



Northern Ireland
Assembly

Committee for Health, Social Services and
Public Safety

OFFICIAL REPORT (Hansard)

Human Transplantation Bill: Mrs Jo-Anne
Dobson MLA

4 November 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
Mr Kieran McCarthy
Ms Rosaleen McCorley
Mr Michael McGimpsey
Mr Daithí McKay
Mr Fearghal McKinney
Mr George Robinson

Witnesses:

Mrs Dobson	MLA - Upper Bann
Mr Andrew Cromwell	Assistant to Mrs Dobson
Mr Donald Cairnduff	Northern Ireland Transplant Forum

The Chairperson (Ms Maeve McLaughlin): You are very welcome, Jo-Anne. We also have Andrew Cromwell, who is assistant to Mrs Dobson, and Mr Donald Cairnduff, who is a member of the Northern Ireland Transplant Forum. I will hand over to you, Jo-Anne, and I will invite questions from members once you have given your views.

Mrs Jo-Anne Dobson (Northern Ireland Assembly): Thank you, Chair. I welcome the opportunity to be here today, on the other side of the table, to brief the Committee ahead of the Second Stage of the Human Transplantation Bill. This is the second time that I have come to the Committee to brief members on changing our local laws on organ donation. The first time was in October 2013 when I was joined by consultant nephrologist, Dr Aisling Courtney from Belfast City Hospital, representatives from the Northern Ireland Kidney Patients Association, the Northern Ireland Kidney Research Fund, William Johnston and John Brown, and Opt For Life's Joe Brolly. Donald Cairnduff is the father of a successful liver transplant recipient. I will just say, Chair, that his son Philip is a very successful gold and silver winner in the recent World Transplant Games. He is very proud of what Philip has achieved. My assistant Andrew Cromwell has assisted with the drafting of the Bill from the very beginning.

Unusually for me, I will begin with a quotation from the First Minister, who, when asked by Joe Brolly and Shane Finnegan from the opt-out system, replied:

"If somebody dies in hospital, they need an organ, so the family are asked. How is that different from the family being asked in an opt-out situation?"

I think that that is a crucial point. I welcome support for the Bill from the First Minister and the deputy First Minister and from Members across the Chamber. I would also like to commend the support that I have received from the volunteers and officers of local and national transplant charities, who work so hard to promote organ donation. You all know my personal reason for bringing forward the Bill: the condition of my son Mark. I believe that organ donation and transplantation is, and should remain, above party politics.

We, in this Building, get much criticism for failing to bring forward legislation that brings a real benefit to the lives of people across Northern Ireland. Few issues could be more important than a Bill that increases life chances, giving all our people — our constituents — greater hope for a new life and organ transplant. Medicine has moved on considerably since the organ donor register was first introduced, and I believe that, as a devolved region of the UK with the right to frame our own legislation, we should follow the lead of the Welsh Government, through their Health Minister, Mark Drakeford AM, and my colleague Anne McTaggart MSP in Scotland, and get behind this Bill as a real opportunity for everyone in Northern Ireland.

I say at the outset, however, that I am a single MLA using my own member of staff, alongside the Bill Office, to bring forward a Bill of this extent and importance. I do not have the Health Minister's army of staff and resources, nor the equal armies of staff of the First Minister and the deputy First Minister to bring forward this Bill. That is why I am happy to work alongside any Member on any aspect of the Bill. I welcome input, help and assistance in bringing it further through the Assembly processes. I am also looking forward to a close working relationship with the Health Department. I had a preliminary meeting with the director earlier this week. I am hopeful that this will provide help and assistance in the weeks and months ahead in achieving the right Bill for Northern Ireland. I am certainly open to improvements and changes that will achieve the right Bill for Northern Ireland.

One of the things that I have learnt over the past few years while bringing forward this Bill is that our local organ donation system is complex and confusing. Even though we are one of the most giving people, with a wide support in society for organ donation, we still have a 50% refusal rate. At the same time, 68% of our donations here come from people who have not interacted with the organ donor register.

With your permission, Chair, I will break down the Bill's content for members. It is fair to say that, of the 22 clauses, the most important are at the beginning of the Bill. The first clause places a duty on the Health Minister to promote human transplantation and to conduct a yearly campaign to inform the public how the new opt-out system would operate in practice, including the role of the family in affirming consent. The second and third clauses set out the requirement for there to be appropriate consent before a transplant can be lawfully conducted. It covers in detail the two types of consent. Expressed consent is where the individual can provide their own consent for a live donation, has engaged with the organ donor register to make their wishes known, has appointed two advocates, or has placed their wishes in a will. That is the current procedure.

For donation after death, it is subject to a procedure conducted by clinicians where the family are required to provide express written consent to confirm the individual's wishes prior to donation proceeding. The Bill makes no change whatsoever to current practice. The second form of consent is deemed consent, where there was no interaction between the individual and the organ donor register during their lifetime. It will be deemed that they would have provided the necessary consent for transplantation to proceed. However — this is crucial — as I have always said, consent is subject to family affirmation prior to donation taking place. That is why having the conversation amongst family members and loved ones is vital. I have always said that a duty to promote, which is contained in clause 1, would be central to increasing public awareness.

You will know that I am not one for statistics, but they highlight the stark reality faced by local people when it comes to organ transplantation. I will spend a little time laying out the facts. The first, and perhaps the most stark, is that 17 people died last year while waiting on a life-saving transplant. The local average is 15 people each year. In 2013, 932 local people underwent dialysis, which is a three-times-a-week life sentence. In a sense, however, they are the lucky ones: there is no dialysis for people needing a heart, liver or lungs; the only option for them is to find an organ or to die. The plain truth about organ donation is that the number available does not meet the demand. That, in a nutshell, is the reason why a change in legislation is required.

Finally, I will focus on finances. Whilst no one can ever put a price on what it is like for a transplant recipient to receive a new life — I certainly know this at home — there will, inevitably, be costs and implications for the Bill. The Assembly research service conducted a research paper into the implementation costs of the legislation and estimated that, over 10 years, it would be between £2 million and £5 million. However, the cost benefit to the health service of increasing transplant numbers is startling: it could be as much as a £7.4 million net benefit to the Northern Ireland economy.

To give you one example, I will focus on kidney patients for a moment. The average cost of keeping a patient alive through renal dialysis is £30,800 per year. I mentioned that, in 2013, 932 local patients underwent dialysis. That meant a total cost of over £29 million to the Health budget, based on NHS cost estimates in one year alone. Each kidney transplant roughly costs £17,000 per patient. Post-transplant, the yearly cost of immunosuppressant medication is roughly about £5,000 per patient, meaning that, for each kidney patient who received a transplant, the NHS estimates that it would receive a saving of £25,800 in the second and subsequent years. That does not take into account the benefits of people returning to normal society, the impact on their families, the community and, in fact, wider society and their normality of life.

It is clear that the lack of available organs is placing major stresses and strains on local patients' families. One of the major reasons for that is that, with the exception of kidney transplants, all transplants for local patients are conducted in hospitals in other regions of the United Kingdom. Liver transplants for adults are conducted in King's College Hospital, London and, for children, in Birmingham Children's Hospital, while heart and lung transplants take place in Freeman Hospital, Newcastle. Imagine the long and difficult trips back and forth to those hospitals and the anguish and pain of living with their condition while waiting on an organ. The lack of available organs means that patients must endure more trips from home to hospitals across the country at considerable strain to them and their families and considerable cost to the health service. Increasing the availability of organs increases life chances and decreases stress, as well as financial costs.

