OFFICIAL REPORT
AITHISG OIFIGEIL

Health and Sport Committee

Tuesday 20 November 2018

The Scottish Parliament
Pàrlamaid na h-Alba

Session 5

Tuesday 20 November 2018

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HEALTH AND SPORT COMMITTEE
30th 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:

Dr Frank Atherton (Welsh Government)
Dr Katja Empson (Cardiff and Vale University Health Board)
Richard Glendinning

CLERK TO THE COMMITTEE

David Cullum

LOCATION

The James Clerk Maxwell Room (CR4)

Scottish Parliament

Health and Sport Committee

Tuesday 20 November 2018

[The Convener opened the meeting at 10:01]

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

The Convener (Lewis Macdonald): Good morning, and welcome to the 30th meeting in 2018 of the Health and Sport Committee. I ask everyone in the room to ensure that mobile phones are switched off or set to silent. Although it is acceptable to use mobile devices for social media, please do not take photographs or record proceedings.

Agenda item 1 is the third of our evidence sessions on the Human Tissue (Authorisation) (Scotland) Bill, which proposes to introduce a system of deemed authorisation for organ donation. Today, we will focus on evidence from Wales reviewing the Human Transplantation (Wales) Act 2013, which came into force in 2015, in order to allow us to explore in greater detail that act and its impact on organ donation rates in Wales.

I welcome Richard Glendinning, who is now with Ipsos Mori and who was formerly director of social research and lead researcher on the evaluation of the Welsh act at Growth from Knowledge UK; Dr Frank Atherton, the chief medical officer and medical director of NHS Wales with the Welsh Government; and Dr Katja Empson, regional clinical lead for organ donation for south Wales, from Cardiff and Vale University Health Board. Thank you for attending—it is much appreciated by the committee. We are keen to learn the lessons of the Welsh experience and experience elsewhere.

I suspect that the central issue for the committee and the Scottish Government in considering a change in the law is whether that change would enable an increase in the rate of donation and the rate of transplantation. I ask the witnesses to start by offering an overview of the general perception from the evidence as to whether the act has met or is beginning to meet its fundamental purposes.

Dr Frank Atherton (Welsh Government): Thank you for inviting us to talk about our experience in Wales. It has been our great pleasure to share our experience with Scotland and other countries. I emphasise that there has been a lot of interest in looking at our experiences to date.

Of course, it is still relatively early days in Wales, as it is only three years since full implementation of our act. We are still in a learning process but, generally, we believe that it has been a positive move. We can talk about the statistics and the figures on donation and consent rates—I am sure that we will get into some of that—but in general we feel that donation rates are going the right way. In Wales and the rest of the United Kingdom, too many people still die while they are waiting for organ donation. That is a tragedy in every individual case, and we want to work collectively on it.

My overarching point would be that the legislation has been a really important part of our process to improve organ donation rates in Wales, but it is not the whole story. We know that a range of things need to happen—we need to get the infrastructure for organ donation right, and we need to get the public engaged. I would say that the most important part of our journey has been to do with how we have used communication during the development of the Human Transplantation (Wales) Bill, during the pause between royal assent and full implementation of the Human Transplantation (Wales) Act 2013, and as we have proceeded with implementation. We believe that legislation is an extremely important part of changing cultural attitudes and working with and persuading the public, so that they believe that organ donation is the right thing to do.

Our success has been very positive. As I said, it is still early days, but we believe that we have a lot of useful experience to share. We believe that this is the right thing for Wales. There is very little public dissent in Wales. There was a lot of discussion and dialogue when the bill was proposed and, before that, when the white paper came out. The process that we went through was an important one, and so is the one that you are now going through in Scotland.

There has not been a lot of abreaction to the legislation. There are high levels of understanding and awareness of it and of the choices that people now have to make. There is a generally positive feeling that this has been the right way to go for Wales.

The Convener: I think that the initial evaluation of the impact of the 2013 act suggested that donor rates had not increased whereas family consent rates had, although there have been developments since then. Do you have a view on why one of the rates went up faster than the other? Is there any reason for the lag in the increase in donations?

Richard Glendinning: I do not think that there was any expectation that there would be an overnight change. The process whereby people's knowledge and awareness of, and support for, the change grows is a gradual one. It is reasonable to expect that we will see change over time.

When we did the impact evaluation, one of the concerns was the fact that we had a relatively narrow window to look at the data—we had only seven quarters of data. In Wales, typically, there would be about 15 donors a quarter, so that was a very small sample to look at. We extended it as far as we could. There were a lot of positive signs on some of the softer measures to do with attitudes of the public and of national health service staff, but during the formal evaluation period that we reported on a year ago, there had been no significant change in donor levels. There was a very small rise over the 21 months before the implementation of the legislation and the 21 months afterwards.

