



Cynulliad Cenedlaethol Cymru The National Assembly for Wales

Y Pwyllgor Iechyd a Gofal Cymdeithasol The Health and Social Care Committee

**Dydd Mercher, 20 Chwefror 2013
Wednesday, 20 February 2013**

Cynnwys Contents

Cyflwyniad, Ymddiheuriadau a Dirprwyon
Introduction, Apologies and Substitutions

Bil Trawsblannu Dynol (Cymru): Cyfnod 1—Sesiwn Dystiolaeth 11
Human Transplantation (Wales) Bill: Stage 1—Evidence Session 11

Bil Trawsblannu Dynol (Cymru): Cyfnod 1—Sesiwn Dystiolaeth 12
Human Transplantation (Wales) Bill: Stage 1—Evidence Session 12

Papurau i'w Nodi
Papers to Note

Cynnig o dan Reol Sefydlog Rhif 17.42(vi) i Benderfynu Gwahardd y Cyhoedd o'r Cyfarfod
ar gyfer y Canlynol: Trafod yr Adroddiad Drafft
Motion under Standing Order No. 17.42(vi) to Resolve to Exclude the Public from the
Meeting for the Following Business: Consideration of the Draft Report

Cofnodir y trafodion yn yr iaith y llefarwyd hwy ynnddi yn y pwyllgor. Yn ogystal, cynhwysir trawsgrifiad o'r cyfieithu ar y pryd.

The proceedings are reported in the language in which they were spoken in the committee. In addition, a transcription of the simultaneous interpretation is included.

Aelodau'r pwyllgor yn bresennol
Committee members in attendance

Mick Antoniw	Llafur Labour
Mark Drakeford	Llafur (Cadeirydd y Pwyllgor) Labour (Committee Chair)
Rebecca Evans	Llafur Labour
Vaughan Gething	Llafur Labour
William Graham	Ceidwadwyr Cymreig Welsh Conservatives
Elin Jones	Plaid Cymru The Party of Wales
Darren Millar	Ceidwadwyr Cymreig Welsh Conservatives
Lynne Neagle	Llafur Labour
Lindsay Whittle	Plaid Cymru The Party of Wales
Kirsty Williams	Democratiaid Rhyddfrydol Cymru Welsh Liberal Democrats

Eraill yn bresennol
Others in attendance

Dr Grant Duncan	Dirprwy Gyfarwyddwr y Gyfarwyddiaeth Feddygol, Llywodraeth Cymru Deputy Director, Medical Directorate, Welsh Government
Lesley Griffiths	Aelod Cynulliad, Llafur (y Gweinidog Iechyd a Gwasanaethau Cymdeithasol) Assembly Member, Labour (the Minister for Health and Social Services)
Pat Vernon	Pennaeth Polisi ar Ddeddfwriaeth Rhoi Organau a Meinweoedd Head of Policy for Organ and Tissue Donation Legislation
Sarah Wakeling	Gwasanaethau Cyfreithiol, Llywodraeth Cymru Legal Services, Welsh Government
Phil Walton	Rheolwr Tîm (Nyrsys Arbenigol Rhoi Organau De Cymru), Gofal a Chydlyn Rhoddwyr, Gwaed a Thrawsblannu'r GIG Team Manager (South Wales Specialist Nurses for Organ Donations), Donor Care and Co-ordination, NHS Blood and Transplant

Swyddogion Cynulliad Cenedlaethol Cymru yn bresennol
National Assembly for Wales officials in attendance

Sarah Beasley	Clerc Clerk
---------------	----------------

Joanest Jackson	Uwch-gynghorydd Cyfreithiol Senior Legal Adviser
Victoria Paris	Y Gwasanaeth Ymchwil Research Service
Sarah Sargent	Dirprwy Glerc Deputy Clerk

*Dechreuodd y cyfarfod am 9.02 a.m.
The meeting began at 9.02 a.m.*

Cyflwyniad, Ymddiheuriadau a Dirprwyon Introduction, Apologies and Substitutions

[1] **Mark Drakeford:** Bore da a chroeso i bawb. Dyma ddechrau'r Pwyllgor Iechyd a Gofal Cymdeithasol. **Mark Drakeford:** Good morning and welcome to you all. The Health and Social Services Committee is now in session.

9.03 a.m.

Bil Trawsblannu Dynol (Cymru): Cyfnod 1—Sesiwn Dystiolaeth 11 Human Transplantation (Wales) Bill: Stage 1—Evidence Session 11

[2] **Mark Drakeford:** Croeso i'r Gweinidog Iechyd a Gwasanaethau Cymdeithasol, Lesley Griffiths. Dyma ein hunfed sesiwn dystiolaeth ar ddeg ar y Bil Transplanau Dynol (Cymru). Mae'r Gweinidog yn ymuno â ni am yr ail waith gyda'i thîm o swyddogion, felly croeso i chi i gyd. Weinidog, yn ôl yr arfer, gofynnaf i chi a oes gennych unrhyw sylwadau agoriadol byr i'w gwneud i'n helpu, ac ar ôl clywed yr hyn sydd gennych i'w ddweud, trown at aelodau'r pwyllgor i ofyn eu cwestiynau. **Mark Drakeford:** Welcome to the Minister for Health and Social Services, Lesley Griffiths. This is our eleventh evidence session on the Human Transplantation (Wales) Bill. The Minister is joining us for the second time with her team of officials, therefore welcome to all of you. Minister, as usual, I will ask you if you have any brief opening remarks to make to help us and after hearing what you have to say, we will turn to committee members to ask their questions.

[3] Do you have any introductory remarks that you would like to put on the record, Minister?

[4] **The Minister for Health and Social Services (Lesley Griffiths):** Thank you for inviting me back to discuss the Human Transplantation (Wales) Bill again. I am accompanied by Pat Vernon on my right, the policy lead for the Bill, by Sarah Wakeling, the senior lawyer for the Bill, and by Grant Duncan, the senior responsible owner for the Bill.

[5] Prior to today's session, I responded to a letter that you sent me, Chair, and I am sure that Members will have seen my response and, I hope, will have found it helpful. Your evidence-gathering sessions have demonstrated clearly what a complex issue this is. I know that you have heard a variety of opinions about the rights and wrongs of what we propose, and I am sure that those will come out in questions today.

[6] I want to mention that we have had the Heart to Heart roadshow over the last month across Wales. I attended one myself and it really opened my eyes to the fact that the public is very aware of what we are proposing, and it is starting a conversation across Wales. I will end my opening comments on that very encouraging note.

[7] **Mark Drakeford:** Thank you. I will move straight to any Member who wants to open the questions.

[8] **William Graham:** Good morning, Minister. You will be aware of the concern that came out in the evidence relating to the definitions of circulatory death and brainstem death. The concerns are particularly about circulatory death. Could you expand on that and give us reassurance?

[9] **Lesley Griffiths:** The only thing that we are changing in this legislation is the way in which individuals consent. We are changing the trigger for consent. People have talked about the difference between donation after brainstem death and donation after circulatory death, but we must remember that that is in the clinical domain and it is not being altered at all. I provided clarification on this in my letter. The Bill allows for a certain amount of preparatory activity to be undertaken prior to consent being established, and that will be undertaken in conversation with families, as it is now. The thing to remember is that this legislation only changes the way in which individuals consent to organ donation and does not affect any clinical decisions at all.

[10] **William Graham:** Thank you for your reassurance on that, Minister. On a separate subject, could you again give reassurance that this will not delay the work of coroners?

[11] **Lesley Griffiths:** This makes absolutely no change regarding the role of coroners.

[12] **William Graham:** I was asking about delay in particular, rather than their role.

[13] **Lesley Griffiths:** In some cases, a person's death may come under the jurisdiction of the coroner, and donation will not be able to go ahead, but it does not change the timescales involved at all.

[14] **Mark Drakeford:** I want to pursue these two points with you a little further, because we probably will not have a chance to return to them. When Sir Peter Simpson gave evidence to us on behalf of the UK Donation Ethics Committee, he said that an ethical distinction could be drawn between donation after brainstem death and donation after circulatory death. That was a suggestion for discussion, rather than a definitive statement. Donation after circulatory death can involve the continuing treatment of the patient in order to ensure that organs are in a fit state to be donated. He said to us that where people have taken a conscious decision to opt in, because they want their organs to be available, there is no ethical argument and therefore taking steps to make sure that they are properly available is consistent with the known wishes of the donor. However, he said that the ethical arguments were more open to debate in relation to donation after circulatory death because of the issue of people continuing to receive forms of intervention that allow their organs to be used. He asked whether it is fair to assume that someone whose consent is being deemed will understand that that is what all of this involves. At one stage in his evidence, he even said to us that maybe the Bill should introduce deemed consent in a one-after-the-other way—that it should start with brainstem death and then only apply to DCD when the system becomes more understood and known to people. Has this emerged elsewhere in the evidence that you have heard in the consultation that the Government undertook?

[15] **Lesley Griffiths:** I will turn to officials in a minute, but, no, it is certainly not something that we have picked up. At the moment, you can only opt in, but with this legislation you can opt in or opt out, and if you do nothing, you will know that that means that your consent will have been deemed. So, I think that it is making people's wishes much clearer. There may have to be a subtle change in the conversations that specialist nurses and clinical leads in organ donation have with the family, but it is not something that we have been picking up.

