



Northern Ireland  
Assembly

Committee for Health, Social Services and  
Public Safety

# OFFICIAL REPORT (Hansard)

Human Transplantation Bill:  
DHSSPS, Public Health Agency

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 Jackie Johnston	Department of Health, Social Services and Public Safety
Mr Ryan Wilson	Department of Health, Social Services and Public Safety
Dr Catherine Millman	Public Health Agency
Dr Eddie Rooney	Public Health Agency

**The Chairperson (Ms Maeve McLaughlin):** OK, folks. You are extremely welcome. I know that you were all in the Public Gallery for the last session. I welcome Dr Eddie Rooney, chief executive of the Public Health Agency; Catherine Millman, Public Health Agency; Jackie Johnston, director of secondary care at the Department; and Ryan Wilson, secondary care directorate at the Department. Please make an opening presentation, and then we will invite questions from members.

**Mr Jackie Johnston (Department of Health, Social Services and Public Safety):** Eddie will cover the survey and I will cover the Department's approach to the Bill.

**The Chairperson (Ms Maeve McLaughlin):** OK, we will start with the Department.

**Mr Johnston:** Thank you very much for the opportunity to present on the Department's approach to the Bill.

In the Second Stage debate, the Minister made it clear that he would prefer to wait to see how the legislation comes into effect in Wales, its impact on the organ donor register, and also the conversion of donors to actual transplants. Having said that, the Assembly voted through the Bill's Second Stage, and, therefore, he indicated that he would make available resources to both Mrs Dobson and the Committee to strengthen the Bill and to resolve issues referred to in the debate.

It is clear to us that, if the Bill becomes law, successful implementation of the new process will depend to a great extent on the actions that we take. For example, the Human Tissue Authority will revise its code of practice, which sets the guidelines for the operation of organ donor activity in the hospital. Action is also needed from the Department because the Bill leaves quite a lot for us to do in regulations; therefore we want to have absolute clarity about what those regulations should entail. We will also have to bid for the necessary resources to make the Bill successful. If it comes into law in 2016, we are required, within three months of enactment, to begin the publicity and information campaign. We will have to work very closely with Eddie to get ourselves ready if that happens because we will probably have to be ready to go with that by September of next year. So we need resources for that, and then we need to determine what a campaign will involve.

We will also have to work very closely with NHS Blood and Transplant (NHSBT) on coordinating the implementation of the Bill with regard to its service. NHSBT provides Northern Ireland with the transportation of organs and operations with the other Health Departments in the UK. Very importantly, we will have to work with professionals in the field to make sure that they have absolute clarity on what the new process will entail to ensure that there is no ambiguity or confusion in the advice that they provide families under the new regime.

Because of all those issues, we have put together a small Bill team. I head it up, with Ryan, and we have a couple of clinical colleagues from the transplantation unit in the City Hospital: Dr Paul Glover and Dr Henry Brown. Dr Anne Kilgallen, our deputy chief medical officer, will provide some signposting advice on ethics.

We have also engaged the draftsman, George Gray, from the Office of the Legislative Counsel, to work with us in bringing forward some amendments. We have met Mrs Dobson and her assistant and gone through the process. We have agreed that we will share with each other this work as it goes forward. It will require fairly intensive work over the next few weeks, but our aim is to bring forward a range of amendments for the Committee to consider, hopefully before Christmas. That is the process that we have put in train to move that work forward as far as possible over the next few weeks. As I said earlier, we want to do a lot of work on amendments, to give the Bill greater clarity, to strengthen it, and to deal with concerns that members have expressed today and also in the debate. Our prime objective is to ensure that we get amendments that the Committee and the Assembly feel comfortable with.

**The Chairperson (Ms Maeve McLaughlin):** Thank you. I suggest that we take your contribution as well, Eddie, and then we will open up for questions.