In the past 12 months, there has been a marked increase, when there have been more than 80 cases. That is probably the highest figure that we have ever had in Wales. The evidence suggests that there needs to be a build-up of knowledge, awareness and support and that a rise in donor levels will come after a period of time.

Dr Katja Empson (Cardiff and Vale University Health Board): Immediately after the implementation of the legislation, there was a lag period in which the specialist nurses acquired familiarity with the terms of the legislation. They understood the act, but it took some time for them to become familiar with it and confident about using the deemed consent terminology in the conversations that they had when they approached families. There was a significant shift in practice from what had previously been a family and relative-centred approach to one that was more to do with the presumptive facilitation of the deceased's decision, and it took some time for the specialist nurses to acquire the skills that they needed for those conversations.

The Convener: That is interesting. Was there any change in the rate at which families were approached, or was it simply that there was a difference in the way in which the terminology was used?

Dr Empson: I do not think that there has been a significant increase in the rate, but there have been improvements in the recognition and referral of patients to the transplant teams. Outwith those teams, the ability of intensive care and emergency departments to identify potential donors and to refer those patients has improved, so there has been a degree of increase. However, the substantial change was around the specialist nurses' familiarity with the use of the different terminology.

Emma Harper (South Scotland) (SNP): Good morning, everybody. In Wales, 41 per cent of people have opted in, according to Dr Atherton's submission. That means that 59 per cent of the Welsh population have still not registered whether they want to opt in or opt out, so you would deem their consent.

Has any analysis been done of the people who have not recorded any wishes to decide on the extent to which we will get those people to opt in or opt out?

Dr Atherton: You are right—41 per cent of people in Wales have chosen to opt in. That number has increased over time; it has been rising gradually, which we believe is positive. The number who opt out—people now have an opportunity to do that—is at about 6 per cent and seems to be stable, which is good news.

Younger people tend to be slightly more likely to opt in. Richard Glendinning might have some further numbers on that. However, we never expected to get to 100 per cent. It is really important that people understand their choices. We do an annual survey, so we know that 70 to 80 per cent of people now know what their choices are. Those people who have a view and who do not wish to donate have a clear understanding of their ability to opt out. It is reassuring for us that the figure for people opting out is staying stable at about 6 per cent.

Richard Glendinning: On the proportion of people who have made no decision one way or the other, it is interesting to see from the research that we have done across NHS staff and the general public in Wales that about three quarters or more of people support the idea that no decision implies consent. There is quite a lot of understanding out there about the implications of not making a formal decision.

As Frank Atherton said, 41 per cent of people have chosen to opt in; I think that that is the highest percentage in the UK. That figure has continued to rise, whereas there has not been much of a rise in those who have opted out. However, there is a general understanding across the public that not making a decision implies consent.

The Convener: It is the highest opt-in figure in the UK other than in Scotland, where we are at 51 per cent.

Richard Glendinning: It is good to know that.

Emma Harper: Dr Atherton mentioned that young people are more likely to opt in. Are you concerned that some groups might have been missed out and that a more targeted approach may be needed? I am also curious to know whether NHS staff have been assessed to find out whether they are opting in or opting out.

Richard Glendinning: There is definitely a higher level of opting in among NHS staff than among the general public. There is variation in the levels of positive opting in. I think that younger people are a bit less likely to opt in. Perhaps the issue is not very high on their radar, because of their age. We need to further communicate and push that point across to people.

Dr Empson: The public awareness campaign that was launched before the implementation of the 2013 act centred around the choices that people had. The three choices were to opt in, opt out or do nothing. The understanding was that, if people did nothing their consent would be deemed. The do-nothing option was very much presented as an option that people had and the expectation was that it would be seen as being on the same level as the opt-in option.

In the first year or two after implementation, there was a feeling that there was a two-tiered opt-in. If someone opted in on the register, that was seen as a stronger opt-in than deemed consent. Gradually, over time, the healthcare professionals who are working with the families of patients are seeing those two types of consent as being on the same level and they present them as such to the families who they are working with.

10:15

Dr Atherton: I am sorry—younger people are less likely to opt in. I apologise if I gave a misrepresentation.

Emma Harper asked whether there are groups that we worry about, and that brings us to the question of ethnic minority groups. I do not have the figures to hand, but we recognise that people in black and minority ethnic groups are less likely to make those conscious decisions and are less likely to opt in as donors.

We have done specific work as the communications have evolved in the three years since implementation of the 2013 act; we recognised the need to do that. A lot of work was done before the bill was introduced to try to understand the views of religious leaders and ethnic minority groups, for example. However, we believe that we still need to do more work to target those groups.

