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Assembly

Committee for Health, Social Services and Public Safety

OFFICIAL REPORT
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Organan Donation Survey:
Public Health Agency Briefing

4 December 2013

NORTHERN IRELAND ASSEMBLY

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Members present for all or part of the proceedings:
Mr Jim Wells (Deputy Chairperson)
Mr Roy Beggs
Mr Mickey Brady
Ms Pam Brown
Mr Gordon Dunne
Mr Kieran McCarthy
Mr David McIlveen

Witnesses:

Dr Paul Glover	Belfast Health and Social Care Trust
Ms Naomi McCay	Public Health Agency
Dr Eddie Rooney	Public Health Agency

The Deputy Chairperson: I welcome Eddie Rooney, chief executive of the Public Health Agency and a regular visitor to the Committee; Dr Paul Glover, regional clinical lead for organ donation with the Belfast Health and Social Care Trust; and Naomi McCay, who is the health intelligence manager — that sounds fascinating — at the Public Health Agency. That sounds like James Bond, only in the health service. You are all very welcome. I invite you to make a presentation for maybe 15 minutes, and then I will ask Members to ask questions.

Dr Eddie Rooney (Public Health Agency): Thank you very much for the invitation to present to you. By way of introduction, I refer to the Committee's evidence session of 23 October 2013 during which views were received from contributors on the evidence in favour of opt-out legislation. There were references to my views during that session and I would like to take the opportunity to express them directly to you in this session.

I declare an interest because in addition to my role as chief executive of the Public Health Agency (PHA), I am chair of the Northern Ireland committee on organ donation and transplantation. I am also the honorary president of Transplant Sport Northern Ireland, a registered charity.

Today, my role is very much in my PHA capacity and my focus will be on the evidence. I will set our survey results, which I will come to in a little while, in context. I want to say a little bit about the international evidence and what that tells us about the impact of opt-out legislation, which is an important part of the context for the survey results.

For Northern Ireland, the bottom line is that there is no reliable evidence to suggest that the introduction of opt-out legislation would, in itself, result in an increase in organ donation rates. International evidence has been the subject of intense debate for several years. The full range of evidence was examined in depth, UK wide, by the organ donation task force in 2008 and, more recently, on behalf of the Welsh Government. The task force in 2008 noted that the evidence was finely balanced and concluded that the move to an opt-out system may deliver real benefits but carried a significant risk of making the current situation worse. On balance, it concluded against introducing legislation at that time, finding no convincing evidence that it would deliver significant increases in the number of donated organs. Its report suggested that the matter be looked at in 2013.

In 2012, the Welsh Government published its evidence, based on international evidence and looking at many of the same sources. It concluded that the evidence provided a convincing basis for introducing an opt-out system in Wales while recognising that there could be no guarantees that a change in the law would result in increased organ donation rates. The review also cautioned against comparing countries with one other, saying that no two countries were the same. Therefore, finding that opt-out legislation worked in one country did not mean that the same relationship would exist in another.

That review recognised the importance of public support and the potential risk of a backlash, which could cause more harm than good if the support was not there. We do not know whether the introduction of opt-out legislation would have a positive impact on organ donation in Northern Ireland or not, based on the evidence at the moment. We know that other countries have shown that it is possible to have opt-out legislation and positive organ donation outcomes, but there is no guarantee that that could be replicated in Northern Ireland.

At the Committee's evidence session on 23 October, Dr Aisling Courtney said:

> *"The legislation has to be a reflection of what we think as a society and not be imposed...We have to get the awareness and education bit right first."*

That has been a lengthy introduction, Chair. However, that is where the PHA public survey and stakeholder engagement started. At the end of April 2013, the Minister of Health announced that he had asked the PHA to conduct a public information campaign to enhance awareness and understanding, and encourage everyone to take action to support organ donation. In preparation for that, he asked us to conduct two specific exercises; to conduct a survey of public opinion, and take the views of stakeholders, including charities, donor families, those waiting for transplants and those providing services.