**Dr Eddie Rooney (Public Health Agency):** Thank you. I will be brief. Catherine Millman, a PHA researcher, is with me and knows all the answers to Mr McCarthy's questions. Just to state an interest, I am here as chief executive of the Public Health Agency. We were responsible for the surveys, and I will explain them in summary form. In my role as chief executive, I also chair the Northern Ireland Committee for Organ Donation and Transplantation, which brings together voluntary and community sector groups and health sector groups. I am also honorary president of Transplant Sport NI, a charity working in this area. However, nothing that I say will be on behalf of the charity; it will all be said in my role as chief executive.

Just to remind members, the PHA conducted two surveys, the first to inform our public information campaign, which was launched in February 2014, and the second to evaluate the campaign. The first survey showed that the Northern Ireland public in general was positive towards organ donation: 80% said that organ donors were heroic, and we had the same positivity through many of the responses. The survey also showed a low level of basic awareness, including of the organ donor register itself, and a low level of general knowledge of organ donation.

It also highlighted some deeper aspects of negative views, centring on a mix of things to do with what we term the "spiritual and tradition" issues and medical distrust, which we heard of in the earlier session. There was also the fact that people just did not want to talk about death and bodies and were really resistant to anything that crossed into that territory. When we did the factor analysis, spiritual tradition was a particularly strong factor and deeply rooted in cultural aspects of our community. The survey asked explicitly about soft opt-out. Fifty-six per cent said that they were in favour; 18% were against. However, we also found evidence of confusion and a lack of understanding of just what the legislation was about. It was at quite an early stage then. When asked about the law being brought in at that point, 16% said that they would object, and 22% said that they did not know.

That information was used to design a campaign, Speak Up and Save a Life, the focus of which was on asking people to consider their donation wishes and to tell their family and friends. We saw that as a building block in improving public awareness and, indeed, public support, for organ donation. The second survey — it was based on 2014 data after the campaign — showed us evidence of increasing support for, and awareness of, organ donation. More people were talking about the campaign, and that was very much in the technical analysis that we do of campaigns. From our point of view, it was a good campaign, as it reached out to many of the target audiences. When we asked again about soft opt-out, we found increased public support: 61% in favour against 56% in the earlier survey, and fewer against — 10% as compared with 18% — with more people wanting more information, from 8% up to 16%. When asked again if the law were brought in now, 18% said that they would object — that was up a little — and 27% said that they did not know. On one hand, there was more positivity, but, on the other, there was possibly a sign of hardening of attitudes at the other end as well.

On the first survey, we did considerable engagement through focus groups, including charities, transplant recipients, those on the waiting lists, donor families, health and social care staff and indeed the British Medical Association (BMA). There was clear consensus: everybody, without exception, wanted the same outcome, which was to normalise organ donation and educate the public; everybody wanted to see an increase in organ donation. The views did differ on aspects of the legislative change and what impact it would have, particularly with the BMA and charities being very supportive, and more concerns being expressed, as we heard earlier, by health and social care staff.

I am happy to take questions on any aspect of the survey. I want to note that, at the launch of Speak Up and Save a Life in February 2014, the percentage of organ donation, which we printed all over the leaflets, was 31%. We have now had to reprint the leaflets pretty much every few months. Officially, it is now 35%. The latest figures, which we will put out in another week or two, show that it is actually 36% now. The rise over that period is the fastest that we have ever seen. There will be more people going on the organ donor register this year than we have ever seen — considerably more. The rise is faster than in any other region of the UK at the moment. I am happy to take questions.

**The Chairperson (Ms Maeve McLaughlin):** Thank you. With regard to the Public Health Agency's role, you indicated that, in the second process, there was 61% in favour of soft opt-out. How much of an increase was that?

**Dr Rooney:** Five per cent from 56%.

**The Chairperson (Ms Maeve McLaughlin):** Given that education and awareness are a critical part of the discussion, do you envisage that there needs to be or should be a sustained campaign on organ donation?

**Dr Rooney:** Absolutely. Education on organ donation is going on every day of the week. We know from experience that it is not just our campaign or that level of campaign: we could tell, before the reorganisation of district councils, for example, that registrations on organ donation registers vary from 11% up to nearly 50%. It could not be attributed to demography; we could attribute it only to campaigning by local families. That is going on all the time. Indeed, in December, we have another event in this Building to promote it. There is no doubt about reaching out to the public through the public information campaign. Before we designed that, we looked very carefully at what Scotland had done, and they said that there was often quite a continued ripple effect. It helped all the other campaigns and local campaigns and really seemed to reinforce them. From the figures that we are seeing at the moment, that really does seem to have happened.

