The Scottish Parliament
Pàrlamaid na h-Alba

Official Report

HEALTH AND SPORT COMMITTEE

Tuesday 8 December 2015

Session 4

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HEALTH AND SPORT COMMITTEE
34th Meeting 2015, Session 4

CONVENER

*Duncan McNeil (Greenock and Inverclyde) (Lab)

DEPUTY CONVENER

*Bob Doris (Glasgow) (SNP)

COMMITTEE MEMBERS

*Malcolm Chisholm (Edinburgh Northern and Leith) (Lab)
*Rhoda Grant (Highlands and Islands) (Lab)
*Colin Keir (Edinburgh Western) (SNP)
*Richard Lyle (Central Scotland) (SNP)
*Mike MacKenzie (Highlands and Islands) (SNP)
*Nanette Milne (North East Scotland) (Con)
*Dennis Robertson (Aberdeenshire West) (SNP)

*attended

THE FOLLOWING ALSO PARTICIPATED:

Gareth Brown (Scottish Government)
Professor John Forsythe (NHS Lothian)
Anne McTaggart (Glasgow) (Lab)
Louise Miller (Scottish Parliament)
Maureen Watt (Minister for Public Health)

CLERK TO THE COMMITTEE

Jane Willilams

LOCATION

The Mary Fairfax Somerville Room (CR2)

Scottish Parliament

Health and Sport Committee

Tuesday 8 December 2015

[The Convener opened the meeting at 10:00]

Transplantation (Authorisation of Removal of Organs etc) (Scotland) Bill: Stage 1

The Convener (Duncan McNeil): Good morning and welcome to the 34th meeting in 2015 of the Health and Sport Committee. I ask everyone in the room to switch off mobile phones, which can interfere with our sound system. I ask visitors to note that members and clerks are using tablet devices instead of hard copies of their papers.

Today we have our final evidence sessions on the Transplantation (Authorisation of Removal of Organs etc) (Scotland) Bill. We will take evidence from two panels. I welcome our first panel: Maureen Watt, Minister for Public Health in the Scottish Government; Gareth Brown, head of the health protection division in the Scottish Government directorate for population health improvement; and Professor John Forsythe, lead clinician for organ donation and transplantation in Scotland and consultant transplant surgeon at the Royal Infirmary of Edinburgh, NHS Lothian.

I will move on to questions after the minister has made opening comments.

The Minister for Public Health (Maureen Watt): Thank you for inviting us to the committee today. I will make a few general opening remarks, after which I will be happy to discuss the bill in more detail.

I understand that the committee has sought and received a great deal of information and opinion on the general principles of opt-out, on whether opt-out would definitely increase organ donation rates, and on what has happened in other countries.

I entirely appreciate that that is necessary to understand the context of the bill. However, the reality is that the international evidence and experience are not clear. That is why the Scottish Government has said that it will be useful to wait and see how the approach works in Wales, which is a country whose health system is more like Scotland's than any other system in Europe.

Let me be clear. This Government does not have a principled opposition to opt-out. However, it is right that we are cautious. If the experience in Wales is that a legislative change in that regard leads directly to an increase in donors and transplants, I confirm to the committee that we will consult on such an approach for Scotland.

However, our focus today must be on the bill that is before us and the measures that it proposes. You will have read the Scottish Government's detailed paper on the bill. You have heard expert oral testimony from clinicians in the field—specialists who support potential donors, donor families and transplant recipients—and you have received written submissions from many of the organisations that are most closely involved in organ donation in Scotland. The vast majority of the people from whom you have heard—even those who are generally supportive of opt-out—have expressed significant concerns about measures in the bill.

In particular, the concept of the authorised investigating person and the role of proxies seem to be fundamentally problematic. The concerns in that regard should not go unheeded. They have been expressed by people who work tirelessly to save lives, who know intimately how the system works and who have no reason to be against the proposals unless they genuinely believe that they would do more harm than good.

I am aware that Ms McTaggart wrote to the committee on 1 December to respond to some of the issues that we and others have raised. I cannot today give a point-by-point response to her letter, but if it is useful to the committee I will be happy to arrange for officials to provide a written response.

I want specifically to pick up on the suggestion that the current system is not working. Ms McTaggart has expressed concern about a recent fall in donation numbers in Scotland and she has suggested that her bill might be necessary to turn that trend around.

Although the figures that Ms McTaggart has presented are correct, her analysis is a little unfair and should not be used as an argument in support of the bill. In the past year, donor numbers have fallen slightly across the United Kingdom for various reasons, but the fall is in relation to the preceding year, which was the best that we have ever seen. Last year's figures are still the second best that we have ever seen. Ms McTaggart is saying that because last year we had only very good levels of performance, instead of the outstanding levels of performance that we had seen in the year before, the system is not fit for purpose. I disagree.

Ms McTaggart has also drawn attention to the rate of donors per million population in Scotland. She says that our rate has increased by only 0.3 donors per million population in the past three years. Again, that is a slightly misleading presentation of the figures. In 2007-08, our donor rate was 10.1 per million population; in 2013-14 it was 19.8 per million. Therefore, we doubled our donor rate in six years. In 2014-15 our donor rate dropped back slightly to 18.4 per million, which reflects a combination of slightly lower donor numbers and an increasing Scottish population, but that rate is still the second highest that we have ever had.

The message is that the long-term trend is more important than year-to-year fluctuations. The long-term trend in Scotland is that donor and transplant numbers are increasing. The transplant waiting list in Scotland has dropped by 20 per cent since 2007. That is real success and real progress, which we should not cast aside lightly.

Of course there is still more to do. We could have a long debate about whether presumed consent in principle, or other measures, would increase our success. However, we are here to talk about the bill and, like the professionals from whom the committee has heard, we have real concerns about the harm that might be done if the bill passes.

There is no doubt that the bill will make the organ donation pathway slower and more complex. That will lead to organs being lost. Our success is fragile, and any misstep might lead to years of damage and more lives being lost. That is not an abstract risk; there are real-world examples of that happening elsewhere in Europe.

Anne McTaggart is to be admired for the fervour and passion that she brings to the matter. There is no doubt that she is committed to her aim of saving more lives through increased donation. So am I, so are my officials and so is every specialist working in the field. We are expressing concerns about the bill not because we do not want to do more or because we are passive or unwilling to try different things, but because change to the legislation for organ donation must be made carefully and cautiously—that is more important than making changes quickly.

I am grateful to the committee for its careful scrutiny of the bill and the thoughtful questions that have been asked in previous evidence sessions. I am happy to discuss the proposals in more detail.

The Convener: Thank you.

Dennis Robertson (Aberdeenshire West) (SNP): We all want to see an increase in the donor rate that translates into an increase in transplants. Minister, Anne McTaggart has suggested that there is sufficient international evidence that proceeding with an opt-out system would result in such increases. You are challenging the evidence, I presume because you think that it does not stack up. Why is that?

Maureen Watt: We know that, with its current system, Scotland is up there among the countries with the highest rates of donors. I think that there are six countries that have opt-out systems and higher donor rates than Scotland and seven countries that have opt-out systems and lower rates than ours—Gareth Brown will tell me if that is not correct. Therefore, an opt-out system does not in itself necessarily lead to higher donation rates and higher transplantation rates.

I am not sure which members of the committee went to Spain, but Dr Matesanz there has said that it is not just the opt-out system itself that is important; it is just as important for a country to have the infrastructure to identify and prepare organs for transplant.

Dennis Robertson: Anne McTaggart suggested that the current opt-in register would still exist under the bill, so there would not be an opt-out per se. The register would still be there for people who wished to register.

Ms McTaggart also suggested that the bill would increase organ donations, and that good awareness raising would lead to additional donations. That view is supported by the British Heart Foundation.

Maureen Watt: We are talking about presumed consent, but the bill refers to investigating persons and proxies, which we believe would add extra complication and detailed hindrances to the existing process. They would prolong the process and raise legal issues that do not exist at present.

I have met specialist nurses in organ donation in Aberdeen, where the rates have increased dramatically. I have also been to Professor Forsythe’s department, where the nurses are excellent at working with families to suggest organ donation if people are not on the register. We believe—as others have suggested in evidence to the committee—that having AIPs and proxies would make the system much more complicated.

Dennis Robertson: Could the bill be amended to address some of your concerns, or does the Scottish Government need to look at existing practice and put in place processes and procedures in an effort to raise the donation rate, which would result in a higher rate of transplantation?

Maureen Watt: On your first question, we do not believe that the bill could be satisfactorily amended to make it good. For example, the AIP is mentioned in the vast majority of the 20 sections in the bill.

On your second question—yes, we believe that we could do a lot more under the present system. We are doing a lot, but it is perhaps not entirely clear what we are doing, and I will bring in Professor Forsythe in a minute to talk about that.

As I said in my opening remarks, we are not against opt-out per se, but we would like to wait and see how the Welsh system progresses. It is the system that is most closely aligned to our national health service system and, if we see dramatic changes there, we will look at consulting on an opt-out bill.

Professor Forsythe, would you like to mention the booklet?

10:15

Professor John Forsythe (NHS Lothian): Absolutely—I am happy to come in. I have been involved in transplants for about 30 years, and in the past few years I have tried, with the support of a number of people around this table—I thank them for that continued support and Ms McTaggart for her interest—to improve organ donation rates. All of that has improved the focus on organ donation. However, when I started the work, I—like a number of members of the committee—went to Spain, because that seemed to be the place to go. I spoke with Rafael Matesanz, who has become a friend and colleague.

I went there thinking that the legislation was key, and I was surprised to find out that, in fact, he said that the legislation was not so important—I have quoted him in lectures on the topic as saying that it contributes little or nothing to the improvement of organ donation rates. He believed that infrastructural changes needed to be made. With the support of a number of people around this table, we have been involved in initiatives that have seen a significant increase in organ donor rates in Scotland over the past few years, but there is still much more to do and there is a plan to make more of those infrastructural changes between 2013 and 2020.

I would focus particularly on a number of things. In some areas, the Scottish Government's plan calls for more of the same. The education pack that is in every secondary school in Scotland is held up as a good model for other parts of the United Kingdom; we need to continue with that and with the publicity. In addition, we need to look at consent and authorisation rates to try to improve them. I know that a number of committee members have asked about that, and there are ways in which we can do that, trying to get up towards the levels that Spain has.

A number of years ago, a member of our Scottish transplant group whose son had donated organs around the turn of the millennium told me that she had been struck by the lack of training of the people who approached potential donors and their families. We have made a lot of headway in recent years, but there is a lot more to do.

We have also identified a whole-hospital approach for the next few years. Organ donation is seen as a very important thing in transplant units and now in intensive care units, but perhaps it is not seen that way all the way through the hospital—through all the emergency departments, the stroke unit and the whole hospital. That is something that Dr Rafael Matesanz in Spain is also trying to bring about to improve Spanish donor rates yet further, and I think that we can do more on that in Scotland.

In the past few years, we have seen a significant increase. When I started doing this work, our donor rate was nine donors per million of the population. We have now seen a significant increase, but there is still much more to do. The evidence for opt-out legislation being the key is not particularly strong, and I worry about the risk of opt-out legislation if it is not carefully framed and very sensitively introduced.

