assessment of the impact of the Welsh legislation.

Mr Connolly: Wales has not quite as good an organ donation rate as Northern Ireland, but it is a little closer to us in standards compared with the rest of the UK. The impact of the Organ Donation Taskforce from 2008 — the committee led by Elisabeth Buggins — is still to work through. We are about five years down the line from the implementation of that. We in Northern Ireland in particular also have specific areas to do with donation after cardiac death (DCD) to improve on. The rest of the UK has been ahead of us on that, and now is the appropriate time for Wales to test the concept of deemed consent.

The Chairperson (Ms Maeve McLaughlin): Do you agree that there is a counterargument that legislation could be effective?

Mr Connolly: Absolutely. We have an open mind on that. We would like to see that it does have an effect.

The Chairperson (Ms Maeve McLaughlin): When wider society looks at the discussion, it sees that it is about not losing opportunities.

Mr Connolly: Yes.

The Chairperson (Ms Maeve McLaughlin): We are looking at the number of deaths as a result of delays on waiting lists and all of that and at what we can do on organ donation. A publicity campaign around awareness does not have to be to the detriment of a legislative process.

Mr Connolly: No, absolutely not.

The Chairperson (Ms Maeve McLaughlin): In fact, they are complementary.

Mr Connolly: It is essential. That is one thing that comes out of it. Every survey that is done shows that the public are in favour of organ donation. About 70% or 80% are the rates that we are looking at, yet only 30% of our population are signed up to the organ donation register. There is a disconnect there. The main problem areas are, I suppose, people at the two extremes of life: young people who, of course, believe that they are not going to die and old people who do not want to consider their impending closing years. There is plenty of work and plenty of opportunity there, and we certainly want to continue with that.

The Chairperson (Ms Maeve McLaughlin): It is useful to clarify that legislation is not necessarily counterproductive to an awareness campaign, that they can run together and that you are open to the notion of legislation.

You are flagging up the issue of losing public support, but surely there will always be sensitivity with this issue, even if legislation is passed. Are your concerns that legislation might be used insensitively?

Mr Connolly: If the legislation is framed in a manner in which it can be used insensitively, it has failed. There has to be a degree of flexibility for the clinician who is undertaking the request of donation from a deceased donor's family or a potential donor's family. In Austria, there is hard opt-out, whereby families are excluded from the decision-making process. That would be totally detrimental. We are a small enough community for word to travel quickly, and it does not take long for it to get into the media

as well. We have to be seen to be doing what families want. We are a very close-knit community in that regard. If potential donors had previously expressed their consent to donation, that would be ideal, because it would take the matter to a different level of discussion.

The Chairperson (Ms Maeve McLaughlin): I assume that, by taking that a step forward, the degree of flexibility that you have talked about is not currently reflected in the Bill.

Mr Connolly: May I defer to Dr Douglas on that one?

Dr James Douglas (Belfast Health and Social Care Trust): I am no longer clinically active, but I am here because I am on the council of the British Transplantation Society (BTS) and I take a medical-legal interest. In fact, a colleague and I wrote an article for the 'Modern Law Review' analysing the Welsh Act. I think that it is the only one that has yet been done, so I have taken a lot of interest in it.

We think that the main strength of the Welsh Act is its encouragement element. It is about encouragement and not enforcement. That is what we think the Welsh Bill does. The main thing is the commitment to promoting education and awareness of the public. It is trying to approach every individual and say, "You are able to deem". That is a very good thing. The possible weakness of the Bill is that, although it states that next of kin have no actual legal right to object in the case of deeming, they will be listened to if they become very distressed. That is a potential weakness of the Bill. It might be preferable if the relations are always given a right to object.

On the way in which the Bill is drafted, we are a bit concerned about the deeming condition in clause 4, which states that deeming is only effective if a person — a relative — affirms that the person would not have objected. We feel that, as that stands, it is taking a lot of the effect of the deeming away and possibly leaving only whatever negative effect it might have. There is, of course, a very narrow difference between not objecting and consenting. The problem is that, as the Bill stands, there is no condition under that rule for the relations of the deceased, if they do not know what the deceased's opinion was, to give consent in their own right. I am sure that that is available under the present law. As the Bill stands, there is no obvious way in which the relations can say, "We do not know what he thought, but we would like to do it". That needs to be changed. Would it not be better just to say that, if there is no objection from the person or the relations, you can do it? In other words, the relations would always have the right to object, like in some of the presumed consent laws in France, Belgium and elsewhere. As it stands, the Welsh Act is fairly hard, but it is alleviated by the fact that it promises that it will never go against the relations if they are very upset. That is a weakness in the Welsh Act. I feel that the drafting of the Bill should be looked at. That is my main argument. I think that the Welsh Act may prove effective, but it will take time to work that out.

The Chairperson (Ms Maeve McLaughlin): Effectively, it is about the legal right of the next of kin.

Dr J Douglas: It is about how it is put. We could finish up with a situation in which we deprive ourselves of organs that people would like to give. It is a matter of looking at the drafting.

The Chairperson (Ms Maeve McLaughlin): Do you think that hospitals could do more to increase organ donation rates? I think specifically about identifying potential donors. Do we have enough staff to liaise with families?

Mr Brown: Thank you very much for that question. NHS Blood and Transplant (NHSBT) is our overarching governing body, and, given the infrastructure changes made in 2008, with the injection of resource for specialist nurses and the clinical leads for organ donations, a big part of its role is to identify donors in ICUs. At each stage of the donation process, it clarifies why people are deemed inappropriate. There are also regular meetings to discuss whether a potential donor has been missed. All that data is picked up on extremely well and audited. It is transparent for the entirety of organ donation, and, indeed, the whole population can identify the data on the organ donation and transplantation (ODT) website. In fact, the hospitals are extremely well resourced, with specialist nurses and clinical leads in every intensive care unit in the country. As a result, all the data that you ask about is completely transparent and easily accessible. Whoever invested the cash is to be congratulated for the amount of infrastructure placed in organ donation. As we have seen from 2008 to 2013, the organ donor rate went up by 49.7%, and that is an incredible legacy for whoever put that in place.

The Chairperson (Ms Maeve McLaughlin): Are staff able to liaise with families?

Mr Brown: Personally, I think that our specialist nursing team is extremely well resourced in Northern Ireland, and we are very grateful for their input.

The Chairperson (Ms Maeve McLaughlin): I raise that because, in our initial discussions on the Bill, it was suggested that we did not have enough staff in place to facilitate the process.

Mr Brown: Do you mean in the intensive care units or the specialist nursing units?

The Chairperson (Ms Maeve McLaughlin): Both.

Mr Brown: I cannot comment on intensive care staffing levels, but specialist nurses in Northern Ireland are currently very well resourced.

Mr Connolly: The only thing that I would add to that is that the training provided to intensivists or anaesthetic staff who are specialists in the ICU field needs to be extended across all personnel who are appointed to ICUs. At the moment, we have a clinical lead — a senior consultant — in ICUs who is responsible for complying with the potential donor audit and identifying donors, but one can foresee circumstances in which someone does not have the skills to deal with a potential donor's family. Those are learned skills that come as part of training. You have seen the results with the specialist nurses. There has been an 80% consent rate for DBD in the Belfast Trust over the past six months. That is the same as for Spain. However, for donation after cardiac death, where patients have had life support withdrawn, the decision has been taken by the medical staff, without specialist nurses with their experience being present. The success rate is 37%, so there is a stark difference. We would like to see a more integrated approach across the board. It already works in some fields.

The whole area of DCD, you must remember, is a very recent phenomenon in Northern Ireland. We have had the facilities to do it only since my two colleagues joined us within the past two years. We are still developing. We anticipate that there will be substantially more donors coming from that area as well. Investment in time and in training medical staff and getting them to work as a team with the organ donation specialist nurses is, I think, going to be very productive.