**The Chairperson (Ms Maeve McLaughlin):** It could also assist with that ripple effect. It is not something that contradicts a legislation process.

**Dr Rooney:** No, it does not. We were very careful that there was a basic message in the public information campaign: to get people talking and to respect that they may have different views on it, but to get them to that first part of talking and expressing their wishes. We are very clear: we want people to support organ donation; we want them to appreciate it. If you look at the information that is going out in various aspects of the media on this, from us and others, you see that we are emphasising the difference that this makes to lives and telling people that, in the balance between your resistance — which we know can be quite strong for many reasons and we respect those views — and saving a life, make that choice, please, and we will give you the information to help you to make that choice.

**The Chairperson (Ms Maeve McLaughlin):** I think that the Department is taking a very worthwhile approach to the legislation. Given what we are hearing about the issues, I would be particularly interested in consent. The issues coming to the fore about clause 4, which deals with consent, are the need to look at either deemed or presumed consent, the clarification required on that in the Bill, and for the Bill to be the enabler of an education campaign process and public awareness campaign. Are we likely to see specific amendments on those issues?

**Mr Johnston:** Yes, we are. Clause 4 is at the heart of the Bill in setting the direction of the other main clauses. The essential difference is that, in the Welsh Act, which we have followed the development of for a couple of years, consent is deemed unless a relative or a friend objects on the grounds in a manner set out in the Welsh Act, which is based on what the deceased's views would have been. Under the Bill, consent cannot be deemed unless there is an affirmation that the deceased would not have objected. We need to make sure that that will not cause complications when clinical staff are talking to relatives in the most tragic of situations to ensure that that is not complicated by going through the affirmation process. We want to explore this with clinicians, with Mrs Dobson, and with the legislative draftsman to ensure that we have as much clarity as possible.

At the moment, the way in which the consent procedure is carried out in the hospital is set out in the codes of practice issued by the Human Tissue Authority. There are proposed amendments to those, but we want to get absolute clarity on the qualified persons under Mrs Dobson's Bill and how they would relate to the notion of affirming that the deceased would not have objected so that we do not confuse the situation. We may need to look at our own code of practice, for example, in Northern Ireland to ensure that there is maximum clarity on it. From that clause, everything else flows. I do not want to get into the detail today, because there is an awful lot of detail that we need to go through, save to say that we have agreed that we will examine the issues together to see whether we can come to a resolution.

I know from talking to Mrs Dobson that the affirmation principle is something that she feels strongly about. I do not want to put words in your mouth, Jo-Anne; you might want to explain that yourself. We will have to have a fairly detailed discussion on Mrs Dobson's views on that and how we can perhaps reach an accommodation.

**The Chairperson (Ms Maeve McLaughlin):** As I said, I think that that is a useful approach. I had correspondence and a conversation with the Minister about what the Department can do to support the Bill as other private Member's Bills have been supported through the relevant Department. I think that that is extremely useful. Are we likely to see amendments this side of recess? Do you have a sense of that?

**Mr Johnston:** I do not think that it will be this side of recess, but we hope to get them to you before the Christmas holidays start. Obviously, the Minister will have to approve them as well. We are working on a without-prejudice basis with Mrs Dobson, so, again, all of this will be subject to his approval before it comes to the Committee.

**The Chairperson (Ms Maeve McLaughlin):** It will be before Christmas.

**Mr Johnston:** We are aiming for before Christmas.

**The Chairperson (Ms Maeve McLaughlin):** I appreciate that.

**Mr McCarthy:** Thank you very much for your presentation. I assure you that my questions will not be too difficult. You were here in the previous session and you heard all of the presentation, which, in my opinion, was fantastic; it gave us a real insight into what is going on. In the absence of this private Member's Bill, and in the light of developments in other jurisdictions, particularly Wales, what type of intervention in this area would the Department have recommended to get organ donations increased?

