Northern Ireland
Assembly

Committee for Health, Social Services and Public Safety

OFFICIAL REPORT
(Hansard)

Organ Donation: Private Member's Bill

23 October 2013

NORTHERN IRELAND ASSEMBLY

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Members present for all or part of the proceedings:
Ms Maeve McLaughlin (Chairperson)
Mr Roy Beggs
Mr Mickey Brady
Ms Pam Brown
Mr Gordon Dunne
Mr Samuel Gardiner
Mr Kieran McCarthy
Mr David McIlveen
Mr Fearghal McKinney

Witnesses:

Mrs Dobson	MLA - Upper Bann
Mr Joe Brolly	
Dr Aisling Courtney	
Mr William Johnston	Northern Ireland Kidney Patients' Association
Mr John Brown	Northern Ireland Kidney Research Fund

The Chairperson: We have Jo-Anne Dobson MLA, Joe Brolly, Aisling Courtney, William Johnston from the NI Kidney Patients' Association and John Brown from the NI Kidney Research Fund. You are very welcome to the meeting. Please give us a presentation of around 10 minutes, and then we will open the floor to members' comments and questions.

Mrs Jo-Anne Dobson (Northern Ireland Assembly): Thank you, Chair, for your kind introduction and the opportunity to present to you today. You will all have your packs with the results of my private Member's Bill consultation on changing the organ donation law to establish a new soft opt-out system. It is certainly a new experience for me to be at this end of the table.

I think that it would be helpful, by way of introduction, to go through some of the findings of the consultation. As many of you will know, I have been associated with organ donation charities for over 20 years. That is because of my son Mark, who was diagnosed with renal failure when he was born. I have been a strong supporter of the organ donor register and have campaigned with the charities long and hard to encourage the public to sign up. However, we always reach a glass ceiling of around 30% of the public signing up, when we know that over 90% of the public support organ donation. Together, we are determined to break through that ceiling.

Since I was elected as an MLA in 2011, I have used my background in organ donation to raise this issue at Stormont. More recently, with the help of the British Medical Association (BMA) and Shane

Finnegan, the all-party group on organ donation, which I am proud to chair, was established. Just before Christmas last year, I tabled a private Member's Bill to provide for a move to a new soft opt-out system of organ donation — a system with family consent at its very heart.

In this room, on 4 June, we launched the public consultation, which ran for 16 weeks. As you will see from the report, there were 1,366 responses. Overall, 82% agreed with a change in the law and a move to a new soft opt-out system. I think that you will agree that this is an unstoppable tidal wave of public support for change. I want to formally thank each and every person and organisation who took the time to respond. The consultation was conducted online and offline, and received considerable media coverage throughout the 16 weeks. Throughout, I was delighted to have the support of the local charities on the Transplant Forum, as well as the British Medical Association, the British Heart Foundation and Opt for Life. I have worked with many of those fantastic people over the years and know many of them personally. It is for them and others who are waiting for a transplant that we need to change the law.

I am delighted to be flanked by a barrister, a consultant and representatives from two charities. As you said, I am joined by Joe Brolly, a barrister who is a prominent campaigner and evangelist for the soft opt-out system. I think that Joe needs no introduction. I am also joined by Dr Aisling Courtney, who is a consultant nephrologist at Belfast City Hospital with vast experience in treating patients pre and post transplant; William Johnston, who represents the Northern Ireland Kidney Patients' Association and has been waiting for a kidney for 17 years; and John Brown, acting chair of the Northern Ireland Kidney Research Fund. Both charities have been extremely supportive to me and, in the report, you will find an overview of the key findings, which show majority support for a change in the law to a new soft opt-out system, the retention of the key role of the family, exemption for those under 18, and protecting the rights and interests of vulnerable adults. On page 10, you will see a breakdown of the position of the various organisations towards a move to the new soft opt-out system. I have been in contact with the one organisation, Christian Action Research and Education (CARE), that opposed the proposal in its response and have offered to meet it soon to discuss it. CARE also had the opportunity to present its views at the previous meeting of the all-party group.

If I may, Chair, I will go through each question in turn, starting with question 1 on page 13. You will see in the report that, beside each question, I have listed a selection of supportive comments, as well as the concerns raised by those who took the time to give their views in the comment box provided for each question. Question 1 asked whether a change in the law is needed to make more organs available for transplant. That received a staggering 82·69% support, which is a clear endorsement of a change in the law to help match the supply of organs with demand. That would help to reduce the average figure of 15 local people who die every year while waiting for a transplant. There was also recognition in the comments of the support for organ donation among the public, but that, for whatever reason, they are reticent to sign up to the current register.

Question 2 asked whether respondents would support a new soft opt-out system of organ donation with family consent and safeguards for children and young people under 18, those who do not have the capacity to consent, those who are not normally resident in Northern Ireland and those whose identity is unknown. A total of 82·42% supported the move to a new soft opt-out system. From the comments, there was clear recognition of the safeguards that would be put in place, not least the importance of the principle of family consent being at the very heart of the proposal. It was also acknowledged by respondents that those who have an objection to organ donation for whatever reason can opt out, which would mean that, in law, their wishes could never be overturned.

Question 3 asked whether the family should continue to play a key role in the decision to donate organs. Family consent is central to that proposal, the only exception being when the deceased has chosen to opt out during their lifetime. Again, the majority supported the retention of the role of the family. However, some felt that it should be a hard opt-out system, as in Austria, where the family is not involved in the decision. That may account for some of the 25% who said no to that question.

Question 4 asked whether people agreed that children under 18 should be exempt from inclusion on the register. Again, the majority supported that principle, which conforms to the age of consent and responsibility. Many supported lowering the age of consent to 16, as I do. Were that to happen, the law would be adjusted to accommodate.

Question 5 asked whether people supported protections for adults who lack the capacity to decide for themselves. The vast majority, 86·53%, agreed with that. Consent must be properly obtained, and, as in other areas, the most vulnerable must receive proper help and support. Members will know about the mental capacity legislation and understand that protecting the rights of vulnerable people is at its heart. That is backed up by the responses to the question.

Question 6 asked who was best placed to protect the rights of the vulnerable: an informed family member, a qualified medical professional, or other suggestions. Again, the responses to this question supported the principle of family consent. Over 1,000 people ticked "family member" and this is absolutely key to the proposal. Some people suggested that those who had power of attorney could be involved, which may be a sensible suggestion.

Question 7 asked how for long someone should live in Northern Ireland before they became subject to the soft opt-out system. The key here is ensuring that consent is properly obtained. There was support for various periods of time: most went for 12 months between someone becoming resident and the opt-out system applying to them. There were also some who felt that, if people were benefiting from the NHS, they should be subject immediately. However, I support calls for a reasonable period for people to become aware of the laws, as is the case in other areas.

Question 8 asked how people felt the change in the law would impact on human rights. Over 73% chose either "positively" or "not at all" as the answer to that question. I truly believe that human rights will be strengthened by this proposal. For the first time, those who do not want their organs to be donated cannot have their wishes overturned. Once someone has opted out, organ donation will not proceed. The family is also central to preserving human rights, as it will ultimately have the final say if someone has not chosen to opt out during their lifetime.

Question 9 asked whether, when a person cannot be identified, they should be excluded from donation. This goes to the heart of the principle that consent should be received before donation proceeds. The majority supported exclusion, with some feeling that donation should proceed. However, when someone cannot be identified, it cannot be known whether they had opted out, and, therefore, their wishes cannot be ascertained and no presumption can be made.

Question 10, the final one, asked for any further comments, and 418 comments were received. A sample is available in the report.

I hope that has been a helpful overview of the responses received and the overwhelming support of the public for the change in the law and the move to a new soft opt-out system for Northern Ireland. I am pleased that the results of my consultation dovetail with the results of Public Health Agency (PHA) survey, which were published last Wednesday.

I thank members for the time to present these results. I am very keen to maintain ongoing dialogue with any individual or organisation that wishes to meet with me throughout the progression of my Bill. As you know, my door is always open. I will continue to work alongside charities such as the Northern Ireland Transplant Forum, the British Medical Association, the British Heart Foundation, Opt for Life, and their members and officers and all interested organisations and individuals, to ensure that they have a strong voice here at Stormont when it comes to changing local organ donation laws.