Recent figures from the British Heart Foundation reveal that 10 people in Northern Ireland are waiting for a heart transplant, and one person is waiting for a heart and lung transplant. According to the latest NHS transplant statistics, no one from Northern Ireland has received a heart transplant in the past year. Just imagine the stress and worry among those 10 patients and their families. I know that I was not alone in the organ donation community in being absolutely delighted to hear that the fantastic team at the City Hospital recently undertook five kidney transplants in one day in September. Although a one-off, it does show that we have the expertise and the capacity to carry out kidney transplants. However, I am conscious that it was a one-off event, and I would like to see more people being given the chance of life.

For some, a transplant is not an option, and they are resigned to the fact that they will end their days on dialysis. For others, it is all about giving hope. I am thinking, in particular, of one family that I know, 12 members of which have a genetic renal condition. The family will never know how long their children have before their kidneys fail. Just imagine for a moment what providing hope to that family would mean to them when faced with the uncertain future of dialysis for any family member. It is about providing hope that a new life will come, and, with the Bill, I firmly believe that we will deliver that hope to families.

I was also absolutely delighted to see the new organ donor register being launched in July across the UK as a result of the Human Transplantation (Wales) Act 2013, which comes into force next month. The changes include provision for people to be a donor, not to be a donor, or to nominate two advocates to help to affirm and make that decision for them after death. I welcome the fact that the Health Minister, Simon Hamilton, welcomed those changes. However, we would need legislation through the Assembly to avail of those changes, which, I understand, our health service has rightly paid its portion for. The Bill will enable those changes to happen.

I would like to hand over to Andrew to give a short overview of public attitudes to organ donation and a change in the law, if that is OK.

Mr Andrew Cromwell: Thank you very much, Chair, for the opportunity to present. I suppose that I did not have the option of opting out on this occasion. *[Laughter.]* I am sorry for that. I want to focus a few comments.

I want to talk about the consultations because three have taken place on organ donation in recent years. There was the members' consultation and then the Public Health Agency's (PHA) consultation

on public attitudes in June 2013. Most recent was the Public Health Agency's survey — I think that the figures are from February 2015 — on attitudes to organ donation. There were 1,366 on- and offline responses to the consultation on the Bill; we also had general public responses from charities, councils, churches, health and social care sectors, political parties and others. A summary report was produced in October of that year, giving an overview of the 10 questions and the responses to them. It showed, in summary, an 82% support amongst respondents to changing the law and to moving to a soft opt-out system. There was also 61% support for retaining the key role of the family and 86% for protecting the rights of those who lacked capacity in the legislation. Those things are reflected in the Bill.

The report on the responses to the consultation is available in the Assembly Library. It gives responses that were positive, as well as concerns raised about each of the questions. It gives a flavour of the views expressed when people took the time to respond.

The Public Health Agency survey at the same time, which was in June 2013, highlighted 56% support for a move to a soft opt-out system. That rose in the PHA's most recent survey to 61% of the public supporting a move to a soft opt-out system.

In 2013, there were 1,012 respondents to the Public Health Agency's consultation, of whom 18% were opposed to a change in the law towards a soft opt-out system. In the 2015 figures, that is now 10%. So, that figure has fallen. That shows that attitudes have changed, possibly as a result of the continued hard work that charities have been engaged in over quite a number of years, and I know that they are keeping up the pressure with the opt-out campaign and with their continued work. The PHA's important Speak Up, Save a Life campaign has also been instrumental. The PHA's influence in bringing that forward has been extremely positive to the organ donation community. Volunteers, family members or anyone who has any connection with organ donation can take solace from the fact that that has been a very successful campaign.

In the response to the PHA's 2015 survey, 79% of those who responded — and I apologise for the continued statistics — agreed with the statement that the soft opt-out system will result in more lives being saved. The figure in 2013 was lower than that at 74%. Interestingly, when the Welsh Government decided to go down the route of a soft opt-out system they found that 49% of the public in Wales were supportive of changing the law; whereas, at present, from the 2015 figures, we have a 61% figure, according to the Public Health Agency. That shows clear evidence of public support from the majority of people for changing the law.

A final point that I would like to make is about bedside rejection. We have quite high rates of that in Northern Ireland. In other opt-in countries in Europe, the average refusal rate is roughly between 45% and 60%. I think that Northern Ireland is in and around 45%. In opt-out societies, that tends to be lower at in and around 2% to 15%. Belgian is closer to 2%. That shows that, in those countries, conversations are taking place, and, when it comes to asking the family whether they know and can confirm the wishes of their loved one, they will be in a better place to understand what those wishes are. I believe that, as a society, that is the direction that we should be moving to because we need to give hope to those who are waiting. We also need to ensure that fewer people die as a result of waiting on our current disparity between organs that are available and organs that are not available. Thank you very much.

Mrs Dobson: Chair, is it OK if I leave the final word to Donald Cairnduff, the father of a liver transplant recipient and long-term supporter and advocate of organ donation?

Mr Donald Cairnduff (Northern Ireland Transplant Forum): I will start by thanking you, Chair, for the opportunity to talk to the Health Committee and to share some of my experiences and views. My story is not dissimilar to Mrs Dobson's. Eleven years ago, in the summer of 2004, my son and I were in Africa on a Habitat for Humanity building project. Shortly before we returned home, my son was weak, listless and sick. On the way back, he was jaundiced and even more sick. He was taken straight to the Royal on the Saturday morning when we got home. Forty-eight hours afterwards, he was taken by air ambulance from the Royal to King's College in London. On the Tuesday evening, I stayed with my sister who lives 30 miles from London, and my wife stayed in accommodation very close to the hospital. My wife phoned me at 8.00 am on Wednesday to say that I should get up to London as quickly as possible, because my son's liver had packed in completely. I got the train up to London, with the news that my son had suffered acute liver failure.

At the time, I knew next to nothing about transplantation. However, I did know that there were a lot of people who needed organs and that there were not enough organs for those people to be restored to

health. I assumed that he was going to die. We were told that if an organ was not available he would not last until teatime. On that train journey up to London, I was sketching out his funeral. It was a surprise and, if the word "pleasant" applies in circumstances like that, it was a pleasant surprise to find that an organ was available. Our surgeon talked us through the processes. My son went into theatre about 3.00 pm on Wednesday, the transplant went ahead, and he was released from theatre at 1.00 am the next morning. Thereafter, he was on life support in intensive care for eight days.

Those were long and difficult days for us, because every day there seemed to be a different problem, and the different problems that arose at the beginning of the day were potentially lethal. We watched him unconscious and on life support battling with those problems with the help of some incredibly caring and professional people in intensive care. Eight days afterwards, he was woken up and has had a long and quite difficult journey since then. Now, at the age of 29, he is in decent health. The life that he got back and the life that he has lived has given us enormous pride and, I think, honours the second chance of life that he was given by his donor and by the people who consented to the donation.

He has competed in the British Transplant Games on several occasions. Last summer, he competed in the World Transplant Games, as Mrs Dobson told you; he won a gold medal and has two silver medals at the recent World Transplant Games. He is working full time and is heavily involved in youth work in the church that he is associated with. He lives a life that is so busy that we barely see him. I think that he has honoured the gift that he was given and made the most of that gift in a way that makes us immensely proud of him.