[16] **Kirsty Williams:** Could I raise one issue, Chair? Can consent be deemed if a person does not understand or know what that actually involves? When you consent to something, you consent because you have an understanding and an appreciation of what will happen as a result of that decision. Given that most of us here—including me—probably did not understand the differences between brain death and circulatory death, how can you deem consent for a procedure and a set of interventions that you would not know about or necessarily understand? Can consent be deemed if people really do not understand the system?

[17] **Ms Wakeling:** Of course, consent cannot be deemed if people do not understand the system. We recognise that consent can only be lawful if people have full knowledge of the system, and full knowledge of what they are actually consenting to by doing nothing and taking no action. That is why, after the Bill is passed, there will be a two-year period where there will be an extensive communication campaign. The system will not go live. People in Wales will be educated and it will be very clear, through the campaign and the associated code of practice, exactly what consent will mean, and how people can opt in, opt in to some of their organs being taken, opt out completely, or do nothing and then have their consent deemed. This will all be explained. Obviously, this is not explicitly covered on the face of the Bill.

[18] **Kirsty Williams:** Is it your intention in your publicity campaign to explain to people the difference between brain death, circulatory death and how organ transplantation works in both circumstances?

[19] **Ms Wakeling:** The duty, which we have all seen on the face of the Bill, is for Welsh Ministers to ensure that there is a significant education campaign so that everybody understands the system. That will not just be a publicity campaign, but an education campaign, two years in length. I cannot remember the exact cost. Separate to that will be a code of practice underpinning the framework legislation that will detail all of these issues. Consent could not be valid if people did not understand the system; it would be in breach of human rights.

[20] **Mark Drakeford:** Mick and Darren both want to ask a question on this point.

[21] **Mick Antoniw:** Just to follow up on that, it is a very important point that you make, and it leads on to the nature of the education campaign that is referred to in the explanatory memorandum. The actual provision there is for a fairly modest budget for the whole of Wales. Perhaps, Minister, you could outline a little more about how you think that that education campaign will convey that information. It seems that what is being said is that a serious issue of lawfulness under the human rights legislation may arise, which will be dependent on our being able to satisfy whomever that every effort has been made. It seems from the explanatory memorandum that quite a limited amount can be done with the money that is available.

[22] **Lesley Griffiths:** At the stage that we are now, we think that the budget that we have set aside is adequate. It has been based on our best assessment of what the communication and education requirements are, but we will obviously have to keep the matter under review as we go forward. I am going to meet the Human Tissue Authority in due course to address some of the points that have been raised. We will obviously have the two-year campaign, but we will keep the communication campaign going after that, and that is why it is on the face of the Bill—there will be a duty on Welsh Ministers to do so. We are considering a lot of options at the moment as to how we communicate and educate, and that is obviously work in progress. There is a question of whether we involve general practitioners, for instance, as people approach the age of 18, because, obviously, they will have to have a specific education

and communication campaign. We will have to target work at students, and we will have to target people who move into Wales so that they know about the education as well. So, at the moment, the budget is sufficient, yes.

[23] **Mick Antoniw:** If I could just follow on from that, what you are talking about is a Wales-wide campaign, addressed to the entire adult population of Wales, to ensure that they have a greater or more thorough understanding of the implications of this. In the regulatory impact assessment, you identify £2.9 million for this over 10 years. That sounds to me to be very challenging, to say the least.

[24] **Lesley Griffiths:** As I say, with the assessments that we have done up to now, we believe that that is right. It is obviously something that we will have to keep under review, because, as Sarah said, there is no way that this will work unless everybody is very understanding. You have to remember that we are not the first country to do this; there are other countries that operate this system very well, and there is no reason why we cannot do that in Wales.

9.15 a.m.

[25] **Kirsty Williams:** That works out at approximately £50,000 per annum. We are all involved in the business of communicating and getting information out to people. Fifty thousand pounds does not go very far in a media budget, a leaflet-printing budget or a delivery budget. I would be very interested in whether you could make available the assessments that you have carried out that give you confidence in that sum of £50,000 a year, given the very serious legal implications for the Welsh Government, should somebody take a case to court over the issue of whether consent had been established or not. I would be much happier, Chair, if I could see those assessments.

[26] **Lesley Griffiths:** I am happy to make those available. You have to remember that we based our assessments on a similar communication campaign that took place prior to the banning of smoking in public places. There was a communication strategy for that, so we had a look at that and did research around it. So, yes, I am very happy to make that available.

[27] **Kirsty Williams:** But we are talking about two very different things: banning smoking in public places and a system in which you deem someone's consent to the removal of their organs are worlds apart. They are also worlds apart in terms of the consequences for the Government if somebody was to take a case to court.

[28] **Lesley Griffiths:** I did not say that it was the same; I said that we based it on that. We had a look at it as a basis.

[29] **Mark Drakeford:** You have agreed to make that available, so Members will be able to see that.

[30] **Dr Duncan:** I would add that, for the communication campaign, the majority of it is front-loaded in the introductory years, with the aim of gaining deep penetration across all of society. The regulatory impact assessment sets out £2 million over those two years. Then there is the ongoing money, which is, I think, as Kirsty said, about £50,000—but there is an additional £50,000 for people turning 18. So, the effort is front-loaded to make sure that everyone in Wales knows about it, and then it is ongoing from that.

[31] **Darren Millar:** On this issue, with the education campaign, we have all agreed that it is very important to get it right and to get the message out. How will you test the success or otherwise of that? If, at the end of the first two years, you find that the threshold of awareness is very low, would you then perhaps delay the implementation of the deemed consent plan

until later in the day in order to boost the rate? Do you have a threshold in mind?

[32] **Lesley Griffiths:** Obviously, we will have an evaluation strategy to monitor the accessibility of the communications programme. We will have a public attitude survey, and that will be repeated and the results published as we go from 2013 to 2016. Also, by monitoring public awareness, by monitoring people's understanding of the legislation, and by monitoring attitudes, we can ensure that our communications strategy and our education strategy can be strengthened if needed.

[33] **Darren Millar:** There will be a threshold of awareness that you have in mind, however. Is it 50% or 60%? What sort of awareness level are you looking for?

[34] **Lesley Griffiths:** I do not have a figure that I can give you now.

[35] **Darren Millar:** How are you going to test whether your communications campaign has been successful unless you have set a clear threshold of awareness among clinicians and members of the public?

[36] **Dr Duncan:** One of the things that we have already started doing is a baseline assessment, and we have published information from our survey of June last year. I cannot remember the exact statistics, so forgive me, but I think that there was already a level of awareness, in that around 60% of people in Wales knew that a change in the law had been proposed. That is already quite a high level, and it is one that we want to build on. Awareness then needs to be tested more deeply as a part of that. I think that these things go hand in hand—testing and refining as you go.

[37] **Darren Millar:** However, we have talked about the need to test for awareness, not just of a change in the law, but of the detail and in particular the difference between donation after DBD and DCD. They are two huge issues, are they not? So, how will you measure that? Have you done any baseline measurements of whether people understand DBD or DCD as issues?

[38] **Dr Duncan:** I do not think that we have any measurements specifically on DBD and DCD. It is difficult to point to the existing system all the time, but I think that one of the questions that you need to ask is about the existing opt-in system that we have and whether people recognise the differences that exist today.

[39] **Darren Millar:** I agree.

[40] Can I just check one more thing? It was referred to in an earlier response. Sarah, you seemed to suggest that these issues could be dealt with in the code of practice to educate those people—that is, family members et cetera—who might be talked to prior to a decision on whether to remove organs. When will we have a draft of the code of practice? We understand that the Human Tissue Authority is doing some preparatory work on this but that it may not be available until the end of the year. Is that not quite late in the day?

[41] **Lesley Griffiths:** That will be ready for Stage 3.

[42] **Darren Millar:** Okay, that is fine.

[43] **Mark Drakeford:** Before we finally leave this topic, I want to go back over the second point that Mr Graham raised with you. We have heard evidence from clinicians that the actions that they have to take in cases of donation after circulatory death can be controversial among clinicians. They are anxious, from time to time, regarding whether they are fully protected by the law if they intervene to keep organs available for donation. They

said that the Bill very helpfully clarifies that and makes it clear that, in Wales in the future, those actions will be lawful. However, they then went on to say that the Bill's requirement to have the coroner's consent could have the effect of nullifying all of that, because the time it would take to obtain that would mean that all the actions they would have taken to make sure that organs are in a suitable state for donation would be set to one side. By the time they get the coroner involved to consent, all that work will have been for nothing. That was the point that Mr Graham was pursuing with you. Have you heard that anxiety? If so, is there anything you think ought to be considered in it?

[44] **Lesley Griffiths:** No, it is not something that has been raised with me. As I said, the Bill will not alter any timescales. However, we could look at that and send a note on it if that is a matter of concern to Members.

[45] **Mark Drakeford:** It would be helpful because it was raised directly with us in evidence that the Bill is very helpful in the way in which it clarifies the position, but that it introduces a practical hurdle that might make all of that not operate in the way in which the Bill clearly intends.

[46] **Lesley Griffiths:** One thing that came through in the evidence you have received is that there are quite a few practical hurdles. Obviously, we can look at those and I am very happy to send a note on that.

[47] **Mark Drakeford:** Thank you very much; that would be very helpful.

[48] **Mick Antoniw:** I have an additional point on a matter that concerns me that relates to what Sarah Wakeling said about the lawfulness of donations depending on human rights legislation and the extent to which there has been proper communication. I would certainly like greater clarity about the level you think needs to be achieved in order to satisfy that particular legal hurdle. This seems to me to be quite a fundamental point.