The Chairperson (Ms Maeve McLaughlin): You think that those changes, by which I mean the 37% that you talked about, is as a result of —

Mr Brown: For your information, there are two types of donor. There is a donor after brain death, which is the traditional donor; for example, someone with a catastrophic injury who is declared brain-dead in the intensive care unit. The organs are retrieved in the warm phase. That has been the traditional donor over the past 20 years. As part of the massive 49.7% increase in organ donation rates over the five-year period from 2008 to 2013, which we referred to earlier, there has largely been a realisation that donors after cardiac death are now a much-valued resource. If you look at the organ donor end-of-life pathways across the UK, you will see that it is now roughly 50:50 across the country. Northern Ireland identified donation after cardiac death relatively recently, as John referred to, and, as such, we are lagging behind the exponential growth in that potential type of donor, yet the specialist nurses in the country are becoming very expert at identifying them and managing the donor families through the process.

If you look at the organ donor consent rates from DBD and DCD across the UK as a whole, you will see that there is a big drop-off in consent rate from DBD to DCD. The key objective of taking organ transplantation to 2020 is to increase the consent rate across the board. One way in which it has been identified to increase the consent rate is to make sure that the specialist nurse is involved with the clinician dealing with the patient when the family is approached at the time of discussion of organ donation. That is where the key message has to go to the intensive care team to involve the specialist nurse before the team approaches a family when considering organ donation.

Mr Connolly: I will clarify what I said, Chairperson. I have the actual figures here. The referral rate from April to September 2015 to include a specialist nurse in the Belfast Trust was 35%. The consent rate given for DCD was 57%. Overall, in the first six months of this financial year, there has been an 18% increase in organ donation in the Belfast Trust.

Mr Brown: A 45% DCD consent rate is huge compared with the rest of the UK, where it is at roughly 40%. Fifty-seven per cent is way outside the box. My view is that Northern Ireland is doing extremely well and improving every month with our organ donation rates. Why would we do anything to stop that

when we have a pilot scheme that kicked off yesterday in Wales that we can take advice from in the next couple of years? The word "hesitation", which we used in our letter to the Committee, is a very apt word.

Mrs Dobson: Thank you for your briefing. Predictably, I suppose, I am going first.

I have nothing but admiration for the life-saving work that you do, and I appreciate you coming to the Committee today. Dr Connolly, I do not know whether you remember me or my son.

Mr Connolly: I do indeed.

Mrs Dobson: All those years ago. You did not actually do Mark's transplant — it was Mr Omar — but you met him in the build-up to it. It was a very difficult time in my life, and I thank you, almost seven years post transplant. Thank you for your support.

I will focus for a moment on the findings of the 2013 PHA public survey, in which health service staff took part, including those directly involved with organ donation. Its findings stated that the greatest hesitation — Tim used that word as well — came from those closest to potential donors and their families. I understand that. The survey went on to state that some were not opposed to soft opt-out but felt that the time was not right for it. I know that you have outlined it in your briefing, but do you oppose soft opt-out in principle or because of the timing?

Mr Connolly: I do think that we have any objection at all to soft opt-out; that is the point that we have been trying to make. We are very supportive of any innovation that can improve organ donation. All that we are concerned about is that we may lose the confidence of the public. In particular, it may come down to the practicalities of the implementation of the Bill — the interaction between ICU staff and potential donor families. If we were to take a hard line and if the medical people involved were particularly zealous and wished to enforce donation against a family's will, which, technically, they could do —

Mrs Dobson: But they do not.

Mr Connolly: They will not.

Mrs Dobson: And I would not want them to.

Mr Connolly: And we would not want them to. I agree.

Mr Brown: Personally, I have an objection to soft opt-out. One of the overarching tenets of medical ethics is the concept of autonomy. Assuming that somebody has given consent when they have not is a violation of autonomy, and I have a grave concern that soft opt-out would be in direct competition with the concept of autonomy. We spend an awful lot of time every day that we operate on people taking very informed consent for every procedure or activity. There has been coverage in the press recently of the case of *Montgomery v Lanarkshire*. Consent is becoming more and more detailed, and people are having to go into consent in so much more detail — sorry for repeating myself — so why on earth are we talking about a procedure that would leave people with less consent, when society as a whole is looking at consent in an awful lot more detail?

Mrs Dobson: OK. In your letter, you raised concerns about the soft opt-out system having, I think, a "detrimental impact" on the public's willingness to donate. That was certainly not the experience in Belgium. Given that we have a similarly high level of trust, if not a higher level, in our health professionals in Northern Ireland, are you aware of the willingness to donate reducing after the introduction of a soft opt-out system?

Mr Connolly: It certainly took a very significant downturn in France and was abandoned in Brazil. I do not think that we will look at Brazil. I have to be careful what I say about the French, but they are single-minded, and I suppose that there was a sort of anti-authoritarian backlash. Of course, bringing in the idea of deemed or presumed consent throws open the whole area of informed consent, which is something that we in the medical profession are really bound by. I know that the General Medical Council (GMC) is looking at that as well. James may be able to advise us on that. It will raise philosophical problems in the interpretation of what is true consent.

On the number of places that have, in recent years, adopted an opt-out system, there was not enough clarity to say that donation was entirely due to the opt-out system, because, almost everywhere, it ran in conjunction with organisational restructuring, investment and training. As I said, I have spoken to Rafael Matesanz on a number of occasions over the last 25 years, and that is his emphasis: it is the skill of the people in the intensive care units that brings about high donation rates. Our problem is the separation between the number of people who have expressed their consent prior to death and those who die without having indicated through either the organ donor register or discussion with their family. That area would, of course, be greatly beneficial to our system. It is that lack of clarity at the time of death that will always be the problem.

Mrs Dobson: When Dr Aisling Courtney presented to the Committee two years ago, she spoke in favour of the opt-out system. I wholeheartedly agree with her comment about translating talking about it into doing it. I know that you referred to it earlier, but I want to, again, pay tribute to the amazing live donor programme that she and Tim lead here. Recently, I spoke to Belgian transplant expert Luc Colenbie, and he suggested that the Belgian experience was that live donor levels eventually plateau. Will you give us your view on that?

Mr Connolly: I think that that is inevitable. Our concern, of course, is that not everyone who is on a transplant waiting list will have a potential live donor. In other words, it does not have to be a family member; it can be a friend or an altruistic donor who is a suitable match. You are absolutely right: there will inevitably be a limit to the number of people, and there will be those who are left behind. That is always on our mind, which is why we engage with the deceased donor programme. We have not given up on it. It is an exceedingly important part of organ donation in its entirety. At the moment, our programme in Belfast is roughly 50% deceased donors and 50% living donors. They work together.

Mr Brown: Our deceased donor transplant rate is up 20% on last year. We have a very good deceased donor programme.

Mrs Dobson: Obviously, a live donor programme is for kidneys only.

Mr Brown: And livers.

Mrs Dobson: And livers. I certainly agree with the view that you expressed in the letter about the power of an education programme. Can you guarantee that the live donor programme will continue to rise in numbers if, as you say, there is hesitation in relation to the change in the law? What is your position on that?

Mr Connolly: That is an area that raises some concern. It is probably more a concern that has been voiced in the media that there is a correlation with countries that brought in an opt-out system and suffered a downturn in living donor numbers. There seems to be that correlation, but there are many ways of explaining it. You could say that Spain's system was so successful with regard to deceased donors that they did not need to invest in a living donor programme. They are now changing that because they have reached the limit of their deceased donor expansion.

We have some way to go in our deceased donor promise in Northern Ireland. Without doubt, the rest of the UK is a long way behind what we have achieved here. The living donor programme continues to expand, which has astounded even us. We expected to plateau three years ago, but we are still expanding year-on-year. I think that, this year, we will have 66 living transplants in Northern Ireland.

