



Northern Ireland  
Assembly

Committee for Health, Social Services and  
Public Safety

# OFFICIAL REPORT (Hansard)

Human Transplantation Bill: British Heart  
Foundation, British Medical Association,  
Northern Ireland Kidney Research Fund

6 January 2016

# NORTHERN IRELAND ASSEMBLY

## Committee for Health, Social Services and Public Safety

Human Transplantation Bill: British Heart Foundation, British Medical Association,  
Northern Ireland Kidney Research Fund

6 January 2016

**Members present for all or part of the proceedings:**

Ms Maeve McLaughlin (Chairperson)  
Mr Alex Easton (Deputy Chairperson)  
Mr Kieran McCarthy  
Ms Rosaleen McCorley  
Mr Michael McGimpsey  
Mr Daithí McKay  
Mr Fearghal McKinney  
Mr Gary Middleton

**Witnesses:**

Ms Jayne Murray	British Heart Foundation
Dr John Chisholm	British Medical Association
Mr John Brown	Northern Ireland Kidney Research Fund

**The Chairperson (Ms Maeve McLaughlin):** Folks, you are very welcome. Thank you for taking the time. We have with us Mr John Brown, the chair of the Kidney Research Fund; Ms Jayne Murray, the head of the British Heart Foundation (BHF); and Dr John Chisholm, the chair of the British Medical Association (BMA). I am not sure who is taking the lead.

**Mr John Brown (Northern Ireland Kidney Research Fund):** I do not mind.

**The Chairperson (Ms Maeve McLaughlin):** I think that you have been nominated, John. I will hand over to you. We will then take Committee members' comments or questions.

**Dr John Chisholm (British Medical Association):** Thank you very much. I am here to give evidence on behalf of the British Medical Association. The BMA is an apolitical professional association and an independent trade union, representing doctors and medical students from all branches of medicine across the United Kingdom and supporting them to deliver the highest standards of patient care. We have a membership of over 154,000 that continues to grow every year. In Northern Ireland, we represent some 5,700 doctors and medical students. Seventy-five per cent of doctors and students in Northern Ireland are BMA members.

I chair the BMA's medical ethics committee, which considers the ethical implications of all matters concerning the relationship between the medical profession, the public and the state. The medical ethics committee and the medical ethics department operate at a UK level. The committee includes 10 elected doctors and eight appointed experts with backgrounds in philosophy, ethics, the law and theology. The department provides a wide range of services and products to support doctors in their

professional lives. We offer individual ethical and medicolegal advice. We publish advice and guidance, including our main ethics handbook, 'Medical Ethics Today', a condensed version called 'Everyday Medical Ethics and Law' and other books and short toolkits on ethics and human rights. All our website resources are on the publicly accessible part of the BMA website rather than the members-only section, because we want those resources to be freely available to and used by everyone, including the public and patients.

We are involved in defending and speaking out about human rights and are particularly focused on abuses of health-related human rights. We provide training for groups of doctors, medical students and international medical graduates. We monitor developments in medical law, seek to influence the law and campaign for changes in public policy. One example of such campaigning has been our long-standing support for an opt-out system for organ donation, which has influenced the implementation of legislation in Wales from the start of last month. It is in that context that I am delighted to have the opportunity to give oral evidence today as the Health, Social Services and Public Safety Committee scrutinises the Human Transplantation Bill. As you know, BMA Northern Ireland has already submitted written evidence, and the chair of the BMA Northern Ireland council, Dr John D Woods, has written to all Assembly Members about organ donation.

The BMA strongly wishes to promote transplantation so as to increase the numbers of donors and of lives saved and is very conscious that people die unnecessarily while on the waiting list for organs that they need in order to preserve and enhance their lives and health. Currently, more than three people a day on average die in the UK waiting for a transplant. We agree that there are benefits to individuals, their families, society, the NHS and the wider economy in promoting transplantation. Part of promoting transplantation is through the Department of Health, Social Services and Public Safety providing information to the public, increasing awareness about transplantation and increasing the understanding and social acceptability of organ donation. The BMA supports the Bill's aim:

*"to save lives by changing organ donation laws, making the donation of organs the societal norm in Northern Ireland".*

The BMA believes that public opinion and awareness are crucial to the success of an opt-out system and that there should be a well-resourced, high-profile, consistent and persistent publicity campaign to enable a more informed public debate and to encourage people to make their wishes about organ donation known.

