OFFICIAL REPORT
AITHISG OIFIGEIL

Health and Sport Committee

Tuesday 13 November 2018

Session 5

The Scottish Parliament
Pàrlamaid na h-Alba

Tuesday 13 November 2018

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HEALTH AND SPORT COMMITTEE
29th Meeting 2018, Session 5

CONVENER

*Lewis Macdonald (North East Scotland) (Lab)

DEPUTY CONVENER

*Emma Harper (South Scotland) (SNP)

COMMITTEE MEMBERS

*Miles Briggs (Lothian) (Con)
*Keith Brown (Clackmannanshire and Dunblane) (SNP)
*Alex Cole-Hamilton (Edinburgh Western) (LD)
*David Stewart (Highlands and Islands) (Lab)
*David Torrance (Kirkcaldy) (SNP)
*Sandra White (Glasgow Kelvin) (SNP)
*Brian Whittle (South Scotland) (Con)

*attended

THE FOLLOWING ALSO PARTICIPATED:

Mary Agnew (General Medical Council)
Rachel Cackett (Royal College of Nursing Scotland)
Dr Stephen Cole (Scottish Intensive Care Society)
Lesley Logan (NHS Blood and Transplant)
Dr Sue Robertson (British Medical Association)
Professor Marc Turner (Scottish National Blood Transfusion Service)

CLERK TO THE COMMITTEE

David Cullum

LOCATION

The James Clerk Maxwell Room (CR4)

Scottish Parliament

Health and Sport Committee

Tuesday 13 November 2018

[The Convener opened the meeting at 10:30]

Human Tissue (Authorisation) (Scotland) Bill: Stage 1

The Convener (Lewis Macdonald): Welcome to the 29th meeting in 2018 of the Health and Sport Committee. I ask everyone in the room to ensure that mobile phones are off or switched to silent. Although you are very welcome to use devices for social media purposes, please do not film or record proceedings, because that will be done for us by Parliament staff.

The first item of business is consideration of evidence on the Human Tissue (Authorisation) (Scotland) Bill that we heard today in informal sessions. I am delighted that a number of those who gave that evidence are in the gallery.

The committee heard from three groups: people who have received donated organs, family members who have authorised the donation of organs, and people who are currently on the organ transplant waiting list. Before we take formal evidence, I ask colleagues, starting with Emma Harper, to feed back on those informal sessions.

Emma Harper (South Scotland) (SNP): Brian Whittle and I had an interesting session. A theme that came out of it was that education is critical for engaging families and potential donors and for getting them to record their wishes on the organ donation register. People are generally supportive of presumed consent, but the critical goal would be to engage people as early as possible and in certain ways so that they express their wishes.

We had some discussion of economic arguments about the costs and benefits of organ donation versus dialysis. That was an interesting side topic.

We also discussed how important it is for a person to know that an organ has been donated as a gift rather than through presumed consent. The feeling is that it is an amazing thing to be given an organ, although donor information is not often sought. However, any available organ is welcome.

Brian Whittle (South Scotland) (Con): The overwhelming message for me was that the public's understanding of organ donation—what is involved in it and what the lifespan of an organ is when it is donated—is very poor. If the person who receives the organ is a young person, the likelihood is that they will need two or even three organs throughout their lifetime. As Emma Harper said, it is about education.

One thing that jumped out in response to one of my questions, which I was not quite expecting, was about where the tension would lie if we had presumed consent and an opt-in. That was quite an interesting discussion.

Miles Briggs (Lothian) (Con): I will not repeat points that Emma Harper described that our group also made. I record our thanks to the individuals and the families who came to speak to us.

I picked up specific points about conversations with families and people across Scotland, which I hope can be taken forward in the bill. It is important that we try to have these conversations with our loved ones and express our wishes.

Key points were made about the public information campaign that will be needed. As Emma Harper mentioned, two key principles were highlighted: one was about the gift of life and the other was that family decision making should be included.

A few points are worth developing. One was about people using advance directives to make known their view. We have not looked at that in as much detail as we should. In addition to that, because of complex relationships and changing family types across Scotland, it might in the future not be clear who the next of kin is. We need to look at that.

It is worth putting it on the record that people's experience of key professionals and organ donor nurse teams is absolutely excellent. Everyone to whom we spoke today outlined how good those people and the support that they provided had been.

The Convener: Thank you very much. Was the group that you talked to made up of families who had authorised donation of organs?

Miles Briggs: Yes.

The Convener: Were other members in that group?

Keith Brown (Clackmannanshire and Dunblane) (SNP): Yes. It was interesting; I thank those who came along. It was quite a difficult session, but it was really helpful. I will talk about some of the issues that were raised.

One issue was the possibility that families could be divided on the question when they are put in that position. Where do the donor's interests lie in those circumstances?

The burden of the extra 24 hours was mentioned by a number of people. Pre-death

procedures have to happen. One woman in particular spoke about being put in that situation when you are in a bit of a dwam—that is the best way to describe it. People have to deal with so much at that time, so is it fair to put people in that situation?

There is also the idea of the organ as a gift. Is it a gift if the state has a pre-emptive right to organs? Is it a gift if it is given by somebody other than the person to whom the organs belong? Those are really interesting questions. It was obviously difficult for the families. My last point about the gift is that the way that it is currently done—with the medal, the recognition and the information that is passed to donors' families about where organs have gone—is really appreciated. That should not be lost, no matter what happens with the bill.

Sandra White (Glasgow Kelvin) (SNP): Miles Briggs and Keith Brown have covered the issues very well, particularly the idea of the gift, which came across strongly.

One of the areas I explored was pre-death procedures. The 24 to 36 hours was quite a harrowing time for the families of the people. I did not realise that in some cases, people who were brain dead were actually still breathing. The evidence that was given was very moving, and I thank the families very much. We need to explore pre-death procedures. People are not educated enough about the different ways in which organs have to be preserved. That issue stood out for me. Keith Brown and Miles Briggs have also raised some really good points.

The Convener: The third group to whom members talked were people who had received donations of organs; I was privileged to be part of that discussion. It was another very moving discussion that put a clear focus on the lived experience of patients who have waited—sometimes for a long time and sometimes for a short time—in intensive care for an organ donation, and the different ways in which individuals respond to those circumstances. There is no right way to deal with that; clearly, people respond in a variety of ways. It was a very useful and informative session.

Alex Cole-Hamilton (Edinburgh Western) (LD): It was very moving and, equally, inspiring. The takeaway for me was definitely the lived experience, as you described, convener. The reality of how little support we offer transplant patients, either pre-op or post-op, particularly in respect of mental health, was quite stark. People are dealing with a challenging and unique set of circumstances. It was described as a "rollercoaster" of emotion, particularly when the person gets a call in the middle of the night to come for their transplant, only to be told when they do that it is not going to happen. The problem also applies in respect of recovery. That, for me, is where there is a real gap. If we do nothing about it in the bill, we will have failed.

I was touched by the fact that all the transplant patients whom we met have been giving back in some way—for example, through meeting transplant patients who are waiting for operations and talking about their experience to help those patients along.

There is anxiety around medication and the fact that we are asking transplant patients to run down their supplies of anti-rejection medication right to the end before they get their repeat prescription. Brexit is a concern, in that anti-rejection medication might be among the medicines that we will struggle to get if we crash out of the European Union with no deal.

David Torrance (Kirkcaldy) (SNP): I record my thanks to individuals who came along today to give evidence. Education will play a key role in our engagement with the younger generation, if the deemed age of consent is going to be 16. The evidence that we took this morning highlighted the lack of support, especially for mental health issues, and it highlighted that it is important that a donated organ is a gift.

The Convener: That is right. The significance of an organ being a gift was fed back in different ways from all the groups.

One of my overall conclusions was about the value of networks. The transplant games were mentioned in our discussions, as was the family donor network. The networks are important, and I am glad that in some way our evidence sessions have allowed more network building to be done by people who are involved.

I repeat the thanks of all my colleagues to all those who provided evidence this morning. It was extremely valuable and will certainly inform our further proceedings.

We move to the first formal session of evidence on the bill. I welcome to the committee Dr Sue Robertson, who is the deputy chair of the British Medical Association Scotland; Rachel Cackett, who is a policy adviser at the Royal College of Nursing Scotland; and Mary Agnew, who is assistant director for standards and ethics at the General Medical Council. Thank you for your patience.

We will go straight to the heart of the matter, which is whether deemed authorisation will achieve the objective that everyone has set for it—that is, to increase donations—or have perverse negative effects. I ask that as a general opening question about the fundamental principle of the bill and because of its being the fundamental tool

within the bill for achieving change. Is the bill fit for purpose?

Dr Sue Robertson (British Medical Association): Before I speak on behalf of the BMA, I should mention, so that you know my background, that I am a doctor who looks after patients who are waiting for transplants and patients who have received transplants.

The Convener: That is helpful. Thank you.

Dr Robertson: Today, I speak on behalf of the BMA, and not personally. We have long supported a move to a soft opt-out system as part of a package to deliver more transplants for patients who need them. We do not think that such a system can be a stand-alone thing. It will not help our patients unless it is part of an investment in infrastructure to support delivery of that ethos, and to make available more organs for donation. However, we definitely support the move: we have done for a long time.

Rachel Cackett (Royal College of Nursing Scotland): Thank you for giving the RCN the opportunity to come. It was great to sit and listen to the feedback from your session with patients and families this morning.

As we said in our evidence, the RCN consulted our membership back at the start of the year on a position on consent for organ and tissue donation. Overwhelmingly, our members support a move to an opt-out. Our Welsh members support the existing legislation in Wales: the Human Transplantation (Wales) Act 2013.

That support for an opt-out came with a series of conditions attached, which we have detailed in our response. I am happy to talk about any of those in the context of how they are reflected in the bill.

You have been talking in your feedback from your informal sessions this morning about education being mentioned a lot. The figures that really struck us from our consultation were that, of our members who responded, only 25 per cent felt that they could speak with confidence about organ donation, only 22 per cent felt that they could speak with confidence about tissue donation and only 10 per cent felt that patients and their families had had much discussion of the topic.