**Mr Johnston:** It is about public information and encouragement, which is the approach that NHSBT has been promoting. We in our own small way in Northern Ireland have been replicating that, largely through the efforts of the PHA.

**Mr McCarthy:** I was going to say that anything that that man gets involved in is successful. That is my opinion, and I have known him for quite a while. Keep it up, Eddie.

**Mr Johnston:** I think that that is the prime way of doing it. In fact, it will have to work alongside the Bill, because the evidence internationally is that simply having legislation in place for soft opt-out does not necessarily result in increased numbers signing on the donor register or converging rates to actual donated organs. Alongside that, there will have to be a fairly extensive publicity and education campaign.

**Dr Rooney:** I began work on this in 2009, at which time we were at the bottom of virtually every list. From my point of view, it has been a period of phenomenal activity. It has been done by the people whom you had round the table earlier, and, indeed, by those involved in the health sector. I have to say that I have never come across anybody in this area who believes that we have cracked this issue at all. We will resolve to explore every way of getting greater success, because we know the impact it has on saving lives. So, far from it; we are continually looking at new ways of getting information out, and I know that others are continually looking at ways of improving the services. It has been a fantastic period to see the changes.

**Mr Easton:** The Assembly deals with all types of legislation. How complex is this Bill compared to others? How differently would it be considered if the process were to come forward from the Minister?

**Mr Johnston:** It is a relatively short Bill in respect of the number of clauses in it, but it is a very complex Bill in respect of the ethical, medical and social issues that it raises. So, with its intensity, we probably would have had quite a long period to produce proposals for consultation and then produce a draft Bill on the back of those proposals. There would have been a much longer timescale to take it through, which is what happened in Wales as well.

**Mr Easton:** OK. Is there a danger that the change in legislation could lead to a large number of people rushing to opt out once it comes into force? Who would have to cope with that? Is that a concern for the clinicians?

**Mr Johnston:** It is an unknown risk. There are a number of risks around it, but that is a potential risk. The education publicity campaign would try to counter that risk by explaining the process, rather than getting into a position where we would simply launch the Bill with no education. Currently, the Bill will not come into operation until May 2018. So, if it is enacted next year, we will have a couple of years to deal with those issues and reassure the public. We are going to discuss with Mrs Dobson whether we can look at the potential for bringing in the commencement date a bit later if there are lessons to be learned in Wales. If that is the case, we could bring forward further amendments to deal with the issues, but we need to talk this through with her. So, there is a possibility around that as well. If Wales runs into problems in the areas you alluded to, we would have time to resolve them if the Bill passes next year.

**Mr Easton:** I am glad that you are working with Mrs Dobson. That is good. As part of the education programme, will every house and every person in Northern Ireland who is automatically on the list from the age of 18 get some sort of notification separately to say, "You need to make a choice here"? How will that work?

**Mr Johnston:** Clause 1 of the Bill is not entirely clear on that. This is one of the areas where we need to clarify what we mean by a campaign; but I imagine that you would have to inform the public properly, as well as having messages in the media and through advertising. Do you want to comment on that, Eddie?

**Dr Rooney:** We need to get clarity to the public about the implications, because, for us, you are likely to get uncertainty from people at the point when it really counts, as we heard from the clinicians, where doubt is put in their minds. Getting that clarity out to them is very important.

**Mr Easton:** If everybody in Northern Ireland is automatically on it, they would need to be aware that they are on it automatically. When people get to the age of 18, they will need to be told. So, there will be a lot of bureaucracy around getting that information out.

**Mr Johnston:** That is why we are required, in clause 1 of the Bill, to run that campaign continually. You are right about making sure that the message is reinforced year after year. That will be a requirement.

**Mr Easton:** It will be a big postage bill for you.

**Mrs Dobson:** I welcome the Minister's letter today at the Committee and can confirm that I have met you, Jackie, and Ryan, and I look forward to the team being put together to look at amending the Bill and receiving what the Minister describes as his Department's considered opinion. I very much look forward to working with you.