During those 11 years, I have had some very powerful and surreal experiences. One of the most surreal and moving experiences is the fact that — for us, for me — the most significant person in my life, outside my immediate family, is somebody whom I never knew: the 48-year-old woman whose liver restored my son to life. I think about her every day and, every day, I think about her family who made the call that that organ should be donated. It is a surreal and moving and, in many ways, privileged position to owe so much to somebody whom I never knew, and to owe so much to a dead stranger who really only interacted with your experience and with the people whom you love after she had passed on. During those 11 years, not a day has gone by when we have not thought about that lady and her family. It has been a defining experience in our life, and my wife and I have done our best, in the years since my son Philip had his transplant, to encourage people to think about donation and to promote the organ donor register. I have given talks to various groups and turned up at freshers' fairs to talk about organ donation to young people who are going on to university. It has transformed not just my son's life but our lives.

Through all the hours working to promote the register and all the casual conversations about organ donation, I have thought long and hard about people whom we never knew and will never know — people to whom we owe the life of somebody whom we love. I have thought long and hard about what the legal position should be on an opt-in or an opt-out system. I have weighed up the arguments for a long time. I recognise that any argument about the best legal position has to balance a lot of powerful arguments on either side. It has to balance the profound and deeply personal relationship that every human being has with his or her own body with the need for everything possible to be done to ensure that very ill people do not die.

Since April 2015, there have been 1,969 organ transplants in the United Kingdom, and over 6,000 people are still waiting for a transplant. It is extremely difficult to balance the way in which society regards organ donation and the way in which the law legislates for it.

I believe, having thought about it long and hard, that a soft opt-out system, such as the one that Mrs Dobson's private Member's Bill proposes, which still allows families the final decision, is the way that we should go. My support for it is based on two arguments, which I will try to articulate as clearly as I can.

The first is a statistical argument that indicates that the countries in Europe with the best donation rates, measured per million of population, are those with some kind of opt-out system. Recent EU data showed that, in 2013, there were four countries in Europe with more than 40 kidney donations per million of population: Spain, Austria, Croatia and France. The same EU data showed that, in 2013, the only countries with over 20 liver donations per million of population were Portugal, Belgium, Croatia and Spain. It seems, from looking at that evidence, that countries that have some form of opt-out system in law are the countries with the best donation rates.

I have thought about this thoroughly, and I recognise that it is far more complex than that. I know that changing the law will not generate better donation rates in five minutes. I would personally not support, for instance, the kind of hard opt-out system that applies in Austria. I recognise that other features come into play in improving donation rates, such as the presence of specialist nurses to talk to bereaved families, the regularity with which brain stem death is tested in ICUs and the retrieval procedures for organs. All of those facets of medical and clinical infrastructure are valid and contribute to increased donation rates, but, weighing all of that up, the statistics are quite clear: countries with some kind of opt-out system have the highest donation rates. As somebody whose son would not be alive without organ donation and who knows people who have died waiting for organs, I am keen that we have as high a donation rate as it is possible for us to have.

The second argument is that I am convinced that a change in the law would generate a different culture in Northern Ireland, one in which talking about organ donation is not something to feel squeamish about or a subject not to bring up in polite conversation because some people feel uncomfortable about it. It would create a culture in which the need for donation, and the decision of whether you wish to become a donor, were spoken about more comfortably and more openly than is the case currently.

I have worked steadily to try to promote the organ donation register. There are currently 650,000 people on the register in Northern Ireland. That figure is as high as it has ever been. That is all the product of some steady and committed work by bodies such as the PHA and by dedicated individuals.

Essentially, being on the register is no guarantee that the people closest to you — the people who would have to make the decision in the event of your dying in circumstances in which organs can be donated — will know what your wishes are. I have spoken to any number of young people at freshers' fairs about organ donation. They say, "Oh, yes, I support that, and I am on the register." My next question is whether anyone in their family knows, and, from time to time, the answer is, "No, I have not told anybody. I would be embarrassed to talk to my family about it." The fact that you are on the register is no guarantee that, come that awful time, when somebody in your family might have to make the decision about donation, they will know what your wishes were. As Mrs Dobson said, most donations come from people who were not on the register and whose families make a decision that may well be based on their innate compassion at the time, because a conversation about organ donation has never taken place within the four walls of their home while the person was alive.

As I see it, a change in the law, accompanied by the sustained and regular public awareness campaigns that must happen before that law is in place, must surely get people in Northern Ireland speaking about organ donation in a way that they do not at the minute. I think that, if that happens, it will lead to a situation in which grieving relatives are more prepared for the question when it comes, and the answer to that question respects the wishes of the deceased.

In short, I favour an opt-out system because the statistics suggest that it works and is a factor in increasing organ donation rates. I would also support a soft opt-out system because it would, I think, help to create a culture in which people could talk openly about organ donation. Then, should the awful situation arise when someone can become a donor, some of the anguish is lifted from a grieving family, the wishes of the dead are honoured, and life is restored to an ill person by a gift freely given.

I am very grateful to you for the opportunity to share these stories and views with the Committee. Thank you.

The Chairperson (Ms Maeve McLaughlin): Thank you. I thank you particularly, Donald, because it is difficult to share personal experience. I had the opportunity to meet you recently, and there is no doubt that the achievements of your son to date in the face of a lot of adversity are very impressive. Thank you for being so open today.

My question is specifically on family consent in the scenario in which a potential donor has expressly opted for organ donation, but some family members are opposed or strongly opposed to it. I appreciate, Jo-Anne, that you are saying that family involvement is critical, but, as I understand it, the Bill would generally empower doctors to proceed with organ removal in those cases. Even if doctors had the legal authority to do so, I am interested in your view on whether it would be inadvisable for them to proceed in the face of family opposition.

Mrs Dobson: That simply would not happen. The doctors would consult the family, and, if they were opposed, it simply would not happen. Their views would not be overridden. When a family is faced with the unimaginable agony of losing a loved one, no clinician or doctor would compound that grief

and despair. It simply would not happen, so be assured. As currently happens, the family is consulted. However, it is a difficult decision, and, as Andrew referred to, the rate of bedside rejection in Northern Ireland is high

There is the possibility in the Bill to appoint advocates to ensure that your wishes are carried out. In fact, the advocate role is part of the new organ donor register that will go live in Wales next month.

Mr McCarthy: Thanks very much, Jo-Anne. It is nice to see you sitting at that end of the table instead of here.

Mrs Dobson: It is not as nice to be here, Kieran. *[Laughter.]*

Mr McCarthy: No, you are grand — it is first class. First, I congratulate you on getting to where you are, the enormous amount of work that you have put into the Bill and your dedication in seeing it through — all with the aim of saving lives. You and Donald have experienced this in your family, and the Bill is a tribute to the work that you have done. I wish you every success as you go along, and I hope and pray that the Bill will come to fruition.

Do you have any estimate of the potential increase in organ donors?

Mrs Dobson: Thank you, Kieran, for your kind words.

If one life is saved, it is worth doing. As Donald highlighted, I am thinking not of Northern Ireland now but of Northern Ireland 10 years down the line, when organ donation becomes the norm rather than the exception. One life saved will be crucial. It will make it worthwhile if only one person can be saved. It is hard to define how many will be saved. As Donald outlined, clause 1 places a duty on the Department to promote transplantation. That will be a yearly promotion to inform people about transplantation and the change in law. If all goes according to plan, the Bill will become law in May 2018. With increasing public awareness and the wonderful work that the charities continue to do, as they have done for many years, the Bill will, as time progresses, save lives. However, if one life is saved initially, it is worth doing.