Although we are clear that those who get into the details of authorisation should be specialist nurses in organ donation—the expertise to do that sits with them—wider discussions need to happen at other points to support families and individuals to make an informed choice, and we need to come back to those in the support mechanism.

There are many other things that need to be in place to make sure that the bill supports an increase in successful donation.

10:45

Mary Agnew (General Medical Council): Thank you very much for giving the GMC the opportunity to contribute to the discussion. We are extremely supportive of the bill's underlying aim to increase donation rates. In our written submission we have not taken a formal position on whether the bill is the best way to achieve it. That is because, in our role as the medical regulator, we think that that is a matter that is rightly for discussion in Parliament, with the public, rather than one on which we would take a position.

The points that we have made are about where we think there could be more clarity on how the bill will work in practice to support health professionals to act ethically in partnership with patients and their families. I strongly underline the theme that has been coming out already of the importance of education, in terms of public understanding and support for health professionals in what can be very difficult circumstances and sensitive conversations.

The Convener: Thank you very much—I appreciate that.

The committee has conducted a survey in order to try to gauge what the impact of the bill might be and to gather some public opinion. Deemed authorisation clearly creates a presumption in favour of transplant for people who do not opt out, but we found that the number of people who would opt out increased, and that most of those who would were people who had no particular opinion beforehand. My question is for the witnesses who have said that deemed authorisation is a good thing and for whom it is a policy position. Is there a danger of a backlash—of losing on the swings what you gain on the roundabouts—from people who have no particular view at the moment being encouraged to come to a view and taking a negative position?

Dr Robertson: Internationally, there is no evidence that the policy is likely to reduce consent rates; in fact, it tends to have a positive effect if it is done in association with other measures to support it. Wales is the closest country to us in terms of the policy. There, there has been similar legislative change in the past couple of years and there is no evidence that consent rates have gone down. Family consent rates have probably gone up. That is, to a great extent, a result of public information and education of families: the subject has become a conversation that people are much more likely to have in the cold light of day, when everybody is well, rather than on the most distressing day of their lives.

We think that the policy is unlikely to reduce consent rates and that it will, if anything, enhance them. We also think that it is really important that

individuals who do not wish their organs to be used for transplant have the opportunity to register that wish.

Rachel Cackett: I agree with much of what Dr Robertson has just said. From talking to colleagues in Wales, I think that the important thing has been that the conversation has been supported by other changes. The conversation is important, so that people get to the point of informed choice. For families, for patients and for staff who support discussions at the end of life, it is important that there is informed choice, whatever that choice is. The college's experience to date has been that the conversation is what matters, which is why we keep coming back to education.

Mary Agnew: I agree with that sentiment about informed consent; early and wide discussion is really helpful.

Keith Brown: Dr Robertson mentioned family consent. My concern is that if the bill is passed, presumed consent will mean that the rights of the state will supersede those of individuals who have not expressed a preference. I am also concerned that families' rights might, in some circumstances, supersede the rights of individuals. We have heard evidence today that family members who are consulted—although there is priority attached to family members depending on their status—might disagree with donation, which can put them in a difficult position.

An example is the lady who mentioned that she had given consent but not for all organs, and regretted having not done so. I am interested to hear where you believe the rights of the donor—whose organs would be used—come in relation to the rights of the state, as expressed through the bill, of families and of the medical profession.

Dr Robertson: That is a very difficult issue. Again, we come back to the need to have the conversation early, which is one of the main thrusts of this. If people have the conversation with their loved ones about what they wish to happen to their organs in the event of their death, their loved ones will know that that is their wish.

Sometimes, obviously, family members disagree. That is very difficult and very distressing and—as I have already said—it can happen on the worst day of their lives. Families would not be asked for consent: they would be asked for information about their relative's wishes. That is, perhaps, an easier conversation for a family to have than the one that they have at present.

As a doctor, I feel that under the soft opt-out, if the healthcare professionals felt that the situation would cause undue distress to the family, we have a duty of care to them, as well, so in such cases authorisation should not go ahead.

Mary Agnew: A doctor's duty is, first and foremost, to the patient. We welcome the principle in the bill of doing what can be done to establish what the patient's wishes are. A principle in terms of the family's involvement would be about being considerate, sensitive and responsive to the people who are close to the patient.

The reasons for refusal are interesting—often, it has been because the patient's wishes were not known, so in the context of a wider system, in which everyone is being encouraged to state their reasons and is given the choice to opt in or opt out, perhaps the conversations will become a little easier.

I very much agree with Dr Robertson that, in situations of extreme distress to the family, you would not want to put professionals in a position in which it was felt that they had somehow to override the family.

Rachel Cackett: Obviously the RCN's position is that we support deemed consent, but as I said, the college has taken the position that safeguards need to be put in place. There are two that are really important in the context of the question that Keith Brown asked.

First, we are very clear that trained health professionals need to discuss the expressed wishes of the deceased person with the family. If members look at the figures that are presented in the Scottish Parliament information centre's briefing, you will see the important difference that the involvement of a highly trained specialist nurse can make in terms of authorisation rates.

It is important to go back to the point that Mary Agnew made, which is that the professionals who do this at a very difficult time for families are highly trained; they are sensitive in the conversations that have and they have an ongoing relationship with the family.

We are also very clear that no practitioner should be put in the position of having to force a donation. Our understanding is that, in practice, that is the situation in Wales. Our position is that, if a family does not want a donation to go ahead, donation should not be forced.

That goes back to one of the issues that we have raised on the bill, which is the duty to inquire. It is absolutely true that the practitioners who are involved at such times, and the SNODs—specialist nurses in organ donation—have to have very difficult conversations with people who are facing bereavement or who have just been bereaved. It is important that we are absolutely clear what we expect of our practitioners.

It would certainly be helpful during the bill's progress to understand better why the duty to inquire is being placed on individual practitioners

rather than being placed at organisation level, because there will, potentially, be disagreements. SNODs are trained to deal with that, to manage the process and to help people to navigate through it. However, it is very important that, in statutory and legislative terms, we understand the duties that we are placing on our individual practitioners.

Keith Brown: I should say that we heard in earlier evidence nothing but praise for the people who are involved in the process, but we are faced with passing a law and difficult questions have to be asked.

I am getting the sense—I do not want to paraphrase unfairly—that the views of the donor are not paramount. Those views could, in the case of presumed consent where the person has not expressed a preference, be subordinated to those of the state in order to allow donation to go ahead, or to the views of the family. It is often down to chance which member of the family is consulted, for various reasons. If the family member is distressed—even though the deceased expressed, when in full control of their faculties, that they wanted to donate—that wish could be overturned by the family.

You have also expressed concern that health professionals should not be put in that position. It could be argued that that could not happen if it were made clear in the law that the views of the donor should be paramount.

I will make a last point. Dr Robertson said that the families might not give consent. That is exactly what has been described—that donation will not go ahead when the family feels strongly that it should not. That is not a definition of consent, I would have said. I am trying to make the point about the views of the donor, because the bill will become the law, if it is passed.

Rachel Cackett: To clarify our position, I will read the wording, because it makes a difference.

> "Trained health professionals must discuss the expressed wishes of the deceased person with the person's family, where contactable, before any donation proceeds. If a family does not want a donation to go ahead it will not be forced."

We come back to my understanding of what the bill is trying to do, which is to say that a conversation is needed about the wishes of the deceased person. There is an important distinction between the wishes of the family and the wishes of the deceased person—an important break that our members felt it was important to put in the bill. When we are dealing with people who are in grief, it is important that the conversation can be had, and that it can be conducted sensitively by people who are properly trained to do that.

The Convener: SNODs demonstrated to the committee some time ago the process of asking questions, and the length of time and complexity that it can require. If a family has a discussion about the expressed wishes of the potential donor but then declines to answer the questions, does that amount to a veto? Is that a realistic proposition? Does it happen? Is there evidence that families, for good reasons or bad—because they cannot or because they choose not to—do not answer the questions that are asked?

Rachel Cackett: I do not sit here as a practitioner who does this every day. I am aware that the committee will hear from colleagues from NHS Blood and Transplant in the next session; I would prefer to leave it to them to answer on that practical detail.

Miles Briggs: I want to develop further the discussion around the rights of the family because, as Keith Brown was saying, they are an important aspect of what could be lost in the new bill. Around 100 donors a year in Scotland are lost due to families refusing to donate their loved one's organs, including people who have actually recorded their wishes in the organ donor register. Should the bill reflect the current convention, which in effect gives families a right of veto?

Dr Robertson: Again, we need to look to Wales. Family consent rates are higher in Wales than they are in Scotland, which perhaps reflects the change in the legislation there and the fact that the public know more now about organ donation than they ever did in the past. One of the themes that came out of the committee's earlier discussion was that education is key. If people understand what is involved and understand the benefits and the needs of the patients—who could be a friend of theirs, a member of their family or them in the future—they are much more likely to wish that they could help them by offering them a gift of life. Whenever I speak to anybody about organ donation and explain it in simple terms, generally they say, "Oh. I understand now. That makes much more sense."

Education is key: educating the public; and educating health professionals about how the process might change. To some extent, educating the public is already being done—we have real-life stories coming out, so people see the benefits of organ donation much more. However, we still need to educate them some more and help them to have the conversations. That would get over much of the perceived problem.

11:00

Rachel Cackett: I come back to the statement that our members have agreed and how we reflect that in legislation and in practice—that is what our

members are asking for. The important point to come back to, and the one that we make repeatedly, is that we need investment in the infrastructure and the expertise to support discussions to go around this legislation. If the current bill is passed, we need trained professionals to be involved in the discussions—our members should not be put in the position of having to force something. I come back to the message about the expressed wishes of the deceased person and how we reflect that in the legislation—I guess that there are many ways to do that. Our understanding is that that is what happens in practice with the Welsh legislation.

Mary Agnew: I would agree with that. With public awareness—such that people are talking to their families about their wishes and these are not decisions that are taken in the heat of a crisis—a greater proportion of families would be much more comfortable and much more understanding of what is going on.

There is a significant shift with this legislation. I would not see it as giving a power of veto, and when we talk about not forcing health professionals, in practice we are probably talking about quite a small number of situations. However, the risk in saying that removal of organs will have to go ahead in some situations is that there is potentially an impact on trust in the medical and nursing profession, so that could be quite a damaging route. You would want to retain the ability to take the family's views into account where they are very strongly held, while seeing the patient's express wishes as what you ought to be following.