[49] **Mark Drakeford:** That would be useful. That point was made by Darren Millar. Mick's point is more from the legal perspective of whether there are precedents in this or other things that have been tested in the courts in the past as to the level of awareness you need to be able to demonstrate to show that you have complied with human-rights-type legislation. If there is anything you can help us with on that, it would be very useful.

[50] **Ms Wakeling:** Certainly.

[51] **Mark Drakeford:** We will now move on to a different set of questions. Lindsay has the first question and Rebecca will be next.

[52] **Lindsay Whittle:** Good morning, Minister. I think that there has been a lot of misunderstanding about this Bill. From some of the correspondence I have read, I think that there is a misconception that there will be hundreds of organs available the minute this Bill is passed. From what I know of the Bill, that is obviously not true. However, there will be an increase in the number of organs used. I am concerned about critical care beds. We have the lowest level of critical care beds in Europe. Will we be able to cope with the number of extra transplants? You may find money to pay for critical care beds, but can you find the staff to work there as well? We hear constantly that there are difficulties with recruiting in all parts of Wales. Can we find the right staff if this Bill is passed? My second, less important—I was going to say 'minor', but it is not minor—point is on the list of people to contact if a tragic incident occurs. It includes immediate family—spouses, brothers, sisters, mothers, fathers—as well as long-standing friends. I have huge issues with that. I am old enough to have friends of 55 years standing and I would never dream of interfering in their personal crisis. Personally, I do not like that part of the Bill, but it is a less important issue.

[53] **Lesley Griffiths:** First, turning to critical care capacity, I am aware that people have concerns about the impact of this legislation on critical care beds. If this legislation is passed, we expect to increase the number of donors by around 25%, which equates to about 15 per year. On average, it is three organ or tissue donations per donor and that would be 45 in a year. Obviously, retrieval will take place in Wales, but the majority of operations will take place in England. I have asked for a piece of work to be done on this, which is being led by Dr Chris Jones, the deputy chief medical officer, and I am awaiting a report on that. I accept that there is more work to be done, but I am assured that we can cope with the extra work. The funding is up to the local health boards. However, you have to remember that it will probably be one per health board per five months; it is not a huge amount and health boards have assured me that they will be able to cope with that. [*Interruption.*] Sorry; the list—

[54] **Mark Drakeford:** Minister, I am sorry; I do not want to interrupt you, but the issue of critical care beds has run through our inquiry, so I want to give other Members a chance to come in on that point, and perhaps we will come on to the list separately.

[55] **Lesley Griffiths:** Okay.

[56] **Kirsty Williams:** Could you give us an idea of when that work led by Dr Chris Jones will be completed? When will Assembly Members have sight of plans for any increase in critical care beds?

[57] **Lesley Griffiths:** It is imminent; I would say that it will be completed by the end of February, and I will share it with you as soon as possible.

[58] **Kirsty Williams:** In their evidence to us, the Academy of Medical Royal Colleges and the clinicians who work in this field said that they have already turned down potential donors because of a lack of capacity within their system, and that they are running at over 100% usage of beds. This means that they would be faced with perhaps cancelling operations for people whom they know will end up requiring an intensive care bed, because of this system. I am a bit alarmed that you say that you are absolutely confident that you can cope with this system, but you also say that, actually, it will be a matter for local health boards. What clinicians are telling us is that they cannot cope as it is, with the current capacity constraints. With such an important piece of legislation, whom are we supposed to put our faith in: in your confidence; in local health boards, which might do something about it; or in clinicians, who say that they are not coping with capacity at present?

[59] **Lesley Griffiths:** If clinicians are saying that, I will have to look at that very closely. I have asked for this piece of work to be done and, as I said, the report back to me is imminent and I am very happy to share it with Members. However, if clinicians are saying that, we will have to look at those arguments very closely.

[60] **Mark Drakeford:** Minister, I do not think that we have heard from a single witness who has not said that they share the Government's ambition to increase the level of organ donation. Many people come and say that they have reservations about whether this is the right way to do it, but nobody has argued with that ambition, and people have suggested other ways. So, whichever way you increase the level of organ donation, there will be an impact on critical care beds. So, in some ways, the issues are slightly separate; would you agree? A Bill is a mechanism—

[61] **Lesley Griffiths:** Yes, I think that we all accept that we need to increase the number of organs available for donation, because we know that it is a very effective form of treatment. So, you are right; it does not matter if we do it by legislation, by raising awareness, or communication campaigns, we need to increase the number. Obviously, the critical care

capacity is very important, alongside the legislation, and if there are concerns, we will have to examine them very carefully. That is one of the reasons why I have asked for this piece of work to be done.

[62] **Mark Drakeford:** We have heard a lot of evidence about the role of the family and how the Bill approaches that. I think that Lindsay's question is slightly narrower than the general issue, because he was asking you more specifically about the presence on the list of close friends.

9.30 a.m.

[63] **Lesley Griffiths:** You are referring to the unranked list of family and friends. It is unranked because that group of people will be required to provide information that the deceased person would not have wished their consent to have been deemed. The legislation will be that, for a person who has not opted in or out, their consent will have been deemed. Friends have been included because, if that person could provide the information, they are as valid as a family member.

[64] **Lindsay Whittle:** How would you know? Clearly, some people discuss issues like this with their family, but they may not discuss it with their friends. Would you, in fact, be taking the opinion of a friend who might be totally opposed to this and may even be making it up? To prove it would be enormously difficult. I might only be able to say, 'Ah, yes; I spoke to them in the pub or in the restaurant'.

[65] **Lesley Griffiths:** It is about safeguarding the deceased person's wishes. As I said, if they have not opted in or out, their consent will be deemed. You must remember that clinical leads and specialist nurses have these conversations with families and friends at the time of the person's death. I mentioned that there will have to be a subtle change, and I think that it is about safeguarding that person's wishes. We have the unranked list, but there probably will not be 20 people in the room. So, that is the reason why we have that list. It could be that it is a friend who would know, but they would have to clarify that that person would not have wished to deem their consent.

[66] **Darren Millar:** On this point of the list, I think that it is absolutely right to cast the net as wide as possible in terms of trying to determine what the consent of the deceased was, but what happens if you get two conflicting pieces of information from people within that pool of people? If the mother says, 'Absolutely; he stated his consent to me three years ago', and the wife says, 'Absolutely not; in our discussions, he made it clear that he did not want his consent to be deemed', and they cannot remember the dates et cetera, who trumps whom in terms of determining whether the deceased has given consent or not?

[67] **Lesley Griffiths:** Obviously, it is an unranked list, so, no-one would trump anyone. If there was—

[68] **Darren Millar:** So, what would happen, then?

[69] **Lesley Griffiths:** The donation would not go ahead.

[70] **Darren Millar:** So, if there is any uncertainty at all, and if one person on that list objects, it would not go ahead. Let us say, for example, that five people on the list say, 'Absolutely; consent was definitely given. We definitely want it to go ahead', but one says, 'No; absolutely not', it would not go ahead.

[71] **Ms Vernon:** I think that disagreements happen now. Much of it comes down to the skill of the members of staff involved who talk to the families to try to elicit from them the

information that they have. In a way, it does not come down to a question of proof, one way or the other, but of skill in drawing out the information from the family members. It may well end up in the donation not going ahead, but it would be a sort of consensual position then that everyone would come to the same agreed position at the end. This is more or less a case of what can happen now when you have disagreements among families.

[72] **Darren Millar:** There is a process now, is there not?

[73] **Ms Vernon:** There is, because at the moment—

[74] **Darren Millar:** So, it is clear about who trumps who in the event of a decision.

[75] **Ms Vernon:** It is, but in the practical sense you still may have a number of family members around the bed, some of whom will agree. Perhaps the person at the top of the hierarchy or the list says, ‘Yes’, and then you may have sons, daughters or whoever saying, ‘No’. So, there is still an amount of skill required on the part of the clinician involved to try to have a conversation with those members about the way they feel.

[76] **Darren Millar:** I appreciate the need to try to get a consensus in terms of the consent, or otherwise, of the deceased, but it seems to me that not having a ranking system will potentially store up problems for the future, particularly if you have a close friend on the list—and the definition of a close friend is rather unclear. I just think that having a ranking system makes it quite clear about who has the final say. The opinion of the witnesses who have been before us is that it is a perfectly sensible thing to have in order to have a person at the top of the tree, as it were, to give the final authority, or otherwise.

[77] **Mark Drakeford:** Mick and Kirsty have both got points on this.

[78] **Mick Antoniw:** I am a little concerned, because I feel a bit more confused over what I think is a matter of clarity as to what precisely the legislation is saying. Your evidence on the previous occasion, and I think that it has been confirmed again today, was that, if there is a dispute, irrespective of the ranking system set out in the Bill, and a member of the family objects, donation will not go ahead. What it seems we have, then, is a situation in which the Bill says one thing, but we are saying, ‘You don’t need to really worry about that, because, if there is any concern, then the procedure will not go ahead.’ It seems to me to be difficult that we are having a piece of legislation on something as sensitive as this that is not absolutely clear and absolutely transparent, so that you can understand from reading the legislation precisely what the situation is. Do you think this might be an area where you would consider bringing in that degree of clarity and saying exactly what will happen? That is, if it is the case that the Government’s position is that there will be no transplantation if any member of the family objects, then that should be on the face of the Bill, or, alternatively, if it is the case that donation can proceed if a certain category approves et cetera—it is that lack of transparency that concerns me. That is the one thing that has kept coming back from some of our witnesses. To add to that, one of the experts who came to give us evidence said that, if it is the case that any member of the family can object, that will probably lead to fewer donations than we have at the moment, and that is why I have a concern about that area.