So in broad terms, the BMA welcomes this private Member's Bill and the intentions to increase the numbers of organs available for transplantation, to increase the social acceptability of organ donation and to change societal culture in that regard. We have supported an opt-out system with safeguards for organ donation since 1999, and we also support continuing improvements in the infrastructure, resourcing and organisation of the organ donation and transplant system. In general, we welcome a move from the current opt-in system to a new soft opt-out system with safeguards.

In Northern Ireland, there are about 162 patients on the transplant waiting list. In the first two quarters of 2015-16, there were 86 organ transplants. Only 43% of the deceased donors in the UK in 2014-15 were on the organ donor register. In Northern Ireland, as of 31 March 2015, there were about 647,237 people on the register, which is only 34% of the population. However, we know that there is a high level of public support for organ donation in Northern Ireland, with 84% supporting the idea of organ donation in a representative sample survey undertaken by the Public Health Agency (PHA) in 2013. Nonetheless, awareness of the organ donor register was low, at 36%, while only 38% had discussed their donation wishes with family and friends.

Experience from Wales is relevant to Northern Ireland. The Human Transplantation (Wales) Act 2013 was implemented at the start of last month, with implementation having been preceded by a public awareness campaign. In June 2015, 64% of the population supported the new law, with its arrangements for opt-out. It would be vital for education and awareness campaigns both to precede and to run in parallel with the introduction of new legislation in Northern Ireland. That campaign would confirm that, under an opt-out system, as with an opt-in system, individuals have a choice to donate or not to donate; their autonomous choice is respected. Individuals would be given information about the new opt-out system and could easily opt out of donation if that was their wish.

There has been a welcome increase in the number of donors in the UK over the past 10 years, but there have also been changes in the characteristics of donors. The percentage of deceased donors over the age of 60 has increased from 17% in 2005-06 to 33% in 2014-15. The proportion of clinically obese donors has increased from 16% to 26% over 10 years. The proportion of deceased donors

after a trauma death has fallen from 16% to 8%. Such shifts in the profile of donors will have had an adverse impact on the quality of organs and thus on the outcomes for recipients. The increased number of donations and transplants that would follow a move to an opt-out system would help to reverse those trends.

Independent research evidence from the University of York, which undertook a systematic review of the published data, shows a positive association between opt-out legislation or practice and higher rates of donation. Four methodologically sound studies comparing donation rates in countries with and without opt-out found that opt-out law or practice was associated with increased donation rates. In three of the studies, the increases were statistically significant. Five methodologically sound studies comparing donation rates in a single country before and after the introduction of an opt-out law all found a consistent increase in organ donation rates following the introduction of legislation.

I will now focus on the few issues about which BMA Northern Ireland has in its written evidence on the Bill expressed its concerns. First, while we support the intention that the family should always be consulted about an individual's wishes, except where a person has appointed a representative to make a transplant decision on their behalf, we would prefer that the way in which the family is involved did not require a positive formal affirmation that a person would not have objected; rather, we prefer that the family should be asked about any unregistered objection. I appreciate that that is a fine distinction, but I believe that avoiding a positive requirement to affirm would place less pressure on the bereaved family and achieve more donations. BMA Northern Ireland has therefore proposed that clause 4(2) be amended to read:

*"But deemed consent is only effective if a relative or friend of long standing [or a person who stood in a qualifying relationship with the person immediately before death] is not aware of any unregistered objection to that transplantation activity."*

We propose that the Bill be amended elsewhere to remove references to affirmation. Such an approach would be more in line with a standard opt-out system with safeguards. In essence, if an individual has not registered an objection and those close to the person are not aware of any unregistered objection, the deceased individual's organs should be available for donation, unless, in a particular case, the clinical team believes that donation is not appropriate — for example, if it would cause significant distress to the family. That is a simple message that is easy to convey. The key issue should be what the deceased person wanted in relation to donation. The family's role should be to provide information to contribute to the decision, rather than to give consent themselves. In that context, it is worth noting that, currently, when an individual's views are not known, the relatives are asked for consent: in Northern Ireland, about 40% of families are refusing consent.