Miles Briggs: Given the conversations that we have had with people over a number of years in the Parliament, which has looked at different bills, to some extent people think that the law has already changed. Do any of you have specific concerns around deemed authorisation in the new bill increasing family uncertainty?

Rachel Cackett: I feel that we keep coming back to the same point, which is that it comes down to the education package that goes around this. If what you want is families to have an open conversation about what a person's expressed wish is, whether, under this legislation, it has been to opt in, opt out or do neither, you want to discuss an active choice.

One of the issues that we raised in our written submission is the money that we see going into NHSBT and the specialist nursing community. That is really welcome and we absolutely support that going ahead, because that is the crucible—that is where the decision making goes ahead. However, our members told us that they thought that there was a much wider need for education—and I gave some figures at the start about how many of our members who responded were comfortable with these issues; so there is a bigger set of money that requires to go out. Those in NHSBT may not be the right people to go out and do this—it may be a Government issue—but we need to go out and work with the wider health community, because we want the conversation to be supported early, whether someone is in a school with a school nurse or in a general practitioner's surgery with a practice nurse. You would not expect those members of staff to have the sort of expertise or to go into the sort of detail that you would want from your SNOD, but you would want them at least to be able to answer some basic questions and to do so in an informed way, to ensure that the public can make the right choice—however they then choose to express that.

Miles Briggs: One of the most interesting aspects of this is the issues that can arise when people have made their wishes known—especially the issue to do with eyes not being donated. I am struck by the fact that the bill might not get around that issue when it comes to families completing the questionnaire, so it is worth considering public information around the questionnaire in relation to individual organs. An individual in our group this morning said that, looking back, they would have donated the eyes. It is a sensitive area. I am sure that you have experience of that.

Dr Robertson: I just come back to your point that that, too, is about public information. We need to teach the public what benefit their eyes could have, in the event of their death, if they gave them for transplantation. We need to show how incredibly grateful my patients, and all patients who receive organs in a transplant, are, and how life changing—or life saving—those things can be. Then, many people, I think, would reflect on that initial reaction of, "Oh, I do not want to give my eyes," and whether they really mean that; and, once they have heard what would happen in that situation, they might reflect on whether they might change their mind. Again, we come back to public information and public education.

The Convener: Given the way in which the bill is drafted at the moment, would there be any risk of legal or regulatory consequences for medical professionals who decided, for the reasons that we have discussed this morning, not to proceed because the family did not wish to do so even though the person in question's express wish was to donate?

Mary Agnew: On regulatory consequences, our approach is about whether doctors have acted in good faith on the basis of the guidance that is available and in partnership with patients and, where appropriate, those close to them. When something comes to us, we have a duty to look at

it and to consider whether we need to investigate fitness to practise, but we take the context into account. We expect the doctor to be able to justify their actions. I suppose the short answer is no, I do not see a problem.

In looking at what we and other organisations might need to do to support doctors to understand and apply this new law, we have raised some questions to get a little more clarity about what is envisaged in respect of the duty to inquire, in so far as it applies to the wider healthcare team as opposed to the specialist nurses involved. Ideally, we would want to see some sort of separation between the decisions that a doctor makes about a patient's treatment and the set of decisions around possible organ and tissue donation—so the really sensitive conversations, which need careful and trained handling. We want to understand the sorts of circumstances in which the duty to inquire might apply to a doctor and what sort of training and support would be made available to them to handle those conversations. Those are some of the areas that we would be keen to see explored as the bill progresses.

Brian Whittle: As has already been mentioned, the bill is going to be law and, as I think Keith Brown said, if you want to create law in this matter, clarity is absolutely paramount. One of the things that strikes me is that, sitting alongside deemed authorisation, there will also be opt-in. There is a different connotation to opting in than there is to not opting out. Might that increase family uncertainty and have the potential to increase refusal rates?

Rachel Cackett: The college's position is that we support an opt-out system with the conditions attached; exactly how that is framed requires a legislative answer. Clarity, though, is absolutely key. If you look through the conditions that our members said were really important to them, you will see that clarity keeps coming out—clarity about which organs are and are not included in deemed consent.

You will also see in our submission that we raise a number of times the issue about the bill, or the documents that accompany the bill, not always having clarity that makes it easy to understand exactly what the proposal is in every situation. Whatever system is chosen and if the bill goes ahead, the most important point is that people have to make an informed choice—whatever choice they make—and we have to be 100 per cent clear about what they are making a choice about. That would make practitioners' and families' lives a great deal simpler when they are trying to have the conversations at the point of real grief. If that is not clear, we do everyone a disservice.

We do not have a position on exactly how that is framed in the bill, but the important point is that, whatever choice is made, it has to be absolutely clear to us all what is being chosen.

Dr Robertson: The BMA position reflects that of the RCN, which is that clarity is key—along with communication. Clarity on what the change in legislation would mean for the public is key—the fact that if you opt out, your wishes will be registered. As the bill is written at the moment, written confirmation of an opt-out would be required. We feel that that will make it harder to opt out and is slightly contrary to making it as easy—if you do not wish to give your organs—to opt out as it is to opt in. Perhaps we might not require written confirmation of opt-out, much as we do not at present.

I can understand the concern about having opt-out or opt-in and, at the same time, deemed consent. That will have to be carefully managed. Certainly Wales left opt-in as an option because some people wanted to do that, and if people want to opt in actively, I do not think that we should stop them doing so, as long as everyone knows that if they do not opt in, we presume—unless they have opted out—that they wish their organs to be donated. I think people having the ability to opt in if they wish to do so is fine.

We know that at the moment about 50 per cent of the Scottish population have opted in but that if you ask people, nine in 10 will say that they would wish their organs to be donated. We are looking for that 40 per cent who have not opted in but who actually want their organs to be donated. Those are the people who we want to have that conversation with their families, because we know that they actually want their organs to be donated. Therefore, yes, I can understand the concern, but I think that we would leave the opt-in option too.

I am not sure whether that was clear.

The Convener: Yes, absolutely, I followed you.

Brian Whittle: The connotation of making the positive step to opt in is different from not opting out; that is the issue. I am looking at this from the perspective of the family who are in the horrible situation of having to have this conversation at one of the hardest times in their lives. From their perspective, if you can say, "Your loved one had opted in and consented to these organs being donated," that is an easier start to the conversation. What I am getting at here is: should we create an environment in which everybody has the option to opt in or opt out? Should that be where we are heading?

Dr Robertson: I bring you back to the current situation. At present, everybody has the ability to opt in, positively, and it is very easy for them to do so, but people have busy lives and they just do not get around to it—and people think, "It is never going to happen to me." Four out of 10 people in

Scotland would wish their organs to be donated if you asked them but have not opted in. Their families may well know that they would wish to do that, but they just have not got around to officially registering their wish.

It is clear that some people wish to opt in. If you change the legislation and make it clear to them that they can opt in if they want or they can opt out if they want, but if they do neither, it is presumed that they wish their organs to be donated, I think that that is better than the system that we have now.

11:15

Brian Whittle: I am one of the 40 per cent—the conversation that we have had here has prompted me to make that decision. There are several things in life that everybody goes through—getting your national insurance number when you turn 16 or getting your driving licence—all of which are points at which, potentially, we could put the option to everybody. We have to get this absolutely right, and that comes back to clarity.

My question is therefore this: would not creating the environment in which everybody has the option to make the decision be a more positive situation than just having presumed consent?

Dr Robertson: You have just made the argument for presumed consent by saying that you are one of the 40 per cent. The problem for many of us is that, as we age, we do not get sent a new driving licence; if we happen to stay living in the same area, we do not register with a new GP; and perhaps we do not use the library anymore because we buy our books online—so actually, the option does not pop up in front of us and we never get round to it.

Brian Whittle: Sorry, convener—

The Convener: Be very quick.

Brian Whittle: I think that we are all agreed that we want the outcome here to be more donations. My point is that the option has never been put in front of me. I am asking: should we, as part of this legislation, be creating an environment in which it is put in front of everyone?

Rachel Cackett: I guess that we come back to the point that the legislation is part of a whole panoply of actions that need to be taken to increase donation rates. So, yes, I think that receiving something in the post—something that hits me in the face and asks me the question and makes sure that I am having the discussion, so that my loved ones are informed about my wishes—is as important as you do. Also when we asked our members detailed questions around an opt-out, 71 per cent of them supported that as one tool to increase donation rates; the thing is that it is not the only tool that should be on the table.

Emma Harper: I remind everybody that I am a former liver transplant nurse. I have also been involved in retrieval and in kidney and pancreas transplants.

Simply put, deemed authorisation allows a conversation to begin, exactly as Brian Whittle described. I am interested in the information from the BMA about barriers to donation. It may be that people are not really familiar with donation or are a bit scared. If someone chooses to donate their solid organs, that is great. However, there are new procedures, such as face or hand transplants, and it can freak people out when we start talking about them. The submission from the BMA talks about the ability to exclude certain parts, and I am interested to know whether the BMA thinks that a good way to proceed would be to allow people to be explicit about which tissues or organs are potentially available.

Dr Robertson: It is difficult. Time moves on and medical advances are very rapid, so things change. This is another public information issue. The key thing is that we are trying to increase the number of organs that are available for patients, and we do not want situations in which people are not clear about what they are authorising. There needs to be a conversation in public about what we are actually talking about here. Are we talking about presumed consent to use any part of the body for transplantation, or are we talking about the common organs that we use for donation? Do we leave space for people to exclude certain parts of their body? If it means that people are better educated and can have their wishes respected when they die, I think our view would be that there should be a way for people to exclude organs.

Rachel Cackett: I come back to the point about clarity. One of the lines that the college has put against its support for an opt-out is that the scheme must be clear about what is included and what is not. We have also said that there should be limitations—that the opt-out should be limited to donations for transplantation and that everything else should require express authorisation. Our members have told us that that would be a helpful way to proceed if we are looking to increase donation rates.