Mr McCarthy: Did you say that 17 lives were lost this year?

Mrs Dobson: Seventeen local people died last year while waiting for a transplant. The local average is 15, and, last year, it was 17. It is alarming that people are dying waiting.

One thing that I have been told by people whom I have engaged with on my journey is that they need hope. At the start of the session, I spoke briefly about a family whom I know personally — 12 members of the family have a genetic kidney condition. One member of the family told me that she looks at her two sons and wonders when it will happen to them. Her mum is on dialysis but will never get a transplant because of complications. As she says, she has the future of her two boys laid out before her. The Bill, if anything, gives hope that a change in the law will mean that she can see her boys having a better quality of life than her brother, mum and the other members of her family who are sentenced to a lifetime of dialysis. When people have hope, and specifically the hope of a change in the law, it makes a big difference.

Mr McCarthy: How quickly do organs need to be recovered in order to be successfully transplanted? Do the checks, balances and safeguards in the Bill provide sufficient time for a transplant to occur?

Mrs Dobson: Obviously, Kieran, time is of the essence. Last year, I visited the NHS Blood and Transport (NHSBT) headquarters in Bristol. All transplants in the UK are coordinated through one tiny room in Bristol. That is where they match an organ to a patient and make the phone calls to patients. It was quite a surreal experience for me, as you can imagine, because, when I was visiting that room, I knew that that was from where, on 5 February 2009, the call came for my son Mark — the call that gave him a kidney came through to that very room.

My experience was that, when Mark got the call for his transplant, Northern Ireland was covered in a layer of snow, and time was of the essence. His kidney came from mainland UK, and, at that time, the City Airport was closed. We got the call at about 6.00 am, and, by 8.00 am, we were in the Royal Belfast Hospital for Sick Children, waiting for that life-saving kidney coming in the aeroplane.

With kidneys, doctors usually like to transplant within 12 hours. Obviously, the sooner a transplant can happen, the more useful the organ is, so there is a window. If there is a delay, a kidney will be matched to the next available person. The window for a kidney transplant is slightly longer than for a liver transplant, as Donald has experienced with his son. For a heart or lung transplant, you need to be waiting in a hospital on the mainland. That window of opportunity is a lot smaller than with kidneys, but time is always of the essence. The effectiveness of a kidney is 24 hours, and any delay affects how long it will last, so we are trying to get the best transplants that will last the longest. My experience is that kidneys are more resilient than other organs.

Mr McCarthy: I wish you all the best and every success in your endeavours.

Mr Easton: Jo-Anne, thank you for your presentation. Excuse me, I have a cold, so I feel a bit funny. I am trying to get my head round this, and I hope that you do not mind me asking you some awkward questions. I take it from what you are saying that, with the soft opt-out option, basically everybody in Northern Ireland will have opted in unless they opt out. Is that right?

Mrs Dobson: People have so many options. I will take you through the clauses. There are two forms of consent. The first is express consent, which is similar to the present system but with the ability to opt out and the inclusion of advocates, which is new. The other form is the deemed consent model, which is new and requires family affirmation. You can express your consent that you want to go on the organ donor register; you can express your consent and appoint two advocates; or you can opt out. If, for some reason, you do not want to donate your organs, for the first time ever, your family will never be approached. Currently, everyone can be approached by a clinician for organ donation. The change means that, if you are vehemently opposed to organ donation and have chosen to opt out, that simply will not happen. In essence, that strengthens your human rights.

The change in the law, which is clause 4, is the new deemed consent model. If a person has not engaged with the organ donor register or expressed their wishes during their lifetime, their consent will be deemed. Crucially, however, this must be confirmed by an adult in a qualifying relationship, and it does not apply to those who have not lived in Northern Ireland for 12 months or cannot understand the concept of deemed consent. It does not apply to excluded material. I said from the very start, when I laid out my wish to plan the legislation, that I wanted a family veto and family affirmation to be in the Bill so that families have the final say. The Welsh model is a deemed consent objection model. Mine is that your family or advocates have to affirm that you were keen to have your organs used.

Mr Easton: Is it right to say that, as soon as you are born, you are on the register unless you opt out?

Mrs Dobson: No, it does not apply to children.

Mr Easton: Is it from the age of 18?

Mrs Dobson: Yes.

Mr Easton: Right. Theoretically, if we were to take Upper Bann, which has roughly 77,000 people on the electoral register —

Mrs Dobson: I am very impressed that you know that.

Mr Easton: Well, there are actually 77,903. *[Laughter.]* Say, for example, that half decide to come off the register and the other half decide to stay on it. If the families of those on the register consent, you could, theoretically, have 35,000 organs being donated. I know that that is a simple way of putting it, but is that what could happen?

Mr Cromwell: Consent would be deemed only at the time of death, so it would not be a matter of people going on to the register or being put on a register against their will during their lifetime, which is, I think, where you were possibly coming from.

This applies when there has been no interaction with the organ donor register throughout a person's lifetime. People can also express consent by putting their view in a will. However, Kieran talked about the window of time, and I think that a will is an inadvisable way to do that because, by the time the process has gone through, the window for donation could have passed.

No one would be put on a register against their will. It would be ascertained at the time of death whether they had interacted with the register in any way: to opt out; to appoint two advocates to deal with the matter on their behalf; or to opt on and agree to be a donor. If there has been no interaction at that time, the legislation would deem their consent, subject to the family's affirmation on being asked the question. Perhaps that answers your question.

Mr Easton: Say that 20,000 people died in one year and all were agreeable to having their organs donated, that would probably outstrip the need for organ donations in Northern Ireland. Could those organs be used outside Northern Ireland, in the rest of the UK?

Mrs Dobson: It is a UK-wide system. My son's kidney came from mainland UK.

Mr Cairnduff: As did my son's organ.

Mrs Dobson: However, it is all about the circumstances in which it happens. Donald has a good analogy for the figure of 26 —

Mr Cairnduff: Put simply, the donation rate in the UK is 26 donors per million of the population. When I talk to young people about organ donation, they very often assume that, if they join the register, they will donate organs. The fact of the matter is that, if they joined the register, they would get very long odds from Paddy Power on ever donating an organ.

The way that I explain it, perhaps simplistically, to young people is that there are 26 donors per million of the population. Imagine that, on the last day of the premier league season, when all the games kick off at the same time, every stadium that is hosting a home game is packed to capacity — only 26 people among all the spectators in all those stadiums will become organ donors. That gives you an idea of how rare it is for people to die in circumstances in which they can donate organs.

Mr Easton: OK. You mentioned the family right to object in clause 4. What would happen if you were faced with the scenario in which a child has died and the father is all for transplant and the mother is not? What would happen if there was a clash or conflict?

Mrs Dobson: A lot of faith and confidence would be placed in the clinicians and the decisions that they would take. That is why I think that it is important, as Donald said earlier, to have that conversation, which, to a large extent, has not been happening. The family would sit down with the specialist nurses, doctors and clinicians to discuss it, but there is not one clinician who would proceed if it would cause anguish or distress to a family. It simply would not happen.