Mrs Dobson: Yes, and it is superb. I am just thinking about the fact that, last year, no one from Northern Ireland got a heart transplant, for example, a point that the British Heart Foundation (BHF) raised.

Mr Connolly: I cannot really speak for that, but heart transplants are fairly few in number throughout the UK. Probably a feature of that is the shift in deceased donors to donors after cardiac death. The number of brain-dead donors and cardiac death donors is now, roughly, 50:50, which will impinge on the availability of hearts.

Mr Brown: That is a very interesting statistic. You see the number going up exponentially over 2008 to 2013, and all organ types are represented in transplant numbers. Donors were 50%, and the number of transplants was 30% in that five-year period because some donors did not have

appropriate transplant organs. Kidneys, pancreases and livers went up, but hearts stayed the same. That is a reflection of donors after cardiac death.

Papworth has now done eight cardiac transplants after cardiac death, and this is a fantastic new resource. It got ethical approval for that only about four months ago. I do not know how appropriate it is for centres to target cardiac transplantation on the basis of cardiac death donors because it is logistically a very big deal to try to get these patients transplanted. I do not think that the living donor programme would impact the cadaveric programme. They work in parallel.

Mr McKinney: At the outset, I commend you for your great work, which brings life to those who have suffered long-term ill health and who maybe faced a very foreshortened life. Your work is hugely valued.

If you do not mind, given the importance that the Minister attached to the letter that came in, may I spend a few minutes talking about that? Who wrote it?

Mr Brown: It was drafted by Aisling Courtney and me and signed on behalf of the whole nephrology and transplant service in the Belfast Trust.

Mr McKinney: Was it a letter or an email?

Mr Brown: It was a letter. Sorry, I am not sure whether it was a letter or an email. I saw it in electronic form. I have not seen it in paper form.

Mr McKinney: Was it signed? Sorry for going into the detail, but I just want to know —

Mr Brown: We have not signed it.

Mr Connolly: Not individually.

Mr Brown: The letter was circulated to clinicians, who had a full say or veto over what was in it.

Mr McKinney: How representative of the body of your profession is the letter?

Mr Brown: I think that it is universal amongst the Belfast Trust.

Mr McKinney: It goes beyond the kidney unit.

Mr Brown: It was signed by the nephrologists and transplant surgeons in the Belfast Trust.

Mr McKinney: How many is that?

Mr Brown: There are eight nephrologists, four and a half transplant surgeons and a staff grade.

Mr McKinney: How many of the wider transplant team were excluded from sight of this letter or from having an opinion on it?

Mr Connolly: That is the transplant team in Northern Ireland.

Mr McKinney: That is it.

Mr Connolly: Yes, there is no other solid organ transplant team in Northern Ireland.

Mr McKinney: It was a considered response, and it covered all of you.

Mr Connolly: Yes.

Mr McKinney: There is no dissent, other than in the content of the letter itself, which refers to "differing opinions" in the medical profession.

Mr Brown: Yes, that applies to the medical profession at large. It applies to our intensive care colleagues, our transplant colleagues and clinicians outside the transplant service.

Mr McKinney: You have arrived at an opinion to defer, but you are not reflecting the full scale of differences of opinion in the letter.

Mr Brown: I do not think that the letter aimed to do that, no.

Mr McKinney: John, you are supportive.

Mr Connolly: Yes.

Mr McKinney: James, you want some changes in the drafting.

Dr J Douglas: Yes, I feel that the Bill as it stands contains problems. As I do not currently practise, I have an open mind.

Mr McKinney: I get that. You want some drafting changes. You, John, are supportive, and you, Tim, are against.

Mr Brown: I am against soft opt-out, but I am for anything that increases the organ donor rate within those —.

Mr McKinney: Yet your colleagues, including John and James, suggest that the soft opt-out system could work.

Dr J Douglas: I have an open mind. I am not certain, but it could work. The Welsh legislation could work, and I think that a change in the law in the UK as a whole could also work, but it could be a matter of waiting to see.

Mr McKinney: You might be satisfied if some reasonable efforts were made with the drafting right now.

Dr J Douglas: I have made the suggestion before, and it may sound silly, but apparently there is no difference between not objecting and consenting. Before the Human Tissue Act — that is all to do with tissue and nothing to do with transplantation — which requires express consent, we had the old, rather poor Act that said that, if there was no objection from either the deceased or their relations, it was all right to transplant. Many legal commentators have said that is a form of presumed consent because you do not know what the deceased thought. You presume: you are going ahead in the absence of objection. The practical effect is the same as for presumed consent, although the words are not used, and, therefore, it never aroused much antagonism among the public. If you use the word "presume", a certain number of people latch on to it and do not like it on autonomy grounds. I take John's point on the tension between general consent and autonomy and the idea that deemed consent is a legal fiction.

I wonder whether — this is probably a matter for the Assembly — we could not have a form of words that had the same effect but did not include "deem" or even "presume", which would allow for transplantation to proceed on the basis of the lack of objection from the donor, the deceased or whatever family member you wanted to include. To my mind, that would be the same thing and would not use the word that some people find noxious. "Presume" gives the impression of taking away autonomy. I have often had that thought, although it is not just my thought. That has been mentioned by various legal authorities, such as Professor Margot Brazier and one of the chaps who write 'Mason and McCall Smith's Law and Medical Ethics'. Is it just a matter of "Softly, softly, catchee monkey"? How could we phrase it in such a way that it would do what we want without using words that some people find difficult to cope with?

Mr McKinney: I accept that, but I am intrigued: you reach a conclusion in your letter that is different from the conclusion that I hear in your evidence today, namely that, if work was done — drafting or comfort work, if I may describe it in that way — delay would not have to be the issue. I will not say that you are contradicting your own conclusions, but I certainly hear a difference in your separate

conclusions on what a difference in opinion would lead to by way of action. Delay might be a welcome approach, but what I am hearing is that you are suggesting options other than delay.

Dr J Douglas: We do not know what the effect of legislation would be. We do not know what the effect of the Welsh law will be. We are giving our reasons for not being sure and for thinking that we might do things somewhat differently, since we have a chance to do so. We do not have to just follow the Welsh legislation; we might be able to achieve a better outcome. As I explained, I think that there were some deficiencies in the Welsh legislation, notably the idea that the family are supposed to have no input and yet will be listened to in fact. That seems to be a contradiction. We think that we could improve on the Welsh law. I think so, and my colleagues have their own reasons. What you are picking up on is that we all have our view on why it might be wiser to wait and see.

Mr McKinney: I am not looking for speed without proper consideration, but proper consideration can be given in a reasoned debate within a time frame. Tim, you talked earlier about the good work that others did years ago to further your career and the outcomes for patients now — not your career individually but your input. I suppose that I am coming back to the same point. Delay is not necessarily the answer; what we need is further proper, timely consideration.

The Chairperson (Ms Maeve McLaughlin): Will the witnesses move their microphones down? There is a problem with the broadcasting. I appreciate that. Thank you, and sorry to interrupt.

Mr Connolly: The delay is not there for delay's sake; the delay is there to give time for the results to come through from the enactment in Wales. You could make any argument on what is an appropriate period to get an appropriate answer. That time can be used very usefully in improving our legislation. James takes a legal approach to it, and I take a very practical, clinical approach to it. I probably speak for most of my clinical colleagues in saying that we do not want something that will end up being contentious.

Mr McKinney: I go back to the letter. Why did I not receive the letter from you? Why did the Minister receive the letter?

Mr Brown: The letter was sent by the clinical director of nephrology to the Assembly. I do not know whom it was addressed to.

Mr McKinney: We are all members of the Committee. I will ask colleagues: did you receive the letter?

Mr Brown: We can only apologise that you did not receive that.