Emma Harper: My supplementary question is about the duty to inquire. The bill sets out that donation cannot go ahead if a “reasonable person” would be convinced by the information that the potential donor’s latest view was that they were unwilling to donate. Does there need to be more detail on the standard of evidence required in order to override donation?

Rachel Cackett: We raised that issue in our written evidence. The duty to inquire falls on individual health professionals, and it is often nurses who negotiate the process with families. There are definitely two questions that need to be answered. First, is that duty rightly placed on individuals? Secondly, if the bill is to proceed in that way, can it be very clear so that our members know what it means for their practice? The last thing that we want is a bill that supports defensive practice because individual practitioners are concerned about the implications of what a statutory duty to inquire might result in.

Those two questions need to be answered. We certainly do not have the answers to them, but they are important questions as the bill goes forward. Practitioners operate with great sensitivity, and they need to know that they have the support of clarity around what we are asking them to do in these situations.

Dr Robertson: I echo what Rachel Cackett said. We think that the individual's views about what happens to their organs are paramount. If somebody has changed their mind and there is evidence of that, it seems right not to proceed with donation. However, there needs to be clarity around what evidence is required. I think that that clarity is very important for the public, but it is also very important for the healthcare professionals involved at the time.

The Convener: Does that clarity need to be in the primary legislation? As a regulator, does Mary Agnew have a view?

Mary Agnew: I have no strong view about the best way to achieve that clarity in legislative terms. My hunch is that it probably does not need to be in the bill—it comes back to the question of the support that goes with the bill further down the line.

Rachel Cackett: I return to the point that the primary legislation contains an individual duty to inquire. We need first to investigate whether that is the most appropriate way of dealing with what I think is a reasonable request. Our position is that the conversation with the family needs to happen in case the individual has changed their mind since they formally opted in to the register. That discussion needs to happen. If there is a statutory duty in that regard, there must equally be something that makes the expectation in the statute absolutely clear. Whether that is done by regulation or through guidance or whatever, we need a failsafe system so that our practitioners are able to operate and the intent of the bill can then be realised.

Sandra White: One thing I have learned about the bill is that if I speak to my family or anyone outside the Parliament about organ donation, although they understand about opting in and opting out, they do not understand anything else. From the private talks that we have had with various witnesses, I know that it is very complicated and very emotional. I did not know anything about pre-death procedures, the 36-hour period and just how families are affected.

We have spoken about clarity and education, and the bill looks to clarify certain procedures when someone is not clinically dead. Those will be in the legislation if we have deemed consent. I have spoken to witnesses, not just today but previously, and there have been some concerns around PDPs. In particular, one issue that has been raised with the committee is whether there is a conflict of interest for doctors. Does that pose a danger? Does the bill make a significant change in terms of authorising PDPs? If PDPs are carried out under deemed authorisation, should there always be express consent? That is three questions all in one.

I was certainly surprised by just how involved people have to be with regard to deemed consent. As I said, I honestly did not realise that families can ask to witness the procedures if they wish to—in certain cases, the bodies were still warm. That was a real surprise to me.

What are the witnesses' thoughts on the three questions that I posed? Do you want me to pose them again?

The Convener: The pre-death procedures are what we are talking about. Thank you, Sandra. Who would like to start? This is another sensitive area, but it is an important part of the bill.

Dr Robertson: The paramount responsibility of a medical professional or a nursing professional is the care of the patient in front of them, so we would not support anything that could put that patient at risk or in harm's way. However, if a professional is in that situation and has a patient who wishes their organs to be used for donation, the PDPs are part of that organ donation happening.

Again, I go back to public information and teaching people what is involved so that nothing is hidden. It needs to be clear to people what they are putting their bodies through so that their organs can be used in the event of their death, when they do not need them anymore. We need to educate the public about what the procedures are and why they are done. We also need to ensure that everything that is done is done for the good of the patient in front of us, which includes continuing to respect their wishes after their death.

Mary Agnew: I very much agree with Dr Robertson. We are currently consulting on revised guidance on consent. Our general principle is that it is vital that patients have good, accurate

information about the types of procedures that they may undergo. Through a public information and awareness campaign, we would see greater public awareness of the procedures—they would be seen as part of what is needed. Of course, there is a range: some things are minimally invasive, not particularly harmful and probably less controversial. However, this is an area in which there is limited public understanding of what might be involved. Bringing it into the conversation would be important.

Sandra White: Thank you. I certainly did not know anything about pre-death procedures, and I do not think anyone else does either. I do not know the reason for that.

You talk about clarity and education. Should people be informed in writing about what may happen when they opt in? Obviously, some organs cannot survive after 24 or 36 hours, so it is important that they are removed as quickly as possible. Should people be informed in writing about that, or should they just be told, "This is the procedure that you are going to go through"? Once someone opts in as a donor, should they be told, "As a donor, this is part and parcel of what will happen to you"?

Dr Robertson: I would have thought that public information is an important part of any legislative change. People should have access to written information if they wish to read it. However, the public should have access to that at any point in their lives and not just at the point of donation. The BMA supports a move to a situation in which organ donation is the norm. That is a long-term ambition, but public information about the processes around organ donation is part of that.

11:30

Sandra White: I have a question about a legal issue for Mary Agnew, who mentioned the duty to inquire. The Law Society of Scotland picked up on aspects of pre-death procedures, and I wonder whether that area would raise any legal questions for you and your organisation in regard to people's assumptions or whatever it may be.

Mary Agnew: It comes down to the point about clarity. One of the questions that we had at an earlier stage in the consultation was how the bill fits with the Adults with Incapacity (Scotland) Act 2000 and how it takes into account situations in which people may lack capacity. I am not sure what the legal ramifications are, but we would be keen to give as much clarity to practitioners as possible to make sure that they feel confident in acting ethically and within the law.

Emma Harper: For clarification, pre-death procedures are procedures such as putting in intravenous lines or giving medication that will improve organ perfusion. They are procedures that might be performed already, such as giving certain IV medication, but they are carried out once a decision has been made to donate. They might be simple things such as changing medication or increasing doses. Can you clarify what pre-death procedures are? It is not about doing stuff to people; it is about helping to support donation once the decision to donate has been made. Is that correct?

Dr Robertson: That is certainly how we see it. Again, that is part of the education that is needed. If someone wishes their organs to be used for transplantation in the event of their death, part of that wish is to try to ensure that those transplants will be of as much benefit as they can be to somebody else. The procedures will change over the years as medicine changes, but what is involved needs to be made very clear to the public so that people know. At present they perhaps do not.

Alex Cole-Hamilton: The committee had an informal evidence session this morning with recipients of organ donations. It was a very inspiring session. One of the things that came out of it was a discussion about the conversations that have to happen if we are to generate an uptick in the number of people who are on our organ donor lists. A gentleman who is an organ recipient suggested that the organ donor register could have a countersignatory box to show that a person's next of kin was aware and had almost co-consented to the person's registration. I understand that that might not be practical, but is there anything that we can put in the guidance for the bill to generate those conversations, for example by saying that the donor list that is being retained should show that a notification process has been adopted? Would that help to engender those conversations so that when people say, "Oh, he was an organ donor," it is not a surprise to their next of kin?

Dr Robertson: Could you clarify what you mean by "notification process"?

Alex Cole-Hamilton: Perhaps the organ donor register could have a field or a box for new subscribers to tick so that an email would be sent to their next of kin. In that way, the next of kin would be notified that the person had signed up, even if they did not get around to talking about it. It would just be an automatic thing that would happen as part of that process.

Rachel Cackett: We need to think through how we have that conversation. It is important that those who are listed in the bill as the people who may end up making the decision, or having the discussion, about a person's expressed intent understand what that expressed intent is. I think that conversation is important. I can only speak personally, but I would find it quite hard to receive

an email saying that a loved one had just registered to donate organs, although I understand the point.

If the bill goes forward, we need to look at all the options that are out there to support those conversations to happen. It is interesting to think about how we use the resources that we have, which could include the opt-in, which it is being proposed at the moment to keep, to encourage a conversation. People will be dealing with a big enough shock at the point when they have to have this conversation, and the fewer shocks there are, the better. Anything around the bill that can support that is a really good thing.

Alex Cole-Hamilton: That is exactly why I asked the question. I think that it is incumbent on the committee not just to tease out the sections of the bill but to look at how we can improve the landscape for triggering those conversations.

Dr Robertson: I am concerned about the lack of conversation in that suggestion. Perhaps the email should come to the person who registers to say, "Remember to talk to your family. Remember to discuss it with them." That would be a much more positive thing than just an email that tells people that a person has registered.

Alex Cole-Hamilton: The point is well made and taken in the spirit it is offered.

The second area that I would like to ask about is the lived experience of the recipients we met this morning. This goes for the families of donor patients as well. In particular, those who were on transplant waiting lists talked of the huge pressure on their mental health as a result of the rollercoaster that they described—the late night phone calls, being driven to hospital only to be turned around and told, "This is not the match we thought it was," or, "The organs are not viable." That creates a huge pressure and strain on relationships, but they do not have any specialist mental health care and counselling. Is that a gap in our society? Do we need to have provision for specialist teams that are dedicated to helping those on a transplant list, as well as supporting them after the fact and supporting the families of donor patients in the round?

Dr Robertson: Can I speak as a professional rather than on behalf of the BMA?

The Convener: Please do.

Dr Robertson: Having done a clinic on Monday at which all my patients were transplant recipients and then having looked after patients on dialysis waiting for a kidney in the afternoon, I think that there is a huge amount of pressure. That emotional rollercoaster that you describe of getting the phone call, being driven from Dumfries or Stranraer all the way to the transplant unit, and then waiting to find out whether this is the one that is going to be yours is huge. The pressure of having a failing organ—whether it is your kidneys, lungs, heart or liver—is huge on your mental health. At present in Scotland I think that too little resource is applied to this group of patients before, during and after transplant or, indeed, to the patients for whom transplant is not an option. Any increased investment and support that we can have for patients in those groups would be very gratefully accepted and is very needed.

Rachel Cackett: We have had many conversations around tables like this one about the pressures on mental health services in Scotland and we know that there are significant gaps. Although there have been announcements about addressing some of those gaps, we are really just catching up and clearly—as Dr Robertson has said from her experience—this is a patient group that has very particular needs.