Mr Cairnduff: For what it is worth — this is only anecdotal so it may not, in your view, have any weight — I know two families who agreed to the donation of the organs of a teenager who was killed in a road traffic accident. In both cases, father and mother were in agreement that it was the right way to go. I cannot even begin to understand the anguish of losing a child, as they did, but, down the years, the fact that they made that decision together has brought them some comfort; it has taken some of the edge off their anguish. That is not to say that, in other circumstances, mother and father might not agree as readily as those people did, but, from the people I know who fit the scenario that you are talking about, they were in fairly firm agreement. Having made that decision, it has taken some of the edge off their grief down the years.

Mr Easton: If there is no family member and perhaps friends are appointed, who appoints those friends to decide?

Mrs Dobson: If you are expressing your consent, you will have the option of appointing advocates. That is in line with the new organ donor register that went live in July. There is an opportunity to appoint advocates. Those are people you trust implicitly such as long-standing friends or family members. It is your wish to appoint those advocates to act on your behalf.

Mr Easton: What happens if you are facing a scenario where somebody does not have a family and something happens, God forbid —

Mrs Dobson: Sorry, Alex?

Mr Easton: If something happens, such as an accident, and you cannot locate a next of kin or a family friend, what would happen?

Mrs Dobson: If nobody on the list of qualifying —

Mr Easton: Yes.

Mrs Dobson: It would not happen. A clinician would not put a family through that anguish.

Mr Easton: You mentioned costs, which, obviously, would have to be met by the Health Department. What would those actual costs be? What would they entail?

Mrs Dobson: The cost of implementing the Bill?

Mr Easton: Yes. What would that all be?

Mrs Dobson: We have a fantastic programme here in Northern Ireland already, so the specialist doctors are already in place. There would be a change in infrastructure and in the law. The findings — I referred to them earlier — from Assembly research were costs of between £2 million and £5 million for the first year. As you can appreciate, I am a private Member so I do not have the departmental figures; it is coming on board only now to help as the Bill progresses. That is something that will be worked through with the Department. I had a meeting this week with a senior director. That needs to be costed going forward, but the initial work done by Assembly research indicates that it would take between £2 million and £5 million to implement. It has done quite a detailed cost analysis. That is over 10 years, so it is a minimal sum of money over that time.

Crucial as well is the change that we have referred to — Minister Hamilton welcomed it — which went live in July to the organ donor register to allow for the advocates and for an opt-out as well. That was brought in to facilitate the Welsh Act, which will go live in December. Crucially, that will enable it to be done as well. Those costings were between £2 million and £5 million, so it is a miniscule sum of money compared with, as I alluded to in my presentation, the vast cost of keeping 932 people on dialysis and the cost of actually getting a transplant. As I said earlier, you cannot put a price on the human cost and the elation of getting that life-saving transplant and getting your loved one back.

The Chairperson (Ms Maeve McLaughlin): Just for clarity, Jo-Anne, on that issue around family opposition, for want of a better word, in the scenario where you are saying that a clinician or doctor would not proceed, given that opposition, is there something specifically in the Bill that you could point us towards that sets that out?

Mr Cromwell: There is reference in the Bill to a conflict, which is what Alex was talking about, where a family member took an opposing view to that of another family member. I think that the central point, and what we should be getting at, is the will of the individual who has passed on. I think that their wishes should be central. However, if there is a conflict, there is reference in the Bill to guidance in the Human Tissue Act 2004, from memory, which sets out and assists the specialist nurses who are fully trained to approach a family at a time of grief. I appreciate that it is an extremely difficult time for that family, but I understand that there is provision in the Bill, which is already in the Human Tissue Act. Such a conflict could happen at present under the current system.

The Chairperson (Ms Maeve McLaughlin): This is an important point. Can you tell us where that reference to conflict is in the Bill?

Mr Cromwell: I understand that it is in the schedule. I apologise, Chair, I will try to find it.

Mrs Dobson: If you have a copy, Chair, the schedule is obviously at the very end of the Bill.

The Chairperson (Ms Maeve McLaughlin): Again, given the importance of this, is that not something that you would consider should be in the Bill itself? This seems to be one of the biggest areas of controversy.

Mrs Dobson: It is in the schedule. As I said from the very start, I am willing to work with any member on any amendments or improvements. I want the best Bill for Northern Ireland and, if there are any concerns or wishes brought forward, I am happy to take those on board and work with them.

Mrs Cameron: Thank you, Jo-Anne and, in particular, Donald, for sharing with us today. It is obviously a very emotive and sensitive subject. You mentioned the word "uncomfortable", and I think that is quite true. For many, it is an uncomfortable subject. I would say that it is controversial, on top of all that. I would like to say that I am one of the 653,000 people on the register. I have been on it since becoming an adult. It is a decision that I made a long time ago. I have always had a concern that there is no way to overcome the fact that somebody in my family can actually overcome my wishes.

Mrs Dobson: That is where the advocates come in.

Mrs Cameron: Because I feel so passionately about organ donation, I am unhappy with the fact that someone, say my next of kin, is able to override my wishes. So, what are you saying about advocates? Let us take an example. Say that a wife decides that she wants to donate and she names two advocates, but her husband is completely opposed. In that situation, should the opportunity to donate arise, who makes the final decision?

Mrs Dobson: I am delighted that you are so supportive. Obviously, the wife has had that conversation with her husband and she knows that he is firmly opposed. It is nevertheless her wish and her body. As Donald outlined earlier, it is important that your wishes are carried out. It would be a very rare situation, but it is good that the conversation takes place because, then, people's wishes are known. In that situation, if you were a supporter of organ donation and your husband was opposed, it would be your right. You can put it in a will, as Andrew said earlier; however, a will is time bound, and we know that time is of the essence. That is where you would appoint advocates to carry out your wishes.

Mrs Cameron: Just to be clear, Jo-Anne, in that scenario, the organ or organs would be donated.

Mrs Dobson: If you had specified that, gone on the register to express your consent and appointed your advocates. If you wanted to, you could put it in your will that you support organ donation and want your organs to be used and it is your express wish that donation goes ahead. It would be very rare, Pam, that a married couple would be at conflict with each other over it. I cannot see my husband contravening my wishes.

Mrs Cameron: I can see it. I really want to clarify this: in that situation, you would see the advocates —

Mrs Dobson: The advocates would be someone you choose to carry out your wishes.

Mrs Cameron: The next of kin could not override that decision.

Mrs Dobson: That is why you appoint advocates.

Mrs Cameron: Do you think that the clinicians would be content?

Mrs Dobson: If you have put down your two advocates, which is a facility that came into force in July with the new organ donor register and will be in this Bill, and if you want your wishes known and are supportive of organ donation, you appoint those two people, in law and on the register, to carry out your wishes.

Mr Cairnduff: As you were speaking, I was trying to put together in my mind a kind of screenplay of the situation that you were alluding to, and it is a frightening one. It is a situation where you are balancing, to use that horrible term, two nightmare scenarios. On one hand, somebody who loves the deceased person but is passionately opposed to organ donation, even though he knows that the deceased person was in favour of it, will have his anguish, his grief and his sense of loss exacerbated even further by the sense that organs will be taken from a person who has just passed on whom he loves dearly. The advocates will be asked to make the call, and they will say that they were nominated and know that she wanted her organs donated. There will be all kinds of stresses and

strains within a family and, presumably, friends of that family, which will last for years afterwards. It could be a very painful and a very unpleasant situation but, in my mind, that needs to be balanced against the wishes of the deceased. The wishes of the deceased need to be honoured and, in balancing two horrible situations, I think that that is the right way to go.