I will give you a summary of the results of the public survey. The survey was based on a representative sample of face-to-face interviews across the Northern Ireland population. We used that approach to capture views across the full spectrum of the community in a form that would allow us, statistically, to draw conclusions about the opinions of the Northern Ireland population as a whole. We have had a lot of questions subsequently about how that differs from the consultation exercise on the proposed legislation. Although consultations provide a very rich source of additional information, they do not have a statistical basis, and conclusions cannot be applied to the general population in the same way as the survey that we conducted.

The results of the survey on the positive side showed very strong support for organ donation in Northern Ireland: 84% of the population were in favour, and only 7% were explicitly against. There was strong recognition of the gift of life as something positive to come out of loss and death. There was also an appreciation of donors as being heroic in our community. The survey showed that the positive attitude and knowledge was generally more strongly associated with those in low deprivation groups, those in good health, people who were already on the organ donor register, and those who had been exposed to organ donation and transplantation, often from a family member or friend.

On the negative side, although 84% were in favour of organ donation, that number reduced the more it was associated with action to do something about that. For example, only 55% thought that they should register on the organ donor register. One result that made us think a lot, particularly because we spend so much time on public information, was that 36% of the population were not aware of the organ donor register. That made us think, because, in much of our statements, we have always been telling people to text "Donate" to a number or to go online to sign the organ donor register without really thinking that over a third of the population were not quite clear about what we were asking them to do. That has really made us think about some of the fundamentals, such as information and basic awareness, in that area.

There were misunderstandings about the age at which you could donate and receive organs; what organs could be donated; how you determine whether somebody is dead, including misunderstandings about brainstem death; and many of the traditions, particularly about whether you could have an open coffin if you had donated your organs. There was also a very considerable gap between what people said and knew we should do and what they chose to do. In particular, 78% said that you should talk to your family and friends about your wishes, but 38% said that they actually did talk to their family and friends. Forty three per cent said that their family or friends would know their wishes about organ donation, and 55% thought that family or friends would agree with those wishes. Quite a body of people felt that they would not agree.

We carried out some more sophisticated factor analysis to try to figure out and understand more about the drivers that affect attitudes to organ donation. A number of them came up, particularly on the negative side. Of those, the strongest relationship was with what we have defined as spiritual: not theological, religious-denominational or doctrinal; it is a combination of those elements and tradition. It is about keeping the body whole for burial. That showed up in our survey more strongly for Northern Ireland than for other countries in which similar surveys have been carried out. There was also a strong element of medical distrust; the fear that, somehow, medical priorities will change in order to harvest organs. There is also what has been termed in the literature an "ick" factor, which is that people did not like to talk about organ donation; they do not like the idea of the body being cut up or organs being inside you. That tended to put them off. It is related to those negative attitudes.

We were asked specifically to look at soft opt-out legislation in the survey. We used the Welsh Government's explanation of what soft opt-out was. When the public were asked whether they would support a change, 56% said yes, 18% said no and 26% said that they needed more information or did not know. That is relatively high for a first survey in Northern Ireland. When Wales conducted its survey in 2012, 49% said that they were in favour.

Later in the survey we asked the same question in a different way, and over a quarter of the people who had said that they were in favour changed their answer. The overall figure reduced from 56% to 49%. The only issue we take from this is that those of us who are involved in this area find it complex, and the public also find it complex. It is difficult to understand and follow, and the message for us, when we carry forward public information, is that we should respect that.

In other findings, 74% thought that soft opt-out would result in more lives being saved. Sixty two per cent thought that freedom of choice would still be maintained, but 26% thought that it would take away from the gift of life and 28% thought that it would give government too much control. If it were introduced now, 16% of the population said that they would opt out, and 22% said that they did not know.

The stakeholder exercise, which was not part of the survey, was a different type of exercise. In that, there was unanimous support for a sustained, well-resourced public information campaign with the aim of making organ donation the cultural norm. The feeling was that the key message should be to consider your own donation wishes and talk to your family and friends.