The Convener: There has been some contention about the figures that have been going around. The UK is behind Spain, which is the world leader in donor rates, and Scotland is behind the UK. Is that correct?

Maureen Watt: We have 42 per cent on the organ donor register in Scotland, and the UK average is 33 per cent. Gareth Brown may want to break that down further.

The Convener: Before we go on to talk about the register, we should note that Sweden has a very high number on the register but that does not equate to actual donations, so I am more interested in actual donations, not the number of people who are on the register. Are we behind the UK or are we running alongside it?

Maureen Watt: That is what Professor Forsythe has been explaining. You need the organ donation infrastructure as well as the number of people on the organ donation register in order to get an increase in the number of transplants that occur. Since 2008, we have improved the organ donation infrastructure, which has led to an 82 per cent increase in the number of donors and a 62 per cent increase in the number of transplants from deceased donors.

The Convener: Would Professor Forsythe agree with that equation? He quoted Professor Matesanz, who does not necessarily equate the number of people on a register with the number of donations.

Professor Forsythe: I agree with the convener. There is not always a read-across from a register to organ donor numbers. What committee members will have experienced in Spain is the whole feel of the publicity—almost a national pride in the way that organ donation is run—and a continued focus on those things, which are required if you are going to keep the donor number at a higher level.

What we have seen in the UK is the different UK countries changing places. When I first started in transplants, Scotland used to be way behind the rest of the UK, but it has improved and come up to around the same level as the rest of the UK. Last year it was lower than the rest of the UK, but the year before that it was not; it changes a little. The donor numbers have improved across the UK, but we can do more—we are still way behind Spain.

The Convener: Any questions from the committee should not be taken to mean that we think that we are not doing well. We are all keen to explore in the broadest sense how we could do better. From our engagement with people on that list who are waiting for a transplant, we know that they are not enthused by the idea of waiting two or three years to see how Wales gets on, because they are losing people every week—that is what they tell me. That is how sensitive an area we are looking at.

Professor Forsythe was talking about the requirement for publicity and raising awareness, but the organ donation marketing budget has been cut by half since 2013-14. That does not seem to me to be consistent with a drive to get that message over. In Spain, they have done the job on the marketing and they continue to do it. My observation was that the Spanish take pride in being the best in the world. There is an expectation about donation.

In our recent evidence, we heard that people on the front line—the organ donation co-ordinators in the hospitals—feel that the current legislation in Spain changes the discussion with people about donation. They believe that that is very important. That is the difference between the professor and the practitioners—the practitioners think that the legislation changed those discussions.

Maureen Watt: I do not think that there is anything in the bill that changes the discussion, but I will answer your question about the marketing budget. In 2013-14, we started a new campaign, and in that year we were developing the campaign and there were a lot of up-front costs. The following year we were putting the campaign into practice and that was the reason for the overall campaign split in the numbers for each year. Gareth Brown can explain that a bit better.

Gareth Brown (Scottish Government): It is correct that the budget halved between those two years. In the year that we had the higher budget we were, as the minister said, in the process of creative development and testing. That is the most expensive part of such campaigns.

When we moved to implementation we took a different approach; we moved much more online to the internet and social media, and we stopped doing direct mailing. Previously we had been mailing a lot of people to ask them to join the register, but the research evidence was that we had taken that as far as we could and we were no longer getting the return on that investment.

Clearly, there are always decisions that the Government has to make about its marketing spend and budget, but that cut was not just made for the sake of a cut—it was made because we were taking a different approach, moving more into online and internet-based approaches. The value of the marketing is to drive people to the organ donor register and to make their wishes known. We have seen the number on the register continue to go up, so a reduction in the budget does not necessarily mean that there is a loss in the quality of the outcome or outputs.

Maureen Watt: Obviously, overall budgets are decreasing, but we are targeting the money that we are spending much better. For example, I went with Pamela Niven, who is behind me, to a black, Asian and minority ethnic project in which peer educators go to the melas in Glasgow and Edinburgh to try to increase the numbers of donors in those communities. That is a really good way of using the money, as we know that a lot of people in the minority communities have kidney disease, and we need to ensure that we increase the number of donors in those communities to match the need in them. That is a specific approach, as well as the online stuff and people being able to register when they take out their driving licence. A number of youngsters automatically join the register when they apply for their licence. Therefore, there are different ways of using the money.

The Convener: I am sorry to invoke again the Spanish professor who dismisses much of that—the tick in the licence application form—and talks about the importance of the conversation that takes place. I think that Professor Forsythe referred to that and said that education and training and the people who do that are the important link to increase donations.

Maureen Watt: We have those leads. Nurse and clinical leads are already in place in all 26 hospitals in which there is an accident and emergency department, but it is about the read-over. I understand that people have to be in the intensive care unit in order to talk about the donation. As Professor Forsythe said, we need other departments in hospitals to think about whether the organs of a person who is at the end of their life can still be of use to somebody else.

The Convener: We heard in evidence last week that Spain has three times as many intensive care beds as we have and that an increase in ICU beds would be likely to increase donations.

Professor Forsythe: Yes. There are differences. The difference between our donation rate and Spain's is huge, and we need to dig into that in much more detail. You are right about the number of high-dependency beds and intensive therapy unit beds. That is not my area, but I understand that those numbers are much higher in Spain.

The idea of the futility of care at the end of life and saying, "Okay—we've done enough. We will now pull back," is acceptable across the whole of the UK, but I understand that it is not at all acceptable in Spain. Therefore, the number of potential donors is much higher in Spain, as is the age of potential donors.

I have spoken to Dr Matesanz at some length and have really tried to learn about the infrastructure. He keeps on talking about infrastructural changes, but he also talks about raising the profile, which he has done in a national way in Spain. We have tried to reproduce that as much as possible. We are on that journey. He talked about the increase in Spanish numbers over a period of many years. It does not happen overnight. We feel that we are on that journey, but there is much more that we need to do.

The Convener: I have two brief questions just to get a balance on last week's evidence.

Sally Johnson of NHS Blood and Transplant gave evidence last week. She said that it has done some work and believes that the bill could increase the number of donors by 70 a year.

Gareth Brown: We asked NHSBT to do some modelling. It is important to recognise that that modelling was based on the Welsh legislation on opt-out, which is different from Ms McTaggart's bill. NHSBT also had to make a number of assumptions in doing the modelling; indeed, I think that Sally Johnson said that there were a number of assumptions. The potential is as it said. The number could be anything between 30 and 120 extra donors a year, and 70 is around the average. However, that is modelling, and it makes a number of assumptions. We are not fully confident that that would be the case. In fact, our concern is that we might lose donors because of some of the provisions in the bill rather than gain donors.

10:30

The Convener: Did Sally Johnson say that there were 100 donors a year in Scotland? Is that the correct figure? I think she said that if we increased that number, we would have problems with capacity.

Professor Forsythe: I think that we had 98 donors last year.

The Convener: So an increase of 25 or 30 donors, never mind one of 70, would be a big increase. Sally Johnson raised the issue of whether we had the capacity to deal with such an increase.

Professor Forsythe: If we were absolutely certain that introducing new legislation would produce that change, I would be pushing people out of the way to be at the front of the queue in arguing for that but, overall, I am not convinced by the evidence. Although there is some evidence that an opt-out system may produce benefit, I can give you examples that show that the introduction of legislation that is anything to do with organ donation generally, if it is not sensitively managed, can damage organ donation across the board, so I am not completely convinced that the number would increase. If I thought that it would, I would be pro the introduction of new legislation.

The Convener: You are saying that we should wait. You agree with the minister that we should wait for two or three years to see how they get on in Wales. Is that what you are saying?

Professor Forsythe: That is what I feel we should probably do at the moment. At the very least, we should be certain that every provision of a bill is as perfect and as sensitively managed as possible, because there are potential repercussions from a bill that is not absolutely perfect that might cause problems. I can give the committee examples of that from the past.

The Convener: We can probably make improvements, but I do not think that we will ever get a perfect bill.

Maureen Watt: To be fair, we have not put a time limit on that—we have not said that we will wait for a particular period of two, three or four years.

The Convener: In that case, I invite you to put a time limit on it.

Maureen Watt: I am not going to put a time limit on it but if, in a year's time, we can see that the Welsh system is making a big difference, we could start consulting on our own bill.

The Convener: Would it be reasonable to review the Welsh legislation and its effect on transplantation in any meaningful way in a year's time?

Maureen Watt: As I said, if there was an immediate increase in the number of organ transplants, which is what we are looking for, we could say on that basis that there was clear evidence for us to start consultation on our own bill.

Gareth Brown: If the level of increase that you say that Sally Johnson suggested that the bill would result in in Scotland is significant, the same will be the case in Wales. Although we do not want to make big decisions on the basis of one year, we will know whether the impact is going to be significant in one year.

The Convener: What piece of legislation anywhere—unless it turned out to be a disaster—could be effectively reviewed after a year of implementation?

Gareth Brown: You can assess—

The Convener: Given that a long lead-in for publicity is built into the Welsh legislation, the Welsh Government does not expect it to have a significant impact in one year, does it?

Gareth Brown: I do not think that it expects the impact to be evident within a year, but there is an annual monitoring of data. In fact, the data is monitored on a monthly and a quarterly basis, so we will be able to begin to detect a trend associated with the only change that has been made, which is the introduction of the legislation in Wales.

Rhoda Grant (Highlands and Islands) (Lab): This is really difficult. I hear your caution and your desire to check things and, at the same time, I hear the evidence that says that we could double the number of donors. If I was someone who had a loved one who was waiting for an organ, I think that I would be infuriated by the attitude that is coming across. Let us be perfectly honest: people will die while we wait. The bill has the ability to save lives.

Obviously, we are at stage 1, and we would be able to amend the bill at stage 2. Some of the issues that the minister has brought up in her written submission to the committee relate to aspects of the bill that I believe the committee would look to amend at stage 2. Why do you believe that the bill is unamendable? I find it a bit confusing that, on one hand, we are told that the bill is nothing like the Welsh legislation but, on the other hand, you say that if the Welsh legislation works, you will look at the bill again.

You are looking at this from two different directions, which I cannot understand. It looks as if you want a good excuse not to implement the bill. That would be fine if it were not a piece of legislation that had the ability to save lives. Given that it is, we need a better explanation.

Maureen Watt: What we want to see from the Welsh act is whether opt-out makes a difference.

Anne McTaggart’s bill is very different from the Welsh act. We believe that the role of the authorised investigating person and the appointment of up to three proxies mean that the bill would slow down the process of organ donation, whereas time is of the essence in this area. As I said in answer to a previous question, the role of the AIP is mentioned in the majority of the sections of the bill. We do not believe that it would be possible to remove those references and still have a sensible bill. Gareth Brown has been looking at that point in more detail.

Gareth Brown: It is important to think about how the provisions in the bill will work. The bill introduces the authorised investigating person, as the minister said, and the explanatory notes suggest that that could be a healthcare professional. The Government’s view is that it probably cannot be such a person. Even if that point is put to one side, the role of the AIP is to make judgments as to whether someone had wanted to opt out, and whether there is any evidence that they did not have the opportunity to do so.