Secondly, BMA Northern Ireland is concerned that the Bill includes transplantation from living donors. We fear that such an inclusion may be confusing and counterproductive and result in more people choosing to opt out of donation. The Human Transplantation (Wales) Act applies only to removing "from the body of a deceased person" any relevant material, and we believe that the same should apply in Northern Ireland. We believe that living donation is best left as it is, under the auspices of the Human Tissue Authority (HTA), which approves all living organ donations and has the appropriate safeguards in place.

We have very serious concerns about clause 8 and the application of any deemed consent system to donation from living individuals who lack the capacity to consent. Any procedure carried out on a living individual who lacks capacity must be in the individual's best interests. Living donations from incapacitated individuals are very rare and take place only after careful consideration and usually with the approval of the court. We believe that clause 8 should be deleted.

Thirdly, we have concerns about clause 5(3)(b) in respect of adults who have lacked capacity for a significant period before death. The length of time that an individual lacked capacity before death is irrelevant; what is important is whether they had capacity for a reasonable period after the new system was implemented and therefore had the opportunity to opt out if that was their wish. Thus, the law should refer to the period for which an individual has had capacity since the new system came into effect, rather than the period for which they lacked capacity.

Fourthly, BMA Northern Ireland believes that an opt-out system should apply at the age of 16 and not 18, as defined in clause 18(1). At the age of 16, there is a presumption that young people are legally competent to make their own important and complex decisions regarding their care and treatment. There is no reason for setting a different age for young people to opt out of organ donation than that set for other important decisions.

I look forward to your questions on our written evidence, my opening statement and any other matters that you wish to raise with me.

**The Chairperson (Ms Maeve McLaughlin):** Thank you very much. We will take all the presentations and then open the meeting up for comments.

**Ms Jayne Murray (British Heart Foundation):** First, I take the opportunity to thank the Health Committee for providing the British Heart Foundation Northern Ireland with the opportunity to speak today on this really important issue for heart patients not just in Northern Ireland but right across the UK.

The British Heart Foundation has been and continues to be a true advocate for the introduction of a change in how consent is registered on organ donation; namely, we fully support the change from an opt-in system to a soft opt-out system in Northern Ireland. We have a long history of supporting any calls for the introduction of an opt-out system for organ donation in Northern Ireland. We have also played a key role in the debate and legislation in Wales and are currently involved in the debate and legislation in Scotland.

The British Heart Foundation is the country's leading heart charity. We are working to achieve our vision of a world in which people do not die prematurely or suffer from cardiovascular disease. Thanks to modern treatments built on our research, huge progress has been made over the past 50 years on increasing survival rates. Most babies born today with heart defects survive, and seven out of 10 people survive a heart attack today. However, cardiovascular disease still kills one in four people and affects seven million people in the UK, including 225,000 people in Northern Ireland. Therefore, there is much work still to do on the issue. In the fight for every heartbeat, we are the UK's largest funder of research into heart and circulatory disease. We provide support and care to people living with cardiovascular disease and advocate for improvement in that area. However, it is on the issue of severe heart failure that we want to focus specifically, and that is where our attention is when it comes to organ donation. Currently, for those with end-stage heart failure, a heart transplant offers the only chance of long-term survival. BHF Northern Ireland welcomes the introduction of the Human Transplantation Bill, as we agree that a soft opt-out system for organ donation should be introduced not just here but right across the UK.

Why do we support a soft opt-out system for Northern Ireland? System change is urgently needed, as the current system is failing to meet the demand for donor hearts. The demand for a heart has increased across the UK by 143% since 2006. Currently, 262 people in the UK are waiting for a new heart, and, in the past year alone, 38 people died while waiting for a heart transplant and a further 47 were removed from the waiting list. In Northern Ireland, eight people are waiting for a life-saving heart. We know that, in the past two quarters, there have been two transplants in Northern Ireland. That is welcome news, but, in the previous 12 months, there had been no heart transplants in Northern Ireland. As I am sure you will all agree, statistics can be quoted, but, as a charity that works with people living with and, sadly, dying with severe heart failure, we know that, behind every statistic, there is a family and an individual waiting for this. Therefore, for us as a charity, it is important that we get the legislation right.