On soft opt-out legislation, all agreed that the current debate is helping to raise awareness. Support was strongest from the British Medical Association (BMA) and the charities. Opposition to legislation was strongest from professional staff, especially those closest to intensive care. The arguments from stakeholders in favour of soft opt-out were that it was better than doing nothing, it would increase the number of available organs and would signal a cultural change. The arguments against soft opt-out were the fear that it will increase refusals, entrench negative views, increase medical distrust and reduce the pool of potential organ donors by people defining themselves out of that.

In conclusion, we have had very positive developments in organ donation in Northern Ireland over the past few years in particular. Service improvements, including specialist nurses and clinical leads, are having an impact and are continuing to improve figures. We are among the leading countries in the world in live kidney donations. Our organ donor registrations are continuing to increase steadily, but everyone involved in this area, I believe without exception, wants to do more. We all want consent rates for organ donation to increase and we all want transplant waiting lists to reduce.

Will opt-out legislation help to make things better? It may, but based on the evidence, we are not sure. We are clear that there is a need to address public awareness and motivate people to follow through on their good intentions with positive action to support organ donation. That work needs to proceed, irrespective of what the Assembly decides in relation to legislation. That is what we are focusing on now.

As a result of the survey that we undertook, we are in the process of using that information to design a public information campaign. Our intention is to be ready to run a campaign in February 2014. The focus will be on getting people to talk about organ donation wishes with their family and friends. It will also be aimed at tackling awareness and the information gap and at mobilising support, particularly among those who are in favour of organ donation but do not do something about it. That applies particularly to the younger members of our community.

I emphasise that the public advertisement will be only one element of the campaign.. We will be working intensely with the Churches, education and the charities to help build an understanding of organ donation and mobilise that support.

I will be happy to take questions.

The Deputy Chairperson: Thank you, Eddie. I have had the advantage of hearing some of that information at the all-party group, but what you have said has expanded on that, and what members have before them is the final version.

The tables in your paper are fascinating, particularly the one showing that Scotland has already achieved a 41% registration level, compared to our level at 31%, England at 30% and Wales at 32%. Obviously, if we could get up to the Scottish level very quickly, that would help. Is Scotland doing anything different to promote organ donation?

Dr Rooney: Yes. Traditionally, donor rates in Scotland have been higher than those in the other UK countries. Scotland has taken a twin-track approach. First, it had a public information campaign and had major growth. It also had a very intensive programme working with the schools. We have had the Scottish team over with us recently to explain what it has done on both fronts, and we have been undertaking discussions with the education sector based on the approach that was taken. It has not been an instant turnaround; it has taken several years for Scotland to get there, but it was the country that went first for the public information campaign and for doing that in a different way. We have learnt quite a bit from that.

The Deputy Chairperson: Even more significant was figure 2 in your paper, which shows that 362,000 people had registered through the driving licence application form. That represents 80% of the people who have registered. GP registration has resulted in only 37,000 people being registered. The Boots Advantage Card has resulted in 38,000. Websites have resulted in 24,000, and a National Health Service leaflet has resulted in 85,000. The figure from driving licence applications stands out. There are 1·16 million people in Northern Ireland who have a driving licence of some description, and 10% of them register every year because they have to renew every year. It means that over 100,000 people a year are having to fill in that form. It has been suggested that one of the quickest and most non-controversial ways of getting that figure up is to make the question on the form, which is currently optional, compulsory. In other words, you would have to tick whether you do or do not wish to opt out or opt in to donate your organ? Would that be a halfway house that gets around some of the moral difficulties that people have with a soft opt-out proposal?

Dr Rooney: It is certainly a positive approach. In England, a mandatory question is now asked in online registrations. Therein lies one of the challenges here, because we cannot do online registrations at present. It is the only practical way of asking a mandatory question.

Countries have varied in their approaches, and the mandatory approach has tended to be a feature in the United States, in particular, and has had considerable success there. It has been mandatory not only with regard to driving licences but in all aspects of the processes around organ donation. Quite clearly, it can have an impact. The issue is that technical developments are needed to get there and legislative change would be required. I have been in discussions with the Driver and Vehicle Agency (DVA) on this matter, and one of the issues is that it is very difficult to run it with the current manual system, which has a different focus. You could end up clogging up the system indefinitely. The online element would be very important in that.