[79] **Lesley Griffiths:** Can you respond on this, Sarah?

[80] **Ms Wakeling:** Yes. There is this conflict in a number of areas in the Bill between what is on the face of the legislation and what will happen in practice, because of the reality that clinicians cannot be compelled to do something against their conscience. We have constantly tried to strike a balance on that—it exists in the current legislation, whereby, if somebody has opted in, the family is still involved in the discussion, and if the family feel strongly that donation should not proceed, then it does not. However, that is not what the

legislation says. We have to be quite clear on the face of the legislation, which is what you are saying, as to what our system would be in Wales, and what we are saying is that you can opt in, opt out or do nothing. If you do nothing, your consent will be deemed if you fulfil the relevant criteria. That, in and of itself, in relation to human rights, would not be enough. There has to be a safeguard for relevant people—family and friends of long standing—to provide information, if they have it, that would lead a reasonable person to conclude that the deceased would not have consented. I think that it is very clear on the face of the legislation what it is proposed that the law will be in Wales.

[81] We then have, in practice, the point that you picked up, that families and friends will raise issues at the bedside. Clinicians cannot be compelled to do something against their conscience. It is about striking the balance. There is an inherent problem there, and I can see that problem. What happens in the current system is that the code of practice details these problems, acknowledges that they exist and talks about how those discussions will go and how they will be handled in practice. It gives practical examples of, ‘If this scenario arises, this is how you handle it’, and that is what we envisage happening for the Wales legislation.

[82] **Mick Antoniw:** However, is that not the dilemma that arises from this? In actual fact, we have legislation that says one thing, but we are saying that, in practice, something else will happen. My practical concern is this: does it not put an impossible burden on the clinicians? If there is one thing that they want—bearing in mind that they are the ones who potentially could be subject to legal action at the end of the day, aside from the issues of conscience—it is clarity and certainty as to the circumstances in which they can act, and, if they do not have that, it raises all sorts of questions about confidence in terms of what the family understands, as well.

[83] **Dr Duncan:** One of the comments that I would make is that it is about reinforcing the safeguarding elements of this. In terms of the unranked list, it is to give a wide range of opportunities for people to bring forward evidence, because it is about respecting the wishes of the individual. The other thing is that the positive side of this argument is that families are more reassured and are more likely to go along with the process when they have greater clarity about the wishes of the deceased. In a deemed consent system, you have that greater clarity regarding an individual’s wishes, so that helps to give reassurance to families as well.

[84] **Kirsty Williams:** However, Mick also made the point that the evidence that we have received from clinicians who are deeply enmeshed in this work is that an unranked list of this kind will potentially lead to fewer donations. We are all signed up here to encouraging more donations, but their concern is that the way in which the legislation is currently framed in terms of the unranked list could mean that there will be fewer donations, because there are more people who could potentially object, or it would put clinicians in the difficult position, which Mick just talked about, with an unranked list, of having a patient in the bed, some family members there and some family members perhaps on the other side of the country, and the clinician thinking, ‘Any minute now, Aunt Mildred might turn up from another part of the country and intervene in this process’. What clinicians need more than anything is clarity to protect themselves, and what we need more than anything to encourage more people to opt in is confidence within the system. It seems to me that we are endangering both those things if there is not clarity on the face of the Bill.

[85] From our perspective as legislators, we cannot afford to envisage what might happen in and around the bed—all we have is the legislation in front of us; that is all that we can judge. We cannot anticipate what it might mean in practice—all we can look at is what is written in front of us in the Bill. We cannot say, ‘It doesn’t matter about clause whatever, because, in reality, Kirsty, what will really happen at the bedside is this’. I do not know what will really happen at the bedside, but I do know what is written in front of me.

[86] **Ms Wakeling:** I think that what is written in the Bill is quite clear in that it sets out the test. If you do not say 'yes' or 'no', your consent is deemed and then one of a set number of people—we have just talked about this list, ranked or otherwise, of the qualifying relationships—can, as a safeguard, provide information. It is not just any information; it is information that, lawfully, would lead a reasonable person to conclude that the deceased would not have consented. So, I think that there is clarity there for the clinicians, because they know that they can lawfully proceed with a donation. The legal test is on the face of the Bill. There should be a safeguard there for deemed consent—people should be able to provide information. The policy thinking is that the list should be quite wide, because someone might not have the traditional husband, wife, mother, son or daughter, but they might have a friend of long standing in their life to whom they have made their wishes quite clear regarding exactly what they want to happen after death, and for that to be ignored would be a problem.

[87] **Lesley Griffiths:** Clearly, the unranked list is a cause of concern for some people, and I think that perhaps we do need to reflect on this. As we have come to the end of Stage 1, I think that perhaps we do need to have a further look at this.

[88] **Mick Antoniw:** There is one point that has not been clarified, and that is the point about the evidence that we have had that says that, where any family member might be able to challenge, it would result in a reduction in donation. I think it is important to understand whether you have considered that evidence and what your response to that is.

[89] **Lesley Griffiths:** We have considered it. At the end of last year, in December, we looked at all the countries with opt-out systems in place, and the international evidence does not support that.

[90] **Darren Millar:** I have a point about clarity on the face of the Bill, Sarah. You have said a number of times now that it is very clear on the face of the Bill—you either give your express consent or not or otherwise, if the situation is unknown, then we cast the net widely to a person on the list. That is fine if one person comes forward with some information, but it is not fine if two people come forward with information that conflicts. That is the situation that we are trying to avoid here in order to assist clinicians and to have that clarity. So, that is the—

[91] **Ms Wakeling:** That is a logical point. It is not helpful, but that does happen now, and there is guidance to deal with that. There is—

[92] **Darren Millar:** Just because it happens now does not necessarily mean that it ought to happen in the future. It would be good if we could tidy that up, and I am pleased to hear the Minister's suggestion that you will be able to look at that. I think that is very wise.

9.45 a.m.

[93] **Ms Wakeling:** The key to this is that it is such an emotive topic, as we are talking about taking people's organs and tissues, and everyone is concerned that this should be done properly, clearly, with legal certainty, and that clinicians will know exactly what they are doing, the deceased will know exactly what will happen and family members are confident of all the processes, otherwise we could face litigation and all sorts of things.

[94] It would not just be any information that they could bring forward. There is a test here: it is information leading a reasonable person to make a conclusion. In the case of conflicting information, which there could be in many cases, we would have to see. That information could be dated—that is, there could be relevant timelines; something from three years ago would obviously be trumped by something from last week—and there is a proof element to all of this that would have to be dealt with in conversations. Again, it is what

would lead a reasonable person to conclude that the deceased would not have consented. It would depend, as I said, on when that information was given—something three years ago would not be as relevant as something that was given last week.

[95] **Darren Millar:** I understand that and I appreciate that, but I do think, for the purposes of clarity, that a ranking list would be helpful and I am pleased that the Minister has given a commitment to look at it.

[96] **Mark Drakeford:** Thank you very much. Minister, you will have heard, from the nature of the discussion that we have just had, that this is an issue that witnesses have raised with the committee time after time. Members of the public in particular have said to us that they are confused by what they see as the difference between what the Bill says, what the explanatory memorandum says, and what has sometimes been said in evidence, and that this adds to their anxiety about the Bill. Sometimes, people go on to take the next step and say that, because of that, the Bill may not succeed in its laudable objectives. That very often plays into an argument about the list and whether the unranked nature of the list adds to the confusion rather than helping to clarify how those decisions would really be made around the bedside. So, thank you for listening to that—

[97] **Lesley Griffiths:** I very much accept that. Legislation, by its very nature, is difficult, but it is very important that we have that clarity, so, certainly, we will reflect on that.

[98] **Rebecca Evans:** I would like to raise three different issues with you. The first is the inclusion of prisoners in the Bill. There is some discomfort that prisoners should be included in the Bill, because most people choose to come and live in Wales. Students will make the choice to come and study at a university here and people choose to live here because we can offer a good quality of life, but prisoners do not have a choice about living in Wales. Why have you included prisoners in the Bill and how do you intend to ensure that prisoners, who are often moved around fairly frequently, understand the Bill?

[99] **Lesley Griffiths:** If they have been here for six months, they are not excluded, but we would have to ensure that they understood the legislation; again, it would be part of the education and communication campaign. Obviously, they would have the safeguard of their family as well.

[100] **Rebecca Evans:** We are all keen to have evidence-based legislation and you have cited international evidence a few times this morning. However, a review of a large amount of research, which was undertaken at the University of York, has suggested that the weight of evidence shows that presumed consent alone cannot account for high levels of donation in some countries, and, instead, it is the availability of donors, the organisation and infrastructure of the transplantation service, wealth and investment in healthcare, and public attitudes to, and awareness of, organ donation that actually make the difference in countries such as Spain. So, what is the evidence that the Welsh Government is using as a basis for driving forward this piece of legislation?