This question is for you, Jackie. Thank you for the overview in your briefing. I very much welcome the Minister's assurance that the Department will work to achieve the right Bill for Northern Ireland. That is essentially what we are all working together for. Given that back in 2013 the First and deputy First Ministers, along with the then Health Minister, signalled their support for the soft opt-out system, what has the Department done to look at introducing the system, other than the PHA surveys? I note that you said in your briefing, Jackie, that you have been following work in Wales for many years. What work has been done, given the commitment back in 2013 from the Department?

**Mr Johnston:** We are an integral part of NHS Blood and Transplant. One of my staff attends NHSBT meetings regularly, as does one of Eddie's staff, so we have been fully tuned into the development of the Welsh system as it has been reported to NHSBT. As you know, we also contributed to the redesign of the organ donor register, which is a UK register, to facilitate the soft opt-out system in Wales.

**Mrs Dobson:** That had to be changed because of Wales.

**Mr Johnston:** Yes. We played our part in that, because NHSBT is a UK-wide service, as you know. We have followed how the Welsh system has evolved closely.

Former Minister Poots, in a couple of statements to the Assembly, following his visit to the renal unit with the First and deputy First Ministers, set out, I thought, a fairly considered way forward. He said that he wanted detailed feedback from the public on attitudes to organ donation. Eddie referred to the surveys, but there were also focus groups involving clinical staff to give them an opportunity to give their views. The PHA produced quite a detailed report, and I think that the view on the back of that was that we should wait and see what happens in Wales. We were not ruling out legislating at some point, but given that what will happen in Wales over the next couple of years is unknown, let us see how that plays out.

**Mrs Dobson:** Essentially, there was no real groundwork carried out in preparation by the Department other than the PHA surveys.

**Mr Johnston:** Other than our involvement with NHSBT.

**Dr Rooney:** Allow me to add to that. The campaign itself was commissioned by the Minister and the Department. The work we were doing through it was very much in line with building up public awareness in a way that would be relevant regardless of what happened with legislation.

**Mrs Dobson:** I understand that. It is important work, and I cannot speak highly enough about the Speak Up and Save a Life campaign. Given the commitment from the First and deputy First Ministers back in 2013, and I remember Minister Poots saying that the soft-opt out system could be brought in by the end of 2014, what tangible work was done by the Department in preparation for the possibility, other than work with Eddie on the campaign? Is it normal when the First and deputy First Ministers and the Health Minister signal their support for something not to move in the direction of travel or pave the way?

**Mr Johnston:** Former Minister Poots set out the policy position shortly after. That was the direction given to the Department on what we were to do. To answer your question directly on whether we were doing any development work for the Bill, we were not doing that work proactively. What we have been doing is shadowing what is going on in other jurisdictions across a whole range of health service developments.

**Mrs Dobson:** Essentially, no work has been done in the Department until now.

**Mr Johnston:** No development on a Bill.

**Mrs Dobson:** And you are working with me now. Thanks for that.

Eddie, you can relax a wee bit; I am going to be nice to you. The Speak Up and Save a Life campaign was superb, and you know that I reference it all the time. What was the process behind the campaign? I know you have alluded to it. How do you envisage planning future campaigns, given the other hat that you wear in the transplant forum? I know many of the charities that you are involved with, and I have been involved for 20 years or more. I would like to see more input from the charities we are involved with considering that they have done all the heavy lifting in promoting organ donation. Do you envisage consulting with members of those magnificent charities and getting their input going forward into the next campaign?

**Dr Rooney:** Yes, we do, Jo-Anne. We actually built them into the consultation process and the engagement process, specifically with that in mind. Indeed, the Northern Ireland Committee for Organ Donation initially started off — certainly when I started — as a group from the health sector and was extended to include three representatives from the transplant forum. So, there are three charity representatives around the table. It is primarily a communication group, but it is also where we put the first ideas out and kick them around.

**Mrs Dobson:** I am glad. They have said that they would like, for example, local accents, rather than actors' accents, to come across as well.