The Deputy Chairperson: Everything else that I fill in now is online, and you are not allowed to go to the next page unless you have answered all the questions on the current page, so you have no way out. In Northern Ireland, we must be moving to online DVA registration for everything. That has to be where we are going, and, that being the case, this is one way around it.

I know that Roy wants in, but there is one final question that I wish to ask. There is not much sense in having a huge number of people registered in Northern Ireland if, when you go to their next of kin, they then say that they prefer that their loved one's organs are not taken. I noticed in your paper that you have had quite considerable success in employing trained health professionals to approach the relatives. If they go about it in the right way, that can lead to quite a dramatic increase in the number of relatives saying yes. If you were able to roll out the highest level of success in that, how many other organs would be made available?

Dr Rooney: I will let Paul Glover answer that. Before he does so, I would say that that approach has been key to the success of developments in Spain, which is taken as the gold standard country. It has been the reorganisation of organ donation services that has made the biggest change there by far, and it is already making a considerable change here. Paul is the expert.

Dr Paul Glover (Belfast Health and Social Care Trust): It is quite clear that consent rates are higher if families are approached by trained individuals. International data shows that. Local data also shows that if a specialist nurse is involved in the approach to the family for consent for donation, there is a much greater chance of that family saying yes to donation, irrespective of whether the person was on the organ donor register or not.

There is probably no one in the world who knows more about how to implement changes on organ donation than Rafael Matesanz. He oversaw the Spanish model, which has been replicated in a number of countries. He is quite clear, and has stated, that no country has had a sustained increase in organ donation rates solely on the basis of changing legislation. The three most important factors that he highlighted that impact on organ donation rates are; first, the public's trust in the medical profession; secondly, their awareness, understanding and support for organ donation and transplantation; and thirdly, the professional approach to the family in seeking consent.

Mr Beggs: Jim talked about the difference in numbers registered for organ donation in different parts of the United Kingdom, and the information in your publication shows that at the start of 2008-09 Scotland was probably about six percentage points ahead of all other regions of the United Kingdom. That gap has widened, but Scotland's starting point was higher. What was happening at that time? Something must have been happening five years ago to lead to there being a difference with other regions. Had Scotland been doing something qualitative even before the more recent campaign?

Dr Rooney: Yes. A lot of the activities going on in Scotland have been built on over considerable time. It is very difficult to compare one country to another. If we look at countries internally, including Northern Ireland, we will see that there is a vast difference, for example, in registrations on the organ donor register at district council level, for no obvious reason other than, we suspect, the success of local campaigning.

In Scotland, you tend to have a flattening of that. That is, it tends to be uniformly higher at local level as well. I suspect that, over time, there has been more successful campaigning in the country and the cultural attitude has been different from other areas, but with the investment in education and in public information, that gap has widened. Scotland has increased more quickly and is now considerably higher than the other three UK countries.

Mr Beggs: When, roughly, did the engagement with education and the increased awareness campaign occur?

Dr Rooney: I cannot give you the precise timings but it is certainly over the past five years in particular.

The Deputy Chairperson: Sadly, at least 15 people die in Northern Ireland each year because organs are just not available. If we were to raise ourselves to the Scottish donor register model and up to best practice throughout Northern Ireland with nurses explaining to relatives on and off the donor register list, would we get to the position where we have enough organs to meet the need without having to go for any change in legislation?

Dr Rooney: That is a very difficult question to answer because several factors need to be taken into account to determine how many organs become available. Very sadly, that relates to the number of people who are dying, and the organs that become available through death depend heavily on recent developments over the past three or four years in the science around the retrieval of organs, the nature of death and who you can take and retrieve organs from.

It also requires a public information element and public support because, at the end of the day, it has to be translated into the consent that people give. Ultimately, that is a crucial issue, because while there might be increased registration on the organ donor register in Scotland, that does not necessarily translate to increases in the consent rate. So, ultimately, it really has to come down to the issue of consent in addition to the development of the services, and that combination of public information and services is critical. Can we get increased organs through that, rather than through legislation? The fact is that we are not sure what impact the legislation will have on that. That is one of our dilemmas.