Mr McKinney: The letter was used by the Minister in a particular way to further arguments in this debate. I would have welcomed receiving it because it would at least have given me time to reflect on the issues that the Minister brought directly, using that letter, to the Floor. The way in which it was used subsequently was unhelpful. I do not have an issue with the content. As I say, we can debate all these things, but the fact that it was not sent to people who are central to making decisions in this regard, as we are here, was unhelpful and will be seen as trying to further one end of the debate. At least, that is the way I see it.

Mr Brown: You will have to accept our wholehearted apology. I am afraid that I have no idea of the inner workings of the Assembly, so you have to forgive my naivety.

Mr McKinney: You are probably on a fast learning curve. The letter was used in what I believe was a political context.

Mr Brown: I am on a fast learning curve in all sorts of things. Our assumption was that this was not a political issue, and one would assume that the appropriate person to address it to was the Health Minister. I offer my unreserved apologies to the Committee as a whole.

Mr McKinney: Did you recognise the political nature of how it was used?

Mr Brown: I am not political in any way, and I do not recognise that in any way. This issue is trans-political, I am afraid.

Mr McKinney: It is an issue that has various sides, and people take different views on it.

Mr Brown: My view is for my patient at the start of the day and at the end of the day, and I am not interested in any other issue.

Mr McKinney: I make the point. I think that you recognise the point. You have apologised.

Mr Brown: I have apologised for it.

Mr McGimpsey: Thank you for coming to talk to us. This is an important issue and, of course, quite a complex one. It is not straightforward. The nature of the problem is that lives can be saved if you get appropriate donations. It is about looking at how to ensure that you have an adequate supply of donations to save lives. In 2008, there was an investment in specialist nurses. Tim, you said something that we have not heard here in years: you said that it is very well resourced. That is good. We welcome that because we do not often hear that about the health service these days. It has had a very important effect, and you are concerned about jeopardising that effect and the position that you are in. I want to be absolutely certain about the size of the problem now; that is, the number of patients in need not being addressed. You talked about 80% of, I think, donation after death — brain death — but live donation —

Mr Brown: That is the consent rate.

Mr McGimpsey: Right. Then you gave us another figure of 37%.

Mr Brown: That is the consent rate for donors after circulatory death.

Mr McGimpsey: So there is a gap there. Are we talking about how we bridge that gap? What numbers are we talking about there?

Mr Brown: Over the last two years, in Northern Ireland, 162 donors were attended by the retrieval teams in the UK, and I think that 98 donors proceeded. The nature of donors after circulatory death is such that only 60% of potential donors proceed to donation. I will not go into the details of that today because I think that it is beyond this meeting. I think that about 170 kidneys were used in Northern Ireland in two years. I use kidneys as an example. I think that the organ donor use per DBD donor is 4.2. The organ donor use on average from a DCD is 2.5. I will not go into the details, but, as a result of the way in which organs are retrieved from those potential donors, there is a slight discrepancy between the two.

Mr McGimpsey: Unscrambling that, what is the need? How many people are losing out? How many people are sitting on your list?

Mr Brown: As of this morning, in Northern Ireland, there are, I think, 15 kidney recipients on our active transplant waiting list, between 10 and 15 liver recipients, five lung recipients, five heart recipients and five on the simultaneous kidney and pancreas waiting list.

Mr Connolly: That is the number on the active renal waiting list. Thirty or so patients are currently suspended from the active list, for whatever reason.

Mr McGimpsey: Is that the gap between donation and waiting?

Mr Brown: Yes, except that it is not quite as simple and straightforward as that, because we are part of the United Kingdom organ donor allocation system. There are 114 patients in Northern Ireland, but they are vying with the population of the rest of the UK, which is around 64 million. As John said, we have transplanted all of our highest waiters in the last two years, which is phenomenal for them. However, the reason you get to the top of the waiting list is time spent on the waiting list. The time spent by patients in Birmingham or Oxford may be getting them to the top of the list before the people in Northern Ireland because they have been on the list for longer. We will always have a need for a cadaveric programme, but it is not quite as straightforward as a gap between donors in Northern Ireland and people on the waiting list in Northern Ireland. The numbers are fairly stark. I got a freedom of information request back from NHS Blood and Transplant last week. Of the 160-odd kidneys that were retrieved in Northern Ireland over the last two years, 9% were transplanted in

Northern Ireland. It is not quite as straightforward as increasing donor rates in Northern Ireland, because it is a national resource, and pretty much all of the kidneys, livers, hearts lungs and pancreases go to the rest of the UK.

The allocation system for donors after circulatory death is different because we are allocated at least one kidney from the pair in Northern Ireland from donors who are retrieved in Northern Ireland. I hope that we will change the allocation system in the next year. At our request, NHSBT is looking at that for us because we feel that we are being disadvantaged by the current allocation system. It is a little more complex than saying that we have 114 people in Northern Ireland waiting for a cadaveric organ, because they are competing with the rest of the UK.

Mr McGimpsey: The 9% that you talked about — presumably that is getting a suitable match and so on.

Mr Brown: No. They are allocated, so the 9% that received the DBD organs that were retrieved in Northern Ireland just happened to come to the top of the list for a Northern Ireland donor.

Mr McGimpsey: We have over 100 on the list at the minute.

Mr Brown: About 115, roughly.

Mr McGimpsey: You said that, recently, one patient had been waiting for 21 years on the list.

Mr Brown: November 2014.

Mr McGimpsey: How long can patients survive on dialysis?

Mr Connolly: It varies, of course, according to age. A younger person will survive longer on dialysis than an older person, but the figure that we commonly quote is that, if you start dialysis at the age of 40, your chance of getting to 50 is 50%. There is 50% mortality over a 10-year period for someone in their forties. Obviously, that gets worse as one gets older, which is exactly what we are seeing. The incident population — in other words, the new patients coming under dialysis — are, essentially, from the 60-plus age group. They do extremely badly on dialysis. In future, I would like to look at that area of extending the role of transplantation into the elderly.

Mr McGimpsey: What is your cut-off date for age?

Mr Connolly: We do not have one. We have transplanted to someone up to the age of 83. I think that is right, and I would be prepared to go higher than that. It is entirely based on what they can physically sustain.

Mr McGimpsey: I am familiar with some of this, and, at any rate, you need an increase of supply. That is basically what we are saying. It is difficult to quantify, but we are part of this larger UK pool, which we benefit from. Ultimately, we do better by being in that pool, but we need to see an increase in supply. We are hoping that Wales will provide some guidance on that. To put it in its most basic terms, we need more organs to be donated. That is the basic problem. How are we going to get that? As things stand, we are not going to bridge that gap. As things stand, if that gap is not bridged, patients will be lost. I understand that you have a hesitation and are saying, "Let's wait and see", but, in the wait-and-see time, some patients will be lost.

Mr Brown: Absolutely, but, at the same time, we are doing very well and we are improving. While we are in a very admirable rush to improve our donor rate, is anything that we do in haste going to undo the good work that our specialist nursing and intensive care colleagues are achieving at the minute? That is our question.

Mr McGimpsey: There is no question of taking away the specialist nurses.

Mr Brown: Not unless James Neuberger has indicated that.

Mr McGimpsey: There is no question of undoing anything that was set out in 2008. All of that will remain in place.

Mr Brown: As far as I understand it, yes.

Mr McGimpsey: Presumably, those advantages are still there.

Mr Brown: Yes.

Mr Connolly: There is still work to be done.

Mr Brown: Looking at the Spanish model, Matesanz says that it is about infrastructure and education. The biggest step forward that Spain took was to put in place the infrastructure. We took that step in 2008. In taking organ transplantation to 2020, we have identified increasing the consent rate as the next big thing for the UK to become the world's best organ donor system. That education must be on how people can consent by signing up to whatever organ donor scheme is available and on educating the family about what the organ donor and their loved ones' views are. That is the next great Rubicon that we have to cross.