Keith Brown (Clackmannanshire and Dunblane) (SNP): I have a factual question, the answer to which may be evident from the evidence that has been given. In the Welsh system, if someone opts in and the family and the clinicians subsequently have a different view, can that be overturned?

Dr Atherton: It can be. That is a fact. We have always described the process in Wales as a soft opt-out process. Katja Empson may have more information about that, as she deals with it more regularly on a personal level. The policy was always that families would have the opportunity to make a final decision, bearing in mind the wishes of the deceased relative.

The good news in Wales is that, although there are occasions when families overrule the presumed consent or the opt-in consent that people have given before they became deceased, that proportion is going down.

To return to the communications issue, we recognised last year the need to provoke conversations in the family about the issues and the conscious decisions that people have made. When people opt in, we encourage them to have those conversations with the family so that the family are aware of their relative's desire before anything untoward happens. We continue to use that messaging in Wales, and that is a key stream for the future.

Dr Empson: There will always be families that have to make the decision to override the decision that the deceased relative had made, and there are a number of reasons why people would make that choice. For the clinicians and specialist nurses involved, the sense now is that we are able to push families harder in what can be a very difficult time. Obviously, it is a very difficult time for the family but, because of the change in the legislation, perhaps we are empowered to have more presumptive conversations with families, to push and challenge them, and to try to ensure that they facilitate the decision that their loved one made in their life.

Ensuring that members of the public are educated to have conversations with their family so that their wishes are known is key. Much as they might choose to make known whether they want to be cremated or buried after they have died and in the same way that they make decisions about other aspects of what would happen to them after they have died, they should make their choices clear to their families.

It would be impossible to work with legislation that somehow enforced the pushing through of the decision to donate, irrespective of what the family's position was in that situation; ultimately, the specialist nurses and clinicians who work with the family would not want to cause harm by pushing through donation if the family clearly felt that it could not support that. The family's support is needed in order that donation can be proceeded with safely. There needs to be the ability to ask the family questions about the potential donor's health and social aspects of their life, in order that the transplant can proceed safely. Trying to make that happen without the family being positive and on board with the process would be almost impossible.

Richard Glendinning: I want to support the point about the conversation, which is a key part of the process. It is less difficult for the specialist nurses to have the conversation in the knowledge that more people have been talking about the issue. The latest research shows that 55 per cent of people said that, at some point, they had had a conversation with family members about organ donation. That leaves a lot of people who have not had that conversation and some of those conversations will not necessarily be contemporary, so there is still a need to promote having that conversation because it makes the conversation that has to be had in due course less difficult.

The circumstances are challenging, for sure, but it becomes slightly more straightforward in the context that the conversation might have taken place within that family and that the wider family was aware of the individual's wishes.

Keith Brown: I want to ask a quick question that should have a factual answer before I move to my substantive question. Would the reverse work if somebody had opted out? Can that decision be overturned by the family and clinicians?

Dr Empson: It can, in practice, if the family can provide evidence that the person had changed their decision. For example, the family might present evidence such as, "He decided that a few years ago when the legislation changed, but the other night we were talking to a family whose son was waiting for a kidney and he said quite clearly that, on balance, he would not have a problem with that."

We ask families to provide evidence about the sort of conversation that they had to support that change in decision. That could happen. It is about the person's last-known wish, and the decision that was recorded on the organ donor register might not be the last-known wish.

Keith Brown: My concern is about where the rights of the donor come in all this. It seems that they come behind those of a number of other groups when a person makes a decision to opt in, opt out or do nothing.

If a person's decision, whether it is to opt in or opt out, which was taken when they were in full possession of the facts, can be overturned, why was it decided not to put that into the bill except in the circumstances that you just mentioned and when additional information can be offered? As far as I can tell—maybe it was in the communications strategy—it was not made plain to donors that their expressed view can be overturned. Is there a reason for not including the family veto in the bill?

Dr Atherton: We might need to go back to the Welsh act, but I believe that it was clear that we were talking about a soft opt-out process, which means that a decision can be overturned. You might need to look at what was in the bill, but my belief is that it was pretty clear.

The Convener: In Scotland, the convention is clear but it is not in the bill. The question is simply whether that is right and whether it is the Welsh model. We deduce that it is, but anything further that you might want to come back to us with on that would be welcome.

Alex Cole-Hamilton (Edinburgh Western) (LD): Good morning, panel, and thank you for coming to see us. I would like to explore why families override such decisions. We had an illuminating meeting with specialist nurses who took us through a role play of the conversations that happen prior to or just after death, when a patient's organs will be viable. They made it clear that, in Scotland, one of the barriers is the sheer number of questions that are asked of families at that time.