The statement that the RCN put out on its position on deemed consent was very clear that the first condition that is attached to our support is that

"Sufficient resources are made available to define and support the additional infrastructure and capacity required to increase the rate of successful donations."

We chose that wording very carefully. This is not just about increasing the rate of donation. It is about increasing the rate of successful donation, which requires us also to look at the wellbeing of the recipient population so that the people who are receiving donations are able to go on and make a success of that. We would be wrong if we did not take account of parity of esteem and consider both their physical and their mental health and wellbeing.

David Stewart (Highlands and Islands) (Lab): I thank the witnesses for coming and for their evidence to date. Could the witnesses outline in their view the best practice on organ donation that exists in Spain, which is very much set up as one of the most successful countries in Europe?

The Convener: Who is an expert on Spanish transplantation?

David Stewart: It looks like I might have to answer my own question.

Rachel Cackett: I had a long conversation with a colleague, who you are going to be speaking to shortly, who knows a great deal more than I do about the detail of organ donation in Spain and how it compares with what is being proposed in Scotland. Rather than giving you an ill-informed response, I would defer to their contribution.

David Stewart: Perhaps I could help out and provide a few bits of information. It is always difficult, of course, to compare countries with

different cultures and different systems, but SPICe provided some information to us today and, in very simple terms, the United Kingdom donation rate is half that of Spain, even if we adjust for the family refusal rates. One of the arguments is that Spain has a very strong system of transplant co-ordinators and donor detection programmes and has great provision of intensive care beds. Although I understand that the bill is focusing strongly on consent and different systems of consent, which I will put to one side, are we missing a trick here? Are there wider things that the committee should be introducing into the bill that would focus on some of those areas, which obviously Spain has shown to be extremely successful?

Dr Robertson: The little I know about Spain is that the infrastructure set-up in Spain supports as much transplantation as possible. There is no point in changing legislation if our infrastructure cannot support the increase in organ donation. So far, the Scottish Government and the transplant networks have done a huge amount to improve the rates of transplantation in Scotland. When you meet the transplant surgeons at the moment, you meet a bunch of very tired people. They are working very hard and I think that not to invest in the infrastructure so that it can deliver the aim of the bill would very much be a missed trick.

It may not be the job of this committee in this situation—I do not know how politics works—but it is very important that we have the infrastructure to deliver this. That includes having ICU beds. It includes having enough highly trained specialist nurses who can have these very sensitive conversations and make this work as easily as it can for families of potential donors and for recipients and their families, and it also includes having enough transplant surgeons so that the transplant can go ahead as speedily as possible, safely and well for everyone involved. There is no point in changing legislation if we do not have the system to support it.

David Stewart: The system of intensive care beds in Spain is crucially important. I think that that was Rachel Cackett's point about successful donations. It may be that it is not for this legislation; it may be a wider issue for the Scottish Government to take forward in building up capacity in the Scottish health service. Am I correct in assuming that there is some best practice in Spain that you think could be successfully applied to Scotland?

Dr Robertson: I would expect that our transplant networks, our transplant surgeons and our specialist nurses and their networks would be able to advise as to what they think we need in Scotland in order to deliver an increase in transplant rates. I would defer to their better knowledge in the situation. We have a very highly trained, very highly motivated group of people who are very knowledgeable and I would ask them.

David Torrance: In Wales, deemed consent applies to people who are aged 18 and over. In Scotland, deemed authorisation will apply to individuals who are 16 and over. Do the witnesses agree with 16 being the age at which deemed authorisation will apply in Scotland?

Dr Robertson: The BMA is very supportive of 16 being the age. We think that there are some people from the age of 12 who are well enough informed to make decisions, but we consider 16 to be the right age for the bill.

Rachel Cackett: The position of the RCN is that this should be limited to adults and that consent for those who are not adults should remain as is. I guess that we come back to a pretty persistent question, which is whether the age should be 16 or 18, and this is not the first piece of legislation where we have had that debate. The college is not taking a position on what constitutes an adult in law for this legislation, but we are very clear that this is for adults, however that is defined in any of the four countries of the UK.

11:45

The Convener: The GMC will have responsibility for regulating all four countries of the United Kingdom. How does the issue look from its point of view?

Mary Agnew: We have not taken a formal position on 16 being the age. It broadly fits with our wider guidance on 0 to 18-year-olds and the wider position under the legislation on mental capacity**,** for example. It will be interesting to see the full debate on that. We will obviously work with whatever the committee decides, but certainly my personal view is that, given the maturity of young people to think about these issues and consent to them, particularly in the context of a widespread public awareness campaign, there is a case for 16 being the age.

David Torrance: My reason for asking is that some of the witnesses last week were saying that there could be a difficulty with the transplant of an organ for which there was no suitable recipient in Scotland but which could go to a country where 18 was deemed to be the age of consent. Do you have any thoughts on that?

The Convener: Is there a cross-border issue?

Mary Agnew: There could be. I think that NHS Blood and Transplant will probably be better placed to talk you through some of those questions.

The Convener: I thank the witnesses for a very informative and stimulating session. We will

suspend briefly to allow for a change of witnesses. Thank you very much.

11:46

Meeting suspended.

11:51

On resuming—

The Convener: Our second session of the morning on the Human Tissue (Authorisation) (Scotland) Bill is with expert witnesses. I am delighted to welcome to the committee Dr Stephen Cole, consultant in intensive care medicine at Ninewells hospital, who is representing the Scottish Intensive Care Society; Lesley Logan, whom we welcome again, who is the regional manager for Organ Donation Scotland with NHS Blood and Transplant; and Professor Marc Turner, medical director and designated individual on tissues and cells with the Scottish National Blood Transfusion Service.

I know that the witnesses will have followed some of our previous evidence. I would like to start with a general question on the fundamental principle of the bill, which is the introduction of deemed authorisation in place of the current system. Will that change achieve the objective of increasing the number of successful donations?

Lesley Logan (NHS Blood and Transplant): I agree with previous witnesses, in that I do not think that a change in legislation will by itself make a difference. By starting a national conversation about organ donation and addressing educational concerns earlier, we will effect a culture change that in time—just as I hope the Welsh are beginning to feel—will make a difference. I think that the halo effect of introducing a change in legislation will make a difference.

We speak to one category of patient families, who are those that are uncertain of their loved one's wishes and who, therefore, err on the side of caution and say no to donation. The deemed authorisation aspect might help in those cases.

Dr Stephen Cole (Scottish Intensive Care Society): There is a mixed range of views on the bill in the intensive care community around Scotland. I think that there are some potential benefits from it, as Lesley Logan said. As a group, we are concerned that whereas at the moment we have the power of the wish, or the gift, that may be lost with the new legislation. We are also very concerned that this is a patient group, whom we heard about earlier, whose families are going through the worst days of their lives. They are coming to terms with the fact that someone they care about is dying; that everything that we have tried to do in intensive care to keep their family member alive has failed; and that death is the next step. That is not a normal set of circumstances for those families and we have concerns that anything that deems what may happen to them after death may end up coming between us and those families in terms of the level of trust that we currently have.

Professor Marc Turner (Scottish National Blood Transfusion Service): I agree with Lesley Logan and with the witnesses on the previous panel. The key issues—at both Scottish Government level and for us as individual organisations—are our engagements with the public, and the support that we give to clinical colleagues in having those difficult conversations. Those are the key elements in building on deemed authorisation to a successful increase in organ and tissue donation rates.

The Convener: As I mentioned to the previous panel, one of the consequences of heightened awareness and greater debate is that the number of people who choose to opt out may also increase. Do you have any concerns about that, or is that more than offset by the increase in awareness of those who may wish to support organ donation?

Lesley Logan: I do not think that we have any concerns about that, but we know that people change their minds. Someone who has opted in may change their mind, but equally someone who has opted out may then change their mind. In the future, we could have the scenario in which someone has opted out but then a loved one has received the gift of a kidney transplant and they do not get round to opting back in. My service would plan to approach all families in which organ donation is possible to ascertain whether any change of expressed wish has happened.

Dr Cole: It is important for the committee to realise that we have come a long way on organ donation in the past 10 years. I have the end-of-life conversation with families on a weekly basis. In the past, it was not uncommon for people to have no idea about organ donation and what may or may not happen, whereas now it is very rare to speak to a family who are not aware and who do not have a view.

Your point is well made—people are more crystallised in their views and public awareness is far greater than it was a decade ago.

The Convener: That is an interesting observation, which relates to the Human Tissue (Scotland) Act 2006. I guess that the question is whether a further change in the law, in the bill that we are considering, will further increase that awareness. Do you have any views on that, Professor Turner?

Professor Turner: I have nothing to add to what my colleagues have said.

Keith Brown: I am sorry to return to a previous topic, but I was interested in a discussion that we had with the previous panel. I am not sure whether

all of you were able to listen to that. Miles Briggs asked a pretty straightforward question about the practical reality of the current system; it was about the family veto, or family consent being required, and whether, once a wish has been expressed, it should not be overridden. I think that Miles Briggs's question was whether that should be covered in the bill, given that everyone seems to agree on the need for clarity.

I had the impression that the previous witnesses did not really want to answer that, or did not answer that, maybe because they want to see the current practice rolled forward. I would be interested in hearing your views. It would be helpful to the committee to know the extent to which clarity should cover that point, not least because the individual—the donor—having expressed a wish must surely have some expectation that that wish will be observed subsequent to their death. Should there still be such a family veto? Should it be written into the bill?

Dr Cole: That is a really well-made point. At the moment, we would approach and communicate with the family. First and foremost, we would make sure that the family understood that there was nothing more that we could do for their relative in intensive care. Only when they have understood and accepted that point would we move on to any end-of-life conversations. That is done collaboratively by me, as an intensive care consultant, and the specialist nurse in organ donation.

12:00

We listen to families' views. Having dealt with this situation on a daily and weekly basis, I would find it difficult in my profession to override the wishes that are expressed by those patients' relatives. The family might say, "Yes, he signed up to the organ donor register. That was an expression of a wish at a point in time. I now have more information, which says that that is actually not what he wanted." As the intensive care consultant who is speaking to that family, I would listen to that. I do not think that we can push families into a situation in which donation is forced through against their wishes. I would find that situation very difficult.