The Deputy Chairperson: We had the story of the young man from Coalisland who died in a traffic accident. Six of his organs were used, two of which were life-saving. The parents went public on that. It was quite clear that the intervention of the nurse was absolutely crucial. Clearly, she was extremely capable and could explain the situation. I notice that you are doing this already, but I would have thought that without any legislative change, an expansion into that to make certain that a tactful, caring approach is made, might be able to deal with the problem. I say that because there are Members of the Assembly who have huge difficulties with the private Member's Bill that is coming through. I am trying to see if there is any other route to where we want to go, without having a long debate on the issue.

Dr Glover: The first thing that I will say is that the specialist nurses are involved in the approach to the families here in Northern Ireland, more so, probably, than they are in any other region of the UK. So, we are achieving that. There are a finite number of donors. At this minute in time, maybe 35% or 40% of families say no when approached for consent for organ donation. The two main reasons why families say no are, first, that their relative had previously stated he did not want to become an organ donor, or, secondly, that the family is unaware of what the wishes of the deceased were. They had never spoken about organ donation. Because of that, families often find that the easier decision to take at that time is to say no. Some data from the States suggests that about one third of families who say no to organ donation ultimately regret that decision. We are asking families to make such a crucial decision when they are at the height of a grief reaction. If they were making that decision in the clear light of day, they might come to a different decision. That is why I feel that the key to this is for us as members of society to let our families know what our wishes are. That does not mean that you have to sign on the organ donor register. However, if your family knew what your wishes were, it would take the burden off them.

The Deputy Chairperson: Again, quoting that article, the parents took considerable comfort from the fact that whilst they missed the young lad tremendously, he had actually saved two lives and helped another four. So, there is a positive aspect to this.

I signed the register about four years ago. To be honest, I had never thought of it until I came on to the Health Committee. I had no theological, personal or moral issues with it whatsoever. No one had ever asked me to sign the donor register or suggested it to me. From your statistics, it is clear that for an awful lot of people in Northern Ireland, the only reason they are not on the register is they have never been asked. Turning the argument on its head, is the soft opt-out option not a way of catching those people and forcing them to make a decision one way or the other? And if they feel strongly about it — and 16% of people have said that they do — making it as easy as possible for them to opt out? Are we not trying to catch a large bulk between the 31% and the 84%, to try to get them to make a decision? One third of them have not even heard of the register's existence. Is that a plus sign, as far as that suggestion is concerned?

Dr Rooney: Certainly, from the evidence that we have on this, trying to bridge that gap in knowledge and information is critical, regardless of what we do, whether we go for new legislation or build with the current system. Our view is that the education element and the public awareness part of this is a building block, regardless of which direction we end up going. I do not think that any form, on its own, certainly not legislation, is a shortcut to getting us to a better place. The evidence, internationally, is that it needs to go hand in hand with education, public awareness and public support, as well as developments in the services. We know what we need to do in terms of basic public information, and our survey results have been quite stark in relation to that. There are pools of support that are untapped in that population, and we will be initially focusing on mobilising that support. That in itself will be a very positive step, but it is not necessarily the whole answer. This is a long haul.

The Deputy Chairperson: From your research, what would be the likely reaction if we went down the route of the soft opt out? In other words, if that became legislation, from the results of your survey, how would the public react?

Ms Naomi McCay (Public Health Agency): We asked people what they would do if there was a change in legislation. About 16% of people said that they would definitely opt out. What was worrying was that 37% of people said that they would do nothing. So you were talking about ambivalence and people not giving it much consideration for opt-in. Equally, probably even more people would give it less consideration for seeking an opt-out register. Paul talked about the importance of family decision-making and the family knowing the individual's wishes, but 37% of people said that they would neither opt out nor opt in. There is a general fear that the opt-in register would go out of use and that we would be left in a situation where there is less clarity about people's wishes, the advantage of the opt-in register will be lost and people will not have sought an opt-out register. So, we would know even less about people's wishes.

The Deputy Chairperson: That is why the driving licence option is a better one: because people will clearly have made the decision.