There might therefore be a bureaucratic impediment to a successful discussion with families at the time of death. They are experiencing one of the worst days of their lives and they might have to answer several hundred questions in some cases.

What happens in Wales? Is it as bureaucratic as Scotland? Have you found any workarounds or shortcuts?

Dr Empson: I am not sure that the process is bureaucratic, as such. A number of questions will be asked of families so that the donation can proceed in a safe manner. We need to ask quite deep questions of the family about their social history and the patient's health to ensure that the transplant goes ahead safely. If the family was unable to support those questions it would be difficult to proceed with donation.

I do not think that they are presented in a bureaucratic way, because ultimately the specialist nurses are well trained and experienced and are able to manage families in that situation sensitively and compassionately. I would like to think that that conversation does not present itself as a tick-box exercise or a shopping list, but perhaps that is the way it might look if you were to simply review the forms that the specialist nurses use. The conversation would take place in a compassionate way.

Some families will look for more information from the specialist nurses about how the donation process goes. They might then be presented with further information by the specialist nurses about the processes pre-death or after death. Other families will want less information, because they simply do not want to know and are happy to let the process run its course.

The specialist nurses are able to share information as and when it is needed, but a series of questions need to be addressed and answered in order that donation can take place safely.

Alex Cole-Hamilton: I understand that, and I should say that the specialist nurses we met had a wonderful manner and turned those questions into a conversation about the life of the person who had just passed away, which I think was quite a cathartic experience—it certainly seemed that way in the role play that we experienced. Do either of your colleagues have a view on whether we could be doing things in a simpler manner?

Dr Atherton: I echo what Katja Empson said: the last thing that we need is to have layers of bureaucracy when people are going through very difficult circumstances, but safeguards need to be put in place and information needs to be gathered. What has just been described is the way to go about it. It is not about legislation, but policy and practice.

Richard Glendinning: I have nothing in particular to add, other than to say that specialist nurses continue to need support and guidance about best practice. That evolves over time—it is a continuous process of updating knowledge.

Alex Cole-Hamilton: I will ask a very short supplementary on that before I move on to a different area. What I am driving at is that, for me, one of the most jarring moments of that role play was when they started asking about intimate aspects of lifestyle and particular risky behaviour. It strikes me that families might not know about risky behaviour and that theirs is a subjective viewpoint. They might say, “I have absolutely every faith that they never engaged in that kind of practice,” but that is not a surety—there are no guarantees. Given that there will be strong clinical measures to test blood and tissue for evidence of contamination or disease, is it really necessary to ask such sensitive questions?

Dr Empson: It is set out in our code of practice that the expectation is that we will explore those themes with families. Our experience of that over the past few years suggests that it is necessary to ask those questions of families. I do not know the evidence behind that or what work has been done to try to prevent the need to ask those questions, but it is my understanding that they are an essential part of the process of safe donation and transplantation.

Alex Cole-Hamilton: Okay. That is absolutely fair enough.

What mental health support is offered to families in the initial 24 hours after the discussion about organ donation and in the weeks and months following a decision to donate?

Dr Empson: It is important to understand that the process of consenting to or authorising organ donation is a normal part of end-of-life care and that it does not require any particular special mental health or psychological support for the families. In many ways, the evidence suggests that families who have gone through the process of donation get an enormous benefit from it; it is a positive outcome for families at an otherwise very bleak time. I do not think that families require particular psychological support over and above what should be offered as part of standard end-of-life care and bereavement care for families who are going through the process of a loved one dying.

10:30

Alex Cole-Hamilton: That is helpful. My final question is perhaps more pertinent. Last week, we had a powerful meeting with organ recipients. We were struck by what we heard about the absence of mental health support for people who are on transplant lists. The recipients described being on the list as a rollercoaster—they might be called several times in the middle of the night to tell them to be ready for a transplant, only to be stood down for whatever reason. That can be tremendously hard, particularly as the people who are involved are very ill. What support is offered to people in Wales who are on transplant lists?

Dr Empson: I cannot answer that, because I do not work on the recipient side—I am very much on the other side of the process. However, the psychological difficulties for patients who are in such circumstances are clear—they face chronic illness and uncertainty about their prognosis while waiting for an organ. When a patient receives an organ, the knowledge that it came from somebody who is deceased is also a psychological problem. I am sure that support is required, but I am not sure what we offer in Wales.

Dr Atherton: Likewise, I cannot answer at the moment, but I recognise the dilemma for the people whom Alex Cole-Hamilton mentioned. When we get back to Wales, we will check the situation with service providers. I do not believe that any specific mental health support is dedicated to such patients but, if it is, we will let the committee know.