[101] **Lesley Griffiths:** I agree; I do not think that any one thing will ensure that we have enough organs available. It is about this legislation, alongside communication campaigns—I mentioned the Heart to Heart roadshows across Wales, and I have attended only one, which was on a Saturday in Wrexham. I was quite surprised at how many people—one thought the legislation was in place already and two were very aware of what was going on. A lot of people who came up to us were already on the organ donor register, so they know. It is about having that societal change in attitudes towards donation. So, I do not think that this legislation will ensure that we have all the organs we need. I think that it is a matter of raising awareness all the time. I think that we have done that. You may have seen ITV Wales last week, when it had, I think, 48,000 people from right across the UK signed up for the organ

donation register. Unfortunately, probably 50% were already on the register, but again, this is about making people aware of it. So, it is about linking in all these things. We reviewed all of the international evidence at the end of last year and we believe that it is time for a change and that this is the right way forward.

[102] **Rebecca Evans:** In terms of public support for the Bill, we have heard suggestions that support has decreased while the debate has been developing and that it is now at less than 50%. Are you concerned that this piece of legislation and the debate surrounding it is damaging the cause of organ donation in Wales?

[103] **Lesley Griffiths:** No, I do not agree with that for the reason that I have just stated. The Heart to Heart roadshow showed that. I was genuinely very surprised at the number of people who wanted to engage. Several people said, 'We thought that this was already in place'. I do not know if anyone saw the programme that I mentioned last week, but there was something on every night. The hits to the website were around 148,000, so I do not agree that it is damaging. Certainly, that is not the impression that we have gained. Grant went across Wales, doing public awareness campaigns, prior to the Bill being introduced to the Assembly.

[104] **Dr Duncan:** To expand on that point, a survey was published last year, giving a figure of 49%, but I think that that is comparing apples and pears. The overall figure of those who said that they favoured it versus those who said that they did not remained at 2:1, because the BBC survey said that it was about 63%. The survey that we published included an extra category: as well as the categories of 'We support' and 'We do not support', there was also a category of 'Would like more information'. So, if you compare them on a like-by-like basis, the figure remains remarkably constant. I do not have the evidence, but just from watching the ITV programme, on a UK basis, something like 69% said that they favoured a change and 31% were in the 'did not want to change' or 'did not know' categories. So, people remain broadly in support of this.

[105] **Lesley Griffiths:** I should add that I have just had some figures from the Heart to Heart roadshow from 25 January to 14 February. About 5,500 people, we think, communicated with us during that campaign and on only six occasions did people come up to say that they thought that it could be damaging or that they wanted to be taken off the register because of the legislation. So, it was six out of 5,500 people.

[106] **Kirsty Williams:** How much did the roadshow cost?

[107] **Lesley Griffiths:** It is part of the contract that we have with the PR agency.

[108] **Kirsty Williams:** Could you give me a ballpark figure? I do not need an exact figure.

[109] **Lesley Griffiths:** For the cost of the roadshow?

[110] **Kirsty Williams:** Yes. We have £50,000 a year and I am interested to know how much a roadshow costs currently.

[111] **Lesley Griffiths:** I do not think that I can give you that figure at the moment.

[112] **Kirsty Williams:** A note will be fine.

[113] **Lesley Griffiths:** I will send a note on that.

[114] **Mark Drakeford:** Before we leave this, I would like to return to the first point that Rebecca raised. I have seen evidence that suggests that the ethical issues involved in deeming the consent of prisoners, who are not in the country by their own choosing, gives rise to a

whole new set of ethical dilemmas. I do not necessarily need an answer today, but is there any evidence as to whether donations have ever been made in those circumstances? If they never have been, does the inclusion of prisoners in the Bill give rise to a whole set of ethical dilemmas for no real practical purpose? Just as we assume that people under the age of 18 can be donors if they opt in, would it not be better to put prisoners in that category, rather than for their consent to be deemed when they are not in Wales of their own choosing?

[115] **Lesley Griffiths:** Okay, I will get back to you on that.

[116] **Elin Jones:** You have talked quite a bit this morning about the need for effective and clear communication with the population in order to be able to deem consent on its behalf. Most of the Government's communication to date on organ donation and this legislation has been around the life-saving properties of organ donation, and especially in the context of solid organs. This legislation deems consent for everything, other than a very short list in section 16. Therefore, with novel transplantation, such as face and hands, this legislation deems consent for such tissues as well. We have heard evidence to suggest that, ethically, it would be better for the legislation just to deem consent for solid organs and to list the organs, rather than deeming consent for everything bar a few exceptions. In the evidence session you gave previously, you said that this would be covered by the code of practice. I still think that the legislation on the face of the Bill should be more prescriptive in terms of the organs for which the state is looking to deem consent for transplantation. Have you had further thoughts on that?

[117] **Lesley Griffiths:** Yes, I have had further thoughts on that. We need to look at having power of direction on the face of the Bill. We can consult on power of direction. We would have the power of direction for Welsh Ministers. One of the reasons we did not want to include it in the Bill—you spoke about what is excluded at the moment—was that we were concerned about having to change the legislation every time a new form of transplantation went ahead. However, I could well understand your concerns. So, I think that the best way forward would probably be to have the power of direction on the face of the Bill.

[118] **Elin Jones:** Would you like to explain to me what that means?

[119] **Lesley Griffiths:** I will get the lawyers to explain.

[120] **Ms Wakeling:** It would be on the face of the Bill that there would be a power for the Welsh Ministers to make directions to NHS Blood and Transplant as to the organs that would be excluded from the deemed consent system. It has been said, in policy terms, that it is not intended that novel forms of transplant, at the moment, as we understand them, would be included in the deemed consent system. It would be a matter of defining those and setting them out in directions.

[121] **Elin Jones:** Would that direction be a statutory instrument in some form? Would it be laid in front of the Assembly at some point?

[122] **Ms Wakeling:** Yes, it would depend on the prescribed procedures set out in the Bill, but it could be. The directions could also be the subject of consultation before they came forward.

[123] **Elin Jones:** The Bill currently states that the code of practice would possibly cover these issues, and that statutory code of practice would be laid in front of the Assembly. I would assume therefore that a power of direction or the direction itself would also be laid in front of the Assembly. Otherwise, we would end up with it not being as good as what is currently in the Bill.

[124] **Lesley Griffiths:** Yes.

[125] **Elin Jones:** So, will that be coming forward as an amendment to the Bill from the Government?

[126] **Lesley Griffiths:** Yes.

[127] **Darren Millar:** I want to clarify the situation in terms of the organ donation register. When we have had personal briefings as spokespeople, there has been an indication that there would be a separate register for Wales. It appeared from the evidence that we received as committee that there will be an extension to the existing organ donation register, with additional boxes for Welsh residents, effectively. Can you clarify that that will be the case for us? Also, you mentioned, Minister, that six people who were on the register out of the 5,500 who came to the Heart to Heart roadshow indicated that they would want to come off the register in the event that this legislation is passed. However, they may still want to stay on the register if they die in England, for example—I do not know. Will there be another opportunity for people to express that wish, so that they can opt in for other parts of the UK, but opt out here?

10.00 a.m.

[128] **Lesley Griffiths:** We want to see one register, because that would be much simpler, and less risky. I have written to the Ministers for health in Northern Ireland, Scotland and England and have received very positive responses about having just one register. Members are probably aware that Northern Ireland is looking at this piece of legislation and the possibility of doing something like this. All three have accepted in principle that one register would be the best way to go, so we are exploring options with the other administrations. I think that officials are meeting next week to discuss the issue further. It is really important that people's wishes are accurately recorded.

[129] In relation to your question about whether somebody could register a wish to donate in England and opt out in Wales, the short answer is 'no'. The intention is that an individual could record only one wish on the register—either to be a donor or not to be a donor. Obviously, the register would record the last wish of that person.

[130] **Darren Millar:** The difficulty is that you have suggested that six people out of 5,500 have said that they would come off the register if the legislation was implemented. I do not know what the total number of people on the register in Wales is. Is it a third of the Welsh population, or something like that?

[131] **Lesley Griffiths:** Yes, it is 31%.

[132] **Darren Millar:** Okay; it is about a third. That means about 1,000 people in Wales would come off the organ donation register if you apply that simple mathematical formula. That is a lot of people, is it not? It is a lot of potential donors. It is not an insignificant number of people who would want to come off the register in Wales, but may want to stay on it in other parts of the UK. Is that something that you might consider bringing forward—some sort of allowance for that?

[133] **Lesley Griffiths:** No, I think that that would just be too complicated. What is really important is that we help allay the fears that people have, and encourage them not to leave the register. One question that I have asked is what conversation took place with those six people in relation to that. I was not there, but I would be interested to know.

[134] **Darren Millar:** On a separate issue, if I may, Chair, just in terms of appointed

representatives, can you give us a little more clarification as to how people will be able to appoint a representative? Also, in addition to that, where more than one person has been appointed, it is suggested on the face of the Bill that those individuals can act severally or jointly in terms of making a decision about organ donation. What happens if there is an opposing opinion given by two people who are supposed to be acting in a joint capacity?

[135] **Lesley Griffiths:** What I would like to see is an appointed representative being named on the register. That is the route that we are pursuing at the moment. In relation to the issue when more than one representative has been appointed—I referred to that in my letter to you, Chair—only one of them would need to give consent.

[136] **Darren Millar:** So, if there are three or four, and three say ‘no’ and one says ‘yes’, consent would be deemed. If someone nominates joint representatives—because the Bill allows for more than one person to be appointed—what happens if they have opposing views?

[137] **Lesley Griffiths:** If somebody has taken the trouble to appoint people, they would know the views of the deceased person.

[138] **Darren Millar:** Not necessarily. Some people might appoint and allow that person to make a decision in the event of their death. Otherwise, they may as well just opt in or out, had they not, if they wanted to make their views known?