Mr McGimpsey: How would that be jeopardised by the proposals? I have no doubt that the Committee will take on board everything that you say about changes, modifications and so on.

Mr Brown: I think that the very interesting person you will get the answer from is waiting outside — Eddie Rooney.

Mr McGimpsey: He is sitting there behind you.

Mr Brown: Eddie Rooney knows this more than anybody else, and I am sure that he will give you a very enlightened update on the views of the public. I cannot answer that question other than to say that I know that a lot of people who would feel that their organs were owned by the state may say no. If that is what the rest of the population believe, something could be harmed. I do not want to harm our donor rate because it is good at the minute and is getting better.

Mr McGimpsey: That education to understand that the state will not have ownership is an important piece of work.

Mr Brown: It is paramount.

Mr McGimpsey: You have already talked about autonomy. Thanks very much; that was helpful.

Mr Middleton: Thank you for coming along today. In the Second Stage debate, quite a number of Members highlighted the fact that it was vital that we took on board the message and heard from professionals like you before we took any rushed action in all of this. The clear message that I am hearing from you is that, whilst you may not be totally opposed to it, you are urging caution and not a rushed approach in all of this. Hopefully, we can take that on board as a Committee.

I am sure that we all accept that a do-nothing approach is not an option either. I think that we need to do more around awareness. It is clear that there is a majority of people who want to donate organs. It is important to say as well that those opposed to an opt-out system are not against organ donation. Some would try to portray that sentiment and that is not the case, obviously. As Tim outlined, this is about the patient and, ultimately, about saving lives.

We heard about the Spanish model and the successes there. Hopefully, we can take something from that. What time frame would be appropriate to assess the success of the Welsh model before we move any further forward?

Mr Connolly: The Welsh Assembly, in drawing up the legislation, predicted that Wales would see a 25% rise in the number of organ donors. The number of organ donors in the last financial year 2014-15 was 71 in Wales, so a 25% increase on that will take 12 months or maybe slightly longer. We will have to wait and see.

Mr Middleton: A year would be fair point to look at the numbers.

Mr Connolly: There are always spanners that could be thrown in the works. It just takes a wrong episode of 'EastEnders' or 'Casualty' to disrupt those figures. You have to bear that in mind. The population is fickle; it does take offence easily and we have seen that on numerous occasions, but it always recovers. So, a year may turn out to be too short or it may be dramatic. I do not know.

Mr Middleton: But you would share the sentiment that a couple of months is a bit rushed to put something like this through at this stage. Data security was an issue raised in some reports that I have read. In recent months, there have been major breaches of people's security, and people will be concerned that, if they go for this opt-out system, somehow their personal data could be at risk. Is there any evidence of that?

Mr Connolly: It has not happened yet but it is already perceived as a risk. Access to the organ donor register has been amended since the Welsh legislation came in. Now, if you wish to express your consent for organ donation, you can do it online. You can also refuse your consent online, and that is recorded. The problem is that the access online is not encrypted; it is not secure. I could put your name down as having consented. So, the theoretical scenario, which is, of course, doctors stealing organs, is that we have a potential donor in an ICU, we look up the organ donor register, the name is not there and someone falsifies the entry. That is an issue. It has not happened but it has been raised as a potential problem.

Mr Middleton: That is serious and something that we need to take into account. I thank you again. Could we get a copy of the words that John said at the beginning?

Mr Connolly: Of course.

Mr Middleton: They will probably be recorded anyway but it would be useful if some of the facts and figures that you outlined were circulated.

Ms McCorley: Go raibh maith agat, a Chathaoirleach. Thanks very much for your presentations. I commend the work that you do. It is obviously very laudable and beneficial to society in terms that nobody can really praise highly enough.

This Bill, as we all know, is about doing something good. I do not believe that there is any intention to cause harm. It is about how we can ensure that we get the right legislation to enable more transplants and improvements in people's lives. Somebody mentioned the effect that an 'EastEnders' episode can have. Is that true? If you did a survey the day after a programme like that, could you get different results?

Mr Brown: I will maybe illustrate that with a point. In 2001, when I was on call in the Edinburgh liver transplant unit, a 24-year-old woman arrived with fulminant liver failure. The clinical scenario was that she needed a liver transplant within 48 hours or she was going to die. Unfortunately, it happened just after the Alder Hey scandal, where children's organs were retained by one of the pathologists there. That woman went to the very top of the super-urgent Europe-wide liver transplant list, waiting for the next available liver to save her life. She waited four days for that liver — she managed to survive for four days — but, by the stage she got her liver, she was irretrievably brain damaged. That was on the basis of the public attitude to the Alder Hey scandal, which meant that the organ donor rates took a massive dip. The public are very reactive to stories such as that.

Dr J Douglas: Another famous example, which is now quite old, was the notorious programme 'Transplants: are the donors really dead?' on 'Panorama' in the early 1980s. That was in the early days of DBD, when it was just beginning to be adopted. As a result of that programme, donation rates plummeted all over the UK. The single exception was Northern Ireland, I think. Of course, the rates do recover. However, in the short term, the public is very sensitive on this issue and does respond, it seems, very rapidly. That is another reason for thinking that a year might not be enough. The Welsh Government have, I think, thought about the possibility that there will be a temporary dip because of the people who do not like the idea of deeming, but it might pick up later as people become better educated and understand it better. These are all things that we do not know. However, what we do know is that public attitudes in the short term are much affected by what they hear in the media. Bad news on organ donation has an immediate effect, and good news has a good effect.

Ms McCorley: Do you believe that a better public awareness or education programme might help to counteract that?

Dr J Douglas: That is basically the whole basis of the argument. We believe that encouragement, not enforcement, is the way ahead. If deeming is part of a package that is about encouragement rather than enforcement, it could be all right.

Ms McCorley: I do not honestly believe that anybody is thinking about enforcement. I think that everybody is coming from the same place. I do not know whether anybody would approve of enforcement.

You talked about the liver transplant case. What would be normal? If there had not been the bad publicity in the media, would there have been a likelihood —

Mr Brown: It is difficult to say. It depends on blood group, but this was a very common blood group case. Some people can get it within four hours and, for some people, it can take three or four days. It is not about that particular case; it is about the fact that the organ donor rate went down across the whole country. In that case, it could have been days or not. If you look at the organ donor rate across the country as a whole, you see that it dipped dramatically.

Ms McCorley: OK. Can you just give me a wee bit more information, just for my own benefit? We talked a lot about kidney transplants. That is the most common. Why is that?

Mr Brown: Why is kidney transplantation the most common? It is because donors have two of them.

Ms McCorley: Right, OK. It is as simple as that.

Mr Connolly: There is more to it. It has to be said that there is a facility for people with renal disease to be kept alive by dialysis. For people with cardiac disease or liver disease, there is no other alternative when they get to the end stage of organ failure: it is either transplantation or die. The renal patients have the option of dialysis in the majority of cases. As such, they accumulate in greater numbers. There is no doubt that cardiac disease is probably much more prevalent than renal disease, but patients do not survive.

Ms McCorley: OK. That is helpful. How many body parts are donated? Is it in the tens?

Mr Connolly: From a specific —

Ms McCorley: What I am saying is that you have the kidney, the liver and then there are other body parts.

Mr Connolly: There are ways of approaching this. You can start from the head and work down. We have two kidneys, a liver that can be split to be put into two recipients, a pancreas, two lungs, one heart, heart valves, corneas, cartilage, bone, skin, the bowel, tendons and vessels, all of which have uses in the medical sphere.

Ms McCorley: As medical science develops, the possibilities will probably increase.