Lesley Logan: To put this in context, there are only six times a year in Scotland that a family overrides someone's decision. On probably half of those six occasions, it could be argued that they are not, in fact, overrides. Instead, someone has signed up to the organ donor register and has then told their family, "I've signed up to the register, but if that time comes I want you to make the final decision."

The reality is that three times a year in Scotland we have a family who may have discord. There may be a mother and a father who cannot make a decision about a child. To be fair, we are trained to manage that situation. We have a conversation with the family about perhaps a limited donation of abdominal organs, because as we know people are very emotionally attached to the heart, for example, in a child. We are trained to have those conversations and, operationally, overrides are not a huge issue to us. They can be managed well by our asking a series of questions such as what conversation the individual had with their family, when they had it and what they said.

If a patient has an expressed wish, we are not approaching the family for their permission. Obviously I am paraphrasing, but we would say, "Johnny was on the organ donor register; he indicated his support for organ donation, so let's work together to make that happen for him." In the future, we might use wording such as, "Johnny didn't opt out of organ donation, which indicates a support for it. Let's work together to see whether we can make that happen for him." We can have those conversations.

I think that overrides do not happen as frequently in Scotland as they perhaps do elsewhere in the UK. That is because we have 51 to 52 per cent on the organ donor register and very high public awareness. We find that families are raising the subject of organ donation with our intensive care colleagues.

Professor Turner: Clearly, this is a very difficult issue. In my view, from an ethical perspective one should give primacy to the views of the donor. Having said that, in reality, particularly for tissue donors, we need to ask the same broad range of donor selection questions as we would apply to a blood donation, for example. Those questions are very extensive in order to protect the quality and the safety of the tissue that will be transplanted into a recipient. Of course, the seminal difference is that for tissue donation the donor is no longer with us, so those questions have to be asked of the family. In reality, the family could have a de facto veto simply by refusing to answer the donor selection questions, in which case we could not proceed with the donation in any case.

Keith Brown: I assume that the answer from all three of you is no—it should not be written into the bill.

Lesley Logan: We have never had a family not want to answer the questions around lifestyle and healthcare choices.

The Convener: That is very interesting. It has never happened. Professor Turner, are you saying that it might happen if a family was reluctant to go ahead?

Professor Turner: At the moment, families can decline to give their authorisation. They can do that directly. In a scenario, for example, in which the donor appeared to have expressed their wish to donate but the family was very opposed—and if the law said that the clinician could override the family wishes—if the family simply did not answer the questions that we asked them, the donation could not proceed in any case for patient safety reasons.

The Convener: Is the general view that there should not be such a legal requirement? Your additional point is that, even if there was such a requirement, it would not necessarily be effective.

Professor Turner: I do not believe that a requirement for relatives to answer questions could be written into the law.

The Convener: Understood.

Miles Briggs: I want to develop that a bit further. First, the group we spoke to this morning were grateful for the understanding of the teams who had worked with them. It was good to hear about the positive experience that they had all had. I saw two individuals who had their medal with them—it was the first time that they had worn it. Those aspects are important, and we hope that they can be developed.

On the point that the bill might send out a confused message at a time when families are tired and their world is collapsing around them, could deemed authorisation increase family uncertainty with the result that refusal rates would stay the same? The information that we were given suggested that around 100 donors are lost in Scotland every year when families refuse to donate their loved one's organs.

Lesley Logan: So far this year we have approached 158 families, and by the end of the year the figure will be close to 200. Authorisation rates this year are up, but you are correct in saying that a high number of families still say no. We are ever striving to provide information to make the process as simple and as streamlined and non-stressful for families as we can.

Dr Cole: The committee might find it helpful to know the totality of intensive care. In 2017, approximately 10,000 critically ill patients were admitted to intensive care units around Scotland; overwhelmingly, those were patients who would not have survived unless they were admitted. They required ventilation, inotropes to support the heart and so on. Approximately 1,400 of those patients—14 or 15 per cent—died in intensive care. That represents the totality of the potential pool of donors. As Lesley Logan said, we approached just over 150 of those patients' families. The reason for that is that many patients die in intensive care in an uncontrolled way. Despite our best efforts to keep them alive, they continue to deteriorate and they die. For organ donation to be a consideration, there needs to be an element of control in the process.

Brian Whittle: It is nice to see Lesley Logan again after this morning's private session. I am going to go back to the situation I was exploring earlier. I am doing that because, as has been said before, in creating this bill clarity is absolutely paramount. Simplicity in the bill, which deals with an extraordinarily complicated environment, is what will make the bill successful. I keep coming back to the tension between the making of a positive decision—"I will be on the register" or "I will not be on the register"—and deemed authorisation, which may not involve a decision having been made. When we have these conversations, inevitably I put myself in the situation. Do you not think that deemed authorisation almost creates a two-tier system for potential organ donation and puts the family in a dilemma?

Lesley Logan: When a person opts in, their wishes are known and it is very easy for a healthcare professional to start the conversation with their family. We can say, "Johnny was on the organ donor register. He has expressed a decision to donate his organs. I would really like us to work together to make that happen. We will give you more information." When a person has opted out, equally, we need to have a conversation to ensure that they have not changed their mind. In 10 years' time, we might say, "In 2017, Johnny opted out of the organ donor register, but we want to make sure that that remained his decision." If he had changed his decision, that conversation would be helpful.

When a person's wishes are unknown and deemed authorisation comes into play, a lot of families err on the side of caution and the default position is to say no to donation. However, unless a person opts out, it will be assumed that they are supportive of donation. Getting that clear message across to the public is key. The French have run some very simply worded campaigns—I can provide pictures of them—that have helped to get that message across to the French public.

As a healthcare professional who is involved in approaching families, I do not think it complicates matters for us. When people are registered, that makes the conversation easier, and when people might be deemed to have consented, that also allows us to be a little bit more culturally presumptive, because they have not made the decision to opt out. We are able to say, "Johnny has not opted out of the organ donor register; therefore, he has indicated his support." The family may well object at that point, but deemed authorisation allows us to start the conversation with something tangible.

As you know from our previous conversations, we always check the organ donor register prior to going in to speak to a family. If necessary, we provide them with a copy of the organ donor register entry so that they can see it for themselves.

Brian Whittle: I am looking at this from my perspective, imagining that I was in that horrible situation. Before I got involved in this particular investigation, I thought that organ donation referred to the liver, heart and kidneys. After that, I was struggling a wee bit. Yes, we have lungs, but the list goes on, as we talked about earlier, and includes tissue, the face and hands. I suggest that it would be much better if that conversation was had with the donor or if the donor was able to tick the boxes that they needed to tick instead of that conversation being passed on to the relatives.

As I said, I am—disgracefully—one of the 40 per cent who has not yet signed up to the organ donor register, but if you put the form in front of me I would tick the box. Should we not be looking at ways in which we can make it easier for everybody to make that positive decision, in order to increase the number of people who say yes or who make the decision to say no? Should that not be put into legislation?

Lesley Logan: For some of the much rarer types of transplant—involving facial, composite tissue and limbs, for example—we would have to approach the family separately anyway, because it comes down to things like skin matching. There is a whole raft of other assessments that we need to make in those situations. The organs that are—for want of a better word—commonly transplanted—the ones that people sign on the register to donate—are the ones that people recognise. Therefore, those are the organs for which it should be possible to have deemed authorised donation.

We also have a uterine transplantation programme in London, and, internationally, you will hear in the press of other types of unusual transplants, particularly for individuals who have been at war. I do not have a problem. We spend up to three hours with a family, as you know, and some of the explanation really can come only through talking with a healthcare professional who knows what is likely to be considered in any individual situation. We do not want to burden families with a whole pile of information only to discover that they cannot donate X, Y and Z or A, B and C anyway. We try to tailor our conversations with them so that they know what we are thinking at an early stage.

Marc Turner is particularly interested in future proofing, so I will hand over to him.

12:15

Professor Turner: I think we would all agree with the principle that it is better to ask the donor while he or she is still alive than to ask relatives after his or her death. We would probably all support the principle of trying to encourage people to have that conversation and to make an informed decision.

Even with those efforts, of course, one cannot force people to make a decision one way or another. Some people might never get around to it; some people might not want to make a decision because their own mortality is too unpleasant to think about. You say that you have not made a decision on organ donation. I have—I have opted in. However, there are many other things that come through my letterbox and in emails that I am too busy to deal with it. I think that I will deal with them at some other time but, of course, I never do.

For me it is not an either/or situation. I think that we absolutely should try to encourage people to make a decision one way or the other, but having deemed authorisation as well covers the gap, as it were, of other individuals as Lesley Logan has described.

Dr Cole: Your point is very well made. When we go in to have a conversation with a family, it is easier for us if their wishes—one way or the other—are known. The family are not then put into a position of trying to make a decision when they are exhausted and grieving and have not slept for two or three days.

At the same time, signing up to the organ donor register, as it currently happens, is an expression of a wish at a point in time; it is not informed consent. It is not the same as someone saying, “I’ll have a hip replacement and these are the things that will happen.” The patient often does not have the full picture or the information that they need to make an informed decision.

Throughout the UK, we have made the decision that that is the process that we will go through and that we will not have formal informed consent in signing up to the organ donor register. The new legislation, as proposed, may take away some of the difficulty in that, if someone has not opted out, they have not made a positive decision not to become an organ donor. Consent will be assumed, and we can start the conversation from there.

Lesley Logan: One of the real strengths of the 2006 act was that it afforded healthcare professionals the opportunity to work with families and provide information to the level to which the family wanted it. Some families say, “He was absolutely supportive of donation. He was on the organ donor register. Do whatever you need to do. I’ll answer your questions, but I don’t want to know

anything." However, some families want to discuss donation in minute detail, and the 2006 act allows us to provide that information.

That is one of the strengths of authorisation over consent, whereby the implication is that it is informed consent. I think it is really important to try to retain that, because that has allowed families under some circumstances to go home, and it allows us and our tissue service colleagues to take telephone authorisation from them. We work with the families to find the best solution for them.