The donation pathway can be quite a long process at the moment. Whether it is donation after circulatory or after brain-stem death, it takes on average 18 to 25 hours. The process will happen after a family has been sitting with a loved one perhaps for days or hours, going through a horrible time. The family is then expected to wait for that further process to take place. We know already that some families who have authorised donation will get halfway through the process, decide that they cannot take the situation any more and withdraw that authorisation. We already lose donors because the process is quite long.

Nothing in the bill simplifies that existing process; it adds to it. The AIP and the role of the proxies are interlinked. If someone nominates one, two or three proxies, the AIP would be legally required to check those proxies and their views first. Even if a family wanted to authorise donation, under the terms of the bill it cannot do so if there are nominated proxies. The AIP has to check those proxies first. A family could be waiting, wanting to authorise but being told that it cannot do so, as the views of the proxies have to be checked.

There could be up to three proxies. Someone could nominate a proxy online on the register or simply in writing, so the AIP has to be able to check wherever in writing the deceased person has notified their wishes. Someone can decide that they no longer wish to be a proxy—

Rhoda Grant: Could I cut you off there because, although that is part of the bill now, we are at stage 1 and there is nothing to prevent us from taking out the provisions on proxies at stage 2.

The provisions are there for a very specific reason: to cover situations where a person does not have a next of kin. That requirement could be covered by having an attorney appointed on behalf of the deceased: some of our witnesses have said that there is no need to have proxies in the bill. However, it seems to work well in the rest of the UK where there are already proxies—there are two rather than three, but they do exist.

Maureen Watt: Proxies are very rarely used. In fact, there are only 15 registered proxies and they have never been used. So why would you have—

Rhoda Grant: You have made my point.

Maureen Watt: Why would you have them in the bill? If the provisions on proxies and AIPs were taken out, the bill that remained would not be a workable piece of legislation.

Gareth Brown: Ms Grant is right that the other parts of the UK have nominated representatives.

It is important to recognise that the Scottish legislation on organ donation that was brought in by the previous Administration came after the English and Welsh legislation had been passed. Thus the Parliament would have been aware of that legislation as the bill went through, and the Government of the day would have given some consideration to having a similar provision in Scotland. For whatever reason, it decided not to do so.

As the minister said, there is provision for nominated representatives in the rest of the UK, but only 15 have been nominated and they have never been used. The bill is legislating for something that our evidence says is not used elsewhere in the UK.

Even if proxies were taken out and those provisions were deemed not to be needed, the bill would still provide for the function of the AIP. The AIP is the individual who has to make decisions on whether something is lawful and judgments about whether someone wanted to opt out but did not have the opportunity to do so, and to be responsible for those decisions. That will take time, as they would have to go through a process to do that. The bill is not reducing or simplifying any of the processes that exist; it is adding a layer.

It was suggested at the previous committee discussion that the AIPs could be the specialist nurses who currently support organ donation. Our view—Sally Johnson from NHSBT said this also—is that specialist nurses could not fulfil that role because there would be a conflict of interest.

The role of the AIP in the legislation is primarily concerned with opting out and whether the person wanted to opt out. They would make judgments about what the person wanted and whether they could be a donor. That is different from the role of the SNOD, which is about making sure that the family is supported. Also, I am not clear whether a health professional could do the AIP job.

Rhoda Grant: If you are saying that the SNOD could not be the AIP because the SNOD's role is directly related to supporting the family, who currently checks that the law as it stands is being followed?

Gareth Brown: There is a quality distinction to make. At the moment, the SNODs make factual checks. They do not have a legally defined role—that is an important difference. They will check whether somebody expressed a wish on the register. If not, they check whether the person expressed a wish to the family. If the person did not, they check what the family wants. The SNODs are checking facts and those facts will be provided to the transplant surgeon who ultimately makes a decision on whether to go ahead.

Rhoda Grant: That is what the AIP would do, so those roles are not—

Gareth Brown: No, it is different because the AIP is legally required to make judgments. It is not about fact checking. It is about saying, "My view is that this person could have opted out but didn't," or, particularly when we are talking about proxies, "My view is that I will wait for this amount of time until we know what the proxy wants and, if not, we will proceed." It is a different role. The individual AIP is legally personally responsible for those judgments in the legislation. The SNOD is not legally personally responsible for making those sorts of legal judgments.

I think that the explanatory notes explicitly say that the AIP will check the lawfulness of donation. That sort of terminology means that they are making a legal judgment. It is not about checking whether a person is on the register. That is different from the Welsh act. From memory, the Welsh act has not introduced that sort of role. It has essentially said that people either opt in or opt out. If you have opted out, that is on the register; if you have opted in, it is on the register; and if you have not opted out, the assumption is that you wanted to donate but that will be checked with the family. Again, it is about fact checking; it is not about making legal judgments in the way that is described in this bill.

Rhoda Grant: That could all be amended at stage 2.

Maureen Watt: If the SNOD took on the role of the AIP, it would create a conflict of interest. The SNOD is there to help the family through the process, but if they have to have legal training to check whether the donation is legal, that puts them in quite an invidious position.

Gareth Brown: Even if you amended the bill in such a way that essentially the SNOD was also doing the AIP role—that investigating role, which is different from what the SNODs do—you would need more SNODs than we currently have. There would be costs attached to that and we need to understand what those costs are. That is not a reason for not doing it, but the current SNOD cohort, which tries to attend all the donations across Scotland, is already stretched because of the increase in the numbers of donors that we have had.

Rhoda Grant: Of course there will be costs, but there will also be cost savings if you give people a new lease of life by giving them a transplant. They will no longer be so dependent on the health services. Surely that is a saving, even if you have to employ more people. Even without the bill, if you are looking at increasing the donor rate, you will have to employ more people and the amount of money that you are talking about is not huge when you think about the lives that you can save.

Maureen Watt: I do not think that there is a direct read-across from the amount that would be saved to the amount that we would have to spend. However, I do not think that cost is the issue here. The issue is the complexity of adding in the AIPs and the proxies, who are not in the system at the moment. As we have already heard, the current system takes a number of hours, while Professor Forsythe might be waiting for the organs. If there is then increased legality in the system that is not there at the moment, we might get families at the end of the process saying, “This is just too much stress in an already stressful situation and we are not going to allow it to happen,” and at the end of the day, the families already have the final say.

Professor Forsythe: It would mean that the retrieval team would have to wait for a length of time but, as the minister said, the most important point to consider is that the families would have to wait longer, after an awful time looking after loved ones in an ITU. We have evidence that if we get anything wrong in the process even once, there is the potential for damaging the whole organ donation programme. That is my worry.

10:45

Malcolm Chisholm (Edinburgh Northern and Leith) (Lab): I pay tribute to Professor Forsythe and everybody else who is doing such great work in the field. He spoke about the evidence on opting out being the key criterion, whereas when we are looking at the bill, we have to establish whether it would help along with other changes. We also have to consider harm, which we can do in a minute.

A lot of the issues have been gone over already. We were struck by NHSBT’s estimates. We have been told about the Welsh Government’s review of the international evidence, which concluded that an association exists between presumed consent legislation and increased organ donation. The organ donation task force found that an opt-out system could increase UK donor numbers. Obviously, it could be done wrongly, but I presume that the Scottish Government would ensure that it was not done wrongly. There seems to be evidence from other countries that an opt-out system that is done correctly in conjunction with other actions improves donor rates. That evidence is coming across quite strongly to the committee. We hear what you say, but given that everyone wants to increase donor rates, is not that evidence quite persuasive?

Maureen Watt: As Professor Forsythe has said, and as others have said in written and oral evidence, we all want the same thing, which is to increase the number of organs that are available for donation. We have tried to show that we are currently doing many of the things that have been done in the Spanish system. Dr Matesanz has said that a law change in itself is not enough and that we need infrastructure. We have talked a great deal about the infrastructure. We have a lot in place, but we can put a lot more in place.

The Government is not against an opt-out system per se but, given the complications that the bill would introduce, the measures in it are not the ones that the Government would put in place if it had introduced its own bill to make the system better and increase the number of available organs.

Malcolm Chisholm: I want to be absolutely clear about what you are saying. Many of your objections home in on the bill, which is, you say, fundamentally different from the Welsh legislation. Does that mean that you would support a bill that was similar to the Welsh legislation, if somebody were to produce such a bill?

Maureen Watt: Gareth Brown has looked at both.

Gareth Brown: We have not yet considered how we would introduce an opt-out system if we wanted to do that in Scotland. I do not think that we could just copy and paste the Welsh legislation, because the underpinning legislation is different. However, the Welsh legislation has not introduced the additional complexity that the bill would introduce.

We have talked about the proxies and AIPs: it is not clear what problem the proxies provision is trying to solve, and the AIP provisions seem to overcomplicate and overlegalise a process that is just about a person’s known wishes. Although we cannot say exactly what our provisions would be, I imagine that if the minister asked us to produce a bill for consultation we would try to make the process as simple as possible.

This is slightly off topic, but it is important to say that there are many things that we could do besides opt-out on which we would want to consult as well. I do not think that opt-out is the be-all and end-all: there are other legal differences that we could make and other suggestions that experts have made. For example, we could look at paying funeral expenses for families of people who become donors. There are complex views on that, but we could test the public’s opinion on it. Other parts of the world take other approaches. There is the concept of reciprocity, under which someone who wants to be prioritised for a transplant should be on the organ donor register. There are strong views on all sides on all those issues. Opt-out is not the only thing that we could consider to increase donation and transplant numbers.

Malcolm Chisholm: We all accept that.

We would definitely want to look at AIPs in detail at stage 2, but the bill does not stand or fall by the provisions on AIPs. We have got the message about that. However, I am genuinely puzzled, having heard the evidence on proxies: I was surprised to discover that we are the only country in the UK that does not have proxies. They would not be used very often in Scotland, but it is not really relevant how often they would be used. Proxies cannot be a fundamental flaw in the bill if such provision already exists in every other country in the UK.

Maureen Watt: If people could have up to three proxies, all three proxies would, I presume, have to be contacted and consulted before consent could be gained for the organs to be donated. That would add another complication.

Malcolm Chisholm: I think that somebody might want to amend the bill to make it two proxies, so that the system here would be consistent with those in the rest of the UK. However, I cannot quite see why the provision is an obstacle if it is not an obstacle elsewhere. The proposal is to have the same system as in the rest of the UK. The fact that it would not be used very often in Scotland is not really the point.

Maureen Watt: Why have proxies, in that case?

Malcolm Chisholm: Why have proxies in England and Wales and Northern Ireland? That is not a logical argument. Anyway, I will move on.

The Government response says that the bill

> “does not adequately address the needs of those who may wish to opt out, but who do not do so, for whatever reason”,

and that

> “This may result in distress to families”.