Mr Connolly: We are probably already utilising them to the extent that we need to. The drive in the medical sphere is to move more towards tissues that are generated in laboratories as opposed to tissues that are retrieved from human donors. That is down to a quantity issue but it is also due to the fact that, in the transfer of any organic tissue — kidneys, livers, tendons, bones etc — there is always the risk of disease transmission. The whole area of prion transmission is one that we do not know anything about as yet. So, there is a move away from using body parts, but we have not got that far yet.

Ms McCorley: I am just trying to get a sense of it, as a cardholder, because it is a nice feeling to know that you could help a lot of other people if something happened to you. That gives me a good feeling, and I imagine a lot of people would feel that way. Education and the awareness programme are very important in all of that.

Mr Connolly: The issue is closing the gap between the upwards of 70% of people who say they support organ donation and the 30% who actually sign up for it. If we can do that, there is a major contribution to be made.

Ms McCorley: That is always the challenge, though, is it not?

Mr Connolly: Yes.

Mr Easton: I am quite open-minded about this and am waiting to be convinced one way or the other. This is a serious Bill because it has the potential to affect everybody across Northern Ireland in some way. Is there potential for better education, better publicity and better learning to deliver a higher increase in organ donations than the provisions of the Bill?

Mr James McDaid (Belfast Health and Social Care Trust): Thanks for the question, Alex. I thank all the Committee members for all your work on this really important issue. We all feel that any measure to improve organ donation is a wonderful thing. We are open-minded as well. A soft opt-out may be a good thing but, equally, it may hurt organ donor numbers. Education is an avenue that is non-contentious. Everybody realises that public awareness campaigns and public education will help organ donation. The soft opt-out option is a bit of a gamble; it is like playing a game of poker without looking at your hand or at other people's hands. Introducing soft opt-out in Northern Ireland may improve organ donor numbers but, equally, it may hurt them. Nobody knows at the moment.

There was a massive public and professional consultation in 2008 in the UK — probably the biggest of its kind — looking into soft opt-out. It came out against soft opt-out, but said that, in the future, it may help. They interviewed a bunch of doctors — transplant surgeons, ICU doctors — and there was a lot of concern among them that soft opt-out could erode trust in the profession and that it was a move back to a paternalistic era when doctors decided what was best, very unlike today, when patient choice is key, as my colleague said about informed consent. The public said that they had concerns about the state or Big Brother coming in and taking away their organs. Faith groups said it took away from the concept of organ donation being a gift. At the moment, we do not know. Soft opt-out may be a good thing, and, if it is, wonderful; we should go for it, but it might hurt organ donors.

In Wales, we have a great opportunity to see what happens in practice, but the education side of it is key, and my guess that it will help even more. At the moment, there is three times more money spent on advertising for blood donors than for organ donors. A big thing that came out of the 2008 consultation in the UK is that people are really aware of donating blood but nobody knows about donating organs, and it is definitely a key thing to spend more money and put more resources into public awareness.

Mr Easton: You mentioned that it could be a gamble. Could it be a big gamble?

Mr McDaid: I do not think that it is a big gamble. If it hurts organ donor numbers, I do not think that it will hurt them in a big way. I just moved here last year, having done all my training in America and England, and I have been amazed by how altruistic people are in Northern Ireland. It is a wonderful community. The people here are very much behind transplantation and organ donation. If it hurts donor numbers, I do not think that it will hurt them in a big way, but there is potential for that. It may well improve organ donor numbers and we hope that, if it is introduced, it will, but, at the moment, nobody knows for sure. There is a great opportunity in Wales to wait perhaps for a year and see what happens.

Mr Easton: Mrs Dobson quoted Dr Courtney. I cannot remember who said earlier, when asked by Mr McKinney, that it was Dr Courtney who drafted the letter? Can you confirm who drafted the letter that was sent to the Minister?

Mr Brown: Dr Courtney and I drafted the letter.

Mr Easton: OK. Presumably, on the basis of your response to Mr McGimpsey, a change here in Northern Ireland could have only a very minimal impact on Northern Ireland patients waiting on the list compared with the UK.

Mr Brown: Absolutely. What we are talking about here will have a minimal impact on Northern Ireland patients, I believe, and the data supports that. Whether that is seen in the rest of the UK as a whole, because we are part of the UK allocation system, that is fantastic, but if the DCD allocation system changes and organ donor rates go up in Northern Ireland, we will benefit in the renal unit here as a result. However, we are talking about very small numbers as to the actual benefit to patients in Northern Ireland.

Mr Easton: Might there be value, as part of our consideration, in members of the Committee visiting your unit and having the opportunity to see you at your work and learn more about the issues that you face day to day?

Mr Brown: Every single member is welcome to come and visit. Our door is open. I am on leave next week, but anybody is welcome. We are very happy to come and speak on a one-to-one basis any time. We wake up in the morning thinking about organ transplantation and we go to bed at night, occasionally, thinking about organ transplantation, and sometimes we stay up all night doing organ transplantation. This is our passion; this is our life, and we feel very strongly about it. I hope that you have got that.

Mr Easton: I can see that. If the Assembly were to pause now and come back and legislate in the next mandate if Wales is seen to be a clear success, do you think that the broad majority of your colleagues would then get behind it and give support?

Mr Brown: If Wales comes up with the numbers. Anything at all to increase organ donation is what we are after. That is the bottom line. If Wales comes up with the goods, fine, but we do not know that yet. As John commented, while the pilot study is in place, why on earth would we not wait to see what happens?

Mr Easton: How long do you want to wait to see how Wales is progressing? A year? Six months?

Mr Connolly: I think that I spoke about the improvements that are being made as a result of the investment in ODT in specialist nurses and clinical leads etc. That work is still ongoing. It will be difficult to disentangle the result of better training, education, infrastructure and funding from any improvement in organ donation that results entirely from a change in legislation. That is a difficult one. I do not think that any of us will have the answer. It will all be about interpretation at the end of the day. All we can say is that there have been 71 donors in Wales over the last year. If they get a 25% increase, as they think they may, such a result may be seen within 12 months. On the other hand, populations are fickle; it only takes one incident to be widely spread through the media for there to be a downturn in donations. You just have to take it as it comes.

Mr Easton: Which is probably why we need to be so careful. The Bill could swing donations the wrong way.

Mr Connolly: Time spent on the Bill will be time well spent. I do not imagine that it is going to be shelved. I have already been invited to sit on one of the committees to look at various aspects of it. I think that there is work to do in refining it, and that will be time very well spent. As I say, James is speaking very much from a legal point of view. My concern is that it must be workable at a clinical level.

Mr Easton: Supposing the Bill goes through and everything is hunky-dory and there is an increase in donations, can you do more transplants with the resources that you have now?

Mr Brown: We just did five in a day.

Mr Easton: That is good. I take five a day too.

Mr Connolly: No. We are already challenged in respect of access to operating theatres, bed space and number of surgeons. We operate together. We have no junior staff; it is only a consultant-provided service. We do not get juniors to come in at 3.00 am; we come in. I think that probably the greatest risk to the Northern Ireland transplant service is the histocompatibility and immunogenetics or tissue typing lab. It is constantly in difficulties with staff retention and recruitment. Even retaining a senior consultant scientist to ensure accreditation is a challenge. The accreditation is already in abeyance. It only takes one small thing for us to fall foul of the Human Tissue Act and no longer qualify as a registered transplant centre. There are issues. I suppose there are everywhere.

Mr Easton: You would need a substantial amount of funding to increase your capacity.

Mr Connolly: The funding is not an issue. The commissioners have been very generous. What we ask for, providing we make a good business case, is granted. It is an arduous speciality. It does not

attract many in the medical profession. There is no private practice at all, and it is difficult to recruit and retain people in those circumstances. You have to be a little odd to be a transplant surgeon.

Mr Easton: Don't worry: some people think that I am odd too. *[Laughter.]* Thank you very much. I really appreciate that.