Alex Cole-Hamilton: That would be helpful.

The Convener: We appreciate that.

Sandra White (Glasgow Kelvin) (SNP): When I have listened to evidence and met families—Alex Cole-Hamilton mentioned that—the positive thing that has come through all the time is that people feel that a donation is a gift, which might not be the case for deemed consent. Do people in Wales think that a donation is a gift, rather than something that involves the state interfering?

Dr Empson: In the consultation period that led up to our legislation, there was much discussion about the concern that the legislative change would remove donors' ability to make an altruistic gift at the point of death. However, the concern has not been borne out in implementation. There is no sense that people no longer see a donation as a gift; donor organs are still valued as a wonderful gift by the public and by people who are involved directly and closely with the process. Key to that is celebrating the donor's life through the Order of St John UK awards and other softer activities outside legislative change that maintain positivity.

The Convener: When Keith Brown asked about family overrides, Dr Empson mentioned that, in some circumstances, a family might still take a different view even if somebody was deemed to have given consent or had positively opted in. Do the rates of family override differ for those categories, or are the numbers that are involved in both so small that they are statistically insignificant?

Dr Empson: I am sorry—I missed the first part of your question.

The Convener: Do the rates of family override differ between the group of people who positively opt in and the group of people who are deemed to have given consent?

Dr Empson: That is difficult to interpret from the raw data. In the period immediately after implementation, I am not sure that we were very good at recording where people were on that spectrum. It is not clear from the way in which we collected and recorded data whether deemed consent was being overridden because of a wish expressed verbally by the family, or whether there was a clear override of a known decision.

I do not think that we had that granularity of information immediately after the implementation phase. We are better at recording it now, because we have understood those different groups better and the information is better captured. In all groups, we have seen a reduction in both known expressed wish and deemed consent overrides. It is difficult to tease out the information and we are talking about very small numbers, so it is difficult to draw any true conclusions from it.

Miles Briggs (Lothian) (Con): I want to ask a couple of questions about consent rates. The submission from Dr Atherton highlights that consent rates in Wales have increased and are now significantly higher than in England. What do members of the panel attribute that to? Has it been the national conversation that has taken place in Wales? Can that be maintained, now that the legislation has been passed and it is perhaps out of people's minds?

Dr Atherton: I will start, and Richard Glendinning may wish to come in on some of the figures. Consent rates are increasing, which we have recognised as one of the positive markers of the programme. Your question was about what part the legislation plays in that, versus what part the communication plays. We have been trying to disentangle those elements, but they cannot be fully disentangled because they are interrelated. We believe, however, that on-going communication is required. We see that some of the things that we measure drop off when communication dips, so we recognise that we need both to continue with annual communication and to tailor that education towards specific issues. We talked earlier about having family conversations, for example. We think that donation rates are increasing and improving as a consequence of both the legislation and the communication processes.

Richard Glendinning: I echo Frank Atherton's point that the percentage has gradually risen. It is at 41 per cent and it has been creeping up year by year over a period of time. The nature of the Welsh system and the widespread recognition that no decision implies consent may cap that figure. It is not necessarily going to surge ahead, but it may continue to rise because there is a gradual build-up of awareness and knowledge.

Miles Briggs: Thank you. On the age of consent, the bill that we are looking at proposes that deemed authorisation would apply to people aged over 16 in Scotland, while in Wales the age is 18. Why was the age of 18 chosen in Wales?

Dr Empson: I think that it was chosen because it is in line with the Mental Capacity Act 2005, but you might want to ask the lawyers. My understanding is that that age would keep our bill in line with other legislation in Wales.

Dr Atherton: It was to do with that and with our general definitions in a range of legislation about the point at which people are classified as adults and have sufficient mental capacity to make decisions of their own.

Miles Briggs: Given that the Scottish age of consent will be 16, if this bill passes, will there be any issues around NHS Wales accepting organs from a 16-year-old from Scotland, as far as you know?

Dr Empson: I cannot imagine that there would be. Much as you will do in Scotland, we receive organs from people who have had their consent deemed. It would not be an issue to deploy the legislation to receive organs from other nations.

Dr Atherton: Our approach has always been that any organs go into the general pool for UK-wide use. We would expect that to apply to Scotland, as it does to Wales.

David Torrance (Kirkcaldy) (SNP): Some of the responses to the committee have highlighted the need for adequate efforts to inform the public about opting out. What avenues are available to people to opt out in Wales?

Dr Empson: People can opt out on the website. They can still opt out through the driving licence, but they are encouraged to opt out by the website that the NHS and the Welsh Government publicise and give links to whenever they send out public information.