The Convener: I assume that there is nothing in the bill, as it is drafted, that would take away that ability. Is that your interpretation?

Lesley Logan: Yes. I hope it is so.

Emma Harper: I would like to address issues around adults with incapacity, because we have not covered that area this morning. Your submissions describe how the provisions state that an adult who is incapable of understanding the nature and consequences of deemed consent is, therefore, not deemed to have consented. However, there are various issues around incapacity, such as whether it is a new issue or whether it has been prolonged or has developed over a period of time. Is there enough information in the bill to allow incapacity to be considered, so that people who do not have capacity are supported?

Dr Cole: I work with patients in intensive care who are critically ill, and 95 per cent of those patients lack capacity when they are in intensive care. It is a short-term lack of capacity rather than a more long-term lack of capacity.

As you will be aware, there are two sorts of deceased organ donation: those following circulatory death and those following brain stem death. Patients who suffer circulatory death remain patients until the point of their death, so the legislation that is pertinent to them is the Adults with Incapacity (Scotland) Act 2000. Patients who suffer brain stem death are considered dead at the completion of the first set of brain stem tests, and the legislation that pertains to them is the Human Tissue (Scotland) Act 2006, which is much more favourable in terms of the death procedures and the other things that you mentioned earlier.

In terms of the AWI for ICU patients, I think the bill as it is drafted is fine. Because it is not my area of expertise, I cannot comment on the chronically incapacitated patient who has long-term incapacity that predates their admission to intensive care.

The Convener: Does Lesley Logan have anything to add?

Lesley Logan: As you know, we adhere to a hierarchy within families or among nearest relatives whom we approach about organ donation, and we do come across relatives who are incapacitated for various reasons. Sometimes, it may be down to something as simple as the fact that they have consumed alcohol or drugs; sometimes it may be that they have a condition such as Down's syndrome that limits their understanding of the process. Occasionally, families are so incapacitated by grief that they cannot even respond to us. In all those circumstances, we work very sensitively with our intensive care colleagues. If we are not comfortable that the family understands the process of authorisation, we make a decision not to consider that. When somebody is on the organ donor register, we already have authorisation to proceed and there is something around sharing knowledge. The situation does not arise very often, in truth, but if you are asking about taking authorisation from individuals who do not have capacity, that is a relevant concern.

Miles Briggs: I want to raise a small point that was raised with us by the panel this morning. It relates to complex families, changing relationships and next of kin sometimes not being clear. What has been your experience of that? We heard this morning that, in some cases, decisions can be divided, especially between the partner and the parents of the individual.

Lesley Logan: We approach the nearest relative as opposed to the next of kin. Sometimes, there is a slight difference in who that is. Occasionally we approach a partner of more than six months when there is still a parent involved—when the individual is a teenager, for example.

Generally speaking, in the time that we spend with a family, we reach a consensus. We are reasonably skilled at doing that. In our experience, if there is family discord it is likely to be between two adults with a child who are, for whatever reason, separated. The father might say yes and the mother might say no. Again, our starting point is the individual's decision, if they have made a decision.

In those circumstances, we give the parents time and space. It is our job to spend however long it takes helping the family to reach a decision. In trying to help everyone, we might go for a limited donation of abdominal organs but not cardiothoracic organs. That allows both parents to feel that they have had some input into and control over the situation. In some circumstances, when there is real strength of feeling, donation may not be possible. A newspaper headline saying, "They stole my son's organs wheeling him down the corridor," would be detrimental to the greater transplant programme and we would not want to be in that situation.

Dr Cole: I echo most of that. The most important thing in that conversation is families'

having time to come to an understanding about what should happen. The conversation is often easier if we have an understanding of the patient's wishes. The more difficult situations arise when a patient did not sign the organ donor register when they were well, so the family does not understand their wishes. Generally, with time and with skilled communication, we can work through that.

Lesley Logan: I will give you a possible scenario. The father might arrive at the hospital first because he works locally, and he might accept death or dying much quicker than the mother, who is some distance away and arrives several hours later. People accept things at different rates, so we have to wait for people to catch up and move forward together. That is the key.

Miles Briggs: It was also raised with us that some families think that clinical research will automatically take place. I am thinking of the Scottish brain bank and things like that for dementia individuals, not necessarily about organ donation. Could that area be improved? I know that it is a separate issue.

Lesley Logan: We take authorisation and conduct the social history questionnaire that you have seen for other purposes as well—for research, training, education and audit. Marc Turner will talk about quality assurance as a welcome change in the bill. We do that so that families do not have to answer those questions twice for different sets of healthcare professionals.

When we hold our remembrance services, we acknowledge those individuals. Sometimes, patients go to theatre for organ recovery and the organs are not suitable for transplant but can be sent for research if we have permission for that. We write really nice letters to the families about their furthering medical education, and they are very pleased to receive those letters. They are also included in receiving the medal and so on.

Professor Turner: Organs and tissues are taken primarily for clinical reasons, but some that are taken are not suitable—perhaps because of microbiological contamination, for example. It is very important to us that we are able to use some of those tissues or organs for what we call process developments, because a lot of the tissues undergo quite complex manufacturing steps and require validation and quality control in exactly the same way as you would expect for a pharmaceutical. Therefore, we are very pleased to see quality assurance written into the bill, because we cannot transact our jobs properly under the Human Tissue (Quality and Safety for Human Application) Regulations 2007 without applying quality assurance.

As Lesley Logan has said, although the principal consent is for clinical use, research use and evaluation are also written in, and people can assent to that or not. That is a very different scenario from asking to take tissues for research purposes only. In that scenario, independent ethics will be taken and there will be an independent consenting process. I would not want to conflate those two situations.

Sandra White: I want to explore again something that I asked the previous panel about, which is the pre-death procedures. Dr Cole, you talked about working in intensive care and mentioned that some people have concerns about the procedures that are carried out. I did not realise that if you opt in to organ donation such procedures are part and parcel of it—I have never seen any information about that. That was a new one to me and I think that people should probably be told about that. Do you share the concerns that we have heard from witnesses about pre-death procedures? How are they carried out just now? In the future, should they be carried out under deemed consent or always under express consent? Those are my three questions.

12:30

Dr Cole: This could be quite a long answer; I will try to make it as short as I can. As you heard from the previous panel, there are a number of things that we do day in, day out for patients, some of which are quite invasive, for example putting central lines into a patient, reintubating a patient, giving drugs and strong medications to bring blood pressure up and so on, taking blood and that sort of thing. What generally happens at the moment is that, if a family agrees to organ donation, the worst thing that can possibly happen to that patient is that the organs are not able to be utilised, because the patient is not physiologically optimised in order to allow a successful organ donation retrieval to take place.

We have had a lot of discussions with colleagues in the Scottish Government about what is in the bill regarding interventions and pre-death procedures. "Pre-death procedures" is not a great term, but it is where we are. We have tried to stratify the procedures into two types: those that are routine, painless and have next to no chance of causing harm; and those that are less common, perhaps more invasive, and have a greater chance of potentially causing harm.

An example of the latter might be a bronchoscopy, where we put a telescope into the patient's lungs and, under direct vision, we hoover out any secretions or contamination within the patient's lungs. That is quite invasive and if you were awake it would be quite uncomfortable, but it

is something that we do routinely to benefit patients who are on ventilation.

It is right and proper to stratify the procedures according to risk, as in patient risk. Remember that this population of people are patients, not donors. They remain patients until they die and then they become potential donors.

To avoid talking forever, I will say that the level that we have in the bill is about right. It is something that we have thought long and hard about.

Lesley Logan: Families who say yes to donation are pretty committed after that point. They want something good to come out of the tragedy and they want to save other people's lives. We are very careful to explain to families what tests or pre-death procedures need doing to allow that to happen.

We already provide families with the information from any tests that are done: blood tests are taken to support the matching of organs with recipients; urine tests are taken to test for any infection or any obvious kidney damage; secretions from the chest are taken to check for infection. Any test that we would do, we already explain.

I would be concerned about having to ask families more questions in a tick-box manner, rather than having a conversation with them that went, "As I have explained, in order for donation to proceed, we need to do a number of tests. The tests will not harm your loved one at any time. They are not painful and we will be doing them to ensure things like the best matching of organs," and so on. That is my thought on that.

Sandra White: I have one more question on this, and then I want to ask about the forms that are filled in, but that will be a short one.

The Law Society of Scotland has raised some concerns about medical ethics. Are you content that the bill covers you with regard to medical ethics in relation to pre-death procedures? I think that we should change the wording to something other than pre-death procedures.

Dr Cole: The Scottish Intensive Care Society has been closely involved with the detail of the bill. We feel reassured by how the bill is worded. As you alluded to earlier in the meeting, medical development takes place at a fantastic pace. Things that are not even thought about today may become commonplace next year. The bill tries not to be too descriptive about the list of tests, but to talk in generalities of the types of test. If we miss out test Y from the list in the bill and it becomes commonplace next year, we will end up in a situation where we have to go back and ask specifically about that.

An example of that is that in the past we specifically excluded the use of heparin in the potential donor, because we were concerned that there was a small possibility that heparin could cause harm by causing bleeds in the brain. Our surgical colleagues regret that that took place and feel that heparin is very important in optimising the potential organ for transplant. That is an example of what we were keen to try to avoid.

Sandra White: Are you quite content about that? The Law Society raised the point and you are quite content in that respect.

This is obviously not a small question because it has been raised many a time—I know that we have spoken to Lesley Logan about the bureaucracy around the 350 questions that people have to answer. We heard again this morning from the group that we spoke to that some of the questions are invasive and embarrassing—I will not go into the details of which questions they felt were embarrassing—particularly if they had their children around them. Is there any way of shortening the questions? Can we put something into the bill so that people do not need to answer those questions? It is a very emotional time for them and they are sometimes not ready to do that.

Lesley Logan: The questions are absolutely necessary because our job is to ensure that transplantation is safe, first and foremost, for the recipients. Marc Turner is better placed to talk about some of this than I am, but we know that some of the questions that we ask are specifically for tissue donation. It may be that in the future we are able to develop a subset of those questions so that, if we identify early on in the process that the patient will never become a tissue donor, we do not ask the questions. We do not want to not ask the questions and then find out that we have a potential tissue donor.