However, families would still be consulted, except for, I presume, the very small number, if there would be any, who would use a proxy, as in the rest of the UK. Under a soft opt-out system, the families would still be consulted, so I am not sure why that would result in distress. Is not the key point that it would change the nature of the discussion? Professor Forsythe will realise that I have changed my mind on the issue. I am just thinking about what would happen if somebody was to ask me. Having that system would change the nature of the conversation and it might well change a person’s decision. That is really the essence of the bill. I feel, having thought about it, and apart from the international evidence, that in the concrete situation of a discussion, people would be more likely to consent if there was an opt-out system. The family would still have the final say, so why would that lead to distress for the family?

Gareth Brown: It is absolutely important to change the nature of the discussions, but we do not need legislation to do that. We have tried to do it already; for example, we have tried to ensure that specialist nurses are always there when a family is approached. Those nurses would approach a family in a different way from an intensive care consultant who perhaps deals with a potential donor only every now and then. If all that the bill did was try to change the nature of the discussions, that would be fine, but—as we have said—our worry is about the other provisions. The nature of the discussions might change, but they would happen later than they do at the moment. Perhaps the family would have to wait longer so that an authorised investigating person could make a decision, and would feel that they were no longer the people making the final decision.

It is important to ask: what is the point of the AIP, if the family will still be consulted and if, ultimately, donation will not go ahead if the family does not support it? At the moment, families can overrule donations, as Anne McTaggart acknowledges in her paperwork. In reality, it is too risky for donation to go ahead if the family does not support it.

Malcolm Chisholm: I will keep an open mind on AIPs, but let us assume that we have taken the AIPs out of the bill, since that provision seems to be the main point of objection. I am not conceding that AIPs will do harm, but let us assume that they might. Your final argument seems to be that the bill could do harm; obviously, we do not want to pass legislation that could do harm. Apart from the AIPs, what harm can the bill do?

Professor Forsythe: Mr Chisholm has described a very clean situation, and his approach to and thinking about such circumstances. Of course, in real life, it does not always happen in the way that he described. There may be different views within a family in the setting of a tragic situation that is already fraught and emotional. I have spoken to people who were involved in the organ retention scandal who said that all they wanted in the circumstances was for nobody to presume their consent. If at any stage we presume consent and get it wrong, that could affect not just that one case but the whole of organ donation.

Mr Chisholm is right that the international evidence on opt-out legislation shows an association between that legislation and slightly higher donor numbers. If you could promise me that there would be a potential improvement but no risk, I would be all for that. However, in the current circumstances, there is potential risk. To move on from the philosophy of opting out to the bill in particular, there are bits of the bill that concern me, because risk is dialled up slightly, which causes me more concern.

Maureen Watt: If we took out the AIPs and proxies, we would be left with a shell of a bill that would not contain what you want it to achieve.

Malcolm Chisholm: I am not sure why anybody would want to take out proxies, because they are already provided for in the legislation in the other UK countries.

Maureen Watt: Maybe you could answer that question. Were you the health minister when the Human Tissue (Scotland) Act 2006 was going through Parliament?

Malcolm Chisholm: I was not, actually.

I have put my cards on the table: I have changed my mind. Why have you changed your mind? You signed a motion supporting opt-out at the beginning of this parliamentary session and believed that it would lead to an increase in donors.

Maureen Watt: I said in my opening statement that I am not against opt-out per se, nor is the Government or its officials, but we do not believe that the bill will do what it says on the tin. Having come into my ministerial post and having seen the progress that has been made under the current system by increasing the number of people who are on the register, and increasing the number of transplants by providing better infrastructure, and having read and considered the bill along with officials and others who have given evidence, I do not believe that the bill will make the substantial difference that we all seek. The trajectory of what we are doing at the moment is towards the levels that we see in opt-out systems.

The Convener: I call Mike MacKenzie.

Mike MacKenzie (Highlands and Islands) (SNP): I am fine, convener. The area that I wished to explore has been comprehensively covered.

Bob Doris (Glasgow) (SNP): I have to say that I am becoming increasingly perplexed, the more we scrutinise the bill. Earlier it was said that the Government is looking for a good excuse not to support it. I put it on the record that I remain completely undecided about what I will do in relation to the bill. The simple test is whether it will enable us to increase the number of organ donations and save lives. If so, and if there are no ethical concerns—I do not have any—we should implement it. However, we have heard many genuine concerns about unintended consequences and it is reasonable to scrutinise those.

On the time delay, we have heard about the role of proxies and authorised investigating persons. It is reasonable to interrogate that a bit more. On the dynamic between the SNOD and the authorised investigating person, I have the most basic question: will someone tell me what SNOD stands for? It seems ridiculous that we are calling it a SNOD.

Professor Forsythe: SNOD stands for specialist nurse for organ donation. I tend to call them specialist nurses because I like that term slightly better.

Bob Doris: Okay. Let us just talk about specialist nurses. They are at the coal face and have to do the job currently—perhaps even as we speak, in fact. The authorised investigating person would be placed within a legal framework and would have to ensure that the law had been followed. Could an unintended consequence be that AIPs become risk averse? If there are grey areas about whether the law has been followed, might AIPs back off rather than give the go-ahead for the organ to be made available? I do not know whether I agree that they might, but we have to scrutinise the bill robustly.

Maureen Watt: If we were to introduce lawfulness and the authorised investigating person, we would undermine the work of the specialist nurses, whose approach is very much about being with the family and talking about the person who is in a critical situation in order to find out what kind of life they have led and whether their organs would be suitable for donation. To introduce a legal aspect that gets everybody’s hackles up could lead to conflict. I will leave it to Gareth Brown to comment on whether it would also lead to risk aversion.

Gareth Brown: John Forsythe might also have a view. My worry is the unintended consequences. The authorised investigating person, who may be seen as a vehicle of the state, would be there to find out whether a loved one's organs can be taken. That would, perhaps, involve the view of a proxy whom family members do not know. The family might be unhappy with that and the situation could turn into the family saying, "The state took my loved one's organs." That would need to happen only once. It might never happen, but I think that that is what John Forsythe means by potential risk.

11:00

Further, as I have said previously, the authorised investigating person would be personally legally accountable for decisions. The terminology in the bill talks about "his or her" decisions and judgments, which means that, conceivably, the AIP might have to justify decisions in court if one thing went wrong or went badly. There is no requirement in the bill for all authorised investigating persons to make the same judgments on things or to allow the same amount of time for proxies, so consistency would be lost and we might end up with the risk-averse culture that has been described. That might not actively cause harm, but it will not bring any particular benefits.

Professor Forsythe: I had not thought of the matter in the way that Bob Doris described; I had thought of it in the way that Gareth Brown has described, in terms of the potential perception that the state or some organisation has forced through organ donation in a way that is not fully in accordance with the wishes of the family.

I can see exactly what Bob Doris was saying about involving other people. From talking to Sally Johnson of NHSBT, it seems that specialist nurses could not take on the role, so you would have to involve another stratum of people. There might be idiosyncratic situations in hospitals, so we could end up with people being risk averse, as Bob Doris suggested.

Maureen Watt: We should never forget the psychological difference between giving and taking, which is powerful, when you think about it.

Bob Doris: There has been a suggestion that the bill could at stage 2—as far as I understand it—be amended so that almost everything is taken out, leaving only presumed consent, even though the structures that would lie behind that are fairly unclear. I do not know whether we should do that—I am still mulling the matter over—but it seems that we could be left with legislation to promote conversations at the point at which families are struggling with difficult decisions. I am concerned about the quality of that conversation between the specialist nurse or whoever and the family. The conversation could be had at an early stage, if the death were anticipated. Sudden death is, obviously, a different issue.

I apologise if I am dwelling on this too much, but I am concerned about that conversation. It might involve someone saying to a person's loved one that they know that their mum, dad, son or daughter is going to slip away, and that they do not carry a donor card, and asking whether the person ever considered donating their organs, which would go to a good cause. Alternatively, it might involve someone slipping into saying, "Well, they haven't opted out, and their organs will still go to a good cause." I am not sure, grammatically, what the underpinning legislation does to the sensitivity of that conversation. The issue is the quality of the conversation. Perhaps the conversation would be strengthened by that legislative underpinning, but I keep going over the issue in my head and coming back to the issue of the quality of that conversation and having in place all the structures to get organs timeously and effectively to the families who need them. How can we improve the quality and consistency of that conversation, irrespective of whether the bill goes through?

Professor Forsythe: As I said earlier, after putting in place infrastructural nuts-and-bolts changes, that conversation is one of the most important things—as Bob Doris suggests. As I understand it, the present law in Scotland is about carrying out the wishes of the individual and is, therefore, written in terms of authorisation rather than consent. As I also said earlier, we have come a long way in terms of how we go about that.

However, our level of consent is not at the level in Spain. That is about how the approach is made. It has been well shown that when people have had good training in going for authorisation or consent, the levels of consent, or success, are much higher. We need to do more in that area and we need to do it now.

Maureen Watt: If we were to strip out the bits that you say are barriers, what would be left would not achieve the outcomes that we all want from the legislation. We would be left with a shell that would not achieve the objectives.

Bob Doris: I suppose that I will have to consider that.

In order for an opt-out system to be meaningful, if someone has an ethical reason to opt out, they should be able to do so. Personally, I do not have an ethical reason to do so and I do not think that most people would have, either—indeed, surveys have shown that to be the case. However, if there was a legal right to opt out, would the state—the NHS—have to have an annual advertising campaign to remind people that they had that right? Would that change the dynamic again? I would not encourage anyone to opt out, but would we have a duty to advertise that right and make sure that people had that information?

Gareth Brown: Absolutely. The bill recognises the need to raise awareness. There is a question about how far in advance of a bill's coming into force we need to raise awareness—we know how difficult it is to get people to opt in to public messages.

There would need to be continuing marketing and awareness raising, if only because there would be an age limit, whether that was 12, 16 or 18—people would be turning the age at which they would be deemed to have given consent if they did not opt out. People coming to the country for the first time, such as students and people travelling from other parts of the UK, would be new to the system and may not have had the opportunity to take in the message, so we would need to continue to try to reach them. In particular, children coming of age under whatever the system was would need to be contacted annually or when they came of age to let them know that if they did not opt out, it would be assumed that they wanted to donate.

Bob Doris: My final question relates to the finances underpinning the bill. If introducing this policy is the right thing to do, we should do it irrespective of the finances underpinning it, but it is reasonable to look at some of the numbers behind it. The cost figure in the financial memorandum has been revised to £6.8 million over 10 years, but the Scottish Government's modelling work shows that the cost could be as much as £22 million over 10 years. There has also been discussion of annual costs of around £2 million.

Putting that to one side, the big message that we have heard from Spain is that it is about the quality of the conversation and having the structures on the ground to make things happen. If the Scottish Government had £22 million over the next 10 years—maybe we are making a bid for more money for this—to invest in local co-ordinators on the ground, networking and the whole-hospital approach, how much more could you do? Where should the focus be?

Professor Forsythe: I have never been given £22 million to spend. I think that we would try to mimic the Spanish system, with more education and publicity. It is important that we continue to drive publicity and awareness raising. We have not mentioned living donation, which has been a lifeline for many people. More could be done in that respect—there could be more training and more could be done to ensure that there is a hospital-wide approach.