Ms McCay: We asked about mandated decision-making, and there was a fair amount of support for it: 56% were in favour of it. Interestingly, the place where people are most likely to prefer to make a mandated decision is in their GP practice. In a different piece of work, we asked GPs about that, and 57% said that they would be willing to register a patient's wishes on his or her records in the GP practice.

The Deputy Chairperson: At the moment, registration through GPs makes up a very small proportion.

Ms McCay: That is due to lack of awareness.

The Deputy Chairperson: So, there is no overall campaign. At the minute, GP registration only accounts for 37,000, compared to the driving licence at 362,000. At the minute, it is an entirely voluntary exercise. Is there any merit in suggesting that all GPs are asked to put the question to their patients?

Dr Rooney: We will certainly be exploring that relationship with GPs. We are certainly not intending to go one single front in terms of building awareness and support for this. We will look at all options.

The Deputy Chairperson: If we got a response rate showing that 56% of people would register, surely that would take us close to what we need. It is difficult to work out, but that would add 60% to the current level of registrations. Is that not close to what we need to prevent people from dying needlessly because there is no organ available for them?

Dr Rooney: It is a positive step, but, as Paul has said, there is a common element running through all of the population, and that is to make sure that we get people thinking, talking and expressing their wishes on organ donation in the first place. That is where we need to concentrate at this stage.

Mr Brady: Thanks for the presentation. Just on the opt-in part, could it be any worse, in a sense, in terms of numbers? It does not seem to work particularly well. Obviously, in Spain, there have been campaigns, and it seems to be a matter of education and changing mindsets. With younger people, that opportunity is there, but with the older generation that may not be the case for various reasons. It seems to me that there should be a promotional campaign about the benefits of donating.

A colleague of mine gave his father a kidney as a living donor, which has made such a difference to his father's life. He took a very conscious decision and went through all the procedures. He was then able to be an example to people that this is something that should happen and that it brings positive outcomes. That message does not get across. As Jim said, that case in Coalisland made a tremendous difference to six different people.

Dr Rooney: The key is to get the message and the information across. We have not yet tapped the full potential of organ donor registration. The graph has been going in the right direction, but less than a third of people are on the organ donor register. There is quite a variation across the country; I think that the lowest district council area is about 11% and the highest is well over 40%. Clearly, we have to look at what is happening in the successful areas and replicate that. The key to that is to get that information and awareness out. Getting the experiences of people, and particularly the donor families, which has been hugely influential locally, and recipients through to the population is such a critical part of that awareness. We use the organ donor register as a proxy, because it is not necessarily mathematically too clearly related to actual organ donation activity at the other side. However, as Paul said, the primary reason why people do not consent to organs is that they do not know the wishes of their loved ones. We can do something about that.

Mr Brady: It is interesting that we live in an area that pioneered kidney transplants in the City Hospital, and yet there still seems to be a reticence in the general public to pursue giving consent or otherwise. Maybe the whole issue has not been highlighted enough. There have been many breakthroughs at a very local level — many medical procedures that have saved numerous lives. Sometimes we live in a wee cocoon, and we do not seem to realise that. Is the promotion a money thing? There have been some very effective television campaigns. I am on the all-party group on chest, heart and stroke. There was a presentation yesterday on the FAST (face, arms, speech, time) promotion concerning strokes. The vast majority of people who were asked about that had seen the television ad, heard it on the radio or read it in the paper. Something like 87% or 90% of people questioned had seen that on television. Those kinds of promotions can make a huge difference.

Dr Rooney: That is very much our business. The same team that developed the FAST campaign is working on a campaign to promote organ donation awareness. It will be done very much in the same way.

Mr Brady: That has been very effective.

Mr Dunne: Thanks very much for the evidence. I have a couple of things. Paul, you mentioned trust in the medical profession. What is the level of trust in Northern Ireland in that regard? Is it fairly high?

Dr Glover: It depends on what newspaper you read.

Mr Brady: That is not a rhetorical question, by the way.

Mr Dunne: Or what radio programme you listen to, maybe.