Dr Atherton: In addition to the routes that Katja Empson has mentioned, we explored whether it would be possible to opt out through primary care records. However, that became quite problematic in Wales, and we did not go down that route. The reason for that was that, in primary care, there is often a delay between somebody making a decision in perhaps a paper-based system—our electronic systems are not quite as rapid as they should be—and getting that on to the register. It was seen that somebody could have elected to opt out but that that was not recorded within a small window and, if the person became deceased, what happened would be contrary to their wishes. We looked at that approach and discounted it, and we have tended to use the routes that Katja Empson has mentioned.

David Torrance: How did you manage to communicate with difficult-to-reach groups, such as the percentage of our population who have difficulty reading and writing and the deaf community?

Dr Empson: An adviser for ethnic minorities and for disability and disabled groups sat with the Wales transplantation advisory group. Specialist nurses—certainly in Cardiff—also did a number of outreach sessions for disability groups to try to raise awareness in them, and they also worked with faith leaders. The Welsh Government did work, and healthcare professionals such as specialist nurses did outreach work in communities.

Dr Atherton: That work to try to understand the needs of special groups and people with disabilities of whatever nature translated into the communications materials that we produced. They were produced in Braille, in a number of languages and in large font, for example. We tailored the information and communication to the needs of the community. That is very important.

Brian Whittle (South Scotland) (Con): Good morning, panel. Thank you very much for coming to give evidence.

Wales has an opt-out system, and you have retained an opt-in system. If neither of those options is taken, there is deemed consent. Where does the public understanding of the potential decisions that can be made currently stand in Wales?

Dr Atherton: That is one of the issues that we regularly look at. We have seen the figures rise year on year. I do not have the latest figure in my head, but about 70 per cent to 80 per cent of people understand what their options are. The figure dipped slightly in one year, and we recognised the need to intensify our communications and remind people of their options. That is not something that we can do and forget; it is not a one-off thing. We have to continually drip-feed that information as part of our communications message. However, we think that we have very high and sustainable levels of public understanding of the three options.

Brian Whittle: I think that Dr Empson touched on this issue. If communication and marketing, for want of a better expression, are at a high level, every possible opportunity is given to those who wish to opt out and that decision is made as accessible as possible, why is the opt-in retained? If the communication is particularly good and a high level of understanding is delivered, why is the opt-in retained? Opting in and opting out are decisions, but deemed consent in those circumstances is potentially a non-decision and is easier to override. That is what we are trying to explore. Why is the opt-in retained?

Dr Empson: That is not something that I have given thought to. Perhaps that is partly historical. In the UK, we have always had the organ donor register, so there has always been the opportunity to opt in since transplants and donations became options.

10:45

The opt-in also encourages people to consider the opportunity. We know that, statistically, when they are asked, most people say that they want to be donors, but fewer people take the action of registering. By maintaining the opt-in register, we allow people to say definitely and clearly, “In the event of my death, I want to donate my organs.” It will take some significant time and an awful lot of education for the public to see that on the same level as not registering—I am sorry, but I have lost my train of thought.

Given that we have always had that register and there has always been the opportunity for people to register their wish to be a donor, losing the facility for people to make that positive choice would go against the positivity around organ donation. If there was only an option to opt out, that would be a backward step for the public of Scotland.

Dr Atherton: There is something about aligning with the register. We have a UK register, and we need to be mindful that other countries have different policies and practices. We need to align with the register.

The other fundamental point that we touched on earlier was that having an opt-in—a conscious decision—is really important to help provoke conversations within families. Whether there is deemed consent or opt-in consent, we need to have those conversations to prevent the issue of families overriding decisions, which we talked about earlier. A conscious decision that is discussed in a family seems to us to be the best option, because it will provoke discussions and lead to higher organ donation rates.

Brian Whittle: Obviously, we are looking to increase donation as much as we possibly can. That is the outcome that we all want. What I am pushing at is whether we could give the maximum opportunity for people to opt out. There could be a conversation with the family to say, “Your loved one had the opportunity to opt out and their decision was to remain, so there is deemed consent.” Would that not be considered a positive decision?

Dr Empson: My concern about that approach is that you would allow people only to make a negative choice. In that situation, the education and publicity campaign that you would have to launch would have to be about making the choice not to donate and to register your wish not to be a donor. The negativity in such publicity might go against the popularity of organ donation, if you see what I mean. It could mean that people would just take away the message that they should register the fact that they do not want to be a donor. You might lose something in your messaging to the public.

The Convener: Richard, do you have anything to add to that from a communication perspective?

Richard Glendinning: No, not really.

The Convener: That is absolutely fine.