I know a person in a similar situation who is passionately supportive of organ donation but knows that her family, particularly her children, are strongly against it and have told her that, if she ever dies in a situation where she can donate organs, they will say no. I think that, for that person, the fact that advocates have been allowed for under the terms of this private Members' Bill will be a very good thing.

Mrs Cameron: A good thing for the wishes of the donor, but obviously not a good thing for the next of kin, who could be traumatised over it. That is very interesting. Thank you.

I absolutely agree on the point about the need for conversation. I think that is absolutely vital. I know that there are some people who have had that conversation and cannot get agreement. I know cases of families who just disagree. Plain and simple; they just disagree. I think that it is very important to have that conversation. Do you see your Bill as a mechanism to force that conversation?

Mrs Dobson: At the outset, clause 1 of the Bill puts a duty on the Department to inform the public of the change in the law and to facilitate that conversation. That will start and will happen once a year to inform people to have that conversation. I think that Donald alluded very well in his comments earlier to the fact that so few people, particularly young people, have that conversation. Anything that pre-empts and makes that conversation happen is crucial, and that is why, from the very beginning — the first clause — I put in the Bill a duty on the Department to have a public awareness campaign. The public awareness campaign will promote and stimulate that conversation, and that and the fact that the law will be changing will allow that conversation to take place. It is crucial. We need to educate people on this, and we need to communicate. Those are two very key points that need to happen.

Mrs Cameron: Donald, you spoke about your son and the 48-year-old lady whose organs saved your son's life. That is tremendous. Do you consider that a gift?

Mr Cairnduff: I will be very frank with you: I would like to consider it a gift. I do not know whether that lady was a willing donor or not. It may well be that she was but had never told her family. It may well be that she was and had told her family; that is what I would like to think. It may well be that she had never considered organ donation in her life and never talked to anybody about it, and that the family made that very courageous call without knowing what her wishes were. It may well be that, in her heart, she was violently opposed to organ donation but had never told anybody. The short answer to your question is that I do not know. I would love to think that it was a gift willingly given — I hope that it was. The gift has been received and honoured by my son, regardless of the circumstances in which it was given. But the short answer to your question is that I do not know.

Mrs Cameron: I am just concerned at the idea, which has been presented to me in the past, that some people consider that for them to have their name on the organ donor register is a gift that they are offering, should the circumstance arise. However, some of those people would be wary of the idea that, in some way, the state would almost own their organs and that that removes the gift that they are giving. I have heard some people express that disquiet to such an extent that they say: "I am on the organ donor register but, if this is brought in, I will opt out". Is it a concern that you could actually lose people from the organ donor register?

Mrs Dobson: That is a very good point. Andrew has details on that.

Mr Cromwell: It is a very valid point, and it was one of the questions in the PHA's initial 2013 public attitudes survey. It questioned 1,012 people and 2% said that they would fall into that category: if the soft opt-out legislation came through, they would consider that they might remove themselves from the organ donor register. So you are quite right; it is a valid concern. However, I think that it is all about making sure that the wishes of the individual, prior to death, are then carried out after death. Earlier, I mentioned some of the bedside rejection statistics that we have in Northern Ireland. Where people are on the organ donor register, we have a rejection rate of around 45%, because they have put themselves onto the register but, as Donald mentioned, perhaps have not had that important conversation with the family. So, at a very difficult time for the family, when faced with that question, they do not know and they choose that the best option for them is to say no, because they are not

sure what the wishes were. They want to honour those wishes but, with not knowing, they choose to say no.

The figures that we have for opt-in societies are slightly different. There is a much lower bedside rejection rate, which perhaps shows that the opt-in system in those countries is, as you say, precipitating the question. It is important. If you take a look at next year or the year after, that may not necessarily be the case. If we look at clause 1 on education, that is something that will gather steam. I paid tribute to the PHA's Speak Up and Save a Life campaign. If we have that, year-on-year, we can look at a system that will encourage the conversation and that would make a difference at the time of asking. The bedside rejection statistics for opt-in in other countries, including Belgium, are roughly between 2% and 15%, compared with our 45%. I would like to think that, when Donald mentioned "the gift freely given", I would like to think that the decision of the families to consent to that means that they have had that conversation and that they are knowingly carrying out the wishes of their loved one after death.

Mrs Cameron: My final question, Jo-Anne, is that, if your legislation is passed and it results in an increase in available organs, what guarantee is there that the people of Northern Ireland will benefit?

Mrs Dobson: As you know, it is UK-wide. My son's kidney came from mainland UK. We are going to benefit already from the Welsh change in legislation, which goes live next month. Both Mark's kidney and Philip's liver came from mainland UK. We are already benefiting and we will certainly benefit from the Welsh change. Similarly, you cannot say where the organ will be used within the UK, but it will mean that more organs are available. We would not want that, because it goes into the pool. It always has to be about the best match to fit the need of the person.

Mrs Cameron: I just want to clarify that there is no guarantee that a rise in available organs within Northern Ireland would necessarily mean that more organs would be available to people in Northern Ireland and that it is a UK-wide situation.

Mrs Dobson: But it increases the chances. As I said, hopefully people in Northern Ireland will benefit from the Welsh Act, which comes into effect next month. However, it is UK-wide.

Mr McGimpsey: Thanks Jo-Anne, Andrew and Donald. I will start by saying that, coming from where I was a few years ago as Minister of Health, and knowing what I know, I very much support this in principle. I understand that the devil is always in the detail, but you have certainly gone a long, long way towards dealing with the issues and have thought them through. As far as I can see, choice is clearly and ultimately the key principle. We are all aware that we are talking here about life; we are talking about saving lives.

I vividly remember, as Minister, going to the Children's Hospital and meeting a wee boy of just over two who was tootling about on his tricycle. It was actually a hospital tricycle, and it supported his liver because this wee one needed a liver transplant. He was tootling about, all hooked up, and I asked a clinician what the prognosis was. The clinician said, "It is very bleak. It is very difficult to find a liver the right size so, as things stand, it is very bleak". When you meet babies in that situation, we have got to find a way to do this in principle, and that is the position I come from.

We talk about kidneys and have a notion that, if your kidneys fail, dialysis can pull you out. The reality is that dialysis will work for a period, but then it stops working. A close friend of mine who was just a couple of years older than me had both his kidneys fail. He was on dialysis for five years, and we lost him last June. He needed a transplant but, at 70 years old, he would not have been near the top of the list. So, what we are talking here is life itself.

I listened to Pam's concerns and her questions are very valid. Will you explain again how choice works? It is deemed consent if you go on the register, which I am on. Everybody will be deemed to be on the register, but that is not the end of the story. Donation will not occur in most cases because you will not get the match at that particular time. How does choice work in such cases? I raise another issue because of what we have been through this week, and it is that these issues can have religious connotations. Have you had any sort of Church objections or can we say that the Churches do not have a problem? I know that you have the support of the charities, but you very often get fundamental Christian objections. Just because of where we have been this week, I am interested in hearing about that.

To my mind, the key issue is supply and demand. We do not have enough organs, therefore people are coming to harm and losing their lives. We are part of a UK-wide system because that benefits us. We do well out of the UK system. Were we looking only at our own narrow pool, we would be worse off than we are. It is a bit like blood donation; we have to get support from blood banks UK-wide. The reality is that we cannot do it all on our own. Will you just run through those points? The key thing is choice.

Mrs Dobson: I will start with your point about the consultation. Andrew referred to the extensive, 16-week consultation that we carried out. Like him, I was delighted with the PHA's two consultations after the one that I carried out.