Dr Glover: That was one of the issues that was highlighted in the Public Health Agency survey. Those of us who are closer to donation have some concerns, particularly in relation to families perceiving a conflict of interest. Families may perceive that the doctors are looking to withdraw treatment because their relative is on the organ donor register and they might see the patient as a source of organs. That is completely unfounded, but those sorts of concerns have been voiced. One area of concern is the public asking why the doctors are making those decisions.

Ms McCay: In the public attitudes survey, around the medical distrust factors, just under a third of people agree with statements such as, "Doctors will withdraw treatment earlier", or, "The surest way to bring about my death is to make plans for it, like signing an organ donor card". Thirty per cent agree with the statement, "If I sign the organ donor card, doctors might take away my organs before I'm actually dead". We found correlation between what the public were saying and the actual fears being felt by the medical profession. There was correlation between those two viewpoints, which is really important.

Mr Dunne: I have a couple of other points. The awareness of the system is important. It is probably true that not all of us are aware of the need for donation until our family, friends or neighbours are affected, and then we really become involved. It is about engagement. How you go about addressing that issue is a major factor. We all tend to perhaps go overboard when that happens. People get involved, and that is all good, but how we try to break that down is a big issue. You talked about increasing awareness. I think that the soft opt-out system is overkill and draconian. What do you think about that? How do you think that the public see that?

Dr Rooney: It is very difficult at the moment for the public to understand the implications of it, but I would emphasise what I said in the presentation, which is that we know that eight out of 10 of the most successful countries in organ donation have some form of opt-out legislation, usually soft opt-out. The two things can work together. What we do not have is any clear consensus on the relationship between the legislation and the success in organ donation activity. The two things can go hand in hand and can exist together.

Mr Dunne: I think that there would be a major reaction to people being on a compulsory list.

Dr Rooney: Again, this is where we have to take account of what is coming through in the survey, those factors that people fear or are concerned about. Over a quarter of people are concerned about increased state control or a reduction on the issue of the gift. Those could be important factors in determining what people subsequently decide to do — whether they support organ donation or not. We need to at least take that into account.

Mr Dunne: Obviously, the condition of the remains is an issue. That is part of the final assessment, I take it. Depending what someone dies from, if someone tragically dies from cancer, are organs take from such a body?

Dr Glover: No. There are certain conditions that are absolute contra-indications to organ donation, so if someone has a condition such as active cancer, automatically, the family will not be approached for consent, because obviously it is important that organs that are transplanted are healthy. That is one of the roles of the specialist nurses, to make an assessment of the patient even before the family is approached, to make sure that they do not have any medical conditions that would stop organ donation from taking place.

Mr Dunne: So, with the soft opt-out option, in that case, would there be no contact made with the family?

Dr Glover: I would envisage it running in the same way. At this minute in time, if there was a patient who we knew had active cancer, we would not bring up organ donation with that family at all, because we see organ donation as being part of the end-of-life care for that patient, but if the patient has a condition that excludes it, it is something that we do not take any further. I think it would be unfair to raise the hopes of a family that possibly something good might come out of their relative dying when in fact it is a non-starter.

Mr Dunne: If they were on a soft opt-out list, there would be no further action.

Dr Glover: One of the potential drawbacks of the soft opt-out is that, at this moment in time, all families are approached whether they are on the organ donor register or not. If we had a soft opt-out option, we would not approach the families of those people who had opted out for consent, so, in fact, we might be asking a smaller pool of relatives for consent for organ donation.

Mr Dunne: One point comes to mind: do you refresh the existing list? If someone has indicated that they wish to donate organs, how do you keep that up to date and relevant?

Dr Rooney: Do you mean the organ donor register?

Mr Dunne: Yes.

Dr Rooney: Yes, it can be refreshed. Anybody can contact us. There is a donation line that people can ring if they want to update or check their information.

Mr Dunne: Is that voluntary?

Dr Rooney: It is entirely voluntary.

Mr Dunne: There is no refreshment done automatically?

Dr Rooney: No, it is done on a voluntary basis.