[139] **Lesley Griffiths:** If they wanted to appoint somebody to make their views known, they would ensure that those people would know the views—

[140] **Darren Millar:** Not necessarily, Minister. I would contend that there would be many people who would not want to make the decision and would therefore say, ‘I want to leave this decision to you as a close friend, or as my spouse, to make that decision in the event of my death’. However, they may appoint more than one person, which you say is perfectly acceptable on the face of the Bill, and those people may have diametrically opposing views.

[141] **Ms Wakeling:** They might, but we do not think that that would happen very often.

[142] **Darren Millar:** If it does, what happens?

[143] **Ms Wakeling:** It is a possible scenario. As with anything, it will come down to the discussion with the clinicians as to what exactly is being contested by the relevant appointed representatives if they cannot agree. Yes, they can act jointly and severally—we have said that—but then it would come down to a clinical decision by the team listening to all those views, and it would have to be decided. If there is an inherent conflict, obviously, it would be dealt with case by case. That is the difficulty with this Bill; we are talking about general frameworks, but obviously this will come down to making a decision every time in relation to one person who is dying. If that did happen, if there was all that conflict, the donation would not proceed, because the clinicians simply would not feel comfortable proceeding.

[144] **Darren Millar:** Would it not be better to allow a person to name an individual—just one person—rather than being able to nominate two or three people to make a decision in the event of their death?

[145] **Lesley Griffiths:** I can see the benefits of that.

[146] **Ms Wakeling:** However, the logic would then be tested because, under the Human Tissue Act 2004—which I know is not always helpful—we are working in a UK-wide system of organ donation. It is a factual position. This trigger for consent is changing in Wales, and we have to fit that into the UK system with a minimum of disruption, as we do not want to

cause any damage—we want to promote donation, rather than reduce the figures. If we start having different rules for different things, such as appointed representatives, it would complicate the system, and what would be the logic behind that? Why would there be a difference in how appointed representatives can act in these scenarios?

[147] **Darren Millar:** I think that I have pointed out the potential for conflict if more than one person is nominated, and it would simplify that, would it not? If more than one person is nominated and they disagree, it causes a potential problem, whereas if only one person is nominated, it becomes much simpler to deem consent or not.

[148] **Ms Vernon:** I would just add that this issue is already covered in the Human Tissue Authority code of practice. In light of the comments that have been made, we could look at whether we should perhaps expand on some of the explanations and scenarios—that is, if there was disagreement or the different appointed representatives could not come to an agreement. We will have a look at what is already there and take that into account.

[149] **Darren Millar:** I have one further question on this. Is it possible for somebody—or is this something that you might consider—just to say, ‘I want my next of kin to make this decision, rather than a named individual’? Is that not a possibility?

[150] **Lesley Griffiths:** Again, it is a matter of fitting into the UK-wide legislation.

[151] **Ms Vernon:** I think that that would come under the category of a representative who had been appointed orally or in writing. You could—[*Inaudible.*]

[152] **Darren Millar:** That might be an easier way.

[153] **Mark Drakeford:** Lynne, is your point on this?

[154] **Lynne Neagle:** No.

[155] **Mark Drakeford:** Right. I will go to Kirsty next and then to Lynne.

[156] **Kirsty Williams:** Minister, I am wondering what system you are going to put in place to monitor the success of this policy. Professor Saunders came to see us before the half-term holiday, and he said that just because a politician might think a policy might be popular, that is not necessarily the only reason one should proceed with it. That is a very useful reminder to us all, I think. He was very concerned about whether we know what success looks like and how we are going to measure it. He pointed to international examples where the law had been changed to a system of presumed consent and, after a couple of years of the experience of that system, the law was subsequently rescinded in those countries and they moved to a different system. He said that there was a complete absence—a big gap in the policy—with regard to how we would monitor the implementation of this policy, what success would look like and how we would judge whether what we had done had worked. What consideration have you given to those points? Also, have you given any consideration to having some clauses in the Bill that would require the Government to review what had happened, in some ways like a sunset clause, that would provide a break after a certain amount of time so that there could be an evaluation and we could therefore decide to either carry on with system because it was clearly doing what it was supposed to do, or revert to an opt-in system?

[157] **Lesley Griffiths:** I mentioned that we will have to have a very robust evaluation strategy to monitor the legislation. I think it was you who asked about the sort of figure we would be looking at. We need to look at the evidence from other countries to determine the impact of the Bill, and the monitoring of donor rates and family consent rates now, and after

the introduction of the Bill, would give us a very good indication of the success of the legislation and the impact of the Bill.

[158] We can track activities elsewhere right across the UK. We are looking at what type of evaluation strategy we will have in place.

[159] **Kirsty Williams:** When will you be in a position to explain to Assembly Members what that evaluation strategy looks like?

[160] **Dr Duncan:** Within the next month or two. The team is currently drawing up a specification, because it will have to go to tender. With the Minister's approval, we can share that with you.

[161] **Lesley Griffiths:** Yes, certainly.

[162] **Kirsty Williams:** Looking at the financial impact of this Bill, the quality-adjusted life year measurement seems to be a lot higher than it would be, for instance, for a drug. We are approached all the time by people who cannot get a drug because the National Institute for Health and Clinical Excellence has deemed that the QALY is too high. For some of these figures, the QALY is much higher than it would be for other interventions. Why is that the case? Why are we allowing the QALY to be much higher for these particular patients, when there are other patients in Wales who do not get treatment because the QALY is set at a much lower standard? How can arguments about equity in how to treat people be addressed given that the QALY is so much higher in the case of transplantation?

[163] **Lesley Griffiths:** We had a very thorough financial impact assessment of the legislation, which is in the explanatory memorandum. It shows the financial benefits that the increased number of organs could bring. I do not accept that we have over-valued the QALY. I know that you have had evidence from others who have asserted that we have over-valued it. We have put our evidence before you. I appreciate that other people have asserted—

[164] **Kirsty Williams:** I am interested in why there is a difference. Why is the QALY for drug intervention set at a certain level, when this QALY is set much higher? This is a much more expensive intervention than would be allowed in a lot of other cases. What is the explanation? Why is that the case?

[165] **Dr Duncan:** In this particular case, it was our economists picking up on advice from the Department of Health. That is how it went down this route. I add to that that the sensitivity analysis, which is in the explanatory memorandum, says that even if you allow for the QALY to be the lower one that you are talking about, there is still an overall cost benefit to a relatively low number of extra donors.

[166] **Kirsty Williams:** The reality is, in terms of cost benefit, it only works out for kidneys because dialysis is very expensive. So, there is a cost benefit to the NHS as a whole if somebody is able to have a kidney transplant. However, with regard to other transplantations, because of the ongoing medical input, drugs et cetera, the evidence for the cost benefit of lungs or liver transplantation is very different to the evidence for kidneys, where it is quite clear that you would save money in the long run if you transplanted a kidney. The other stuff is less clear. Is that correct?

[167] **Ms Vernon:** I think that the regulatory impact assessment sets that out.

[168] **Mark Drakeford:** Just to make sure that I have understood the point, the QALY argument is affected by the impact that a particular treatment has on the life of the individual. So, a transformative treatment like a kidney transplant will have a high QALY impact, but a

drug that may improve someone's condition but not to a transformative extent would have a different QALY. That is how you end up with different QALY figures for different types of treatment. Different types of treatment have different levels of impact on the life of the individual. That may not be right for the way in which it has been done here, but that is the debate that underpins the figures.

[169] **Kirsty Williams:** I guess that 'transformative' is dependent on where you are in that system.

[170] **Lynne Neagle:** By the Government's own admission, the increase in the number of organs is going to be pretty modest. The committee has heard evidence that, in reality, the system will not change very much at all for the reasons you have described, with relatives' views being taken into account. We have also heard evidence that there is a fair level of risk involved of damaging the organ transplant system in this country. As part of your review of international evidence and the work you have done on the financial aspects of this Bill, has the Government undertaken any detailed examination of whether you could spend a similar amount of money on other ways of increasing organ donation, such as an aggressive, vigorous uptake campaign in Wales?

10.15 a.m.

[171] **Lesley Griffiths:** In looking at the international evidence, countries that have a soft opt-out system consistently outperform countries that do not have that legislation. I hear what you are saying about communication and campaigns, and we have certainly had those. We have implemented many of the organ donation task and finish group's recommendations. We now need to do something different—it is time for a change—and I think that this is the best way forward.

[172] **Lynne Neagle:** Has anyone sat down and made an analysis? Presumably, there are measurable outcomes from the Heart to Heart campaign. There have been previous uptake campaigns. Has anyone sat down and done some work on what would happen in Wales if we spent £8 million over a number of years on aggressively promoting this?

[173] **Kirsty Williams:** We have been very good at it, and that is why our donation rates are better than everyone else's rates.

[174] **Dr Duncan:** To pick up on those issues, the paper that best sets this out is probably the one by Abadie and Gay, which is referenced in the explanatory memorandum. They looked at different studies, including just communications. The evidence seems to be that it is not just communications and not just the law—it is both/and—because legislation helps to change society's norm and communication helps to take it forward. Even taking the fact that Wales has done tremendously well—we lose sight of that at times—the 49% increase has probably reached a plateau. The register is staying at around 31%, so most of the conversations with the deceased's relatives are with people who do not know the wishes of the individual. So, the whole thrust of the legislation and the evidence implies that if you clarify people's wishes through legislative change, families get greater reassurance and are more likely in any conversation to say 'yes', because they know that people had the opportunity to opt out and did not, or, if they did opt out, to follow those wishes. So, it is both/and, Lynne, and not just communications.