On a final note, I highlight that I have dedicated this report to the late Josie Kerr OBE, who lived in my home village of Waringstown. Josie was the co-founder of the Northern Ireland Kidney Research Fund and she did so much to highlight the importance of organ donation. I have been told by other founding members that she would have been so proud of what we have achieved in working together towards changing the law.

Chair, I will now hand over to Joe Brolly, who will give you his perspective, and then to Dr Aisling Courtney.

Mr Joe Brolly: The big key question in this is how to change society's attitude to organ donation. I have spent a lot of time with Dr Paul Glover, who is the lead clinician of Northern Ireland's transplant system. He is the head of NHS Blood and Transplant (NHSBT), so he has all the figures at his fingertips. I will go through some of those in a moment.

The issue for Northern Ireland, which is significantly outperforming the rest of the United Kingdom, is how to improve a donation rate in the low 20s per million. At the moment, our donation rate is just shy of 22 donors per million of population. How do we get from that rate, when an average three people die every day, UK-wide, up to the 30s — from 32 to 35 — like the donation rates of the leading countries in Europe?

The evidence is very clear. If, for example, the argument for the soft opt-out were brought into a court of law, God forbid, it would be a cakewalk. I think that the court would have no hesitation in deciding that, as a matter of logic, common sense and evidence, this is what works and this is what saves the maximum number of lives.

The choice is between two family consent systems. The first is the one that we have at the moment, in which you can opt in online if you wish, but your family still makes the decision in the hospital. Last year, for example, the families of 125 people who were on the organ donation register and who were in a position to donate their organs refused consent. That represents about 700 life-saving operations.

The other family consent system is the soft opt-out, whereby, in future, you would not have to go online, unless you did not want to be a donor. We know what the problems are with lethargy, and, with the best will in the world and with a huge amount of publicity over the past six years since the NHSBT was founded — we have a state-of-the-art infrastructure — we still have the problem that only just over a quarter of people go on the register and, even then, there is a very high family refusal rate. That is in circumstances where we know that this society believes that organ donation is a good thing. So the starting point for us was to look at why civilised European countries that are comparable to ours such as Spain, Croatia, Belgium, Portugal and Austria, do not have waiting lists in practice, and why they are saving so many lives in comparison to ours? We did research on that, and we spoke to the relevant clinicians in various countries.

My adventure started with a phone call from a girl from Dungiven who married a Belgian, which would be a very exotic transfer for anybody from Dungiven. She had heard me on 'Talkback', talking about the need for more people to sign the register. She said, "Look, Joe, do what we do in Belgium, where it is just part and parcel of the dying process". So I started my research and met all the relevant people.

The first thing to say is that people have absolutely nothing to fear from this. I met Dr Glover last night, who is the lead clinician and head of NHSBT. Our infrastructure is brilliant; it is state of the art. We do not need to do anything with the infrastructure. The clinicians are very happy with it, and I have seen it working in practice. I have spoken to the clinicians, so there is no issue with that. All the leading countries have three things: they have very good infrastructure, which we have; they have very good awareness, which we do not have at the moment; and they have a soft opt-out law.

When Dr Glover met me last night, he had just come from having that very difficult discussion with a family who had lost a loved one, to all intents and purposes. Their loved one was on a ventilator and was not going to survive, so he had gone with the specialised nurses that we have and very sensitively offered the possibility of organ donation to the family. By the time that he had left them, they were starting to fill out the consent form, which is about 15 or 16 pages, and the family were very carefully taken through that. It takes about an hour to go through it, and that is very deliberate because the family have to consent, and it has to be free and informed consent.

Under this proposal, it will be exactly the same family consent. There are two points that members need to be aware of. The first is that there is a European minimum requirement, as a matter of law, which we have signed up to, as have all the contracting states, that states, whether it is an opt-in or opt-out system, that the family must consent. So, as a matter of law, the family must consent. Members will be aware of the recent wrangle in the Seanad when it was recalled to discuss the bringing into law the European directive in the Republic of Ireland. Part of that directive is that the minimum requirement in law is that the family must consent. People should be reassured that this is based on family consent, and it is the only way that it can work.

There is another point, which is important, which is that the intensive care consultants will not work a system that is not based on family consent. Doctors will not work it. Doctors would be quite entitled at the moment, as matter of law, to take organs where someone is on the organ donor register regardless of their family's wishes. That does not happen and will never happen because clinicians will not operate the system. So, make no mistake; it is based on family consent.

The important thing from the point of view of members is that the evidence is overwhelming. No doubt, some members will be aware of the world-leading Abadie/Gay Harvard research, which is the respected touchstone throughout the world. The Abadie/Gay research was undertaken by Harvard University, in tandem with the University of Chicago, and the findings were published in December 2005. They looked in particular at why it is that the world leaders in Europe — Spain, Portugal and Croatia — have such huge rates of organ donation and low family refusal rates of around 5%. For families in those countries, organ donation is the norm. The question we have to ask ourselves, therefore, is why it is the norm.

The Harvard research — I will read from the conclusion — stated:

> *"we construct a dataset on organ donation rates and potential factors affecting organ donation for 22 countries over a 10-year period. We find that while differences and other determinants of organ donation explain much of the variation in donation rates, after controlling for those determinants presumed consent legislation has a positive and sizeable effect on organ donation rates."*

Presumed consent legislation is the soft opt-out. On the whole, when variables are accounted for, those countries have roughly 30% higher donation rates on average than what are described as informed consent countries.

The second key piece of research that is the touchstone for anyone who has a genuine interest in this area, which I know members do, is the UK Government's research, which they asked the York group to undertake in 2009. That research was published by a very heavyweight team, and it ought to have informed the Government's approach to organ donation. However, they choose not to run with soft opt-out at that stage, in spite of the report's conclusions. I will make copies of all this available to all members; I ought to have brought copies with me. They did a systematic review, investigating the impact of soft opt-out legislation on organ donation rates and looked at the four main studies that had gone before. All four studies found a statistically significant association between soft opt-out legislation and higher organ donation rates.

In the conclusion, the report states:

> *"The available evidence suggests that presumed consent is associated with increased organ donation rates, even when other factors are accounted for."*

The report goes on to assess the difference in the leading countries before and after soft opt-out, and how societal attitudes changed. All the main studies concluded that societal attitude changed when soft opt-out was introduced. If you think about it, you realise that it is a matter of common sense, because the question for you and your family becomes this: is there a reason why we should not be a donor? Does anyone feel strongly enough about it to go on the register and rule themselves out? Once that becomes the question, you can see that it more readily accords with the research that shows that the vast majority of people think that organ donation after death is a good thing.

The problem is very real. On Saturday, I spent six hours with a young man — a friend of mine — who is dying because he did not get lungs in time, and it is too late for transplantation now. He is 26 years of age. I have photographs on my phone that I can show you of him wearing his mask. It is just too late. We have hundreds of organs going to waste every year, even though people believe that organ donation is a good thing. It seems a shocking waste of life in a society as civilised as ours, where there is such goodwill for this.

The second crucial piece of evidence, apart from the research — as I said, I will make all the research available to members, along with all the notes — is the league tables. I know that Roy, for example, has an intimate knowledge of this area. It is often said that the league tables never lie. If Manchester United win the league, it is because they are the best team in the league.

Mr Dunne: That is true.

Mr Brolly: Exactly. For the past eight or nine years, the league tables have shown that the top six or so countries for organ donation — Austria, Portugal, Belgium, Croatia, Spain — rarely change. Bearing in mind that we have had state-of-the-art infrastructure in the UK for six years, the current rate in England is 19 donors per million people. Meanwhile, three people die every day. The current rate in Spain is 36·7 donors per million people. That is almost 100% higher.

A good friend of ours, Orla Smyth, whom you know, travelled to Spain for a transplant, and, on the morning she arrived, there was a choice of two kidneys. The same situation would not arise here. In Spain, you are talking about 36·7 donors, and I will give you the figures from last year. The rate of donors per million of population in Croatia is 35·3; in Portugal, it is 32; in Belgium, it is 30; and in Austria, it is 31.