Mrs Cameron: Thank you very much for your presentations today; they have been very valuable. I am in awe at the work that all of you do. At the outset, I would like to apologise to you as a group for feeling the need to apologise to the Committee for communicating with the Assembly. We are on a very steep learning curve with regard to human transplantation. I very much welcome the fact that the Bill is in front of us and that we are discussing it, because it means that it is getting a wider airing and more conversations are taking place. That is all very good as long as what comes out is positive for people consenting to donate organs. I am on the organ donor register and have very real concerns about any form of presumed or deemed consent, but I remain to be convinced.

There has been mention in broad terms of the risks attached to us getting this legislation wrong. Can you outline exactly, in practical terms, what you consider those risks to be?

Mr Connolly: The risks that we see come down to bad news stories really. An interaction with a specific donor family that may be contentious in itself will not extend beyond that. It will bring about a breakdown in trust between the contributing medical party and the family themselves. We hope that that never applies, but, if there is a divergence of opinion, to put it better, there is the option of families taking out injunctions against a hospital trust that may wish to enforce organ donation or, shall we say, uphold the law, because, under this Bill, families have no legal right to veto consent or donation. We hope that most medical professionals would have the common sense to take their wishes into consideration, but it might be worth exploring that further.

The problem is, of course, that, if an issue like that should arise, it will invariably get into the media, and then it will become amplified. As I have already alluded to, it does not take much in the way of a story to cause swings in the population's willingness to donate. Those are the issues that I think are a problem. There may be specific legal issues, and, James, I think that you would be better to speak on that.

Dr J Douglas: As it stands, I feel that the Bill produces very little deeming because it says that deeming is only effective if the close relation, or whoever you have, affirms that the person would not have objected. As your Bill stands, somebody has to affirm that the deceased, he or she, would not have objected. That involves having someone stand up and say that the person would not have minded. As it stands, there is very little actual deeming. You have the word "deeming", but there is very little actual deeming. You have someone saying that the person would not have minded. I feel that, as it stands, it will make practically no difference but that, because it has the word "deeming" in, it might put some people off when they hear that they have to give deemed consent. As it stands, I think that it will make practically no difference, so I do think that it needs to be changed.

My personal view is that it is almost impossible to ignore the relations. It is all very well to say that a person has deemed consent, but, when people are very upset, it is very hard to go against them. One of the problems in the Welsh Act is that it goes against them in theory but does not go against them in fact. It is saying that their ideas will be taken into account.

There is a way of looking at it that might reduce that. Just accept that if you have no objections from the deceased or from relations, it is OK to go ahead. That would reduce the number of times when you will be in conflict with the family. That would still be quite like deemed consent, so I think that it is worth looking at all of these issues to see whether we can get a better way of phrasing it. That is my main argument here.

The Chairperson (Ms Maeve McLaughlin): Pam, can I come in if you do not mind? If the issue of consent, either deemed or presumed, and the legal right of families were clarified or removed from the draft Bill, would that alleviate your concerns?

Dr J Douglas: Yes, I think that it would. We would nearly be back to the old Human Tissue Act that we had in the old days. I have an open mind. If the Welsh Act works, we will have to accept it. If the Welsh Act works, I can tell you that there will be a law in the UK as a whole. There are a lot of people across the water who strongly support presumed consent. If the Welsh Act is shown to be very successful, I have no doubt at all that, within a few years, we will have a Westminster Act.

The Chairperson (Ms Maeve McLaughlin): Even if the Welsh Act works and all of the findings from that process are very positive and it has an increasing impact, we would still need legislation that deals with the issue of consent.

Dr J Douglas: We would. In my view, the encouragement is more important than the enforcement. The Welsh Act is testing out the image of possible enforcement; you cannot go against deeming, but it relies much more on encouragement. The Welsh Government are explicitly stating that, although the opinion of the relations is not supposed to have legal effect, it will be listened to if they are distressed. In a way, that is somewhat inconsistent; it is a contradiction. I feel that it would be better, if we are having some sort of deemed consent, to accept that the relations are so important that their decision will be listened to in every case. If they are really against it, fair enough.

The Chairperson (Ms Maeve McLaughlin): I am sorry, Pam, I just wanted to clarify that; go ahead.

Mrs Cameron: OK, Chairperson; you are perfectly entitled to butt in. Thank you for that clarity and the time that you have given us on the subject today. Fearghal has questioned the involvement and the number of clinicians, who thinks what and who you are representing. How strong are the feelings of clinicians about the potential risks?

Mr Connolly: I do not think that we can speak in terms of strength of feeling. We have raised this as a potential issue, but we have no evidence yet that it is an issue. We are just curious; we would like to wait and see the effect in the Welsh jurisdiction. I do not know whether my colleagues would differ from that view.

Mr Brown: I completely echo everything that John said. Strength of feeling is very difficult to measure. No one is standing in front of Belfast City Hospital with a placard saying, "Soft opt-out down", but everyone would really like to see what happens to the Welsh system and whether the curve goes one way and then another, or whether it goes down or stays on the same path. If it stays on the same path, you will invest a lot of money in changing a law that is not making any difference to what we are achieving at the moment with our organ donor improvement as it stands. We are talking — I think I read it somewhere — about a figure of £5.5 million; is that what it is going to cost to change this Act?

Mr Connolly: In Northern Ireland.

Mr Brown: In Northern Ireland. So, £5.5 million will be taken out of public funds — I have made it clear that I am not a politician — to introduce an Act that has minimal impact on Northern Irish transplant recipients and could potentially harm organ donor rates. You guys are the ones making the decision — as John says, I cannot speak for the rest of my colleagues about how strongly they feel about it — but we would just like to see what happens.

Mr McDaid: My feeling is that I am not strongly for or against soft opt-out, but I feel very strongly that we have to base our decision on data. We do not have to base it on feelings, thoughts or debate. We need to look at the data, and we will have the opportunity to look at the data from Wales one year from now, after which we can make a decision. I feel strongly about that.

Mrs Cameron: You need time to gather that information. I appreciate that. Since we started talking about this legislation, I have repeatedly voiced my concern about the length of time that we have to scrutinise the Bill. It is a huge concern of mine that we are being forced to rush because we are running out of time. It is interesting that the two words from your presentation today that stand out for me are "caution" and "haste". It has been very useful to hear your views today.

Dr J Douglas: If I may ask a question, Chair, I know that the Scottish Parliament had a plan to introduce something along the Welsh lines. Do you have any information on what they are thinking?

The Chairperson (Ms Maeve McLaughlin): I do not; I am looking to the Committee Clerk on this. We have not engaged with Scotland. However, we are looking at other regions and at international evidence as well; it is something that we will be seeking to do.

Mrs Cameron: I have one last question. The Committee has such a tight timeline and has agreed — although I did not agree to it — to a two-week call for evidence in order to consult, I suppose. Do you see that as sufficient?

Mr Connolly: That may be difficult. I have had some communication with the Family Law Bar Association. I do not know whether it has been in communication with the Committee, but, from my discussion with it, I know that it would be interested in presenting its interpretation. I am not sure of anything more than that.

The Chairperson (Ms Maeve McLaughlin): OK. That would be useful. Please direct it towards the Committee. It has not contacted us yet.

Mr Buchanan: I want to thank you folk for coming and presenting today and answering quite a number of questions already. We are all aware that this is a very sensitive issue. I want to say at the very outset that I am disappointed at the way that Fearghal McKinney sought to politicise this issue, because it is not a political issue. I want to make that absolutely clear. I am really disappointed that a member of the Committee would seek to politicise the issue when it is not that. I want to put that on record.

The Chairperson (Ms Maeve McLaughlin): I have heard that, but I am going to intervene as Chair. There was a reflection or interpretation in that letter that we have been given a different view of today. Any member is within their right to question that. The letter itself referred to enforcement of legislative decrees. That is not what any of us is in the process of doing in relation to the Bill. I have had issues clarified today that have been very useful. Nonetheless, we are entitled to drill down deeper.