To an extent, we had to put in place the British version of the Spanish system in terms of the clinical input into organ donation in each intensive care unit. We would look to use that in a different way. I suspect that that is what Rafael Matesanz was referring to when he said that legislation can be a distraction in these circumstances if we are not careful.

Maureen Watt: The £22 million is the estimated cost over 10 years, and half of that is the AIP costs—it is not mainly publicity costs. We would rather that the money went to increasing the infrastructure.

Gareth Brown: There are a range of new technologies for looking after organs that have been donated that could also benefit from investment. We sometimes lose organs that have been donated. There is lots of research and technology around improving the survivability of organs after they have been donated, but we could probably do with more.

Bob Doris: I have no further questions, convener—although I do not think that Professor Forsythe will mind me asking: if he had £22 million to spend, how would he spend it? That is now on the record, anyway.

The Convener: It is on the record, but whether it is on the table is a different matter.

To follow up on that, the witnesses might wish to say something about the targets that have been set and the on-going strategy. You have referred to publicity and other things. The target to increase the overall deceased donation rate between 2013 and 2020 has been in place since 2013, so the strategy is there, but has it recently been reviewed to ascertain how we need to improve it to ensure that we either meet or go beyond the target? What do we need to do?

That leads to another question. Do we need increased investment in this area to tackle the broader issues? Given that in the hospital hierarchy in Spain, the responsibility does not lie with nurses, should this area be doctor led? Do we need to tackle a culture where intensivists—as I think they were described last week—do not see it as their role to harvest donations? Do we need to increase the number of intensive care beds? Do we need to consider the gap in donations? The likelihood is that people who die in A and E will not be able to donate, regardless of whether they wished to do so, because they were not in an intensive care bed. What review of the Government's strategy has taken place? What recommendations are we likely to hear about?

Maureen Watt: The strategy is constantly under review. We consider the targets, and we get the figures monthly. We believe that the targets that we have set are entirely achievable, but it takes all the things that we have mentioned throughout this whole conversation for that to happen. Those are all laid out in “A Donation and Transplantation Plan for Scotland 2013-2020”, which John Forsythe has with him, and they build on the progress that we have already made. We believe that the targets are achievable, although—

The Convener: So, you are going to tell us that there is an annual review, that action points come out of that and that there is an additional investment or a disinvestment. We have learned about disinvestment in terms of publicity. Did we use the money for the strategy to fund other initiatives that people would find useful?

Gareth Brown: We have the plan that we have had since 2013, and I think it is reviewed on an on-going basis.

The Convener: We have had that answer. Has it been reviewed? Is it reviewed on an annual basis? Is there no formal structure, other than monitoring the strategy throughout that time period?

Professor Forsythe: I chair the Scottish donation and transplant group, which has transplant clinicians on it, as well as people who have received transplant organs, people who are waiting for transplant organs and donor family representatives. At every meeting, and in between meetings, we review the action taken and we review figures.

Two years ago, we were talking about a 98 per cent improvement in organ donor numbers. The numbers have stalled over the past few years, so more needs to be done. I have tried to highlight that. If we did not see a continued rise up to 26 donors per million population in 2020, I would be the first one to be shouting and looking for more changes.

The Convener: I am confident that you would—and I am sure that you have.

What recommendations have you made? You have had those meetings, and you have seen the number dip. In order to address some of the issues, what have you recommended that has been taken up and what have you recommended that has not been taken up?

Professor Forsythe: I can go over the issues again. I have highlighted the things that we are continuing to do, both in terms of the whole-hospital approach and looking further into aspects such as consent, authorisation and training. In terms of—

11:15

The Convener: May I stop you there? What does “whole-hospital approach” mean?

Professor Forsythe: It is easy for people in a hospital to be involved in their own sub-specialty and not be aware of organ donation and transplantation, so a whole-hospital approach is about looking at particular hospitals to see whether we can spread the message across the whole hospital and using the organ donation committees that are set up at health board level to ensure that people think about donation and transplantation across the whole hospital.

The Convener: What does that mean in terms of action and investment?

Professor Forsythe: For me, it is about trying to use the staff who are now embedded in each hospital. We want to use the embedded specialist nurse and the clinician in the intensive care unit and we want to do more with the emergency department clinicians who are involved to increase awareness of the problems across the whole group.

The Convener: Has the approach evened things out? Have some hospital units caught up?

Professor Forsythe: Yes. I can point to certain hospitals—

The Convener: Has there has been progress across the board?

Professor Forsythe: There are still differences across Scotland, but I can point to hospitals where there has been a significant improvement in organ donor rates over the past number of years—that is particularly the case in NHS Grampian, in Aberdeen.

Gareth Brown: Convener, I think that you are trying to get at what we are doing now. We have a seven-year plan. You are asking whether we are being passive and just sitting back. As John Forsythe said, we are not being passive. The Scottish donation and transplant group, which John Forsythe chairs independently, reviews the position meaningfully on an on-going basis.

We operate within the UK. We share organs across the UK and receive organs from other parts of the UK. I attend NHSBT board meetings, and I know that the committee heard from Sally Johnson that NHSBT also has a plan and is actively trying to make a meaningful difference.

A prime example of that is NHSBT’s recent review of the organ retrieval teams that it commissions, which operate across the UK. Given how busy the teams are, the way in which they are set up can lead to delays. Two or three teams might be out when a potential donor arrives and the teams must finish the work that they are doing before they can be redirected to a hospital in another part of the country. With NHSBT, we and other UK Governments have actively considered how we can make the system work better in the past six to 12 months.

In Scotland we have reviewed our relationship with NHSBT, how it employs SNODs on our behalf and how it undertakes retrieval to ascertain whether we could do better. We convened a group to do that under the auspices of the SDTG, which has concluded that we should have a dedicated SNOD manager in Scotland.

We are not passive. We have a seven-year plan, and we know that improvements take a long time. Even in Spain, there has not been a one-year change. As we heard, we would not expect a one-year change in Wales on the back of its legislation coming into force. Likewise, we have to give our plan time, but that does not mean that we will be passive over the course of five or six years.

The Convener: I hear what you are saying. However, I was trying to find out whether we are emulating Spain by adopting some of the core principles that have increased rates—it is perhaps not about having an opt-out or an opt-in system but about having a doctor-led system with a part-time or full-time transplant co-ordinator in every intensive care unit in Scotland. Alternatively, are we going down the road of building up specialist nurse capacity? There is a big difference between the two.

Maureen Watt: There is no doubt that we have learned from what Spain is doing and the infrastructure that it has put in place. We have clinical leads in place and we are working to our plan to increase rates. We are not doing nothing; we are working really hard on what happens under the current system, as Gareth Brown explained.

The Convener: Professor Forsythe, there is a big difference between a clinical lead and a transplant co-ordinator.

Professor Forsythe: There is, but I mentioned the large increase in Grampian, which is partly down to a clinical lead in a particular unit, who has changed the focus in relation to organ donation.

When we went to Spain, we certainly saw that the presence of the doctor and their championing of organ donation within the intensive care unit was important. Clinical leads have become key to the development. You are right to say that they will not be present all the time but, with a combination of the clinical leads and the specialist nurses, we have tried to make best use of the resource.

The Convener: Nanette Milne wants to come in. Is it on Grampian, Nanette? I am joking. I am sure that your question is not necessarily about Grampian.

Nanette Milne (North East Scotland) (Con): I seek clarification in relation to Bob Doris's point about opting out. It is my understanding that there is a right to opt out, which has recently come in under the Human Tissue (Scotland) Act 2006. Is that right? How aware is the population of that? Is it being advertised?

Gareth Brown: There is a point about the interpretation of the law. The Human Tissue (Scotland) Act 2006 does not explicitly say that an individual has the right to opt out; rather, it says that an individual can withdraw their authorisation. Ms McTaggart's view is that that is not a legal right to opt out. I would agree that that is a point of interpretation for a court to decide. However, we have a mechanism whereby individuals can, under the new NHS organ donor register, express their wish not to donate. In Scotland, if someone has expressed such a wish, the donation would not go ahead.

On whether the public know about that, we have tried this year, in light of the Welsh legislation and the new organ donor register, to make clear our message to the public that they should make their wishes known, whatever they are. If people want to donate, that is brilliant; if they do not want to donate, it is important that we know that. Indeed, it is more important to know that people do not want to donate—I think that we would all agree that the more people make their wishes known, the better. We have not necessarily couched it in language such as, "If you want to opt out", because that could be confusing and we are worried about mixed messages. Instead, we have said that people should make their wishes known, whatever they are.

Nanette Milne: That was very helpful.

The Convener: Do members have any other questions?

Bob Doris: I will be brief, convener. Some interesting points have been made, including by the minister, about the situation being dependent on how the legislation works in Wales and the length of time that it might take before that can be analysed.

The Scottish Government and the NHS are looking to develop the structures that underpin and support organ donation timeously and effectively; they are also looking at enhancing the role of the specialist nurses. In Wales, legislation underpins the good-quality conversation that I asked about. Would it be reasonable to assume that, if legislation empowered people to have a more effective conversation with the family of a person who has passed away, we would see a fairly quick increase in organ donation? Once legislation is in place and the dynamic changes—if that is what is derived from putting a legal framework in place—would we not see quite a quick turnaround in the position? Will the Scottish Government monitor the situation in Wales? I do not mean that a full review should be commissioned. Instead, one year after the legislation has been on the statute books and the dynamic around those conversations changes, will the Scottish Government look to see whether there has been significant change? If there has been, will we get a pledge for action in short order? We should not have to wait for a number of years before we introduce the policy. I apologise for repeating myself, but if we are saying that legislation underpins that good-quality conversation on the ground, surely we will find that out quickly.

Maureen Watt: If we see an increase in donation in Wales that can be put down to the law having been changed, I think that we would start the process of looking at and consulting on opt-out here.

We have seen that one year's statistics can be a blip. We would have to monitor whether the number on the organ donation register in Wales had simply shot up on its own or whether that was the result of a complete change to the infrastructure. I said at the outset that Wales is the best example. We are looking to see what happens there because, unlike Spain and other countries, it has an NHS structure and is therefore the closest example to how we structure healthcare in Scotland.

Bob Doris: Okay. Thank you.

The Convener: As Professor Forsythe said, it is all about risk. If Wales delivers, would you need to come back here in a year's time, or in two or three years' time, and apologise? Would you feel the need to apologise for the people who did not make it over those years? That is what you are asking of them.

Maureen Watt: No, because what we have been saying for the past hour and a half is that we do not believe that the bill will achieve the increase in donors and transplants that we all want.

The Convener: Maybe that is a safer strategy, minister.

Thank you for attending this morning. [*Interruption*.] Oh! I was so busy thinking about getting the member in charge of the bill, Anne McTaggart, into the seat where you are sitting, minister, that I forgot to give her the opportunity to ask some questions before we finish this evidence-taking session.

Anne McTaggart (Glasgow) (Lab): Thank you, convener, panel and committee members.

Given what I have heard this morning, I am not sure whether I should just sit and cry or ask a question. I am deeply saddened, disheartened and downright disgusted at some of the mistruths that have been peddled here this morning. It appals me that, with such mistruths, we might set hares running among some of the vulnerable and needy people in our society. I have always stated that the bill will not resolve everything and that it is part of a three-pronged approach based on evidence from the Spanish model.