[175] **Lynne Neagle:** Communication campaigns are one thing, but we took evidence before recess that the Government could have looked at systems such as every GP asking patients on a regular basis, which is a much more proactive way than relying on someone to pick up a leaflet or to attend an event. Have those types of issues been explored?

[176] **Dr Duncan:** We have considered different options. We need to bear in mind that all these things need to be done in any case as we go forward. We considered the issues regarding GPs. Touch wood, I have not been to my GP for a couple of years; different parts of society go to GPs at different times. You might also have single-person practises that may disagree with this. There is a for and against in each avenue that you go down, so it is a question of using a range of access tools to inform people.

[177] **Lesley Griffiths:** Kirsty made the point that we have been very successful, but since I have been Minister for health—it is nearly two years now—the figure has stuck at around 31%. We do not seem to be able to budge above that. I have said before that not one thing will make the difference we want. I think that this Bill will help to make a big difference, but we need to look at the ongoing communications campaign as well.

[178] **Mark Drakeford:** Minister, we have very regularly heard witnesses say that for £8 million on the table from the Welsh Government for an additional 15 donors a year, they could get us those 15 donors in a much more straightforward way than by changing the law, with all the complexities and anxieties that that brings. As a result, I am going to allow Members to pursue this issue with you for a little longer. Darren and Rebecca want to ask you about this, and I have one point that I want to put to you.

[179] **Darren Millar:** In response to Lynne's first question, you made an assertion in terms of international comparators that those countries that have presumed consent systems consistently—that was the word that you used—outperform those that do not. Can you qualify that position? As I understand it, there are many countries where there is a presumed consent system in place where organ donation rates are actually much lower than here in Wales, for example.

[180] **Lesley Griffiths:** Looking at the evidence that we reviewed—and you mentioned Abadie and Gay—we find that countries with presumed consent legislation have 25% to 30% higher organ donation rates than informed-consent countries. Gimbel et al demonstrated that countries that practise presumed consent had, on average, an extra 6.14 donors per head of population compared to countries that practise informed consent. The evidence is that those countries do consistently outperform.

[181] **Darren Millar:** Are you comparing like with like? The health systems in some of the countries that you might refer to, if you take an average picture, will be very different from our health service in Wales and those, perhaps, in western countries. You need to compare like with like, do you not? We know, for example, that in Sweden, with presumed consent, there is a much lower donation rate, yet Germany has a higher rate with informed consent. So, there are all these anomalies, are there not? It is not actually clear, to be honest, that legislative change to presumed consent is the driver for improved donation rates. All the evidence in Spain seems to suggest that the driver for improved donation rates there was absolutely nothing to do with the legislation, but that it was actually the systems that were put in place many years after the legislation had been passed.

[182] **Dr Duncan:** I will put forward a counter view to that, if I may. The Abadie and Gay paper did an analysis that allowed for many different societal factors in those countries, for example, whether it was due to economic wealth, health systems, or religious views. It allowed for those and there was some complex mathematical modelling behind it. It said that, allowing for those differences, you could still produce evidence that the countries with presumed consent systems are associated with higher rates of organ donation. I think that we have always been at pains to say that different countries have different needs. I cannot remember the exact page, but, in one of the evidence papers that we produced around Christmas time, there is a graph that shows the donation rates for different countries in terms of informed consent against presumed consent. If you looked at the top half of the graph, you

would see around 20 countries there, 17 of which have presumed consent. It is that type of thing. That supports our argument that those countries that have presumed consent are associated with higher rates of donation. That is mainly due to families having greater clarity regarding individuals' wishes, which is brought about by the debate that the change in the law encourages.

[183] **Darren Millar:** So, it is therefore more about communication et cetera, rather than the legislative change. That is essentially what you are saying, is it not?

[184] **Lesley Griffiths:** I think that it is both. I am not sure whether it was you, Darren, or the Chair who said that people have said to you that they could get the extra donors. With respect, why have they not?

[185] **Darren Millar:** That is a fair challenge. You will also be familiar with the University of Ulster study, which looked at the international comparators and sort of suggested that a change in the law will not be the game changer; it is actually about the processes that are in place when someone is in a situation where a donation is possible and the question is essentially put to family members and those people around.

[186] **Lesley Griffiths:** The one thing that we want to get from this, obviously, is clarification of people's wishes. You are right; that is a very important aspect of the legislation.

[187] **Rebecca Evans:** Returning to Lynne's point on the information campaign, we have heard from you this morning that, under this Bill, the information campaign will include explaining the difference between circulatory death and brainstem death. I can imagine that that will switch off large swathes of people immediately. Would it not be better to spend the money on a really positive campaign saying, 'Organ donation is a wonderful thing; you can transform someone's life. Have a conversation with your family'? Would it not be better just to spend the money on that and perhaps achieve greater results? Like Dr Duncan, I rarely visit my GP, but there are things that we all do: we all pay our council tax or register to vote. I have done both of those things recently, but on neither occasion was I asked whether I would like to sign up to be an organ donor. Why is that?

[188] **Lesley Griffiths:** I think that legislation switches a lot of people off, with respect, so we will have to be very robust and careful about how we undertake the communication and education campaign. We are doing that already; we are saying 'Have the conversation'. The Heart to Heart roadshow during the summer shows last year was part of that; that was another aspect that we did with the public relations company about having that conversation. We have all said that it is not just one thing, and I can see that people would ask, 'Why not spend the money on this?' We believe that this is the best way forward to increase the number of organs available for transplantation. We have talked about the financial cost, but it is not just about the financial cost, but the cost to that person. We all know that lives can be transformed. We have all met those people. In relation to what you said about council tax, and somebody else, at the Heart to Heart roadshow, raised applications for driving licences, we can do those things as well, but it is now time to bring forward this legislation and time to have that very different societal change.

[189] **Rebecca Evans:** The Heart to Heart campaign is great, because it is a positive campaign, but the tone and the technical nature of the campaign will have to change if this legislation is brought in, so that people genuinely and fully understand what the Bill will mean, and then it will be a technical campaign about explaining these different forms of death and so on, which is much less attractive to people. You are not going to talk about it around your kitchen table in the evening.

[190] **Lesley Griffiths:** Again, I go back to when I answered Kirsty's question about the ban on smoking in public places. Whenever you have a change in legislation, it is important that you make sure that everybody is aware of that information, and that is why it is on the face of the Bill. That is how important the communication campaign is. It will be a continual campaign. Even after the legislation is introduced, it will be long-running; there will be the two-year campaign and then onwards. However, it is not just one thing; we will have to do a variety of things.

[191] **Darren Millar:** On communication, you made reference a few times this morning to the comparison with the smoking ban communication campaign, but there were duties on local authorities, on premises owners and businesses to communicate that to people. This is a very different campaign, is it not?

[192] **Lesley Griffiths:** Yes, it is very different.

[193] **Darren Millar:** So, to base the costs on that experience—

[194] **Lesley Griffiths:** No, I did not say that we based the costs on that; I said that we looked at that. We are much higher in cost than that, but it was something that gave us a baseline; that is what I said. We did not base the costs on it.

[195] **Darren Millar:** What was the cost of the smoking communication campaign? Do you have a figure?

[196] **Lesley Griffiths:** I do not have the figures to hand, sorry.

[197] **Mark Drakeford:** You promised to let us know, did you not? You have said already that you will let us know how you made the comparison between this and that. I have one question on this that I want to get on the record. In relation to the difference between using a changing-the-law approach and an educational approach, we heard evidence about black and minority ethnic communities specifically in this area. We know that the need for donation is higher and that the level of registration is lower, but we heard that, in a cultural sense, this particular change in the law causes considerable concern to people of particular faiths. All of us around this table, I am sure, will have had considerable correspondence from those communities, raising those concerns, and the point was definitely put to us that the Koran is positive about organ donation, but that an educational approach for people with language issues or literacy issues and things like that would be much more likely to succeed in raising the level of donations from those communities than the deemed consent switch that the law change would bring about. So, I am interested in your response to that whole argument.

[198] **Lesley Griffiths:** We have had meetings with specific groups. It is important that we reach all parts of society, and, as you mentioned, some of the groups that you referred to are the ones that we are trying to help even more, because their rates of donation and transplantation are very low.

10.30 a.m.

[199] Officials have had a lot of discussions with a number of non-governmental organisations to ensure that we can reassure people and that we can use agencies that they trust in order to get that information out. That is why we have this long, two-year period. There are specific groups that we are considering and we have engaged professional advisers on both general communications and faith groups, and it is something that we are very aware of.

[200] **Kirsty Williams:** On the definition of 'death' and what constitutes death, a lot of the

correspondence and evidence that we have had suggests that, sometimes, there is not necessarily a consensus on what constitutes death. One of the clinicians we heard from stated that he felt that there should be a definition of ‘death’ and ‘deceased’ on the face of the Bill. Have you considered including such a definition on the face of the Bill as to what constitutes ‘death’ in a Welsh context?