Emma Harper: I am interested in issues around deemed consent and people who might have incapacity or might not have the ability to understand what deemed authorisation means. The Scottish bill includes safeguards so that authorisation for donation cannot be deemed for certain categories of people with incapacity. It talks about people who have, over a significant period, lacked the capacity to understand deemed authorisation. Does the bill present enough information so that people who do not have capacity will not just be deemed to have provided consent when they have not had the ability to understand? What do you do about that in Wales?

Dr Empson: Our legislation protects that group of people. The code of practice puts it in the area for the specialist nurses to explore.

Of course, people who lack capacity can still donate through the same process that we had before the legislation, whereby their thoughts and feelings about donation could be explored with the family and we could go down the route of allowing them to become donors through their expressed wish. However, their consent would not be deemed in the same way as it would be for somebody who had capacity in their lifetime. The workaround for that is through the conversation that takes place with the specialist nurses at the time.

Emma Harper: The Scottish Independent Advocacy Alliance has said that the provisions in the Scottish bill need to be strengthened to support adults with incapacity. The bill talks about a “significant period” of incapacity. Does it need to be more prescriptive? A “significant period” could mean anything—a month, a week or six months. Should the bill be stronger on that?

Dr Empson: The situation is not clear; there is no specific time period in our legislation. There are potential advantages and disadvantages both ways. There could be a cut-off point at which somebody suddenly lacks capacity. In some ways, it is safer to allow the healthcare professionals who are involved to make that decision, based on their understanding of who that person was and for how long they had not had capacity.

It should be in the code of practice that it is the duty of healthcare professionals to explore whether the patient had capacity to deem consent and the length of time for which they had not had capacity. I cannot see an advantage to having a specific cut-off point, because there might be a patient who had lacked capacity for just a few days more than that, in which case it would not sit right. I think that it is best to leave it to the judgment of the healthcare professionals who are involved at the time.

Sandra White: I want to ask about pre-death procedures. The proposal from the Scottish Government is slightly different from the proposal that was put forward by the Welsh Government, because your legislation refers to part of the Human Tissue Act 2004. The Scottish proposal is that there should be more clarity and that there will be guidelines on procedures that can be carried out before death. Can you give us a bit more information about what happens as regards pre-death procedures in Wales, particularly under deemed consent?

Dr Empson: There are accepted practices and things that can be done to support a potential donor and facilitate their becoming a donor. Those are agreed at UK level through the work that was done by the UK donation ethics committee. I do not think that we approach families and ask them for specific consent for those procedures unless families are looking for information and want to understand it in greater detail. It is accepted practice by the healthcare professionals who are looking after the potential donor at the time. We understand that the family might not always wish to know the finer and more difficult details of the medical actions that are taken in relation to the donor.

Sandra White: That seems very different from what we have heard from families of donors. We heard from someone who had gone through the process; they were talked through it and were able, if they wished, to see some of the procedures.

You talked about people's consent and their understanding. Your answer suggested that people do not understand the pre-death procedures that go ahead under the 2004 act, which allows a body to be kept alive to preserve its organs. Do you agree with those processes being undertaken in Wales under deemed consent?

Dr Empson: Families understand and are very much involved in the process, but we would not want to ask a family whether they agreed to a whole array of blood tests, to us starting this infusion and that treatment, and to us giving steroids and starting a particular type of treatment. Going through those specifics with a family would be unnecessary, but a family would be very much involved and would have the opportunity, for example, to observe things such as the certification of death by neurological criteria—to watch the brainstem death test taking place. We would support and encourage that if a family wanted to have that involvement, although not all families choose that. However, it is important that a family should not have to consent to every activity that might need to be undertaken with the potential donor.

Sandra White: Under deemed consent, there is an opt-out system, and people do not have to sign anything. Do you support pre-death procedures in that situation?

Dr Empson: Deemed consent would be the same as expressed consent from people who opt in. The problem is that, when people sign up to the organ donor register, they are uninformed about the process that will take place. Unless someone works in an intensive care or emergency department environment, they will be unfamiliar with the process by which somebody becomes a donor. Sharing that information in a publicity campaign would probably not be in the interests of the vast majority of the public, who will not want to understand the level of detail that is involved.

When a potential donor is going down the route of donation, appropriate information is shared sensitively and compassionately with families. Families are given the opportunity to observe and understand processes, but we would not want to put families through a tick-box process for every investigation, test or additional infusion that might be started.

Dr Atherton: When the Human Transplantation (Wales) Bill was discussed in the Assembly, the issue was looked at. The conclusion that we reached was that we would replicate section 43 of the 2004 act. I am obviously not a specialist in the matter, but I understand that the Scottish bill is slightly different. The issue will need to be looked at carefully. We chose to align the Welsh bill closely with the 2004 act.