One objection was lodged by Christian Action Research and Education (CARE) in Northern Ireland. I then met Mark Baillie, who came to my office. As I said, I wanted to engage with everyone, as I wanted as wide a consultation as possible. I wanted everyone's views to be made known. Once we went through the detail and he was reassured about the family veto in the Bill, he withdrew CARE's objections, which were the only objections.

We met extensively with Church groups. Goodness, we met so many groups, and CARE was the only one that objected. However, as I said, it withdrew its objections. Incidentally, I think that CARE has supported the Welsh model. CARE Wales has been very supportive of the Welsh model.

The first part of your question, Michael, was on the two forms of consent in the Bill. Express consent is similar to the present system, but there is the ability to opt out. Currently, if you are opposed to organ donation, your family can still be approached. Under the Bill, if you want to opt out, it will be quite simple to do so, and your family will never be approached. That strengthens for the first time your rights if you have a reason for not agreeing with organ donation.

The change in the law is at clause 4 for deemed consent. Alex was quite good in his line of questioning earlier, and we teased the issue out considerably. That will happen only upon your death. If people have not engaged with the organ donor register, or expressed a wish during their lifetime, their consent is deemed. Crucially, however, that must be confirmed by an adult in a qualifying relationship. That is that family veto — in essence, that affirmation or safeguard — from the family.

That is where the choice comes in. You have the choice to express your consent. You also have the choice, as Pam highlighted in her questions, to appoint two advocates if you wish, which is important. Donald referred to the ick factor. Some people do not want to think about organ donation. They may not want to make a decision either way. Those people have the opportunity, if they are not minded either way, to appoint two advocates to make that decision for them.

It is a big conversation, and we may have our ideas about organ donation, but some people simply do not want to opt out of or opt on to the register. They do, however, want to appoint advocates. That will be facilitated by the Bill. I think therefore that all choices are covered.

Mr Cromwell: The ick factor was one of the things that the PHA survey looked at. I remember that Dr Eddie Rooney, who presented to the Committee, referred to that. Appointing advocates is a powerful new tool to enable people to choose two people to decide for them. That prompts the conversation, because when you are choosing two people and providing their details to NHS Blood and Transplant (NHSBT), it is a natural assumption that you have that conversation with those people and that they are au fait with your wishes.

Equally, if you do not wish to think about organ donation but, through the promotion that will go on as a result of clause 1, decide that you wish to interact with the register but just cannot come to the point of making the decision yourself, you will have the new power and ability to be able to choose two people to make that decision for you at the time. Those are two important strengths of the advocate system.

Mr McGimpsey: Therefore, we can we say that the PHA is in support of the Bill.

Mrs Dobson: Certainly from the work that it did on its public attitudes survey that Andrew referred to, the Speak up and save a life campaign. I remember Dr Eddie Rooney's opening remarks at the launch of the campaign, which will probably haunt him forever. He said that if he were a Member bringing forward a private Member's Bill on organ donation, he would be happy with the findings of that report.

Mr Buchanan: Thank you, Jo-Anne and Donald, for your presentation. When you have the personal touch, it brings it home to members much more. You are someone who has experienced it and gone through it, and your experience has certainly brought it home to members today.

Jo-Anne, Spain was mentioned, and it is known as the world's best for organ donation rates. However, back in 1979, Spain passed —

Mrs Dobson: Were you born in 1979?

Mr Buchanan: Yes, I was. I might not look it, but I was.

Back in 1979, Spain passed presumed consent legislation, and that failed. It did not work. Ten years later, in 1989, Spain went through a crucial organisational change, and, out of that, it created an organisational infrastructure for transplantation. As a result, Spain is now known internationally as having the best donation rates. What do you deem to be different about the Bill that you are bringing forward, which is presumed consent legislation, that will close that gap and make work what did not work in Spain? What is the difference?

Mrs Dobson: For a start, you are going back to 1979.

Mr Buchanan: Absolutely, but it did not work then.

Mrs Dobson: If we are talking dates, before I bring in Donald, I will take you back to 1986, when Belgium first introduced the system. Belgium introduced it in one of its regions first, and it was such a success that all the regions of Belgium adopted it as time progressed. Donald, do you want to comment on Spain?

Mr Cairnduff: I was well aware of that. When I talked about donation rates in countries with an opt-out system, I said that a change in the law would not, on its own, generate significant differences. Medical and clinical infrastructure is very important. I am aware of the fact that Spain is the gold standard for donation rates, and that was not the case for some years after it introduced opt-out legislation.

My view may be simplistic, but, from talking to medical people in Northern Ireland and trying to ferret my way through a vocabulary that I barely understand to get to the main points that they are making, it is that the medical and clinical infrastructure in Northern Ireland, and in the United Kingdom as a whole, is good. There are more specialist nurses in ICUs than there were previously, and the culture whereby specialist nurses take over difficult conversations that the clinicians perhaps do not have the sensitivity to conduct is progressing well.

That change in medical and clinician infrastructure is the bedrock of a change in legislation, and, from my limited knowledge, I think that we are doing reasonably well in the United Kingdom. A cultural change needs to come in on top of that. The word "force" was used earlier, when it was mentioned that the law would force conversations, but, as I said in my presentation, I would rather see it as a change in the legislation encouraging conversations and a cultural change over years, whereby talking about organ donation is not regarded as something uncomfortable or squeamish but as something that is very good for people to talk about.

The medical and clinical infrastructure, without which a change in the law will make no impact whatsoever, is of a high standard in the British Isles. The cultural change, which I am convinced will ensue from a change in the law, will help increase donation rates in a medical and clinical context, whereby the people who can make the best use of increased donations are already working to a very high level.

Mrs Dobson: Obviously, medicine has moved on considerably from 1979. Medicines and methods evolve all the time. Although medicine has moved on, and transplants have moved on, the law is not keeping pace with those medical advances.

Mr Buchanan: I was pointing out the scenario only because I wondered what the difference was.

To come a bit more up to date, there were an abysmal number of transplants in the UK in 2007 — 809 — and the organ donation rate was at an all-time low, which was worrying. A task force was then set up, and, every year since 2007, the number has increased. In fact, in 2012, it increased by 50% and, in 2013, by 63%. Those are small steps, but the number is increasing.

I believe that, for your Bill to be effective — this has been talked about today — there needs to be education and communication. What I am asking is this: if we were to have that education and communication tied into the system that we already have, under which there has been an increase since 2007, would that close the gap, for want of a better expression, or would your Bill make even further advances? That is what I am trying to get at.

Mrs Dobson: It is a good point, Tom, and I think that Andrew mentioned it earlier. We are thinking of Northern Ireland not just next year or the year after but 10 years down the line. You are completely correct about the need for an education programme. That is why clause 1 creates a duty to inform and promote a campaign once a year. That is crucial. The measure cannot work in isolation. It needs to be combined with the education programme.

You are quite right that we have come a long way. I am impressed by your statistics on the UK rates from 2007. Last year, however, 17 people in Northern Ireland died while waiting for a transplant. The average is 15. We therefore need to do something. We are blessed with fantastic charities in Northern Ireland, run by volunteers who do amazing work. I am proud to have been associated with some of those charities for over 20 years.