Moving to an opt-out system would better reflect the wishes of the public. We know that nine out of 10 people support organ donation, but only three out of 10 — about 34% — go on to sign the register. We therefore believe that there is a need to change the system of how we register individuals' views on consent so that the system is generally more accurate and representative of those views, and at reflecting the views of local people. In short, we believe that an opt-out system with safeguards would increase the donation rate. Under the system, people would have the right to opt out and choose not to donate their organs, and the built-in safeguards that we believe should form part of the Bill would ensure that the family is always consulted and asked about unregistered objection to ensure that the deceased individual's wishes are respected at all times. However, we also state that a system change is not the only thing: it is not the magic bullet. Investment in infrastructure and in the training of staff involved in organ donation is necessary to ensure that clinical systems can cope with the increase in transplantation activity. Equally important is the need for an education and awareness campaign both before and post our change in the law. That is important. That is why, over the past two years, the British Heart Foundation, along with the BMA, the Public Health Agency and numerous charities such as our colleagues here and those in Opt for Life, has always advocated the importance of raising awareness about the family having a discussion.

I now turn to the evidence. We broadly welcome the Human Transplantation Bill. We are incredibly supportive of it, but we have a few concerns about a number of the clauses, specifically clause 4, which concerns deemed consent and deceased adults. The British Heart Foundation Northern Ireland believes that the aim of the legislation should be threefold. First, it needs to help precipitate the increase in the number of organs available for donation. It must do that. Also — this is paramount — it needs to respect the wishes of the deceased; that, to us, is critical. Thirdly and equally important, it needs to give families or the qualifying person an important confirmation role at the point of donation. However, we believe that clause 4(2) in its current format does not deliver on those aims. In its current format, the legislation will make donation more difficult in deemed consent circumstances. We are aware of the sensitivities around the role of relatives at this distressing time. However, as I have outlined, the key issue is that it should always be about what the deceased person wanted in relation to donation. We believe that the family's role is to provide information to contribute to that decision, rather than to give actual legal consent. We believe that the proposal could lead to confusion. Relatives should be asked whether they are aware of the unregistered objection; however, they should not be specifically asked to affirm that the individual wanted to donate. If families are expected to affirm that the deceased would not have objected, that could place the wishes of the family or the qualifying person above those of the deceased. It shifts the balance slightly. It could also make families reluctant to provide affirmation when they have absolute proof of it; there is a number of aspects.

Whilst BHF Northern Ireland firmly believes that the family or the qualifying person of the deceased should play a role at the point of donation, we support the Welsh legislation approach on the issue: giving families the opportunity to object to donation on the basis of the views of their loved ones — donation rather than asking them to affirm in every case of donation that the deceased did not object. In short, we are concerned that the use of the word "affirm" could be seen as family consent, which undermines the principle of an opt-out system. We agree with the BMA Northern Ireland recommendation to change the wording to:

*"Deemed consent is only effective if a relative or friend of longstanding of the person is not aware of any unregistered objection to the transplantation."*

We know that familial consent rates in the UK are among the lowest in Europe, and that presents a serious barrier to increasing the number of organs available for donation. It is therefore paramount that any public awareness raising accompanying the campaign should aim at encouraging the public to have a conversation with their loved ones about their wishes for organ donation. Any campaign should focus on upstreaming the conversation that they are having with the living much sooner. As we know and as statistics have revealed, about 40% of families in Northern Ireland do not consent. We understand that: they are being asked to make probably one of the most difficult decisions of their lives on one of the most horrendous days of their life. Much more needs to be done to have that conversation earlier. That is why it is so important.

Secondly, in relation to clause 6, "Express consent: children", BHF Northern Ireland supports the age of consent for donation being lowered from 18, as outlined in the Bill, to 16 years of age in order to reflect the age that a young person is legally deemed competent to make their own decisions. At 16, there is a presumption that young people are legally competent to make important and complex decisions regarding their care and treatment. We see no reason for setting a different age for young people to opt out of organ donation than for other important decisions that they make in their life. However, we believe that those under the age of consent should not be prohibited from becoming an organ donor if they want to do so, although the consent of the young person as well as that of their parents should be obtained. That would pull the Bill into line with the Human Transplantation Bill and the Human Tissue Act 2004, which allow children to register their consent from the age of 10.