Sandra White: The subject is difficult to broach, but it has been raised, and I have maintained an interest in how the process works in other areas. What we propose is slightly different and will involve a wee bit more information and guidelines.

The Convener: In his helpful submission, Frank Atherton compared the Welsh legislation with the Scottish bill and drew conclusions about the Welsh legislation's effectiveness. Having answered members' questions, do the witnesses wish to add anything that they feel that we should bear in mind for the next stage in the process?

Dr Atherton: I thank the committee for the opportunity to give evidence. All of us in the UK are on this journey, and it is good that it is shared. It is one of many experiences that we can learn about and share across countries. I wish the committee good luck with its deliberations.

The Convener: Keith Brown has made a late bid to ask a supplementary.

Keith Brown: I back what the convener said and thank the witnesses for their evidence, but I will raise one thing. Dr Atherton responded earlier to a question from Miles Briggs about 16-year-olds; I know that the point that was raised was probably not expected. The idea that a country that passed a law that says that people must be 18 to donate an organ would accept organs from 16-year-olds jars a little. It would be useful if Dr Atherton provided a basis for that when he writes to the committee.

Dr Atherton: I am happy to do that.

The Convener: I thank the witnesses for their comprehensive evidence. We look forward to hearing a little more from them on the basis of our conversations.

11:00

Meeting suspended.

11:03

On resuming—

European Union (Withdrawal) Act 2018

Food and Feed Imports (Amendment) (EU Exit) Regulations 2018

Materials and Articles in Contact with Food (Amendment) (EU Exit) Regulations 2018

Sprouts and Seeds (EU Exit) Regulations 2018

Animal Feed (Amendment) (EU Exit) Regulations 2018

Food Additives, Flavourings, Enzymes and Extraction Solvents (Amendment) (EU Exit) Regulations 2018

The Convener: Agenda item 2 provides an opportunity for the committee to consider five further proposals by the Scottish Government to consent to the UK Government legislating using the powers under the European Union (Withdrawal) Act 2018 in relation to a number of proposed UK statutory instruments.

A private paper has been circulated to colleagues that highlights a range of issues and some points of clarification that we might wish to seek from the Minister for Public Health, Sport and Wellbeing, who has already been to see the committee in relation to other regulations.

I hope that members have had the opportunity to look at the questions. They will see that the essence of them is to obtain clarification on a number of areas. Do colleagues have any comments to make on the suggested further questions that we might want to put to the Scottish Government?

Sandra White: I have read through the papers—thank you for providing them. There are lots of issues that I would like to raise, but I will just ask about the recurring theme of costs. Who is going to bear the costs? Will it be the public purse, the Scottish Government or local authorities? It appears that local authorities will have to meet some costs. I am interested in finding out a wee bit more about that. Four or five of the issues come back to the fact that it is going to cost, but we do not know how much.

The Convener: That is fair enough. The advice that we have had from the Scottish Parliament information centre and the legal department says that we should go back to the Government on costs.

Your point about local authorities is also fair and it might be worth adding that to the questions. We could ask the Government to confirm whether there will be additional costs for local authorities.

Sandra White: I think that there will be.

The Convener: Indeed.

Keith Brown: Convener, the letter that you received from the minister says that the Scottish Government has not yet had

> "sight of the final SIs and they are not available in the public domain at this stage."

I have made this point before and I want to put it on the public record. Although we are likely to ask for more information, the committee is being asked to approve the instruments as part of a legislative process. The jeopardy in that should be obvious to us all. Trying to agree something without having seen it when it could go off in different directions and there are competing views on whether it is category A or category B is difficult.

However, I have no objection to the questions that are suggested in the briefing being asked of the Scottish Government. I was probably less concerned about costs, or at least about those that might fall on the Scottish Government; that is part of the nature of government. However, I have no problem with the questions being asked.

The Convener: Thank you. The general point about seeking confirmation from the minister that we will get certainty about the final content of the statutory instruments is something that we can accommodate within the terms of our questions.

Alex Cole-Hamilton: I just want to put it on the record that I previously intimated to the committee that I and my party will be dissenting on all such regulations that come before us, for two principal reasons. The first is to do with the level of power that they will confer on ministers without the scrutiny of Parliament, and the second relates to my party's general resistance to all aspects of the EU withdrawal process.

The Convener: That is noted. If members agree to seek further information on the instruments, we are not at the point of coming to a final conclusion on them. However, Alex Cole-Hamilton's point is noted with reference to these instruments and to others.

I thank colleagues. There seems to be general agreement that we should seek the further information that has been described.

11:07

Meeting continued in private until 11:38.

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