There is a way of doing that and I have provided to our Government colleagues, who will come to you in turn, some examples of questionnaires from Australia and the United States of America. My medical director, Professor Forsythe, has done something similar with some of the European questionnaires. You will see that they are pretty much all the same.

The authorisation form is a slightly different matter and we work hard to try to reduce the questions that we ask from that. We do that by asking the healthcare questions first, so that we know as professionals what we can exclude. For example, if we know that somebody has had a heart attack, we are not going to approach about heart donation, so we do not need to ask those questions. If we know that someone is a diabetic, we are not going to approach about pancreas donation. We will make those exclusions on the authorisation form to try to contract the process.

The questions generally are very, very similar, if not almost identical, to those that are asked around blood donation.

Professor Turner: I agree with you that the questionnaire is a very extensive set of questions. Whether there are 350 questions, I am not sure. I will take your word for that. Some of them are nested questions, so you might ask a preliminary question such as, "Has your relative been overseas recently?" If they answer no, you move on from that and if they answer yes you go into more detailed questions.

The questions are more stringent for tissue donation than they are for organ donation because sometimes the risk benefit ratio is slightly different in those two scenarios. The questions are consistent with those that we ask of blood donors, although they are obviously phrased and framed in a slightly different way. They also tend to be consistent across both the UK and Europe. That is because of the regulatory framework that we work within. They are guided by, for example, the Human Tissue (Quality and Safety for Human Application) Regulations 2007, which are UK-wide, and are themselves a transposition of the European Union tissues and cells directive. The granularity around the questions is put in at a UK level by the UK blood services joint professional advisory committee.

Questions can also change. We have complex geographic exclusions because things such as malaria, West Nile virus and chikungunya fever change their distributions in the world, so that is a very complex set of questions. I come back to what Lesley Logan said: they are evidence based and they are there to try to secure the safety of the product that is ultimately going back to the patient. That is what is driving the complexity.

Dr Cole: I would make a plea that, with the new bill, we shorten the authorisation process as much as possible. It already takes a long time and is exhausting for relatives.

In the previous evidence session we heard questions about intensive care capacity. Intensive care is a very scarce resource within Scotland, and occupying a bed for an additional 12 or 15 hours may, in some circumstances, mean that somebody else who needs an intensive care bed is not able to access one locally.

The Convener: That is an important point.

Sandra White: The flip side of my question is whether there is anything in the bill that would make bureaucracy worse. Is there anything in the bill that would drag the process out even more?

Lesley Logan: My understanding of the changes to the duty to inquire is that we would not be expected to go to the ends of the earth and be phoning relatives in Australia or wherever. We generally always have the nearest relatives in the room, or close by, to consider whether anyone has additional knowledge. We also ask in the medical and social history questionnaire whether there is anyone else who we should be consulting about their decisions. I think that that is probably okay.

I would not like to think that the additional questions about pre-death procedures would lengthen that process because, as you saw from our armchair theatre this morning, the families want to get back to the bedside. That is absolutely where they rightly should be and we are mindful of that.

Alex Cole-Hamilton: I thank the panel again for their input. We were all very struck by the informal evidence session with Lesley Logan and her colleagues and I thank them again for that.

We talk about these being difficult decisions and difficult discussions to have with people who are enduring, as you said, the worst days of their lives. All the decisions that they have to make in that very short window of time place an immense degree of pressure on their mental health.

This morning, we also heard from people who are on the waiting list for transplants. They, too, experience a rollercoaster of waiting and false dawns when they get the phone call and jump in an ambulance, but are then turned around. It strikes me that we have no longitudinal mental health specialist support for either group of people, either the recipients in the long wait before they get an organ and in their convalescence afterwards, or for the family members who make the difficult decision to permit donation. Obviously, people do not necessarily need support until the very end, because in many cases they do not know that it is going to happen, but they need support around the decision and then in the weeks and months to follow. Is there a gap and is this bill an opportunity for us to close it?

Lesley Logan: There is a gap on both sides. I used to manage the transplant programme in Edinburgh and I know that the social workers and the recipient co-ordinators follow up patients who are called in for transplantation but are then stood down because the organs are not available. A discussion around the resource for that would be very timely, especially if we are hoping to increase the number of transplants.

A couple of years ago, I spent some time in Sydney with the Australian transplant and donation service. Earlier this year, I was with a donor in Scotland and we had waited some 24 hours for the son to come from Australia to be at his mother's bedside. He agreed to donation, which proceeded, and I used my contacts in Australia to ensure that he was invited to a

remembrance service there. The electronic conversation that I had with my equivalent in the Brisbane area was that she would also invite him to participate in what all Australian families are offered, which is up to two sessions with a psychologist or a bereavement counsellor to support them in their decision to agree to organ donation, in case there was anything that they wanted to pursue.

I knew that that existed, but I have never had a family have that offer. We direct them to organisations such as Cruse Bereavement Care. We do follow up our families: we write to them within two weeks of the donation to give them some information about the recipients. We also invite them to the annual service, as you know, and on an annual basis we can provide updates, but we do not do anything specifically for those individuals whose loved ones have donated and who might require on-going psychological support, unlike some other countries.

12:45

The Convener: Stephen Cole, do you want to add anything to that?

Dr Cole: No, only to echo what Lesley Logan said.

David Stewart: What assessment have witnesses made of the Spanish system of organ transplantation?

Lesley Logan: I was in Munich last week at an international donation and transplantation meeting at which I was beefing up my knowledge about Spain. First, we need to be careful that we are compare apples with apples. The UK definition of a donor is someone who goes to theatre and has an organ removed for the purposes of transplantation. In Spain, the definition of a donor is somebody who goes to theatre for donation, so they are not the same thing.

In the Spanish system, families are re-approached up to six times to see whether they will say yes. We might feel that that is a little bit harassing. If the family says no, staff wait half an hour then go back in. If the answer is still no, they wait another half an hour and then go back. That is well understood in Spain's intensive care, so their donation rates are high. The Roman Catholic Church supports organ donation, and people have extended families, so there are demographic, cultural and religious reasons why donation might be better supported there.

Stephen Cole has spoken, and may speak again, about intensive care bed numbers. What is really interesting—I do not think that anyone knows this yet—is that the latest surge in donation rates in Spain is because of a new initiative that they are calling intensive care for organ donation. Families of individuals in hospital wards who are not ventilated are being asked whether, following the individual's catastrophic event—for example, a stroke—and their having entered a pathway of care in which they are likely to die, donation may be possible; if so, they are electively ventilated. That causes significant ethical concern.

In Spain, donation after circulatory death is different to the circulatory death donation that we pursue in the United Kingdom. They can retrieve organs in all their hospitals, whereas the UK model is that our retrieval teams are highly specialist doctors: seven abdominal teams and six cardiothoracic teams service the UK. The model of healthcare is also very different. All those things together contribute to the quite different numbers that you see.

Croatia is also a very high donating country but it has, I think, only nine organ-retrieving hospitals. It is much easier to manage nine hospitals and to move them all in the same direction. Scotland has 25 such hospitals and 14 regional health boards. There are big differences, but we watch all the time to see whether there is anything that we can consider.

David Stewart: That is very useful. All three of you will have heard my question to the previous panel. I have always been very wary of comparing countries, even within the EU. That said, very crudely—as you will have heard me say—the UK's donation rate is half Spain's rate, even assuming the same family refusal rate. That is quite striking. Notwithstanding cultural differences, is there best practice that we can pick up that might be included in the bill?

Lesley Logan: I should also have said that the organ discard rate in Spain is very high. Staff approach and get permission for donation from patients whom we in the UK might consider to be not suitable. The result is that organs are discarded and not transplanted. It is very important to us that, if we pursue donation, we are pursuing it for the expected outcome. We never remove organs unless we know that they have been placed and accepted by a transplant centre for a named patient. That is another difference.

Dr Cole: I heard your comments to the previous panel. As well as public awareness and education, I would like to highlight the fact that Scotland has fewer intensive care beds per thousand population than the rest of the UK, and many fewer than southern European countries and the United States. That is a cultural situation that we have developed within the UK and Scotland. Intensive care is a very scarce resource.

My other hat is for my role in the Scottish Intensive Care Society audit group, so I know

about the numbers of patients who are admitted to hospitals. One of the ways through which we could effect change would be to invest more in intensive care capacity around the country. Donation would be a by-product of that, but it would also benefit the wider population in terms of lives saved and people returning to normal health.

Lesley Logan: Another thing that is worthy of note is that the further south in Europe you go, the higher the number of road traffic accidents that cause trauma. Only 3 per cent of our donors in Scotland come to us through road traffic accident trauma, because our roads are safe in comparison with those in southern Europe.

David Torrance: Do you agree that 16 should be the age for deemed authorisation?

Professor Turner: It is not for the SNBTS to take a position on that question. It is a question for the people of Scotland and for Parliament. Whatever age is decided is the right cut-off, we will respect that and apply the appropriate regulations.

The Convener: Thank you very much. There are no different views from other witnesses.

David Torrance: Could different ages for deemed authorisation across the UK cause legal problems for transplants?

Lesley Logan: I am not aware of any such problems, at the minute. In Scotland, we would still accept an organ from a child who died in Wales. Allocation of organs has not in the past been problematic in those circumstances.

Professor Turner: I might be able to answer the question by analogy. When we changed the regulations on blood donation around deferral of men who have had sex with men, England, Wales and Scotland changed to a 12-month, and now three-month, deferral. Northern Ireland did not change. It has continued with permanent deferral, at least for now. We obviously had to come to an understanding with Northern Ireland because sometimes, in times of shortage, we support healthcare there by providing blood, for example. It was agreed that Northern Ireland would receive blood from us, from either NHSBT or from SNBTS, that would obviously have been selected and screened according to our donor selection and testing criteria, and not theirs.

In the scenario that I think you are suggesting, where there might be a difference in age between, say, Scotland and England, both countries would have to accept the application of the criteria of the other jurisdiction.

The Convener: That is a relatively straightforward matter, in your view.

I thank our witnesses. It has been another very useful session.

12:54

Meeting continued in private until 13:36.

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