I would like to thank you for giving me the opportunity to speak to you today. I welcome any questions.

**Mr Brown:** First, I thank the Committee for asking us here. The Northern Ireland Kidney Research Fund is about 45 years old; it is wholly voluntary, no one receives a salary, and we rely on public donations. Why do we support the Bill? Research is making progress, and there is light at the end of the tunnel. However, a cure for kidney failure, or a means of preventing it, is still in the future. Therefore transplantation is still the only answer.

At the end of November 2015, upwards of 800 people in Northern Ireland were on a dialysis programme. Even with an increase in the living donor transplantation, more than 100 patients are awaiting a kidney transplant. One of the aims of the Northern Ireland Kidney Research Fund is to

promote organ donation, which we do through advertising, education and outreach. We have discovered that many members of the public support the idea of signing the register, but inertia appears to prevent that. The soft option, as we see it, protects human rights and leaves the next of kin with the final choice.

Our awareness of those who are in desperate need of organs has led us to examine every way possible to increase the number available. How did we arrive at a decision? We have attended cross-party committee meetings on organ donation and are aware of varied opinions and concerns. We have listened to the debate and have relayed the information to our executive committee. At our quarterly executive meetings, which are attended by members from all our groups, we canvassed responses and sent the minutes to those who were unable to attend. Our medical advisers have outlined their views, and we have heard the views of Jo-Anne Dobson MLA, Lynne Callow, who has experience of the Welsh Bill, and Joe Brolly.

We have also attended discussions in the offices of the British Medical Association along with representatives from other charities with an interest in promoting organ donation, including the Northern Ireland Kidney Patients Association, Liver Support, and the British Heart Foundation, and we have reported the outcome to our executive meetings. In all discussions on the subject, it has become clear that there is a need to educate the public to make an informed choice to communicate their decisions to family members. Along with publicity campaigns, we believe that people need to have that conversation. That is why the uptake rate is so low.

I will now turn to our response to Jo-Anne Dobson's private Member's Bill. The Northern Ireland Kidney Research Fund supports the proposed soft opt-out system but has some reservations. We see it as a way of increasing the organ donor register. We are satisfied that living donations are adequately covered by the Human Tissue Act 2004. As discussion with family is pivotal, we stress the need for education for all potential donors, enabling them to arrive at an informed decision. The soft opt-out system should be applicable from the age of 16. We believe that simplifying clause 4 to read "unless an objection can be recorded" would facilitate the decision-making involved at such a sensitive time.

If this system were introduced, we believe that it would result in more people having kidney and other transplants. Keeping a person on dialysis costs approximately £35,000 a year, whereas after the first year of transplant the patient costs approximately £5,000 a year. Therefore, apart from the human considerations, there is more money for the Health Minister to use on other projects.

**The Chairperson (Ms Maeve McLaughlin):** Thanks to all three of you for that. My initial question is for the BMA. What I hear from all three of you is that the move to soft opt-out is welcome but the challenge from some sectors is that there is little evidence to prove whether soft opt-out or deemed consent processes would have a positive, negative or neutral impact. How would you respond to that?

**Dr Chisholm:** I refer again to the independent research evidence from the University of York that I quoted earlier from two sorts of studies, comparing countries with soft opt-out with countries without soft opt-out and comparing within countries before and after the introduction of legislation. In all nine studies, there was evidence of a consistent increase in donation rates as a result of the introduction of opt-out legislation or practice. It is not possible to determine cause and effect in that situation because, obviously, you cannot do a controlled trial; all you can do is to look to see whether there has been a change in donation rates as a result of legislation being introduced. You cannot say categorically that it was the legislation that did it because, as both of us said in our evidence, another important factor is the need for properly resourced infrastructure and organisation of the donation and transplant system. That is also required. For example, in Spain, it was only when attention was given to the importance of improving the infrastructure for donation and transplant that donation and transplant rates increased. You cannot categorically say that the effect of introducing legislation is to increase donation rates, but all the international evidence points in that direction.