I am coming to my question, convener.

The Convener: Please.

Anne McTaggart: The Scottish Government has set a target—and I will go over this again, as it is one of the mistruths that have been peddled. The Scottish Government's target is to increase overall deceased donation rates from 17.9 per million population in 2012-13 to 26 per million population by 2020. In the past three years, the rate has increased by only 0.3. We are now three years into the seven-year plan, but given that we have only gone up by 0.3 and need to get up to 26, can the minister explain whether the plan is working well enough?

Maureen Watt: As I have said, there are fluctuations between years. The issue is not just the infrastructure or the opt-out; there are various other factors that determine whether organs are actually presented for donation and transplantation. We have put the plan in place and the rate is increasing; as the graph that I am holding up for the committee shows, the number of transplants and the number of people on the transplant list are converging over time, and we have seen an increase in the number of transplants. We are not convinced that Ms McTaggart's bill will achieve the increase that she is talking about.

Anne McTaggart: What will, minister?

Maureen Watt: Well, for the past hour and a half, we have been talking about the ways in which we believe rates can be increased.

Anne McTaggart: So why have we not done any of that to date? We have had this information since 2006, and Mr Forsythe has been in this field for who knows how many years. Why are we the worst in the UK for organ donation rates? Why should we not strive to be better? Why should our system not be like the one in Spain? Mr Forsythe, you are the front man in this.

Professor Forsythe: My memories of transplantation include watching people who are dying being resuscitated by transplantation—

Anne McTaggart: They are behind you.

The Convener: Let the witness respond.

Professor Forsythe: I have also been at a retrieval at which I helped to lay out and put in a bridesmaid's dress a seven-year-old girl—an organ donor—who, about two weeks before, had been a bridesmaid. I have seen both sides of donation and transplantation. I admire your passion, and I promise you that I am just as passionate about organ donation and transplantation. I have spent the last number of years trying my best to increase the number of organ donors, and up until a couple of years ago, we had made fantastic improvements.

11:30

You are right—the last couple of years have not been as good. However, we have many things that we want to do to improve the situation. If you can reassure me and say with absolute certainty that opt-out legislation will change things, without risking anything—and we should remember that it is potentially very risky—that is great. I have to say that I have some concerns, but I promise you that my passion matches yours. In fact, I have had this passion for the 30 years or so in which I have been involved in the area—and, actually, I take it badly if somebody threatens that passion.

Anne McTaggart: Not as badly as I am feeling right here, right now, Mr Forsythe.

Given the fact—

Maureen Watt: We would not object to the bill—

Anne McTaggart: The Welsh Government put its law in place after carrying out an international review of organ donations in 2012. There is international evidence covering 50 years. Who are we to say that those people are wrong? They have specifically said that eight out of 10 of the highest-performance organ donation rates are in countries that have an opt-out. Minister, why are you letting us sit the worst in the UK?

Maureen Watt: I think that some of the evidence that you are citing comes from the 2006 Abadie and Gay study, which took a sample of 36 countries—or 54 per cent of the countries with an opt-out—and looked at detailed data from 22 of them. It concluded that organ donation rates were higher in presumed consent countries by 25 to 30 per cent. However, that was due not solely to opt-out but to other factors. As we have said, Scotland is up there with regard to donation rates; the rate is higher than in some countries with opt-out, but lower than in others with opt-out. It is not opt-out alone that makes a difference; we also need to have the infrastructure in place. What we are saying is that, after taking a lot of evidence ourselves and consulting people in the field, we think, sadly, that the bill is not going to do that. Moreover, as Professor Forsythe has pointed out, there are not only opportunities but risks attached to it.

The Convener: Final question, Ms McTaggart.

Anne McTaggart: The surveys that have been carried out by this committee, me and the British Heart Foundation—indeed, the majority of surveys—reckon that soft opt-out should be brought into play. Are we saying that the British Heart Foundation, the British Medical Association and the transplant recipients and their families, who are in the public gallery today and from whom I have taken my evidence, are wrong?

Maureen Watt: The social research study that was carried out in Wales during the passage of the Welsh bill sought to update the 2006 work, and it concluded that although there was an association in this respect,

> "it cannot be inferred ... that presumed consent *causes* increased organ donation."

Anne McTaggart: Fifty years of international evidence proves that it does work.

Maureen Watt: Convener—

Anne McTaggart: Seriously, I cannot see this not happening, and I am dumbstruck to hear that the Scottish Government thinks that organ donations can be increased if it sits back and rests on its laurels.

The Convener: Minister, you may respond, if you wish, before I close the session.

Maureen Watt: I think that we all want the same thing, but we must make sure that we do it absolutely correctly. John Forsythe, Gareth Brown and I have sat for a long time, speaking to other people, and we do not believe that the complications and complexities of the AIP and proxy provisions in the bill, which we have discussed for quite a long time this morning, will lead to the outcome that we all want.

The Convener: Thank you all for giving us your precious time this morning and for the evidence that you have provided.

I will suspend for a moment to allow our next witnesses to be seated.

11:35

Meeting suspended.

11:40

On resuming—

The Convener: We continue with evidence and I welcome Anne McTaggart MSP, the member in charge of the bill; Diane Barr, senior assistant clerk in the non-Government bills unit; and Louise Miller, solicitor in the Scottish Parliament solicitors office. I invite the member in charge to make an opening statement before we proceed to questions.

Anne McTaggart: Good morning, everyone. I thank committee members for their patience and for inviting me to give evidence on my bill. The Transplantation (Authorisation of Removal of Organs etc) (Scotland) Bill aims ultimately to increase the number of deceased organ donors in Scotland and save more lives. The committee has met organ donor families and transplant recipients in order to understand the impact on their lives of waiting for or receiving an organ donation. Any of us could find ourselves in a position where we require an organ to improve or save our lives; any of us could have a loved one in that position.

Despite improvements to the NHS infrastructure, additional resources and an annual publicity campaign by the Scottish Government, unfortunately the demand for organs still far outweighs the number of organs that are donated. There are 571 people in Scotland waiting for a transplant, although that does not include the large number of people who become too ill for a transplant and are taken off the waiting list. As a result, three people who are in need of an organ transplant die each day in the UK. That is far too many. Many more face years of ill health, often with no guarantee of there being a suitable donor. People in Scotland deserve better.

More than 50 years of evidence shows us that a soft opt-out system of organ donation works. There is no reason why Scotland could not be among the best performing countries in the world for organ donation. There is a lot of support for the soft opt-out system in Scotland. Eighty per cent of those who responded to the consultation on the bill supported the proposal. The committee's survey results showed that there was majority support for all the bill's proposals. The bill aims to convert that support into donations. The committee has heard of improvements in the organ donation rates since 2007. The Scottish Government argues that we should therefore just continue to do what we are doing. The improvements are absolutely welcome, but we started from an extremely low rate and, as we have heard this morning, the data for the past year is not so positive. There is a reduced number of deceased organ donors and transplants and an increase in family refusal rates.

The Scottish Government takes the view that doing better than it did in 2007 is good enough. With respect, convener, should that really be the extent of our ambition here in Scotland? This is not a party political issue and it never has been. It is solely about saving lives. Please, please consider the impact that this legislation could have on people's lives.

Opt-out legislation is not the only solution, but I believe that it must be part of a solution. Let us shape the bill together and make it the best bill possible—one that gives us the greatest opportunity to increase organ donations, to save lives and to give those 571 people who are awaiting organ transplants the gift of hope.

11:45

Dennis Robertson: Thank you and good morning, Anne. You have sat through many evidence sessions and have heard the evidence, as we have.

You cite the international evidence. There seems to be a dispute to some extent in that what you are citing and what the Government is suggesting are two different things. Why would that be? You say that the international evidence is clear that the opt-out system works, but the Government says that there is also evidence to suggest that it does not. Who is right?

Anne McTaggart: Thank you for your question, Mr Robertson. Fifty years of international evidence was considered for the Welsh bill. The Welsh Assembly used that evidence to make the bill into the legislation that it is today—it came into effect on 1 December.

Mr Robertson, if you do not want something to go through, you can pick holes in it for 22 pages and throw the kitchen sink at it; you can do whatever you think is best. However, I am not sure why we would not accept the international evidence. We accept it for other bills that we put through. I am not really sure why—sorry.

Dennis Robertson: Okay. First, like you and, I believe, all other members, as well as Professor Forsythe and the minister—given what we have heard from them today—everyone is saying, look, let us find a way of getting increased donors, which will result in more transplantations and higher survival rates. I think that everyone is on that same page. The difficulty seems to be with how we get there.

You are suggesting that soft opt-out will improve the situation. The Government is suggesting that it may not, and Professor Forsythe seemed to be concerned that there was a slight risk that your proposed approach might result in fewer donations. That is where his concern comes from. Given that he has many years' experience, and given his passion—he gave an example today that showed that it is not an easy process for him and his team—do you not accept that there may be some aspect of risk to the soft opt-out system?

Anne McTaggart: Absolutely not. The soft opt-out system that is in the bill would give clarification to people. We will always find that there are people in our society who will never, ever want to donate their organs, and that is absolutely fine—we live in a big world. We also have to respect other people's wishes.

If someone does not—and never will—want to donate their organs, the bill gives them an easy option. The bill clarifies things. Their family will not be approached if that is the case. It was never my intention that families should be approached in such circumstances. My intention, in introducing the bill, was to increase the availability of organs.

Dennis Robertson: I accept that 100 per cent. In questioning you, we are not suggesting that we should not increase the availability of organs. Everyone agrees that we need to increase donation rates. Our job is to consider whether the bill has any risk attached to it, and we have heard contradictory evidence.

In the current system, people can opt in to the organ donor register. Do you think that a soft opt-out system presents the best possible opportunity to increase organ donation?

Anne McTaggart: Yes, absolutely. The committee heard some evidence this morning about risk. We have looked at the international evidence and considered why some people felt that the system did not work for them.

We have to have public buy-in. We cannot sit in our ivory towers in the Scottish Parliament and make laws that affect everyone without there being consequences. We have to listen to what the people say.

I tried to explain that we have done research, looked at straw polls and taken evidence from the people out there and some of our consultants. There always will be people who are against organ donation—and that is fine—but my proposed approach will give those people a safe option.

We have to have public buy-in. We need a three-pronged approach: we have to have legislation, advertising and education. People need to be aware of what is involved and the good that they will be doing for others.

Dennis Robertson: The gift of an organ in the hope that it will save a life is something that I think that we all admire.

Could a two-pronged approach work, with education and awareness raising, but without legislation?

Anne McTaggart: I have been hoping and praying that that would work, but it has not worked to date, so I am not sure why it would work from now on. There was a drop in the figures last year and as we look into next year there is a further drop, so I am not sure that the system is working. If it was working, I would be more than delighted. I would rather not be sitting here at the committee—no offence, convener—but unfortunately I am here and we have to regard the bill as a serious option—the only option—for moving forward, along with education and advertising.