**Dr Rooney:** Yes, very much so. I give credit to the health sector workers. Sitting with my volunteer hat on, I found — and I am sure that this is one of the things that you found — that nearly all of the volunteers who deal with these people all the time are full-time workers in the health sector. So, there is some amount of work supported locally by, for example, the specialist nurses — organ donation (SN-ODs). At virtually every event that I have been to — and I have been at events everywhere from the north to the south — there has been support from people in the health sector who are otherwise full-time workers.

As for the way forward, we take a very careful view on campaigning generally. We rest campaigns, because we tend to do them intensely. The assessment is very important in that. We have been tracking this one very carefully to see whether we are getting the ripple effect we were hoping to get. Certainly, there is something happening there.

**Mrs Dobson:** The clinicians referred earlier to the fact that, in the three years that this has been in the public domain, it is all good publicity and gets the conversations going. They alluded to the fact that —

**Dr Rooney:** We cannot tell how each component works, but something seems to be happening at the moment. Our next phase will be to consciously build on that and bring it up to another level. That will obviously be done in the context of legislation as well, because we want those things to reinforce one another and not be treated separately.

**Mrs Dobson:** OK. Thank you.

**The Chairperson (Ms Maeve McLaughlin):** Sorry, I failed to bring Pam in on Alex's point, so I will bring her in now.

**Mrs Cameron:** Thank you, Chair. Thank you for your presentation today. I just wanted to come in on the back of Alex's point about the Welsh legislation. You said that, had it been done through the Department, it would have taken a prolonged period. Do you have the timeline of how long it took, from start to finish, for Wales to bring it in? Do you know how long it spent consulting?

**Mr Johnston:** I believe that it was going on for a couple of years.

**Mrs Cameron:** A couple of years. I am just very much aware that we have a few months. That was it. Thank you.

**Mr Buchanan:** Eddie, you mentioned the increase in the number of people on the organ donor list from 2009 onwards through the good work that you folk have done; so, congratulations. That is the goal that we are looking to get to, albeit some of us may be looking to get there by a different vehicle. Do you see this legislation driving those numbers up?

**Dr Rooney:** It can help. Again, certainly when Wales looked at public opinion, it gave a cautionary note from its international evidence review, which said that it is important to get public opinion in order



for legislation to work. The two things really do go hand in hand. There is no doubt that the debate that has gone on for the last couple of years about soft opt-out is getting through to the public. I think that these messages reinforce each other. We do not quite know the science of how they do it. My word of caution for us all is that we have still only 35% or 36% of the population on the register, so we have a long way to go. While, for us, it is has been a great period of change and improvement, the message clearly — and the research has shown this — is not reaching enough people with the right intensity, so we have a lot of work to do on that. The issue for us really is to make sure that the process of legislative change works in harmony with the wider issue of public information and that it becomes a very positive message for people to make sure that they are encouraged to support organ donation and make the choice.

**Mr Buchanan:** You were here during the last presentation and you heard some of the concerns. How difficult or unusual a position would you, as civil servants, find yourselves in if you were to implement the Bill and the specialists dealing with it a day to day basis were uncomfortable with or maybe even resistant to it?

**Dr Rooney:** I cannot answer that as a civil servant; I am an ex-civil servant. I am still a public servant, so it is just a minor change. As with all aspects of legislation, it crosses into the issue of ethics, and professional ethics in particular.

Technically, under our existing legislation, if you are on the organ donor register, that can be taken as consent; but I do not think that any clinician, certainly in this country, would ever make a decision against a family based on that. I think there are issues where you get that interface between hard-felt professional ethics and what happens in legislation. It is all the more important that consultation periods, like this, should really flush out those issues and make sure that, at the end of it, you get clarity. From the point of view of anyone facing those hard decisions, the clarity of the law is incredibly important. So, the more work we put into this stage of it, the better for all of us and that includes getting the information out to the public, which is the Public Health Agency's interest.

**Mr Buchanan:** That is key; and it is why some of our colleagues earlier expressed concern that it seems that this is being rushed through so quickly, with little time taken to fully exhaust all the options and get the right message out to the people. Good work has already been done and we should build upon what is already there, rather than rush something through that may be detrimental to the work already done. That is the concern that I am hearing around the table today.