Our rate in Northern Ireland is very good. I want to say one important thing to everyone: one reason why I met Dr Glover last night was to get the most recent figures, because we are keen to see what impact the public discussion has had on organ donation rates. He is quite happy to come before the Committee if required and tell you this himself, but he is reporting that there has been a spike — a significant increase — in family consent since January this year, which coincides with the public debate, discussion on 'Talkback', articles in newspapers, all the things that Jo-Anne has been doing and all the discussions that have been taking place.

It has been found that, increasingly, people are more willing to donate. A lot of people seem to think that the soft opt-out has already been introduced. What has happened, in line with the public debate, is that, rather than being afraid or confused, the public are being encouraged. People are losing their fear factor because they are listening to the issue being discussed and are hearing the stories. The NHSBT is well on track to exceed its official target for this year. Its target for last year was easily exceeded: it was 20 donors per million of the population, and that figure has already reached 22.

I do not know whether members are aware of this, but the rule of thumb is that there are 4·5 successful transplants for each deceased donor. I know that 4·5 transplants is not possible, but that is the average. So between four and five people have a life-saving transplant as a result of each deceased donor. That is all good. The evidence is clear.

I should say that we have been going through pretty much the same process in the South of Ireland. When I say "we", I mean Opt for Life. Just three weeks ago, the South finished its public consultation, and the Dáil Joint Committee on Health and Children, which is a very powerful, cross-party group, has unanimously endorsed the soft opt-out, so that will inevitably become law in January or February.

We are keen on the soft opt-out, as are Wales and the Republic of Ireland. There are very few countries left that do not operate the soft opt-out, one of them being the UK, England in particular. I am going to make an interesting point about England. Is it permissible for me to give members something to read, or is that outside protocol?

The Chairperson: If need be, we can circulate the information.

Mr Brolly: England is lagging badly behind, and there is no reason for that because it has a brilliant infrastructure. That comes back to the point that all the leading countries have three things: infrastructure, soft opt-out and good public awareness. As society's attitude changes, the infrastructure is there to convert organ donations into good transplant figures, which saves a lot of lives.

England is stuck on 19 donors per million of the population after six years of having a state-of-the-art infrastructure and throwing £10 million a year into a publicity campaign to get people on the register and so on. Last year in England, 125 families who had a loved one on the register refused consent. England is trapped in the orthodoxy of opt-in, and it is one of the few European countries that still has an opt-in policy. The conclusion by the task force in England is that, because the Government have not legislated, we must dispense with family consent. The English answer to the problem of being stuck in and around 20 donors per million of the population is to dispense with family consent.

I saw Ms Buggins being interviewed, and I sent her some e-mails that she did not respond to. Members will see from the extract that I just circulated that Ms Buggins, who is the heavyweight head of the NHS transplant service, is saying that they must get rid of family consent. We believe that that is the antithesis of this. The gift is a gift of love. It means something in the community. I cannot begin to tell you how many families I have spent time with — bereaved families who allowed organ donation to proceed, and some families who did not allow it to proceed and who contacted me and asked me to speak to them. When I was in hospital, I saw people being transplanted and the difference that that made, and I saw families experiencing that huge elation of a loved one being transplanted. However, the essential quality of all this must be that it is a gift — a gift of love — and the family then receive the great benefit of knowing that their loved one has been the source of life for possibly five or six people. You are engaged in something very important. I ask all of you to keep an open mind. I have a totally open mind. It does not matter to me. I just want to save lives, so it makes no difference to me how they are saved — none whatsoever. I want to see what works.

We are very close to a state-of-the-art organ donation system. Dr Courtney will speak to you a wee bit more about this. Obviously, the intensive care consultants have to retain neutrality on the issue, but they are very prepared to operate this system, and they will operate it. However, we are very close.

The two components that we lack at the moment are the soft opt-out and greater awareness. Eddie Rooney is due to talk to the Committee about the awareness campaign that is in waiting.

Genuinely, this is a classic no-brainer. That is not just me saying that; it is simply a classic no-brainer. It will save lives. We are very confident that the research is correct, the league tables do not lie, and the experience in other countries will be reflected here. We have the most vital part in place: the infrastructure. The law and the debate that will go with it, and what we have seen since January with the spike in donations, is all good. It is not to be feared. If public representatives go out and extol the virtues of this organ donation system, people will be very confident in it. It will be a great feel-good act, which, I believe, we will be very proud of. We will save the maximum number of lives. We will not be left with the situation that I was in on Saturday, when I spent time with a kid who is dying because there are no lungs. It does not make any sense.

Mrs Dobson: Chair, I do not know whether there is anything left to be said after that powerful presentation. I hand over now to Dr Aisling Courtney.

Dr Aisling Courtney: Thank you for the opportunity to come here. Joe has given you the legal side of the issue and lots of facts and figures, and Jo-Anne has given you the local side of things. I come at this from a different angle — a doctor's point of view. The reason why I ended up doing transplant medicine was because, when I was a junior doctor, it was the one thing that really made a difference to people's lives. Therefore, it is the one thing that really transforms people's lives. When you come into medicine, you think that you want to make people better and save lives. Of all the areas that I travelled through as a junior doctor, transplantation was the one thing that really grasped my attention more than anything else. In Belfast, obviously, that is kidney transplantation, which is transformational for people. That is why I am interested in it and why I do it. To me, it is obvious that people should donate because I see the difference at work, day in and day out. I had 28 people at my clinic on Tuesday morning who had all received kidney transplants at varying periods of time. It makes a huge difference, and that is why I do it. I come at the issue not so much with the facts and figures, the league tables and the evidence in the reports, which you can all read, although you may or may not remember all the details. However, the bottom line is that kidney transplantation and other transplantation transform and save lives.

From the public consultation, it is obvious that the people who know about transplantation and donation, and have had something to do with it, are in favour of organ donation and the soft opt-out. That makes sense, because if you have an awareness of why transplantation works and what makes a difference, then, as Joe said, it makes sense that we should do it.

In Northern Ireland, as a community, the rate of deceased organ donation, which is much higher than the rest of the UK, is most impressive, as is the rate of live kidney donor organ donation. The kidney is one of the few organs with which you can do with one organ. Our rate of live kidney donors is twice the UK average, which it has been consistently over the past three years. That simply reflects the fact that we are still a fairly cohesive community, have good family ties and are a fairly generous population. As a whole, Northern Ireland consistently outperforms all the other regions of the UK.

My feeling is that, in Northern Ireland, that same spread of generosity and altruism will also hold true for deceased donors. As Joe said, we have the infrastructure; if we have the education and awareness for the part of the population that does not know much about donation and transplantation, they will also be in favour of the opt-out.

In summary, transplantation is transformational. It saves lives, and that is why I do it. It is challenging, but it is a great job. People who know about donation and transplantation know the impact that it has, and they are in favour of the soft opt-out. As a society, we are very generous, and our live donation rate is twice that of the UK average. I think that that will transfer to deceased donors. The awareness campaign is a key element, which, very conveniently, will run in parallel so that people are aware of the benefits. That means that the soft opt-out option very obviously becomes what we ought to do. The bottom line is that it works; the real question is how we, as a community and a society, and as Committee members, find the best way to translate talking about it into doing it. That is the key, and that, I guess, is your job. I will hand over to you on that.

Mrs Dobson: Would it be possible to allow William to say a few words?

The Chairperson: Yes, sure.

Mr William Johnston (Northern Ireland Kidney Patients' Association): I come at this from a personal viewpoint. I have been unfortunate enough to have been waiting for a transplant for 16 years. That is a long time, and it should never be that way. The soft opt-out Bill can be summed up in two words: freedom and hope. The hope is that the more organs that come forward, the more chance there is for me to get a transplant, which will free me from a life-saving dialysis machine to which I have to be linked up every other day.

It is funny to say that, in some ways, I am fortunate that it is my kidneys that are failing, because I can be kept alive by a machine. However, there are people who are waiting for a liver, a heart or a lung transplant who will not be kept alive and can survive for perhaps only a couple of months until an organ becomes available for them. The demand for organs is real.