Mike MacKenzie: I commend Anne McTaggart for introducing the bill. Whether or not the bill receives parliamentary support, it has brought a much-needed focus on the area and led to a valuable discussion.

The soft opt-out is the essence of the bill. The committee has heard that some aspects of the bill are problematic and give rise to concern. To what extent are you prepared to accept amendments to the problematic aspects of the bill? The minister said that such amendment would leave a “shell” of a bill, but it seems to me that provisions can be inserted as well as removed by amendment. To what extent can the Parliament turn what is a caterpillar of a bill at one end of the process into a butterfly at the other end of the process? What are the technical and legal limitations on us in that regard? Louise Miller might comment on that.

Anne McTaggart: I will comment before I bring in Louise Miller. Mr MacKenzie, I have said from the outset that this is not my bill but our bill. I want people to know that if amendments need to be made we should make them. Let us make this the best bill possible, for the people who require it—the people who are not in the privileged position of being able to vote on proposed legislation, as we are.

The bill is not written on tablets of stone. I am not saying, “Well, I’ll refuse everything if I don’t get my own way.” I have been hoping and praying that the Government would come along and say, “That is fine; that is wonderful”, because I do not want the debate about the issue to be party political. We should be voting with our consciences and people should be looking at the hard evidence, as the committee has done.

Sorry, this is a long answer, so I will cut it short. I am up for amendment. It is our bill, not my bill. Louise Miller can give you the technical jargon.

Louise Miller (Scottish Parliament): I hope that I will not give you too much jargon. I can give a technical answer: as long as amendments meet the criteria for admissibility and are within scope—they are not wrecking amendments, for example—there is no reason in principle why the bill cannot be amended as extensively as the Parliament wants to amend it.

I do not think that we can get away from the fact that even if the authorised investigating person role is removed, judgment will still need to be exercised. The Human Transplantation (Wales) Act 2013 provides for the exercise of judgment; it is just less specific about who makes the judgments. I guess that there is a policy call about whether introducing a role for an authorised investigating person is the right way to go. However, in principle all amendments are possible.

Mike MacKenzie: Thank you.

Nanette Milne: On a point of clarification, Anne McTaggart has said several times that the international evidence goes back 50 years. I am sorry to say that this year it is 50 years since I qualified in medicine. When I qualified, I was not aware of transplantation anywhere in the world, so I am intrigued by what you said. Can you direct me to the historical evidence?

Anne McTaggart: Some of the countries from which we have taken evidence are Spain, Croatia, Malta, Belgium, Portugal, France, Austria, Estonia and Slovenia. We have taken evidence from all those countries, which have figures that are well ahead of our figures. We looked at eight of the 10 best-performing countries—obviously we also looked at countries that have not done so well, because we have to learn from mistakes. Those are some of the countries that have been researched.

Nanette Milne: When did transplantation start in some of those countries, historically? I am asking purely for information, because I do not recall transplantation happening much before the 1980s.

Anne McTaggart: I wish I was such an anorak that I had a mental picture of the position in each country. I just know that we looked at evidence that spanned more than 50 years. In some countries transplantation might have started only five or 10 years ago. I am sorry—I can get more detail to you about when transplantation started in those countries and when they implemented the soft opt-out system, if that is required.

Nanette Milne: It is not that important. I just found it interesting.

Anne McTaggart: If it is important, we can get the information to you.

Rhoda Grant: When you were drafting the bill, did you envisage different roles for the specialist nurse for organ donation and the AIP, or did you envisage the same person carrying out their role slightly differently, because the bill would change the conversations that people have?

Anne McTaggart: When we were putting the bill together, we looked at the Welsh bill, of course, and the Northern Irish legislation. We are not talking about two different people. The AIP is not a different person.

12:00

We have looked at the roles of—we do not like calling them SNODs—specialist nurses and clinical leads for organ donation, and there is not much of a difference. I am not sure why we in Scotland would have someone to do a different role from the role that the UK is introducing. Ireland would have the same person and Wales has the specialist nurse. I am unsure why we would invent another layer of staff.

In the bill we have set aside £0.5 million for enhancing the current role. That would be done through post-qualification experience and education. That is what is being done with the 2013 act in Wales, which came into force on 1 December. I am not sure why we would be different.

Rhoda Grant: Would you be happy with stage 2 amendments to clarify that role and ensure that an additional layer of bureaucracy was not put in the system? There was a concern that such an additional layer would slow up the process. The longer the process takes, the more chance that a family will decide against donating, because of the situation that they find themselves in.

Anne McTaggart: We work under the British transplantation system. I am not sure why Scotland would be any different or why we would put in an extra role or tier of staff. The role of the AIP is the same as what Wales has and what Northern Ireland is proposing in its bill. I am not sure that we would want anything different, but further clarity would be welcome. I could give you further clarity on some of the research, as well.

Bob Doris: It may be worth pointing out that if someone does not agree with you, it is not necessarily for party political reasons. I do not know how I will vote on the bill—I really do not, Anne. I am not picking holes in the bill. I have a responsibility to my constituents to scrutinise the proposals robustly and it is reasonable to say that. I will do that scrutiny now.

You said that you are open to amendments on the AIP. I understand that specialist nurses are not particularly keen for that role to exist, as it could create an additional layer of bureaucracy. Do you have concerns over that role?

Anne McTaggart: Absolutely not. I will put the question back to you. Why would it be different from anywhere else in the UK? Why would we have a different structure?

Bob Doris: I do not know how I will vote on the bill, but I have asked the question. The reason that I asked the question is that you said that you are open to amendments.

Anne McTaggart: Of course.

Bob Doris: One of the most significant aspects of the bill that has been debated is the AIP. You said that you do not believe that there is anything wrong with the structure that you are proposing. That leads me to think that you are willing to amend the bill into a bill that you do not think is particularly good. It is unclear why you would seek amendments if you did not agree with them.

I will ask the question another way. Is there anything in the bill that could be improved on? Are there any weaknesses in it?

Anne McTaggart: I have brought the bill to the table to ask for people's views and opinions. I want people to share their ideas so that we can make the bill the best that it can be, to increase organ donation.

Some of the Government's 22-page response contradicts itself, but am I looking for amendments? Yes. I am totally open to reasonable amendments.

Bob Doris: Okay. I am genuinely conflicted because you believe that the role of the authorised investigating person is absolutely fine as it is and that it should not be changed, but you would be open to an amendment to change it. What about the role of the proxy? Do you think that you have the balance right on that? Would you consider an amendment on that?

Anne McTaggart: We have looked at that and asked in the bill that there be three proxies. We are looking to amend that, possibly to two proxies. That would be in line with the UK system as it currently stands.

Bob Doris: Okay. My understanding is that, under the Human Tissue (Scotland) Act 2006, anyone over the age of 12 can expressly opt in or opt out of the system. I think that 16 is the threshold in the bill. Will you seek to change that, or are you content with it?

Anne McTaggart: We did some work on that with the Scottish Youth Parliament and looked at some of the research behind that. The Scottish Youth Parliament was hugely involved in putting the bill together. The age just now is 12. The Welsh Government is looking at the age of 18, but we have looked at setting the age at 16, as that is the age at which people acquire many other legal rights in Scotland. That is why we said 16. We have not had many objections that say that the age should be anything else.

I am sorry; have I answered the question?

Bob Doris: I am trying to paint a picture. Each part of the bill presents an opportunity, but also potentially exposes the current system, which is improving—not in the past couple of years; I really get that—to risk as well as to opportunity. Proxies have been identified as a risk and it has been pointed out that there is an aspect of risk in the authorised investigating person. Changing the age at which someone can deem that their view can be expressed could be said to be a risk in respect of rights. I am trying to paint a picture that shows that, as we go through it, the bill dissipates a little bit. I am keen to understand where you see that it would be important to have amendments, or whether you would be conceding what you think are the principles of the bill if there were to be amendments.

I am still not really sure where you think that any weaknesses are in the bill. Witnesses who want to increase the numbers of organs that are made available to save lives and improve the quality of lives saw that there are perhaps some weaknesses in the bill—I do not think that that was the Government. I am trying to tease out where you think the weaknesses might sit.

Anne McTaggart: We put the bill together and we have taken evidence from, I say this again, the British Heart Foundation, the British Medical Association, organ recipients and their families, other organisations that work at the front line and the Scottish Youth Parliament.

I said earlier that we looked at evidence that has been taken. Some 67 per cent agreed that the age should be set at 16.

On the point about proxies, the Scottish Youth Parliament raised the concern that some young people—often looked-after and accommodated young people—do not have next of kin or even family members whom they know would have agreed with their decision. That is where the proxies come in. That is in line with the UK system.

In the Parliament, we are looking at people voting at 16. We put the age of 16 down as a marker because I always see that the Scottish Parliament is streets ahead, that we are the front runners, and that we are up for making a difference in this world. Therefore, why would I not be ambitious and why would I think that 16-year-olds would not be allowed to make that decision?

Bob Doris: I think that the right currently sits at the age of 12.

Anne McTaggart: With parental consent.

Bob Doris: Yes. I think that that is the point that has been made.

Once we strip all that away, my personal view—nobody else's—is that this is about the structures that need to be in place but also about a good-quality conversation involving the appropriate healthcare professional and the family. Will providing a legal framework for that make the person who has that conversation more empathetic or more sensitive? I just think that there is a disconnect between putting in a legal framework and the holding of good-quality conversations on the ground. Is that a reasonable suggestion?

Anne McTaggart: It most certainly is a reasonable suggestion, and it is one that I have thought about greatly, but we need to ask whether what we are doing at the moment is raising donation rates and awareness sufficiently. No, it is not. We are not saving enough lives. Therefore, we need to try something different, to think out of the box and to promote organ donation as best we can.

Over the past two years, people in Wales have been asked whether their awareness of organ donation has been raised and 80 per cent of them have said that it has been. That is what we aim to do. I know from trekking round the whole of Scotland that no one ever wants to have the conversation around their kitchen table about what they want to be done with their organs or what should happen after their death. That is a fact. It is simply not part of Scottish culture to talk about such things. We would rather shy away from that conversation.

Some of the data that I have looked at is heartbreaking. I think that the British Heart Foundation has done some work on family refusal rates. It found that when families get to that stage—heaven forbid that that should happen—they do not know what their loved ones wanted to happen and, just in case they make the wrong decision, they sway in favour of not allowing organ donation to take place rather than allowing it to take place. Studies have been done on that, and that is where I have taken my strength from.

I cannot think of anything more distressing than being in that situation and having to make a decision in circumstances in which you do not know what your loved one wanted. Dealing with that situation will never be easy, but I think that my bill would make it easier. It would allow families to have that conversation. Having that conversation is not comfortable, but it means that people in your family would know if you wanted your organs to be donated or, alternatively, if you definitely did not.

Bob Doris: Sometimes politicians are allowed not to know. I genuinely do not know whether the bill would change that dynamic.

I apologise for returning to the structures of the bill. It would appear—I am guessing—that if the bill were to progress, it is likely to be significantly amended. It could change quite dramatically. It might be filleted, which would mean that there was very little of it left—that brings us back to the conversation that I keep harking back to—or it might be dramatically amended, to the extent that its provisions, as presented to the Parliament, would not have been consulted on. If the bill were to be dramatically changed, would it have to be consulted on further?