I take you back, if I may, to the launch of my consultation a couple of years ago. One of the founding members of the Kidney Research Fund was sitting in the Great Hall, and she said to me, "Jo-Anne, I have been working at this for 42 years. Please, do this for the people of Northern Ireland. We need to make this law happen". Despite the fantastic work of those charities, and they do amazing work, and despite the number of people on the waiting list still being in the low thirties, we cannot get over that plateau of so few people being on the register. We need to do something. For me personally, and for the charities, a do-nothing approach is not an option, because 17 local people died this year. If one life can be saved — just one — through a change in the law, it is a chance worth taking.

Mr Buchanan: I have no difficulty at all with that. I am looking at the wide spectrum, and there are people for it and people against it. Those against it feel that something is going to happen against their will, because they are going to be on a register automatically —

Mrs Dobson: No, you opt out.

Mr Buchanan: They will be on the register until they opt out. I will be on a register automatically, until such times as —

Mrs Dobson: They are not on a register, not until they die, essentially. It is then when deemed consent kicks in. If people do nothing, they will not be on a register.

You are on the register if you express consent or if the advocates whom you appointed do so for you, as I highlighted earlier. Alternatively, if you are opposed to organ donation, you can register that you do not want to be an organ donor. The safeguard of family affirmation will happen only upon death. As Donald highlighted, the fact that there is that safeguard in certain circumstances means that there is no automatic green light to transplantation. Therefore, you are not on a register or a list somewhere. That simply does not happen. When you die, the clinicians and the specialist team will go through the register to see whether you expressed your consent, opted out, did nothing, appointed advocates or are not on it. You will not magically be on a register or be thought to have deemed consent. That simply will not happen. Thomas, that is why I think that it is good to have the conversation, in order to rule out the misinformation that, miraculously, you are on a register somewhere, because that certainly will not happen.

Mr Buchanan: Education is key, because, when it comes to the death of a person, and the family is asked whether they wish to donate the person's organs, it is too late. At that stage, the family is going through a very difficult time. It is something that happened to me when I lost my little boy. The clinicians, or the people who were there at that time, asked me, "Do you want to donate the organs?" It is certainly too late for that conversation then, when you are going through what you are going through. You need to have education first, and you need to be talking about it and putting it out there.

If that is done, you need to ask whether your Bill will make a difference to what we already have in place.

Mrs Dobson: Thank you.

Mr G Robinson: At the outset, I congratulate and commend Donald for his passionate presentation. It was absolutely excellent.

Mrs Dobson: It was.

Mr G Robinson: Jo-Anne, you touched on the excellent work that has been undertaken by the kidney transplant unit in the City Hospital and its recent great achievement in equalling the record for kidney transplants performed in one day. It has also achieved the best live donor levels in Europe. What is the view of the consultants and the other medical staff who carried out those operations on your legislation?

Mrs Dobson: I have engaged extensively with and meet regularly everyone involved in organ donation. You are right: it was spectacular.

Mr G Robinson: It was brilliant.

Mrs Dobson: No one was happier than me to hear about those five transplants in one day. I think that they were just one transplant short of the record.

Mr G Robinson: Yes, they equalled it.

Mrs Dobson: George, I think that that goes to show that those people in the City Hospital, most of whom I know, are passionate campaigners and advocates for organ donation. We have the specialists and the consultants there: they are already there to carry out those transplants. However, I do not want those five transplants from September 2015 to be a one-off. I want that to become the norm. I want more "five transplants in one day". Think of the difference that it would make to people in Northern Ireland if that became the norm rather than the exception.

You spoke earlier about the live donor scheme — altruistic transplants — for which Dr Aisling Courtney and her team are world-renowned. Interestingly, when I was in Brussels last January, I met Dr Luc Colenbie, who is head of transplantation in Brussels and leads a European team. He explained that, as has happened in Belgium, you reach a point at which the altruistic transplant/ live donor scheme almost peaks. Everyone who is able to do live donation has done so. It is fantastic to be able to do that, but it is not the answer. It is great for someone to give that gift and to save a loved one, but it peaks. That is what they have found in Belgium. Therefore, we need to look at other ways of increasing organ donation. If we can do that through a simple change in the law and, as Tom and others have spoken about, an education programme, an awareness-raising programme and providing information, those conversations will take place, and transplants will not be the exception but become the norm. We certainly have the expertise in Northern Ireland to make that happen.

Ms McCorley: Thank you very much, Jo-Anne, Donald and Andrew for coming today. I echo what everyone has said. I fully endorse what you are doing. I am on the register, and I think that it is necessary to be.

I need to leave, so I just want to ask a quick question, Jo-Anne. In circumstances in which people are on the register and have no relatives whom they are close to or who live close by, if those people pass away, and some relative pops up, would that person, who is a relative but may not have had contact with the deceased for a long time and who has no relationship with them, have a right to go against their wishes?

Mrs Dobson: If people are on the register, they have therefore expressed their interest in donating an organ. That would be reflected by the specialist nurses who are so well trained to deal with such situations. The clinicians would take that decision with the relative, but there is also a list of people in a qualifying relationship. If you have expressed an interest in organ donation, that will be reflected through the clinicians to a close relative or someone whom you have not seen for a while. People in a qualifying relationship are included in the Bill, but if there is any doubt whatsoever, the clinicians will make the decision. They have the expertise and the ability to make that decision.

Ms McCorley: Therefore, it is possible for them to rule out a person from having a say. Let us say that it is a sister or a brother who has been estranged for years, and there is no other living relative.

Mr Cromwell: If people have expressed their consent during their lifetime, the specialist nurse will evidently approach the relative on the basis of making known the view that the individual expressed during his or her lifetime. Therefore, if there has been very little contact between relatives and the deceased in those circumstances, it will naturally follow that relatives will wish to try to carry out what they knew as the only evidence that they had of their loved one's wish, which would be their signing, at whatever stage, of the organ donor register. If that is the only evidence that relatives are presented with, which the specialist nurse has the ability to provide them with through the NHSBT database, it would be hoped and expected that they would take the view that the individual had, because it is all about ensuring that the wish of the individual prior to death is carried out.

Ms McCorley: I totally agree that that is the way that it should be. I am just trying to think what might happen in a scenario in which one person has a completely opposing view and comes along for the purpose of using his or her power to oppose. Would the clinicians then make the decision?

Mr Cromwell: No. The clinicians would have an input into the decision, but, naturally, it would be left to the relatives to work alongside them. A clinician would not conduct an operation or a transplant without there being the appropriate consent. In fact, the Bill —

Mrs Dobson: It would not proceed without the consent. There is an extensive document to be signed.

Ms McCorley: Therefore, that person who has not had contact may have the final say.

Mrs Dobson: Currently, that is the case.

Ms McCorley: OK. In your Bill, that would not necessarily be the case. Are you saying that it would be different? Would this legislation change that?

Mrs Dobson: It would be in line with current practice.

Mr Cromwell: That is similar to the question that the Chair asked earlier about potential conflict of opinion. We would be open to looking at that and at the detail around what you say. I take the point about relatives having a totally opposing view and not wishing to follow through on the organ donation, but, as I said, the only evidence that individuals, having not been connected to a relative, would have would be their expressed consent if they had provided it. It would be hoped that the relatives will use their ability as it stands at present when they engage with the clinicians to help ensure that what they are doing is not necessarily based on their opinion but on the opinion of the individual prior to death.

The Chairperson (Ms Maeve McLaughlin): OK. I thank all three of you for that today. It was very informative for us as we move ahead. Thank you for taking the time, and I particularly thank you, Donald, for sharing your experiences.