Organ donation is about saving and transforming lives. It is about transforming and saving my life. I go everywhere now with my mobile phone because I live in hope that it will ring and it will be the City Hospital asking me to get myself in because it has an organ for me, which will give me, and my family, freedom. They have had to live through this 16-year ordeal.

I very much support Jo-Anne's soft opt-out Bill. To me, as Joe said, it makes sense. I cannot understand why it has not been in place before now. It will remain a gift of life. People will still have control over their organs; it will not be state-controlled, and the family will always have the final say. I am looking forward to the possibility of the soft opt-out Bill being adopted, and I look forward to my life being transformed and saved by the fact that more organs will be made available.

The Chairperson: Thank you all. There is no doubt that this is important legislation. Thank you for your stories, specifically, and for your honesty, in particular, William. That has to be acknowledged. We have flagged up the robust registration process. The notion of the soft opt-out has been looked at. How can we be assured that the registration process will be robust for the opt-out to take place? I do not know whether you have any thoughts on that.

Compared with other European models, the figures for donors in the North of Ireland is quite impressive, as is the fact — this was referenced a number of times — that it makes sense. I am interested in the relationship with the Public Health Agency model and its work. Jo-Anne, the figure that you suggest, through the consultation, as being in favour of this system is 82·4%, which is particularly high. It shows the public view. Some of the figures that we are getting back from the PHA are around 54% or 55%. What is that differential about? How can those two figures be brought in line?

I am aware that the biggest challenge is changing society's awareness of the issue. Joe referred to that. How can the public awareness campaign be driven, even from the Health Committee's point of view? That is a critical piece of work.

My questions concern the difference in response rates between your work and that of the PHA and how they can be intertwined; the robust registration process for people opting out; and the public awareness campaign. I am not sure who is going to address that.

Mrs Dobson: Do you mind if all of us respond?

The Chairperson: No.

Mrs Dobson: Obviously, Chair, the next stage is the drafting of the Bill. Be assured of this: I want to listen to all suggestions and concerns from members. There will be a very robust registration process. I reassure everyone that nobody will ever know if someone chooses to opt out because it will be totally confidential.

Dr Courtney: The Public Health Agency awareness consultation was across the board, so it picked up people who did not know anything about transplantation. The majority of people who responded to the consultation on the private Member's Bill will have had some level of interest in transplantation, will have heard about it or will have had some connection to it. As I said, if you know anything about transplantation and donation, you are in favour of the soft opt-out because it makes sense. Responses to the consultation on the private Member's Bill would have come from people who are interested in the issue. If people are interested in donation, they usually think that the soft opt-out is a good idea.

The Public Health Agency conducted an across-the-board survey, which did not depend on people knowing anything about donations. I think that that explains the difference in favourable responses. It is to do with the population, as Joe said. People can be lethargic. If you have nothing to do with people who are sick or in need of a transplant or organ donation, you are unlikely to pick up a consultation document and fill it in. That is why there is a difference.

That takes me on to your second point about the awareness campaign. My feeling is that that is absolutely crucial. As the difference in percentages shows, people are in favour of the soft opt-out if they are aware of it. An awareness of organ donation and transplantation is vital. That is what will make the soft opt-out a success. If people are aware of organ donation and transplantation and realise the benefits, they will agree with it. If you try to impose a soft opt-out on people who are not aware of the issue, you will get people's backs up, and they will ask, "What's it all about?" Public awareness is absolutely vital. It is fortuitous — perhaps that is the wrong word — that the Public Health Agency will run its awareness campaign in parallel. If people are aware, there is strong support for the soft opt-out. The soft opt-out legislation is a natural progression of what society wants to do. If it were the other way round, we really would run into difficulties. If people are made aware of the benefits of organ donation and transplantation, they would agree with the soft opt-out, and it would be a natural reflection of society's wishes.

Mrs Dobson: Aisling made some very important comments. I was at the PHA launch last Wednesday. What concerned me — Dr Rooney mentioned it — was the fact that the organ donor register has been running for so long, yet so few people are aware of it. People thought that opt-out had already come in. Obviously, timing is crucial. As Joe mentioned, the Bill on the soft opt-out will run side by side with an education programme, and there are three crucial issues: infrastructure, education and the move to the soft opt-out. As Dr Courtney said, people were fully aware of organ donation issues when they replied to our consultation. It was laid out in such a way that every question was explained fully, whereas perhaps the PHA survey was more difficult to understand. At the launch, Dr Rooney told me that if he were in my shoes, bringing in the soft opt-out option, he would be very encouraged. In fact, it backs up the percentage, which I think was 56%. Do not forget that Wales initially went down the soft opt-out route with 49%. If any of us sitting here were elected with 56% of the vote, we would be fairly happy.

Mr D McIlveen: Jo-Anne, we will be as gentle on you as we can. Any of us could be in that seat in the future. We have to bear that in mind.

Thank you very much for the presentation. I have just one question. You mentioned the Public Health Agency document. Do you support its findings?

Mrs Dobson: I support the fact that, overwhelmingly, we need an awareness campaign. Joe and I referred to that. People simply do not know about it. I know that all the publicity that we generated has kept the issue to the fore in the media. However, even Dr Rooney was surprised by the lack of understanding of the issue. With that in mind, I am heartened by the results and the fact that it will create awareness. We all know how crucial it is.

Mr D McIlveen: Seemingly, there is a huge gap between the opinion that came through in your consultation and that which came through in the PHA's engagement. I note that a comment was made that perhaps the PHA document did not reach out to people who might be likely to respond in such a way. However, table 1 of the PHA document states that almost 100 respondents were clinicians or nurses — medical professionals who work with donors. In fact, the percentage of support for opt-out went down as you moved away from the general public towards clinicians.

Mrs Dobson: That is not what we found. Dr Courtney referred to clinician support.

Mr Brolly: Obviously, there is real sensitivity. The business end is with intensive care consultants, because everything happens in ICU. That is where the real sensitivities are. Interestingly, the first time that I met Dr Glover, who is the head of the NHSBT, he did not have any sort of handle on the research, the tables or anything like that; he simply had his experience of day-to-day work as an intensive care consultant and having those conversations.

Mr D McIlveen: I say this as someone who is on the organ donor register; I just want to get to the core of the issue. If we were being cynical, we could argue that a consultation that is run through an external website, which, I think, this consultation was initially, is anecdotal, whereas when it comes to the Public Health Agency's survey, bearing in mind that it spoke to three clinicians and one nursing sister in Altnagelvin; five clinicians and two nursing sisters in Craigavon; 11 clinicians in Belfast; three clinicians and other professionals, including 48 ICU and ED theatre nurses —

Mrs Dobson: Sorry, David: do you have the list of people who responded to my consultation?

Mr D McIlveen: Yes.

Mrs Dobson: The consultation — paper copy and online — lasted 16 weeks. It was the longer consultation. I do not know where people were if, through the media, they were unaware of what was happening. You will find that 1,366 is a very high number of respondents.

Mr D McIlveen: With respect, that is not the point that I am making, Jo-Anne. I am not questioning the genuineness of the people who responded to your consultation. I am saying that I do not think that anybody could argue that the people who responded to the Public Health Agency survey are not those who are at the coalface of dealing with families and patients who are going through this very difficult situation. I am trying to get an understanding of why support for presumed consent was even lower among that bracket of people than it was among the general public.

Mrs Dobson: It is not presumed consent: it is soft opt-out. It is never presumed. As we mentioned, the family is always at the heart of it. I hate the term "presumed consent". It is soft opt-out, David.

Mr D McIlveen: What if there are no living relatives?

Mrs Dobson: It is all contained in your documents.

Mr D McIlveen: Can you explain it to me? What would happen in the case of a family —

Mrs Dobson: Obviously, the GP would play a crucial role in that situation.