**Mr McGimpsey:** I will be brief. As far as I can hear, we can find our way through most of this; but there is a concern that we might lose public confidence. There could be a temporary dip — I think that is how it was described — in the number of people coming forward. Wales must have faced this, looked at it and decided that the gain was worth the risk, and adopted the harder opt-out rather than the soft opt-out. How do you see it going forward? To a large extent, it is your job to deal with that and address it. You have made good gains in getting people on the register, going way back. You accept that there is a temporary challenge to be dealt with. How did Wales deal with it, and how do you see yourselves dealing with it?

**Dr Rooney:** Michael, when Wales did its international review in 2012, they took the evidence they could find internationally and, like all of us, they found that it is not that clear. However, they included it with their assessment of public support in Wales and the mechanism. They put the three together and said there was:

*"a convincing basis for the introduction of an opt-out system in Wales."*

They also recognised that if public opinion was not there, and the term they used was "potential backlash", then it could do more harm than good. So, it is a delicate balance.

Initial research highlighted to us that we should all be careful to try to understand the depth of feeling and what it is that drives the negative element. For us, it was not anti-organ donation but other factors in the nature of our culture and society. Those are issues around traditions, like open coffins, and fears around that. A lot of the myths are very much in the mind of the public and are a potential source of resistance. There is an issue for all of us to make sure that we understand that and the implications that, if we trigger those fears without having dealt with them and got support, then I am afraid that we will have a sizeable element of the population that is, potentially, resistant and we might find it pushing to the other side of it. However, there is an issue for all of us in the messaging and information that goes out. We must make sure that those issues are understood and addressed.

They are complex; we had to drill very deep. Catherine was at the heart of trying to understand the dynamic and the relationship between those issues, from medical distrust to the cultural traditions that interface. Together, they are quite a powerful issue.

**Mr McGimpsey:** Do you believe that you can address those issues?

**Dr Rooney:** Certainly, within our area. We have gone for a very simple message and it is this: please, save a life — do it please. We are trying to put a stronger positive above the issues that make people hold back. As we heard from the clinicians; when you look at consent rates, you find that we are still losing a lot of potential organs. Whatever it is, whatever we are doing, part of the story is that we are just not getting enough information out yet. We have to try harder. We have still some way to go to get over the fears and make sure that people, when faced with that question, do not refuse consent. We have still a lot of work to do to get there.

**Mr McGimpsey:** Once this goes through, there will still be the question at the end of the day, at the point; is that not right?

**Dr Rooney:** Yes, there has to be. They have to get to the people.

**Mr McGimpsey:** So, you have to get a positive rather than a "no".

**Mr Johnston:** It is important, too, that we are in a position to coordinate with the national campaigns that the NHSBT will run, which will not deal with soft opt-out. They will deal the situation in England and Scotland and try to accommodate what we might do in Northern Ireland and what they are going to do in Wales.

Wales spent a year preparing the ground for the system to come into existence this month. We need to learn about what happens in Wales over the next six months to a year and whether they need to take corrective action in terms of publicity if the number of people opting out increases. The timing of the information campaign is going to be important so that there is not a range of mixed messages going out that will totally confuse the public.

**Mr McKinney:** Thank you for your contributions. Does uncertainty contribute to some of the variances you are finding?

**Mr Johnston:** Uncertainty in what context?

**Mr McKinney:** Uncertainty in the debate. Eddie, you mentioned that people are wanting more info. What do they want more info about and in what context? That creates uncertainty and, I would have thought, would skew your figures.

**Dr Rooney:** All our work is based on simple messages going to people, because it is about the receipt of the message to get people to change their behaviour or take an action. It has to be motivating. Where there is ambiguity and the message comes out in the context of battles of interpretation, that will inevitably send confusing messages to the public, particularly in an area like this.

We heard from the clinicians that everybody is aiming for the same end in that we want to save more lives. It is making sure of the simplicity of that message to the public along with doing something that we know will make a difference. Hence, we focused on the "Speak up and save a life" message. One point made, which we have seen, is about medical distrust, when you get questions about trust and who is making decisions. We have to be sensitive about where the population are on those issues, which can send confounding and confusing messages. That uncertainty can lead people to hold back.