**The Chairperson (Ms Maeve McLaughlin):** How do you address the concerns of consultants, which range from the view that there is no need for legislation at this time to the view that the process of deemed consent is flawed?

**Dr Chisholm:** I am disappointed by those views, but, obviously, in the medical profession there is a range of views. All I can say is that the BMA, which in Northern Ireland has 75% of students and practising doctors in its membership and has a similar percentage of doctors and students in its

membership throughout the UK, has, whenever the issue has been debated since 1999, voted consistently in favour of a soft opt-out system with safeguards. The majority view in the medical profession is in favour of moving in that direction.

**The Chairperson (Ms Maeve McLaughlin):** All three contributions referred to clause 4. Specifically, the BMA talked about rewording clause 4 so that it says:

*"deemed consent is only effective if a relative or friend of long standing of the person is not aware of any unregistered objection to that transplantation activity."*

The Heart Foundation said something similar. I am interested in how a "friend of long standing" would be defined. I see a similar issue with "qualifying relationship" and its status. What are your thoughts on that?

**Dr Chisholm:** The Bill, as drafted, sets out what qualifying relationships are and says that, if you like, the order of precedence of qualifying relationships will be set in regulations and can be amended from time to time. The BMA is supportive of that approach so that, in effect, the person or persons who are being asked about any unregistered objection that they know about are those who are closest to the deceased individual. There is far less pressure put on the relative or friend if the question is phrased in a way that is related to knowledge of an unregistered objection, so that the relative or friend is placed in the position of supporting the wishes of the deceased person, rather than the more difficult situation of being asked to affirm that the deceased person did not object. It seems to the BMA and clearly to the British Heart Foundation Northern Ireland as well that that is close to the relatives being asked for consent and could lead to a failure to gain the increase in donation and transplant rates that is on offer by moving to an opt-out system.

At present, 40% of families in Northern Ireland refuse consent. We fear that the affirmation procedure outlined in clause 4(2) might lead to a similar proportion of families refusing or declining to affirm. As I said, the international evidence suggests that, if you move to a presumption of donation in line with both legislation and the deceased's prior expressed wishes, that is likely to produce a considerable increase in donation rates. Our fear — all three of us have said this — is that the affirmation procedure might not lead to the step change in donation rates that a soft opt-out system ought to lead to.

**The Chairperson (Ms Maeve McLaughlin):** The whole principle of the Bill is in and around deemed consent. You do not feel that the removal of firm opt-out would change the principle or objective of the Bill.

**Dr Chisholm:** The publicity preceding the implementation of the Bill and continuing after it will hopefully lead to a lot more conversations in families about donation wishes. All three of us have mentioned in our evidence that that would be part of the cultural change that we want to see. It will hopefully mean either that more individuals will have made their wishes known or that, through that cultural change, more relatives and friends will be positive about the benefits of organ donation and about it being a wonderful legacy to come out of the terrible event of a death and be supportive of it. We hope that, culturally, more people in Northern Ireland will be more supportive of organ donation. Nonetheless, there are risks that the affirmation process puts too much pressure on relatives on what, as Jayne said, is the most horrendous day of their life. They are confronted with a bereavement and then asked to make one of the most difficult decisions that they will ever be called on to make. We want to remove the obligation to make a decision from the relatives by merely asking them if they know of any unregistered objection by their deceased relative or friend.

**The Chairperson (Ms Maeve McLaughlin):** You also said that you had very real concerns that the Bill included transplantation from living donors: will you explore that a bit?

**Dr Chisholm:** If that remains part of the Bill, the message is confusing and counterproductive and might well result in more people choosing to opt out of donation because of a fear that organs would be removed from them while they are alive. There would be a much clearer message in the new system in Northern Ireland and a much clearer message for the public information campaign if, as has happened in Wales, the legislation is confined purely to donations by deceased persons and the transplantation of organs from deceased persons. The Human Tissue Act already provides a satisfactory mechanism throughout the UK for dealing with organ donation from living persons. It would be better to separate the two issues and have the Human Tissue Act regulating donations from



living persons and the Human Transplantation Act here in Northern Ireland dealing with donations from deceased persons.

**Mr Easton:** I am slightly confused. Are you saying that the Bill would allow people's organs to be removed while they are still alive? Is that what the Bill suggests to you?