Mr Brolly: This has to be workable, so if there is a situation in which there is no family consent, there is no organ donation. It is as simple as that. It is exactly the situation that pertains at present. If, God forbid, you are an orphan, you are on the organ donor register and have made your wishes clear — you might carry a letter stating, "In the event of my untimely death, I am an orphan and wish my organs to be taken" — your organs will not be taken. It is the only safe way to proceed. Of course, you cannot measure the cost of a human life or the contribution that could be made by a human who has died in those circumstances. However, it is safe. It keeps the medical profession safe and retains public confidence. So, in the Bill, there would be no question of a situation arising in which next of kin was not consulted before organ donation. That is at the heart of this. There is no way that that could be otherwise. Do not forget that, apart from anything else, David, it is the law. A clinician cannot break the law. We cannot break the law. Members here cannot break the law by putting in a provision to say that if an individual is on the organ donor register and no next of kin can be found, extraction can proceed. It is never going to happen, so it is not an issue that will arise.

Mr D McIlveen: That leads on very nicely, Joe, because what scares the life out of me as a legislator is the unintended consequences of any bad law. Obviously, you are more aware of that than I am.

Mr Brolly: I see plenty of bad laws.

Mr D McIlveen: I would say that you see many of them. I will personalise this because the PHA survey highlighted that, because we live in a society that has quite strong religious views, that probably has an impact on views and feelings about that model, particularly among a slightly older generation. From my point of view, because I am on the organ donor register and had the choice to do so, I opened a conversation with my family to the point that now, even though I believe that my family would have some reservations about organ donation in principle, if I were to be hit by a bus today or tomorrow, I am fairly confident that, because they know about my consent to it, they would not be inclined to intervene. If we were dealing with a soft opt-out system, as you are proposing, Jo-Anne, I fear that it probably would not open up that conversation. I know that you are saying that it is a soft opt-out. However, if I do not remove myself from the register, family consent is presumed. I am 99% sure that, in that kind of scenario, my family would not consent to it.

Joe, you mentioned countries that have had increases in organ donation. I am trying to ensure that we do not find ourselves in the same position as other countries that we can think of, such as Brazil, Norway and Sweden, which have seen decreases.

Mr Brolly: That is not right about Sweden.

Mr D McIlveen: Brazil is probably the best example.

Mr Brolly: That is a very different society, and there are different considerations. Also, there has been a series of scandals about organ donation in Brazil.

Mr D McIlveen: There has been a collapse, and all that I can say to you is that, personally speaking, if this system were brought in today, I am fairly sure that you would lose a donor from this table.

Mr Brolly: Your initial point about the discussion with the family is right. That is the key. As Dr Glover will tell you if he comes here, it does not really matter whether a person is on the organ donor register, because it is the family that makes the decision. This is about the family having a handle on what their loved one is interested in, and whether they are interested in organ donation. So, the conversation is the key.

The problem is that after six years, when people were supposed to be having these conversations, we are spending £1 million every year on publicity so that people will sign the organ donation register and speak to their families and people are not doing it. We have a refusal rate of over 40%.

So, there are two points. I agree entirely with what you say. The question is about how best to achieve a societal shift to where families are not afraid of organ donation, have no concerns about it, are not worried about it, believe that it is a good thing, and where society in general believes that it is a good thing. The answer is to look to European countries with comparable situations and systems to ours. When we do that, the evidence is overwhelming. When countries such as Spain, Portugal, Belgium, Croatia and Austria have rates that are between 75% and 100% higher than that in the UK, you ask yourself what the difference is. No one knows more about this than Aisling.

Mrs Dobson: Sorry, Joe, can I come in? David knows as well as I do, as we are both here at Stormont, that it would be a miracle if this were to come in tomorrow. We both know that there will be a lead-in time, as there is in Wales. If we do nothing and wait to see whether this is a success in Wales before deciding to adopt it five years down the line, 75 people may die waiting for a transplant. I do not think that a do-nothing approach is the answer.

This will not happen tomorrow. There will be a lead-in time, as there is with Wales, with an informed education programme as well. That is crucial, and it is naive to say that this will not generate the conversation with the family. If there is a change in the law coming, it will totally generate the conversation with the family.

The Chairperson: Four other members wish to come in, so I ask members to come to their questions as quickly as possible. The same applies to the responses, without stifling debate.

Dr Courtney: David, your points are very important. I am not on the politics side of things, but I imagine that, as Members, your job is not to make things worse by making wrong laws. You are right about that. Part of the concern among clinicians is that this will make it worse, and part of the reason for some of the responses being negative towards it is that we do not want to do that. You are right about that, and the campaign by the Public Health Agency will have to be thought out very carefully.

This is about awareness of organ donation and having that discussion with families, because you are right to say that if this is introduced in the wrong way it can make things worse. None of us want that, so I welcome your inquiry and your spot-on questions. For your own discussions, the key is to ask Eddie Rooney how we can take this forward. Your points are valid and crucial, and I welcome discussion with members about this. If we do this wrongly and badly, we will be worse off. So, you are absolutely right.

Mr D McIlveen: Finally, looking at how the law can be improved, how would you feel, Jo-Anne, about consent meaning consent? Currently, we have an issue around when people consent, as I have done, and where my parents and my family in general who are living behind me can still overrule my genuinely made decision. In your view, would it not be better law to ensure that people who wish to donate are not overruled and that, effectively, consent is taken as consent, rather than presumed consent? I know that you do not like the term "presumed consent".

Mrs Dobson: It is with family consent, David, and it is crucial to have that conversation with your loved ones. I feel that the campaign will generate more conversations with the family, as we said earlier. The family will ultimately know the feelings of their loved ones; it is naive to think they will not. The only way that the family will not be aware is if you are opposed to organ donation and decide to opt out. Currently, the family could still decide to donate your organs. I think that this will strengthen human rights. As we said earlier, family consent is at the heart of this and is crucial.

Mr Brolly: Your point is a good one, David, and it is one that we have reflected on at length. I have discussed it at length with clinicians and families.

Presumably, you have a family. If your point were accepted, and if you were dying and your grieving children and wife were told, "He is on the organ donor register; his organs will have to be taken", and for whatever reason, your wife decided that she could not face that, the organs would be taken. In any event, you know the minimum legal requirement, Europe-wide: it cannot occur.

If, God forbid, your wife dies, and she is on the organ donor register but you cannot face it, for whatever reason, and it happens against your will, that would be a blow to the cause of organ donation and to the sacredness of that particular time. In the end, it is a family decision. Death affects more than the individual, which is why systems throughout Europe, whether opt-in or opt-out, are based entirely on family consent. I hope that that answers the point; it is the best way I can put it.

Just put yourself in those shoes. If something happened to your beloved son, and God forbid anything happens to him, they would not say "I am sorry, Mr McIlveen, but he is on the organ donor register and this is the law".

Ms P Brown: Thank you, Jo-Anne and the rest of the panel for your presentation. We had not discussed this, but David has stolen a lot of my points.

Mr Brolly: I hope you have not been cogging. *[Laughter.]*

Ms P Brown: This is something that I feel very strongly about. I fully support organ donation and always have done, and I welcome any raising of awareness so that families can have that very difficult conversation and hopefully make firm decisions about their wishes.

I have been on the organ donor register for as long as I have been an adult, and I have always carried a card. It has been challenged by a family member, and arguments have been had over years about my wish to donate my organs if something happens to me. They have said that they will not let it happen. It is a conversation that we have had on many occasions. I have always found it deeply frustrating to know that, should anything happen to me, my organs would not be donated, which is completely against my wishes. It is a huge issue for me.

Mr Brolly: He loves you too much.

Ms P Brown: When somebody goes to the bother of putting themselves on the register and has genuinely expressed their wishes about what they want to happen to their body when they pass away, for that to be cast aside by any family member is, to me, obscene.

Mr Brolly: It is reality, and it is not going to change. Doctors will not transplant; it is as simple as that. They are entitled to transplant now if you are on the organ donor register, but they will not do so. Is that right?

Dr Courtney: Yes. Your point is valid, Pam. I would feel exactly the same, but no clinician is ever going to take your organs if you are not there to say so. It is false, but, unfortunately, it is reality. Our hope with this idea is that there will be a greater tendency for organs to be donated in this sort of situation, because it will become more normal to do so.