Ms Brown: Thank you for an interesting presentation. Most of the questions have been asked, so this is more of a comment. I have always supported organ donation and have carried a donor card since my teens, although the Deputy Chair would probably tell you that that has been for the past two years. I am very much in favour and really want to see the organ donation rate going up. That is the main point of this process. I welcome the idea of training GPs in a similar way to nurses to talk people through the process. That would be good for individuals to make well-informed decisions.

It is important that we speak to our families and relatives about this. It is vital. As someone who has always carried a donor card, I would be very distressed to think that when the time came and if my organs were of any use, someone close to me would actually stop that donation from happening. That is a distressing thought when you feel passionately and donating is something that you want to do. The crux of the matter is having that conversation and, if need be, convincing your friends and family that that is what should happen, and expressing your wishes clearly.

The education point is interesting too. Which country did you say it was? Scotland? Using education as a tool is very important. According to your statistics, quite a number of people between the ages of 16 and 29 were not aware of the organ donation register. That is interesting too. I am sure that we could do a lot between GPs, driving licences and education that would raise the bar on the available organs. I hope that this will come to fruition before too long and we will see some of those lives that are lost each year being saved.

Dr Rooney: I entirely agree, at this point in time in particular, about getting people to have that conversation with their families. If we can break that barrier and get the population behind that, that will make an enormous difference, irrespective of what we end up doing or not doing with legislation. It is really one of those fundamental building blocks that we need to address now.

Ms Brown: That is critical because no matter what system you have, it still comes down to the consent of somebody other than yourself. That is the most important part of this.

Mr Beggs: There is public discussion on organ donation. To a great extent, there has been for some time, and I think that will have a positive impact. Do you intend to carry out an ongoing review of the public's view of this subject as those views may change with that discussion?

Dr Rooney: We now have very good baseline information, which, typically, we would collect before undertaking a public information campaign. Our intention is to revisit those elements, certainly in the first wave of a campaign. We expect that we will be campaigning on this for some time, because we are not talking about just a short, sharp development. It will be much broader than simply public information through advertising but, yes, we will revisit the survey at some stage.

The Deputy Chairperson: Why are those closest to the retrieval of the organ the most opposed to a change in legislation?

Dr Glover: One reason, as I have already said, is the potential among the public for a perceived conflict of interest. The other thing that we feel is very important is that organ donation is in fact a gift, so when someone signs the organ donor register, they make a positive decision that that is what they want to do. With soft opt-out, some people will have made a conscious decision that they want to donate their organs, but there will also be members of the public who will not have opted out because they did not get around to it or due to apathy or whatever. There is not the same sense, possibly, of it being a gift. There is also the potential for an element of pressure on the family. If this is seen as being the law and the family feel that they must conform with the relative's wishes or if the relative has not opted out, the family are in a position of wondering whether he did not opt out because he wanted to be a donor or because he just did not get around to it. That may not, in fact, make the decision any easier for the family, unless they have had that conversation that we have been talking about.

The Deputy Chairperson: What surprised me was that by the time it gets to them, the qualified nurse has gone through what is obviously the most difficult issue of talking it through with the family. By that stage, they will come to the clinician with a well-explained consent. Why would they then feel a difficulty about taking the organ?

Dr Glover: It is not in relation to taking the organs. The way the consent process works is that the clinicians will approach the family on the subject of organ donation with the specialist nurse. Usually it is the specialist nurse who takes on the discussion about consent. The specialist nurse can provide the family with the relevant information that they need to make the right decision for them. Those of us who are closest to the system do not feel that the current system has failed. We feel that it still has not been properly developed. Fundamental to all this is the sense that this is a gift, and that it is something very positive.

The Deputy Chairperson: Finally, while all this is going on, are we watching the Welsh situation to see what transpires? Is that maybe an option — that you have your campaign and you watch to see the success or otherwise across the water and go with whatever they come up with?

Dr Rooney: All the UK countries are watching the Welsh situation very carefully. We hope that it works, because we want to do the right thing to increase organ donation activity. The information that we glean from Wales will be important for informing us.

The Deputy Chairperson: Thank you very much for your help. It is a very interesting if somewhat difficult subject. As you know, there is a private Member's Bill, so we will come back to this quite a few times if that is pursued.

Dr Rooney: Thank you very much.