**Mr Johnston:** There is also the potential negative impact. People on the organ donor register are aware and want to donate their organs. The issue is whether they will be sufficiently concerned to convert to register as an opt-out. You will be dealing with a section of the population that is already well-informed because they have made a decision to register that they want to donate their organs. Will they be in some way influenced to change that?

**Mr McKinney:** Has any questioning been done around that?

**Dr Rooney:** Yes, that issue was picked up in the research.

**Dr Catherine Millman (Public Health Agency):** We asked, if there was a new system of opting out, which of the following best describes what you would do. Twenty-eight per cent said that they were not on the register and would not opt out; 28% were on the register and would remain on it — in other words they would do nothing and were still going to donate their organs; 12% said that they were not on the register but would opt out; 6% were on the register and would take their name off it; and 27% did not know and were unsure at that time.

**Mr McKinney:** Maybe we could see some of those figures, because you ran through them fairly quickly. In earlier evidence, they talked about the delay and said, "Let's see what happens in Wales". I was hearing a bit of a contradiction, because further evidence was that it would be very difficult to disentangle any ups, downs, sideways or whatever, in the Welsh experience. How will you measure the Welsh experience? How would you disentangle what the clinicians feel is clearly a disentanglement, if that is a word?

**Dr Rooney:** We tend to work on the public information side. We mirror the information gathered in other countries, and we are looking very carefully at all of it to see how public awareness and public attitudes are tracked. We are looking at Scotland, England and Wales in that regard, and, through this process, we will be continuing to gather our own information to track our public attitudes.

**Mr McKinney:** Yes, but you can see where I am concerned. I hear people saying, "Oh, it's better to wait. Let's see how it goes". Then, in the next breath, they are saying, "But we wouldn't know how we'd know".

**Mr Johnston:** I do not think that that is strictly accurate, because we will have two systems operating in the UK. We are going to have a voluntary system in England, here and Scotland, and a statutory soft opt-out system in Wales. So, I think you will be able to look and see whether there is a correlation. You will be able to see whether the numbers in Wales dip as a result of the legislation coming in, while the levels in the other three jurisdictions remain the same. It depends on the degree of dip. If it is a significant dip, you could argue that there is a correlation; if it is not a significant dip, then it might be down to other factors. I think that there is an opportunity to do a bit of comparing to see whether that has an impact in Wales. Eddie has been involved in a step forward campaign. You can see that a campaign like that has had a definite improvement here, for example, compared to the other jurisdictions.

**Mr McKinney:** If we do not legislate in this mandate, it could be any length of time before we have it. We could achieve the certainty, which you think people need, in that space of time.

**Mr Johnston:** There would certainly be no negative impact.

**Mr McKinney:** In terms of the context of my previous questions, you are saying that certainty causes differences in opinion, depending on what is said loudest or softest in the debate. You would think that, if we achieved some certainty, it would achieve a better outcome.

**Dr Rooney:** I talked about the certainty. I think it depends on the communication of debates and how the public take that. I do not think that anybody could assess what the impact would be of the legislation taking six months or 12 months, because nobody has yet been able to assess the impact of legislation, even internationally. There is no agreement or consensus on that; it varies from country to country. We are all in pretty new territory. That is why there is such an interest in looking at Wales. They have taken a new, and very robust, position, and the way in which they have done it, regarding the public information around it, has broken new ground. That is why we are looking at that. All of the evidence and reviews that have been gathered do not give us a clear picture of what the impact of legislation has been in any country, and we cannot draw from those examples. We are in new territory, Fearghal.

**The Chairperson (Ms Maeve McLaughlin):** I thank all of you for your contributions today. We look forward to the developing role of the Department, in particular, and any forthcoming amendments. We look forward to getting sight of those and reflecting on them. Thank you very much; it has been very useful.

**Mr Johnston:** Chair, it would be useful if we could have a discussion with the Committee Clerk on how you want us to bring forward the work. That would assist us in our planning over the next few weeks.

**The Chairperson (Ms Maeve McLaughlin):** OK. I have no issue with that. Thank you, again.