Mr Brolly: The point that Aisling makes is that in the few remaining opt-in societies in Europe the average refusal rate of families is between 45% and 60%. The average refusal rate in opt-out societies is between 2% and 15%. For example, it was just over 2% last year in Belgium. That is the norm in such societies, so your wishes will virtually inevitably be followed through.

When the new question is, "Is there a reason why I ought not to be a donor?" and when society is aware of it, and there is a strong public awareness in schools and through the media, and people know that it is an easy thing to do online, the reaction of the vast majority of them will be, as it has been in countries comparable with ours, "I think organ donation is a good thing after death."

You are right, David; there is also a societal issue. From the conversations that I have had, older people are a wee bit more superstitious. There are a lot of myths, "Oh, God, they will take my eyes" or "Oh, God, they will disfigure the body", when, of course, none of that happens. It is an important part of the public awareness campaign to make sure that people understand how sensitively the whole process is carried out and what a beautiful thing it is, because the consolation to families is enormous.

We do a roadshow and go to various towns and places, and I have met countless families who talked about the great sense of consolation it has been in even the most desperate of circumstances. They get a wee letter to say that their loved one's organs were used successfully to transplant four or five people. I was cycling through Toomebridge when a woman stopped me. "Joe," she said, "my nephew, Brendan, died last year and his organs were donated and he saved six lives." It is a huge consolation to people to know that. Your point is right, Pam, but this will never change.

Mr Johnston: The current opt-in system is not stimulating that conversation; it is the opt-out system that will do so. Whether or not you want to decide to donate, at least you will have that conversation. When you do so, do not wait until it cuts to the time when your loved one has died and you suddenly have to have the conversation. The opt-out system will encourage you to have that conversation way in advance of your ever having to make that terrible decision.

At the moment, the opt-in system is not stimulating the conversation that has to be had with loved ones. That is why the soft opt-out option, and this whole debate, is tremendous, because it is stimulating that conversation and is acting as a catalyst for people to sit down and discuss organ donation for the first time. I have met so many people who said that it never occurred to them. It will occur to you now, because the soft opt-out option will encourage you to have that conversation.

Ms P Brown: I had conversations with people about organ donation and there is a strength of feeling among those who wish to donate that this is something that they want to do and is a gift. I think that there is still quite a bit of opposition, and backs may go up when you say, "We will presume that you are consenting unless you opt out."

Mrs Dobson: You underestimate the generosity of the Northern Ireland public.

Mr Brolly: It is still family consent, so the family will be treated in exactly the same way. Nothing will be presumed.

Mrs Dobson: So, the gift will be preserved.

Mr Brolly: In exactly the same way.

Mrs Dobson: I think, Dr Courtney, you spoke about the generosity of the Northern Ireland public.

Mr Dunne: So, you do not need it then.

Dr Courtney: Pam is right, and David is right as well. We have to be sure that we do this right. If we do it wrong, it will be a disaster. So, you are absolutely right, Pam, we have to be sure that we do it right.

You are both pro-donation but are raising valid concerns, and it is reasonable to do so. We do not want to do this badly and then be worse off than we are. We have to have the education and awareness process first. The legislation has to be a reflection of what we think as a society and not be imposed. If you impose things on people, you know fine rightly that it will put their backs up. We have to get the awareness and education bit right first.

Mr Brolly: I would like to say something that may be of interest to you. Aisling was modest in how she described the living donor programme. Aisling's living donor programme, of which she is the clinical lead, is the flagship living donor programme throughout Europe. It is the No 1 living donor programme. The point that we have a generous society is well made but it is not being reflected in our deceased organ donation rates. So, how do we effect that shift?

Ms P Brown: It is interesting. I am very supportive of living donation. If I had a close family member who needed a kidney and I had a kidney that was good enough and matched, I would be happy to donate it. That should be encouraged. It is good to have that awareness out there.

Jo-Anne, you said that the only organisation that was opposed was CARE. I am sure that you agree that it covers a very wide spectrum across Northern Ireland and across the religious divide. You have to recognise that there is that opposition as well.

Mrs Dobson: Of course. That is why I said from the very start that I wanted everyone to reply. You will see every comment listed in the consultation; the positive and the not so positive. I have nothing to hide; every comment is listed.

CARE was invited to speak to the all-party group on organ donation, which, as you know, I chair. It presented to that group. I have written to CARE again to invite it to meet me to reiterate its concerns. I am waiting for it to get back to me. My door is always open to any organisation. If you read through the list of support, and the fact that that one group is against this, that is quite telling.

Ms P Brown: Would the system that you are opting for put a person on the donor register automatically?

Mrs Dobson: It is soft opt out. It is about changing the law. It is not presumed —

Mr Brolly: You would not be on a donor register.

Ms P Brown: It is presuming your consent.

Mr Brolly: No, you would not be on the donor register. Your family makes the decision. That is it. If society decides that that is what it wants to do.

Ms P Brown: But it automatically puts you on to —

Mr Brolly: It does not.

Ms P Brown: Does it not put you on to the donor register?

Mr Brolly: No. Your family makes the decision.

Ms P Brown: It just presumes that, unless your family objects —

Mr Brolly: You would only do something in future if you did not want to be a donor. For example, if you have some rational or irrational fear, you could go online and rule yourself out. It is a confidential process, and that would be the end of the matter; your family would not be approached at the hospital. We have a very good integrated system now. The specialised nurses know exactly who is on the register.

Ms P Brown: Can you see the situation in which somebody may not have opted out, and their family may not object and their organs could be donated, but where actually the person may not have wanted their organs to be donated?

Mr Brolly: You could save five lives. You weigh these things up. That situation happens all the time now; the family have no idea. The difference between family consent rate where the person is on the register and family consent rate where the person is not on the register is surprisingly small; there is a swing of about 10%. Often, families have no idea. They could say, "We assume that, like us, he or she is in favour of organ donation. We think that it is a good thing. It will be a great consolation to the family. It will save lives." There is no perfect system. You can think about all the —

Ms P Brown: The person should have the decision, though.

Mr Brolly: The individual?

Ms P Brown: Absolutely. Their decision should be respected.

Mr Brolly: You made that very clear, but you are going to have to go to Strasbourg to tell them that they are in error. It will be a longer process than this.

The Chairperson: I have five members looking to comment, so I remind people of time.

Mr Dunne: I thank the panel very much for coming in. We are supportive of the issue, but the method of delivery is in question. Jo-Anne, will you clarify how you carried out your survey? Obviously, you trawled Northern Ireland and probably further afield. You received 1,866 responses.

Mrs Dobson: I launched the consultation here on 4 June and I opened it for 16 weeks. I think that the minimum period for consultation is six weeks. I wanted to have a long consultation to give everyone the chance to respond. I advertised it extensively through the media and through the excellent work of the transplant charities, which are all fully supportive of the change in the law. I think that, with all the transplant charities together, many thousands of people were very aware of it.

Mr Dunne: How many responses did you get?

Mrs Dobson: It is all in the booklet. Did you get a chance to read it yet?

Mr Dunne: How many did you get?

Mrs Dobson: I received 1,366.

Mr Dunne: Are they written responses or was it a mixture?

Mrs Dobson: It is a mixture. If you take the chance to have a look —

Mr Dunne: Was it online?

Mrs Dobson: It was online and in booklet form.

Mr Dunne: Will you clarify how the online system operated?

Mrs Dobson: It was operated through SurveyMonkey, which is the usual format for online consultations. It was advertised extensively in the press, on Twitter, and by the charities to make people aware.

Mr Dunne: Is there a risk that people made multiple inputs to the system?

Mrs Dobson: I suppose that that is a risk with any consultation. Did you have a look at the format of the consultation? I have a copy of it here. There were boxes for comments. I do not think that you were here for my introduction, but I listed every response to the question. I used boxes, and most people left written responses. I think that we would have known if there had been multiple responses. The responses were very personal.

Mr Dunne: Were the names and addresses given in those responses?

Mrs Dobson: It is confidential. I think that the e-mail addresses were given.

Mr Dunne: So, the names and addresses were not given; it was just e-mail addresses.

Mrs Dobson: Is that not the —

Mr Dunne: Are you satisfied with the authenticity of the whole procedure?