**Dr Chisholm:** That is the case. In particular, we have grave concerns about clause 8, which deals with the transplantation of organs from individuals who are alive but who lack capacity. We think that it would be wise for clause 8 to be removed from the Bill, because, if you like, the message to the public would be a confused one if the Bill left the potential for deemed consent in relation to incapacitated individuals. It is a much more confused message for the public and could lead to a far smaller increase in donation rates than those who support the Bill would like.

**Mr Easton:** Chair, that is a very worrying interpretation. It is something that we really need to get our heads round. Mark it down.

**The Chairperson (Ms Maeve McLaughlin):** Thank you. Just on clause 8 and the issue of relevant material, maybe other legislation just looked at transplantation and donation in terms of solid organs. Is that an issue for you?

**Dr Chisholm:** As I say, our preferred option is that clause 8 be removed from the Bill and that the Human Tissue Act, which, we believe, works well in this regard, should be the continuing way in which such issues are dealt with. As I mentioned in my initial statement, if you are dealing with an incapacitated individual — it is very rare, anyway, that organ donation would take place in those circumstances — the norm is that the particular circumstances of the case are assessed via a court hearing, which allows for consideration of the reason. Examples of where such cases may arise relate to donation to a close relative, where the incapacitated person might, because of their genetic inheritance, be a suitable donor, but we believe that it is a very rare circumstance and that that issue is best tested on a case-by-case basis in the courts.

**The Chairperson (Ms Maeve McLaughlin):** Jayne, the three witnesses said that clause 4 should be reworked, but you welcomed the Bill with other safeguards. We are interested in what they should be.

**Ms Murray:** Basically, with the soft opt-out system, it is always about increasing the number of organs and also about the individual's views. It is about getting representation and consent. We recognise, however, that there is an important role for the family to play. As it is, there are safeguards at the minute in the system. In practice, it is quite clear that no clinician would go against a strong objection, and we believe that those safeguards should remain.

**Mr McKay:** Jayne, you suggested the inclusion of a new clause, which makes sense to me, about the facilitation of those who have deceased from Wales but who live in the North, taking into account the introduction of legislation there. Can you comment on that? You also talked about the facilitation of those under 16, which I would be open to, but can you explain how that would work in practice? I presume that there would be some concerns there as well.

**Ms Murray:** Addressing your first point about consistency across jurisdictions, obviously there are four jurisdictions at work across the UK. The British Heart Foundation believes that time is of the essence in each case; transplantation surpasses borders. For us, the pathway needs to be quick. Therefore anything that can be done to streamline that across jurisdictions is very important. For example, when somebody needs a heart in Northern Ireland, that heart could come, depending on suitability, from anywhere in the UK. That is still the case.

What we recognised when we went through the Bill was that there did not seem to be anything — possibly it is a loophole, and that is why we raised it, if not for inclusion in the Bill at least for consideration down the line — to deal with the situation where someone from Wales who is obviously covered by their legislation is visiting Northern Ireland and something tragic happens. Time is of the essence, so, if they are in a position to donate, we are keen that the Bill should include a clause that considers those who qualify to have given deemed consent under the Welsh Act. That deemed consent should at least be carried over to comply with the Northern Ireland organ donation law as well. We are keen to see symmetry among the jurisdictions. I do not know exactly — I am not an expert in law — but it is something for the Committee to consider to make sure that there are no loopholes. It is really important as time is of the essence in each case of transplantation.

In answer to your second question about clause 6, my understanding is that in Wales the age is set at 18. Like the British Medical Association, we believe that it should be lowered to 16. There is the presumption that young people at the age of 16 are legally competent, so it makes sense. They are asked about their care and treatment, and this is as important an issue as their care and treatment. They should be considered in that. However, how that would work practically needs further explanation. To be honest, I could not answer that question directly; we would need to look at it.

**Mr McKay:** What about those under 16?

**Ms Murray:** My understanding is that in the case of a person under 16 and over 12, they are asked for consent and their parents are asked for that consent to be obtained. That should remain.

**The Chairperson (Ms Maeve McLaughlin):** I thank all three of you. You have been very clear and succinct. As a Committee we will reflect on all that we have heard. Thank you for your time today.