Mr Buchanan: Absolutely. We have seen how organ donation has increased over the last five years thanks to the good work that has been done. How do you see that progressing, given that there was a robust educational programme and publicity campaign around what is already in place?

Mr Brown: That is a really valuable and very interesting question. NHS Blood and Transplant (NHSBT) has to be worried because most of that 50% increase came from the introduction of donation after cardiac death. It is seeking to increase the donor rate by another x amount. It is trying to get it up again, but it has crossed the Rubicon. It has got the big easy win; it is now going to have to go for the marginal gains, and the marginal gains are an increase in the consent rate. How you go about educating the whole of UK society to increase the organ consent rate is a very difficult and different game to what was being played in 2008. I think that it is going to have a very difficult job achieving the targets that it has set itself for taking organ transplantation to 2020, but I would be delighted if it did.

Mr Buchanan: What concerns would you have if we, as politicians, were to legislate for something that could have a negative effect but was left for you folk to implement? How would that harm morale from your side of things?

Mr Brown: I am pleased to say that, by law, the transplant team cannot interact with the donor services. Therefore, you would have to address that question to the clinical lead for organ donation and the organ donor services in Northern Ireland.

The Chairperson (Ms Maeve McLaughlin): They will be in front of the Committee next week.

Mr Brown: We would not have to pick up those pieces other than that we would see our organ transplant rate go down, which would be devastating.

Mr McCarthy: Gentlemen, thank you very much for coming and spending so much time with us. I, like others, want to congratulate you for the work that you continue to do. This lady to my left, Mrs Dobson, has a son who is now 22. If it were not for you people, that boy would not be here, so well done and congratulations. As far as the Committee is concerned, she is the inspiration that something should be done. The passion and commitment has been quite obvious today. All the questions have been asked but, John, you said at the start that Spain had 54.2 per million and Northern Ireland had 54.1 per million. Will you go back over that for us?

Mr Connolly: OK. Spain's figures are often quoted. It has the highest deceased organ donor rate in the world. In the last financial year, the rate was 36 per million population. That should yield 72 kidneys per million population for transplantation. They transplanted 54, not 72, so there is a wastage.

Their rate was 54.2. Ours is 54.1. We have a more mixed programme of living donors, DCD and DBD.

Spain is now having to reassess its programme. They realise that they have reached the limits of what they can achieve with a deceased donor programme. Twenty-five per cent of their donors are now over 70 years of age, hence the discard rate. In other words, you may count them as a donor, but you will not use their organs.

Mr McCarthy: What is the reason for the older population rather than the younger?

Mr Connolly: It is the nature of death at the moment. There is a severe downturn in the numbers of brain-dead donors as a result of road traffic accidents and trauma. That was traditionally a high source rate in Spain. They have learned to drive better and wear seat belts and do all the things that we imposed way back in the 1960s, 1970s and 1980s. That has made a difference to them. They now realise that with their 80% consent rate across the board, they are not making any progress.

Rafael said that their current donation rate is a third of what they need to meet the needs of the Spanish population, so there is an enormous way to go. They are now having to look at what we have already been doing: promoting a living donor programme and DCD — in other words, donor after cardiac death — programme.

Mr McCarthy: What is their population compared with the UK?

Mr Connolly: The population of Spain is about 47 million as opposed to around 63 million.

Mr McCarthy: OK, thanks very much and continue on with the good work. One never knows when one will need your services.

Mr Connolly: I hope not.

Mr McCarthy: Well, you never know. Jo-Anne's son is living proof, and we are all very proud that she went through it and had some part in this.

Mr McKay: Thanks for the presentation. It was fairly interesting. A lot of this comes down to risk, and there is a degree of risk in any change in legislation. Social attitudes also need to change. The point was made about something that happened in the 1980s and, across the board, donation rates went down, but here they stayed the same. Is that right?

Dr J Douglas: Yes, that was a famous episode in the early 1980s in which a programme suggested that brain-dead donors were not dead and might have recovered. That was shown to be based on false information, but it did not prevent a massive drop in organ donation over a period of months. That is just one of many examples of a dramatic public response to this sensitive issue. Of course, brain death is a difficult thing for the layperson to grasp. It has taken a long time to establish it, but it has been made clear that brain death is, in fact, an effective way of establishing death. Of course, when the individual observes the brain-dead person, it can be very difficult. This whole issue is surrounded with sensitivity.

We are dealing with death, something that people do not understand, so it is a very sensitive issue. I suppose that is behind the worry of how the public will react to any changes. Against that, the public are also aware of an increased need for donations. Encouragement is a big part of it, and I think they can be educated to accept a system that is seen to be fair and not reducing their autonomy in any significant way. Putting it up to you to make your mind up could work, but, because the issue is so sensitive, I think we all agree that there is uncertainty and we cannot get away from that.

Mr McKay: The Bill passed its Second Stage in the Assembly with the support of a majority of Members and has come to Committee, so it is heading towards being made law. We need to look at other ways to mitigate the risk of a downward trend after this. Education is a big part of that, as is leadership, if people in the medical industry and politics were to come out and say, "The public need to change their attitudes". We have seen legislation go through here before that the public opposed, but, once it was introduced and their fears were dealt with, it became quite effective.

Mr Connolly: The other great area of potential is schools. Like all things, it is about educating the children. We saw that particularly with the anti-smoking campaign. You educate the children at school that smoking is bad, the message gets taken home and the smoking parents are nagged — I will not say "to death" because that is not appropriate. There are many strands to this, and, as we have seen, the group that supports the legislation most strongly is the 18 to 30 age group, yet that group has the smallest number of people actually signing the organ donor register. So, there is work that can be done. There are endless possibilities for improving our system. It takes time, but it takes dedication and commitment as well; that is why the Bill is extremely useful in making it a statutory requirement to promote transplantation. What more could we ask for?

Mr McKay: Is there anything else that could be included? If we go ahead with the soft opt-out system, there is a duty to promote, but are there other measures that could be put in through primary legislation or regulations to mitigate any possible negative effect?

Mr Brown: There are three strands to increasing your donor rate and to achieving a societal shift in attitudes to organ donation. I pay tribute to the Committee and to Members because this discussion is maintaining it in the public domain, and people get education from news reports about the Human Transplantation Bill. They are all small marginal gains whereby the whole of society is educated. The first of the three strands to increasing organ donation through societal change is the infrastructure that is in place. If there are any improvements in infrastructure, it would be great to have them. An all-Ireland retrieval service would perhaps help, but we will not go into that now.

The second thing is education, which John mentioned: education, education, education. It does not matter whether it is education from hearing it on the news or someone going into a classroom to talk about it. It is all about getting it going. The debate that has been ongoing for the last two, three or four years — I do not quite know when it started — has led, I think, in a very strong measure, to the increasing organ donor rate that we see because it is in the public domain and is getting people talking.

The third thing is legislation. If legislation could be passed in a way that is palatable to the rest of society, you are a winner on all three fronts. Thanks very much to the Committee for doing what you are doing and for keeping this in the public domain: we and our patients are the beneficiaries. Please do not lose sight of that fact.

The Chairperson (Ms Maeve McLaughlin): It just remains for me to thank you all. I reiterate our appreciation for the incredible work that you all do. I think that you have heard that across the board today. It has been useful for me, as Chair, because it has clarified several things from the original correspondence. I have heard a number of views today. I have heard that, potentially, there is a sense that we all need to be cautious to ensure that we get robust legislation that has the right outcome. I have also heard that there is no evidence at the minute that there may be an issue and that, if the Bill was an enabler of clarification on deemed and presumed consent, it may alleviate some of those issues. Thank you very much for your time. We will reflect on the valuable evidence that you have given us.