Mrs Dobson: Of course I am; yes.

Mr Dunne: What evidence do you have of that authenticity? You have no addresses. You have only e-mail addresses for a large number of responses. How are you convinced that the responses are authentic?

Mrs Dobson: I am convinced by the words used in the responses. I urge you to read them. We made the list of replies to the consultation available. Gordon, I urge you to take the time to read through the responses. It is very clear —

Mr Dunne: The Committee will be looking through a lot of responses. How else did you carry out the survey?

Mrs Dobson: There were paper responses as well. Copies were given out and distributed through the charities. I am aware that people sometimes do not want to do a paper response. It was made widely available.

Mr Dunne: Do you accept that death comes suddenly to many homes and families? I say this to everyone here. It is a shock, a terrible time, and people go through a trauma. Thankfully, in Northern Ireland, death is still treated very much with respect. We still have a time of mourning, and people are keen to have a funeral. Do you really think that people want to be approached about this issue at that time? You are proposing legislation that will mean that people are automatically put on a list. Is that necessary? Do you not feel that it is too much to put people on a list whereby they then have to be consulted?

Joe, you alluded to the fact that the public awareness campaign is working. There has been a greater uptake of donation.

Mr Brolly: There has been a spike.

Mr Dunne: Is that not a better way forward, Joe, rather than going in heavy, putting people through this, obliging them, and putting them on the list automatically?

Mr Brolly: I think that your language is loaded, I have to say. It sounds as though you have made up your mind, if you do not mind me saying so. It is not a question of going in heavy. It is a question of looking at what works but basing it very much on family consent. Families will still be consenting in exactly the same way as they do at the moment. Make no mistake about it, Gordon: the current system is based entirely on family consent.

The second issue that you raise is about asking people at what is a difficult time. As part of the protocol that is operated in intensive care, every single potential donor's family is asked the question; every single one. That is the bottom line. That is the job of the specialised nurses. We have 11 specialised nurses, and the first thing that they are trained in is how to ask the family. Every single family is asked. You are right: it is a very traumatic time.

The big issue for consultants and nurses at the coalface is how to create the situation in which people expect the question to be asked and where families have already considered it. You are right that it is a terrible, terrible time. The issue is not about asking the question: they must ask it; that is their job. Everybody is asked. The figures are audited, and they are very rigorous about it. The issue is how we create a situation in society in which families expect the question to be asked.

I know that this is anecdotal, but the girl McNicholl who lives in Belgium told me that it is just part and parcel of dying there. It is exactly the same in Austria; it is part and parcel of dying. If you read the paper on the incredible rise in Croatia in the last eight years, you will see that society there now expects the question to be asked at that difficult time. The most shocking statistic in the PHA survey is that almost 30% of people did not know that there was an organ donation system.

Mr Dunne: That is my point. Surely, public awareness is already increasing. You have already given us evidence of that. It is working and that is the way to do it.

Mr Brolly: Public awareness at the moment surrounds the soft opt-out debate.

Mr Dunne: I think that the only time, at the moment, that we may come across this is when we apply for a driving license. We can increase that. Opportunities could be presented when applying for a passport and at various other points. That is the way forward.

Mr Brolly: I am not against any of that. All I say to you is this: the first thing that is done by anyone who has a rational and objective desire to create the best system is to look at the best systems and ask what they do.

Mrs Dobson: Best practice.

Mr Brolly: You are absolutely right about public awareness. The public awareness campaign on the soft opt-out —

Mr Dunne: Sorry; what is soft about the soft opt-out?

Mr Brolly: It is called that because the family make the decision.

Mr Dunne: They have to face that?

Mrs Dobson: They have to face it anyway.

Mr Dunne: At that most traumatic time?

Mr Brolly: Absolutely.

Mr Dunne: At the most traumatic time.

Mr Johnston: If they have the conversation beforehand, it will ease making the decision a wee bit.

Mr Brolly: The form used by the specialised nurses already, the consent form that takes about an hour to fill out, is exactly the same one that will be used under this system.

Mr John Brown (Northern Ireland Kidney Research Fund): With the system that we want to bring in, a certain proportion of people will not be asked. They are the families of people who have signed the opt-out. Those families will not be approached. That is a section of the population that will not face that trauma.

The Chairperson: I think it is also a reflection about the statistics on the number of people who are signing up, and the need to address that. The stark reality is that, when you talk to people, they say: "I did not know how to go about it for the lack of information."

Mr Dunne: Chair, you made the very point; 36 people did not know about the register. That is the importance of it. Let me say, finally, what I said at first: the method of how we go about this is what needs to be debated. I respect the work that you are all engaged in; it is very good work indeed. I would not agree with Joe's politics, mind you.

Mr Brolly: You do not know what my politics are. I have not voted for about 20 years —

Mr Dunne: That is another issue, Joe, but we will get you on the register.

Mr Brolly: I used to vote for the Women's Coalition.

Mr Dunne: That is another register that you need to be on, Joe. In all seriousness, we salute your courage in making a donation.

Mr Brolly: Thank you very much.

Mr Dunne: It was a very courageous thing to do. I know that there is a campaign, and we are all supportive; but the method of how it is delivered is very important.

Mr Brolly: I agree entirely. It is a very important debate.

Mr Dunne: That is where we are.

Mrs Dobson: It is important that, as Joe said, we learn from best practice. We know where this works.

Mr Brolly: Just as an aside, I did not sign the organ donor register until I came back after the transplant.

Mr Dunne: You did not?

Mr Brolly: I did not know that there was an online register. I thought that you had to fill out —

Mr Dunne: Public awareness is the issue, Joe.

Mr Brolly: It is a huge issue; as are those three things. You are absolutely right and I could not agree with you more.

The Chairperson: Let us move on.

Mr Brady: Thank you very much for the presentation. You will be pleased to hear that I am not going to question the validity of your consultation, otherwise we could question the validity of every consultation.

I have a couple of points. What has come through in your presentation is common sense. We are talking about improving the quality of life for people and saving lives in many cases. From a personal point of view — I would not have known that much about it — but a friend and colleague who worked with me as a political adviser donated a kidney to his father three years ago. It was a huge thing; and, of course, you did that yourself, Joe.

It is interesting. Joe talked about two things. One was about counselling and talking to families. I imagine that, in the logistics of all this, there is a very clear timeline for an organ to be donated, taken, and transplant procedures to be carried out. I imagine that it has to be done very quickly.

Gordon said that it is a traumatic time. However, when sudden death occurs, the deceased undergoes a post-mortem. Do families object to that, given that, presumably, organs are removed and replaced? That is a "violation" of bodies.

Mr Brolly: I will ask Aisling to deal with that.

Mr Brady: I wonder how many families object to that.

Mr Brolly: You raise an interesting point. In Austria, by law, every death requires a post-mortem. On research in Austria, they found that people are not afraid of organ donation because a post-mortem takes place in any event. I will ask Aisling to deal with the point about the timeline.

Mr Brady: That is the point I was trying to make. In general, people do not object to that procedure, so I really do not see the difference, in a sense. Joe mentioned older people, the eyes and all that. Bodies are violated, in a sense, if they have to go through a post-mortem.

Dr Courtney: You are absolutely right, Mickey. It has to be part of the public awareness and education that you do not have a body that is mutilated —

Mr Brady: I did not know previously, but I am fairly aware of what is involved now, because I know somebody very well who went through the process. The people who will respond to the consultation are probably better informed than the general public, as is the case with many things. That is an important point.

Dr Courtney: You are absolutely right. When I came back to Northern Ireland to take up the live donors programme, I thought that, because we are in Northern Ireland, everybody will know somebody who has given a kidney or got a kidney. Enough of it is going on, and everyone will know somebody who either gave or got, and it will become normal.

Mr McKinney: I apologise for being late; it was because of a clash of Committees. When you talk about this issue, you nearly have to start the debate with each individual, and that brings me on to the idea of public information. You have had your consultation, and we have heard views about it. Perhaps some people who are keen on the debate will involve themselves in that consultation. Is there an added onus to seek out deliberately and actively other views to make that consultation more robust or, in other words, extend your consultation in another way, even through the progression of legislation, and ensure that, afterwards, there are robust and properly resourced public information campaigns continually for an extended period to make sure that people are as fully informed as possible?