Anne McTaggart: As I said earlier, I would rather not be in this position. If I thought for one second that the current system was working, I would not be in this position—I have loads of other things that I could be doing—but the system is not working, which is why I introduced my bill.

If you are asking whether there is a different way of doing this, whether by filleting the bill, adding something in or taking something away, my answer would be that if anyone is able to come up with an idea that will increase organ donation rates, bring it on. I am up for that.

Bob Doris: I think that we would all say, “Bring it on,” if we could be assured that what is proposed would save lives by dramatically increasing—or even marginally increasing—the number of organs that are available for transplant, but we must test the evidence.

One thing is for sure, though. Irrespective of how the bill progresses, the service that you have done for the community and families who are waiting for organs is huge. That simple act of putting the matter in front of everyone and raising awareness will, in itself, make more organs available. I commend you for that, Anne.

12:15

Anne McTaggart: Thank you.

The Convener: Does the committee have any other questions? I have a couple to be addressed, just to balance the evidence.

The general question is, given that there has been a lot of focus on Wales, why did we not just bring forward the same bill as they have in Wales?

Anne McTaggart: I wish it was that easy, convener. Can Louise Miller give some technical answers on that?

The Convener: That is what I was looking for.

Anne McTaggart: Thank you. Just in case you thought I was swaying you.

The Convener: What are the differences between what we propose and what Wales has implemented?

Louise Miller: Basically, the answer is that the legal background is different. What we have in Scotland at the moment is the Human Tissue (Scotland) Act 2006. That covers the post mortem removal of organs for transplantation and also for any other purpose—research, clinical audit and all those other things. It is a large and reasonably complex piece of legislation, and it is completely different from the existing legal framework in England and Wales prior to the Welsh bill.

The way that the Scottish bill has proceeded is to amend the 2006 act in relation only to transplantation, and to deceased, adult donors. It is a series of limited amendments to the legislative framework that we already have. Because that legislative framework is different on either side of the border, we could not just copy out the Welsh bill. It would have been great if it was that easy; it would have been much quicker to do, but it was not feasible.

The Convener: Does Colin Keir have a question on that?

Colin Keir (Edinburgh Western) (SNP): It is similar, but it is aimed more at the legal side of the argument. I congratulate Anne McTaggart on bringing the matter of organ donation forward. I do not think that anybody disagrees that there should be more organ donation.

Something was brought up in what was a private meeting, so I cannot say who it was, which related to the idea of organ donation being a gift, as has been said so far—it is something that people have agreed to do. I was asked to find out whether we know of any other thing for which there is a presumption that the state will effectively take control of it—in this case, of an organ—to take whatever it is forward. The bill is a presumption in favour; is there anything else out there that presumes the same?

Louise Miller: It is not really a presumption in favour. I know that that probably is the way that the public will see it. However, it is more of an alternative route for removal of organs, which is authorisation by operation of law and a specific set of criteria that have to be met before there can be authorisation by that route.

There is a very limited presumption in the bill, which is a presumption that there was a reasonable opportunity to object, if a residence criterion over a certain period is met. That presumption can be rebutted by evidence that shows that the person did not actually have a reasonable opportunity to object.

What the bill actually provides is an alternative route for authorisation, which can be taken only if the qualifying criteria have been met. It does not remove the other routes to organ donation—those will still exist. It will still be possible for a person to opt themselves in, under section 6 of the 2006 act. Somebody who positively wants to give that gift and gets round to doing something about it, can expressly opt themselves in—that will still be possible. It will also still be possible for the nearest relative to authorise removal under section 7; that is not being taken out of the 2006 act. The bill is just providing a third, parallel route to organ removal, which can be used only if certain criteria are met.

The Convener: You have dealt with much of the issue surrounding the proxy, but we have heard in evidence that there is concern, rightly or wrongly, that the proxy could be used to override the wishes of the family, which would in turn have a negative impact on the level of donations. Can you respond to some of that evidence?

Anne McTaggart: We have heard some of that being peddled. Under the bill, the proxy decision to authorise the removal of organs for transplantation or to refuse that authorisation is decisive. That is to say, it cannot be overridden by another relative or by NHS staff. In practice, however, the current NHS policy is not to remove organs, even where there has been authorisation, if it would cause significant distress to relatives. I do not think that we would want to put our clinicians, or our society, into any sort of disarray. The family’s wishes will be granted, but I want to put on record that that is the current law but that we do not put it into practice at the moment. I would not foresee any clinician overriding the wishes of the family if they were distressed. There will be clear instructions—as there are now—and clear lists that they would have to check on the way.

The Convener: The concern is that the bill, if enacted, would change that type of approach. That is the concern that has been raised in some of the evidence that we have received.

Anne McTaggart: We have also heard concerns from people who most definitely want to donate their organs but who know that their family members would go against that if they passed away before them. We have heard that evidence as well, and those people also have the right to have their wishes granted. The bill would mean that they could specifically place that decision with a proxy, although clinicians will not go ahead with a donation if there is a family that is distressed by that. Clinicians do not do that at the moment and that would not change. We would not jeopardise the whole scheme to distress and upset families. If it was going to be so distressing, the clinicians would not proceed—as they do not just now.

The Convener: I understand that. However, the question is, then, if that would not happen why should it be put into law that that circumstance would apply and that a proxy—

Anne McTaggart: That is a different conversation, convener. I think that it may have been Mr Doris—I am sorry if I am wrong about that—who mentioned the need to empower specialist nurses and the clinical leads on organ donation, and to enable them to have the power behind them. The conversation would start with the question, “Are you aware that your loved one had any objection, because they were on the register?” That conversation would be different now; it would be a different approach. There is now 46 or 47 per cent family refusal, and the British Heart Foundation has looked at that evidence and has found out that that is simply because we are not aware of what our loved ones would want to happen.

We have to try to eradicate that. Obviously, if someone had opted out, the family would not be approached, because that would be hard and fast. However, in other cases, there would be a different conversation that would empower the staff to move forward. As the member is probably aware, the evidence from Spain, where there is an opt-out system, and some of the other international evidence shows that such a system is not the silver bullet or the be-all and end-all and that other things have to be put in place to increase organ donations.

Bob Doris: The bit that I am still trying to get my head round is whether there could be unintended consequences. People can exercise an opt-out only if they are aware that they have that right, so there would have to be promotion of that. Please correct me if I have got this wrong but, if people opted out, that would be hard and fast and therefore, in theory, there could be fewer organs available—I am not saying that there would be, but that proposition has been put to us. The other side is that you believe that, because the quality of the conversation between specialist nurses and families will be enhanced by having the legal framework, that will increase the number of organs, which would outweigh the risk.

Do you see any risk at all from the bill? For example, if there is an awareness-raising initiative to tell people that there is new legislation and that they can opt out if they want, and that has to be refreshed from time to time, some people might decide to opt out. That would then become hard and fast, should tragedy happen and the person no longer be with us. That is a potential risk, but you think that it will be offset by the dramatically improved quality of the conversations, although I have an issue with whether the bill would dramatically improve the quality of those conversations. Do you accept that there would still be a risk?

Anne McTaggart: There will always be risk with such issues. There are risks now, and there will always be risks. You are exactly right that the issue is how we try to mitigate some of the risks. I know that it is far too soon to say this, but the Welsh Government has now initiated its opt-out system after a two-year run-in publicity campaign, and the amount of people who have opted out and who have made it clear that they do not want to be part of the organ donation register is in single figures. As I mentioned earlier, we live in a big country and there will always be people who definitely will not change their minds on the issue, no matter what we do. There will always be a set of people who will opt out. That will just give them added security that their family members will not be consulted.

Bob Doris: That is helpful—thank you.

Dennis Robertson: We are looking at the soft opt-out option, which I have been a supporter of for many years. That involves presumed consent but, if we are harvesting organs—that is the term that is generally used—we will still have the conversation with the family. I would hope not, but is there not a risk that someone could overturn that presumed consent, just through that conversation? We know that it is a very distressing time for families. It is possible that, in that conversation, the family could say no. They could say that, although the person had not opted out, they had changed their mind. I know that we can introduce proxies, but surely at some point if the family is so distressed, that conversation might not happen, as I think that you have suggested.

12:30

Anne McTaggart: Absolutely, Mr Robertson. You are right that there will always be risk and it is about how we manage that risk and set the bill up to enable an increase in organ donations.

I mentioned the 46.1 per cent family refusal rate earlier, and that figure has increased by 7 per cent this year. I and others believe that that rate comes down to family members being unaware of the person’s views.

I hear what you say, Mr Robertson. I do not think that the risk would outweigh the benefit but that is exactly what happens just now and we do not want to frighten other people into signing up. We would increase our awareness, education and advertising, and the discussions that people have around their kitchen tables, which are far more important than anything that I have said. We would increase awareness of people’s wishes and families would know.

We have to bring the conversation to our families, first and foremost. The only way to do that is to introduce this legislation. I hear what is being said about risk and there is always a risk. People who are paid loads more than I am, and who have been in the business for longer than I have, make those decisions and the bill would give them security and strength—it would empower them to carry on making those decisions.

The Convener: I have two final areas to cover. You have suggested six months’ residency, but we have heard evidence that a year would be better given the complexities that can arise. Why did you decide on six months?

Anne McTaggart: The six months should provide people with enough time to become aware of the soft opt-out legislation and take action to opt out, if that is their wish. Six months is considered to be long enough to give a reasonable opportunity in most circumstances.

We heard evidence from Mr MacKenzie. We all have the responsibility to know the laws of the countries in which we work, visit or are resident. We have been working on the period of six months. If people do not think that that is enough time, I am willing to have that conversation.

The Convener: Whether the period was a year or six months would not be fundamental to the success of the bill, would it?

Anne McTaggart: I do not see that as fundamental.

The Convener: Different views have been expressed on the question of cost. The Scottish Government has stated that its costings remain accurate and that particular costs are associated with the AIP role. You have the opportunity to put on the record your response to those views on the cost implications.

Anne McTaggart: As outlined in my letter to the committee of 29 October, the estimated cost of implementing the bill is £6.8 million over 10 years. It is not £22 million, as there are no recurring publicity campaign costs. That is covered by the Scottish Government's obligation under section 1(b) of the Human Tissue (Scotland) Act 2006 to

"promote information and awareness about the donation for transplantation of parts of a human body".

There are no costs for AIPs as that is not a new role. There will be costs for training, which I have estimated at £0.5 million. The Scottish Government's estimate of £22.2 million over 10 years is at odds with the rest of the evidence that the Finance Committee received. The majority of the stakeholders agreed with the estimate in the financial memorandum. So far the Welsh costs have been verified as actual costs and they are on target. I am aware that Wales is still in the early stages, but I thought that I would make that point. The Welsh legislation is being implemented within the allocated budget of £7.5 million.

The Convener: As there are no more questions, I thank Anne McTaggart, the member in charge of the bill, the NGBU and the Scottish Parliament solicitors. Thank you for your attendance and evidence this morning.

12:35

Meeting continued in private until 12:54.

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