Mrs Dobson: Will Dr Rooney be here afterwards from the PHA? Is he presenting today?

The Chairperson: No, he is not here today.

Mrs Dobson: OK. That robust awareness and education programme is due to start in February. As Joe said earlier, nothing can be done in isolation. So, the soft opt-out option, the infrastructure and the awareness campaign will all run in tandem. My consultation has been very robust and lasted 16 weeks.

Mr McKinney: I understand that, Jo-Anne, but I am saying that, even here, among people who are educated on these matters, we are getting views. It is just to make it belt and braces. I am not being critical, but even here we have conflicts.

Mr Brolly: It is not so much belt and braces; it is an absolutely fundamental part of the three-pronged strategy that works in all the leading donation countries. Eddie Rooney is very much in tune with soft opt out, and he will make a presentation about exactly how envisages it being publicised properly and in a widespread way. I understand that he will appear before the Committee at some point. He has done that in anticipation that this may happen. He will address that. However, you are absolutely right: the three constituents are soft opt out, public awareness and good infrastructure, and we have one of them at the moment. That is, our infrastructure is very good and one of the best in Europe.

Mrs Dobson: It is a natural progression, Fearghal, to the next stage.

Mr McCarthy: Apologies for being late and missing your presentation. I have read the information, and there is a lot in it. I will not detain you long. There is 90% support consistently in the public surveys across the UK for organ donations, yet only 30% of the population sign up to the organ donor register, despite all the hard work by the charities. That shows that the organ donation register is outdated and requires replacement. I wish you every success in the work that you and your fellow campaigners are engaged in, Jo-Anne.

Mrs Dobson: It is a valid point, and the statistics of over 90% in support yet only 30% on the register show that the current organ donation register is not fit for purpose. We cannot seem to break through that ceiling. I think that it is currently about 31%, but the public will is there to do it. We cannot just tinker around the edges and maybe put a foot in and a foot out. We need to make a system fit for purpose for the 21st century. As Joe said, I am sure that you will get a chance to read the transcript. Soft opt-out has been proven in the lead countries in the world as the way forward.

Mr McCarthy: Is that the best option to bridge the gap?

Mr Brolly: The Dáil Health Committee, which is a cross-party Committee, is very influential and recommends legislation to the Minister. Two weeks ago, it unanimously recommended that soft opt out should be introduced. It concluded that the opt-in system was a barrier to family consent and organ donation. On the whole, it frustrated the aim that it was supposed to achieve. In essence, that is what we believe.

Mr Beggs: Thank you for your presentation and the wide range of expertise, from those waiting to get an organ donation to clinicians. I also thank you for your extensive research, Joe. You are coming out with stuff that I was not aware of, so I appreciate that.

It seems that the soft opt out gives a double protection because family consent will be required, and if an individual feels strongly, it is the only current method of them being sure that they will not face organ donation. The current system does not ensure that.

Mrs Dobson: It strengthens human rights.

Mr Beggs: So, I can see protection there. You spoke of three stages to reach the optimum position not only to save life but to improve the quality of life for many. You said that infrastructure was the first stage, awareness the second and the soft opt out the final stage to maximise the whole thing. What is the next part of the process in the awareness stage that the Department should be undertaking?

Dr Courtney: Interrogation of the Public Health Agency survey is important to identify which groups are unaware or neutral and to target information at those groups. Eddie Rooney and his team have expertise in doing that. There is no point in educating those who are already convinced. You may not want to invest resources in those who respond with a definite no. However, those in the middle group, who are unaware or neutral, are the key people. It is a case of making them aware of the benefits of organ transplantation and they can then make up their minds about whether or not they support it. Those are the key people. There is no point in educating those who already agree. There is limited return for your investment with those who are dead set against it. It is the middle people. They identified the types and character of those who are neutral, unsure or do not know. Those are the people who should be targeted to make most use of education.

Mr Beggs: I declare that I am on the organ register and have been for many years. I find it strange that those who are vociferously against organ donation want to stop it from happening to others, instead of just accepting the protection that exists for themselves. Why do they want to stop others from benefiting from the potential of transplantation?

Mrs Dobson: I cannot understand it. When you have had an up-close-and-personal experience and you know, as we all do here, what it is like living with a person who needs an organ, I just cannot understand it. Thankfully, such people are in the minority.

Mr Brolly: This is classically an issue of life and death, heart and soul, with which politics ought not be played. Members must approach this issue with their individual consciences. It is not even an issue for parties to have a policy on. It is about individual conscience, looking at the thing rationally, and from the perspective of the sacredness of human life. It should be done harmoniously, however it is done. Whether people agree or disagree, harmony is important.

The Chairperson: In relation to the interrogation of the PHA consultation, the PHA provided us with some information today and will be in front of the Committee. Has there been any indication or commitment from the Department that, if this Bill becomes law, it will fund public awareness on this issue?

Mrs Dobson: Its public awareness campaign starts generally in February, as far as I am aware. In the brief comments I had with Dr Eddie Rooney last week, he said that if he was in my position, trying to introduce a private Member's Bill on soft opt out, he would be heartened by this legislation. At is progresses, the public education and awareness campaign will be geared to the three-pronged approach that Joe alluded to. Timing is crucial, and I feel that the timing is perfect. We are at the stage to draft the Bill, and I think that the timing is perfect.

The Chairperson: The point I am making is that, with this huge piece of work being done, it needs to be funded in order to get the best result. That is the big challenge in continuing to raise public awareness. That is just a comment; it is something that the Committee may want to reflect on.

Mr Brolly: Do not forget that you will save a fortune on this. The figures are very stark. Aisling, could you address the figures? The flagship programme is obviously the kidney donation programme — the deceased donation programme — which is far too small here. Aisling will give you some idea of the savings that are available.

Dr Courtney: They make superb viewing in support of live donation. The majority of people on dialysis in Northern Ireland are on hospital-based haemodialysis. They come into hospital three times a week, and the cost of that per annum is estimated at £35,000. After a transplant, they reckon the first year costs around £17,000, and each year thereafter costs around £5,000, which is mainly for drugs and hospital visits. Once you get past the first year, you are saving £30,000 a year for the majority of people who get a transplant. It is a real spend-to-save initiative, and we have been really fortunate that the Department has grasped that and has a longer-term view on it. It is a similar idea; it is about having the vision to see that, if we invest in this now, we will save ourselves money down the road. I cannot speak highly enough of the Department in its support of the live donor programme in that regard. However, someone has got to have the vision to see that it is a spend-to-save initiative, and we need to spend the money first, realising that the savings will come later.

Mr Brolly: The saving on the deceased donation, and these are the official figures, show that:

> *"The average lifespan of a deceased person's kidney post transplantation is 10 — 15 years, which means an average saving to the exchequer of £289,000 — £439,000 per transplanted patient".*

The source of this information is Dr Aisling Courtney, consultant nephrologist and head of renal transplant service. That is from Dr Courtney's paper on the subject that she delivered around nine months ago.

Mrs Dobson: That is not taking into account the mental anguish and torture — and it is torture. Like Joe, I have met so many people, including William, and I have seen that there is mental anguish in waiting.

Mr Johnston: I would like to say something about the promotion and awareness. For the past 40 or 50 years, six charities in Northern Ireland have been promoting organ donation. Volunteers have been standing on streets putting forward our donation cards and getting people signed up. Do not underestimate the voice that the charities can give you. We are a voluntary force, and all we need is support from the PHA and from you. We are out on the street, and we have done so many things in the past 40 or 50 years to try to promote organ donation. We have hit a ceiling of 30%, and we now need something to stimulate it a bit more to give us a bit more power to go forward and to increase organ donation. At the end of the day, it is the gift of life. That has to be remembered.

The Chairperson: I appreciate that, but I am conscious that we have to move on. Thank you all for your honesty, your presentations and the work that you have done to date. As a Committee, we will follow through our due process, and we will also talk directly to the PHA in relation to its public awareness campaign, which I think all members have said is crucial. Thank you for your time and your participation today.