[201] **Ms Wakeling:** Yes, we have given this quite a bit of thought. The current position is that there is no legal definition of ‘death’. The Human Tissue Act 2004 provides that the Human Tissue Authority can issue a code on what is death in this context. It has not done so to date and I think that that is still the up-to-date position. Again, in Wales, we are only changing how you consent to organ and tissue donation; we are not changing any of the clinical practices around this subject. It was thought best, as with the Human Tissue Act 2004, not to define ‘death’ on the face of the Bill. If we have a definition in Wales and start changing the law in this area— It comes back to the fact that we have a UK-wide donation system; we do not want to damage people’s views on donation and we certainly do not want to reduce the numbers. If we start tampering with, or introducing new concepts in the Bill, which, of course, we can do in a Wales-only piece of legislation, we have to consider the wider context. The current law, which will continue under the Bill, is that the Human Tissue Authority will issue a code on death. Obviously, there are real difficulties around this, which have been raised in evidence in great detail, and that is probably one of the reasons why the code has not been issued, but that is the correct place for that to be dealt with.

[202] **Mark Drakeford:** You said in your letter to the committee that you were reviewing the use of the word ‘deceased’ in section 12 of the Bill, because that is the section that deals with actions that have to be taken in DCD cases to preserve organs for transplantation. So, we know that you will be doing that.

[203] Minister, I have a final clarification question. The issue of the code of practice came up earlier. In your letter to the committee, you say that you intend to make available to the committee a briefing on the likely content of the code in time for Stage 3. I think that you said earlier that we might actually see the code by Stage 3. I just wanted to be sure about what you thought you would be in a position to do.

[204] **Lesley Griffiths:** I am sorry; I should have said that there would be a draft code of practice by Stage 3.

[205] **Mark Drakeford:** Thank you very much. Minister, you have been very generous with your time with us this morning. We are grateful to you for that. I think that the discussion has shown that these are very complex issues and the time was well-spent in exploring them with you.

[206] Diolch yn fawr iawn ichi gyd am Thank you very much to you all for coming
ddod i’n helpu ni y bore yma. to help us this morning.

[207] **Lesley Griffiths:** Diolch. **Lesley Griffiths:** Thank you.

[208] **Mark Drakeford:** Fe gawn egwyl o **Mark Drakeford:** We will now have a five-
bum munud yn awr cyn inni weld y tyst minute break before we see the next witness.
nesaf.

*Gohiriwyd y cyfarfod rhwng 10.33 a.m. a 10.42 a.m.
The meeting adjourned between 10.33 and 10.42 a.m.*

Bil Trawsblannu Dynol (Cymru): Cyfnod 1—Sesiwn Dystiolaeth 12

Human Transplantation (Wales) Bill: Stage 1—Evidence Session 12

[209] **Mark Drakeford:** Rydym yn awr yn dechrau'r sesiwn nesaf. Rydym wedi derbyn ymddiheuriad gan Vaughan Gething nad yw'n medru bod gyda ni y bore yma.

Mark Drakeford: We will now start the next session. We have received apologies from Vaughan Gething, who is unable to be with us this morning.

[210] Croeso i Mr Phil Walton, a diolch am ddedd i'n helpu ni. Dyma ein deuddegfed sesiwn dystiolaeth ar y Bil Trawsblannu Dynol (Cymru). Mae Mr Walton yn gweithio fel rheolwr tîm nyrsys arbenigol ar drawsblannu organau yng ngwasanaeth Gwaed a Thrawsblaniadau'r GIG yma yng Nghymru. Mr Walton, yn ôl yr arfer, gofynnaf a hoffech chi wneud unrhyw sylwadau agoriadol byr, ac ar ôl hynny, trown at aelodau'r pwyllgor i ofyn cwestiynau.

I welcome Mr Phil Walton and thank him for coming to help us. This is our twelfth evidence session on the Human Transplantation (Wales) Bill. Mr Walton works as a team manager of specialist nurses for organ donations in the NHS Blood and Transplant service here in Wales. Mr Walton, as usual, I will ask whether you have any brief opening remarks that you would like to make and, following that, I will turn to committee members for their questions.

[211] If you have any opening remarks that you would like to offer us, that would be very useful; they can be as brief as you like, and we will then go into questions from Members.

[212] **Mr Walton:** Good morning and thank you for inviting me. My name is Phil Walton and I am a specialist nurse for organ donation. I have a background of over 10 years in critical care nursing. I work for NHS Blood and Transplant, which you will know is the organ procurement organisation for the UK. I have been a specialist nurse for organ donation for three and a half years. I am based in Hywel Dda Local Health Board, and, specifically, in Carmarthen and Llanelli, which are the hospitals that I am responsible for.

[213] In recent months, I have been placed in the position of team manager for organ donation services in south Wales. My role as a specialist nurse is to be resident in the hospitals in Carmarthen and Llanelli and oversee the local implementation of the organ donation taskforce recommendations and the National Institute for Health and Clinical Excellence guidelines that have been given to us. I also ensure that local policy runs alongside the recommendations and meets the need of the local population, because not every hospital has the same needs.

10.45 a.m.

[214] Finally, I work on the facilitation of organ donors, so I meet donor families. I am at the bedside with potential organ donors and I facilitate the process from the initial approach through to the retrieval of organs in theatre. It might be useful to say that in the last four and a half years, or since the taskforce recommendations were released, we have seen a considerable increase in organ donation in south Wales in the patch that we are responsible for. There has been a 42% increase. That is due to the organ donation taskforce recommendation implementation and the NICE guidelines in collaboration with the clinical leads on organ donation, the specialist nurses on organ donation and the chairs of the donation committees in those hospitals. So, some very hard work has gone into that. I think that that is everything that I need to say at this point.

[215] **Mark Drakeford:** Thank you; setting out the job that you do is very helpful. Members will be interested because we have heard regularly during the evidence sessions of the work that specialist nurses do at this point. So, they will be interested to hear from you a

bit more about the specifics of that and how things operate in practice.

[216] **Lindsay Whittle:** Good morning, Mr Walton. I think that you were in the public gallery earlier when I questioned the Minister about the extra resources for specialist care beds that will inevitably be required if this Bill is successful. Are you confident that we in Wales could cope with an increase in demand for not only care beds, but specialist staff? Are they available and is the training available for these members of staff to cope with what could be a little bit of an increase in demand?

[217] **Mr Walton:** I am afraid that I am not really in a position to answer the question on critical care beds. We know that there is a shortage of beds in Wales—we have one of the lowest numbers of critical care beds in Europe per 100,000 population. There have been occasions when donations have not gone ahead because of a lack of capacity. It is what it is and we have to take that as it is on the day.

[218] On staffing, we have 15 specialist nurses across Wales. We are funded for 15, based on the potential for organ donation that we have in the region. That was set out as a baseline when the taskforce recommendations were first released and when there was a massive influx of specialist nurses across the UK. Each region had to look at its donation potential and was then funded for an establishment that would meet that. If the legislation were to prove to increase organ donation, meaning that there would be a higher demand for our services, then I am sure that there would be an evaluation of whether we would need more staff. The training that goes hand-in-hand with that is in-house and comprehensive, and I am confident that NHS Blood and Transplant would continue to support that training.

[219] **Mark Drakeford:** Can you recruit to these posts? That is another thing that Mr Whittle was asking about. Is it a job that nurses are keen to do or is it a job for which you have to be a pretty special sort of person?

[220] **Mr Walton:** The job normally attracts people from a critical-care background. That is where a lot of us gain our experience and that is obviously where the majority of donors come from. You have to have something about you to do the job. However, we have had a high level of interest in the recruitment processes that we have already conducted this year.

[221] **Kirsty Williams:** We have had a lot of discussion about the role of relatives in this process and whether the ranked list of relatives, as opposed to the unranked list of relatives, is a better way of doing this. Much of what we heard from the Minister this morning was, 'Do not worry about the Bill because, in reality, it will all work swimmingly'. As someone who has to have conversations with families, do you think that this Bill will make your job easier or harder? How do you begin to address some of those issues where there is a disagreement in the family because, under this Bill, any expression of disagreement would have to be taken into consideration? For those of us who do not know about this world and the conversations that happen, could you talk us through that process?

[222] **Mr Walton:** We will work within the Bill and we will get the guidance as and when it is passed. The hierarchy of relationships in the Human Tissue Act 2004 is not without its problems. It is legislation that exists in practice at the moment and requires us to negotiate the matter on any given day. The example that we might give is of a brother, who ranks second or third on the list of qualifying relations and who may be estranged from his brother—he may not live close by or has not seen his brother for 15 years. On hearing that his loved one is unwell, he appears at the bedside. The nuclear family, as we once knew it, does not really exist in today's society. A friend of long standing, on this occasion, almost certainly will have more information than the brother who has been estranged for 15 years. We, as specialist nurses, are very used to the guidance that we have; we have worked with it for a long time and are quite comfortable with it. If it remains, there would not be any change in the way that

we approach families. If it is to change, we would certainly work with the new system.

[223] Each category would have its own set of problems. In dealing with disagreements, the practical side is that we would see and get a feel for who is at the bedside—whether they are a wife, husband, mum, dad, brother, sister, children, or whoever—and work out who is closest to the patient. The next of kin is not necessarily the parent or brother; in some cases, they are appointed, as you were discussing earlier. We will get a feel for who is at the bedside and will bring the most important people, who are closest to the patient, into a room to have a discussion. Often, it does not turn out to be 10 or 12 people—it might be a maximum of three or four. You have quite an in-depth discussion about what that person was like, about their thoughts and feelings and about what their general feeling toward organ donation might have been. You try to prise from them that level of detail. Does that answer your question?

[224] **Kirsty Williams:** Yes, it does. Obviously, you are highly professional individuals, and you will work with whatever politicians decide to give you. However, I wonder, from your professional experience as someone who has worked under the current system and will, potentially, work under a new system if the Bill becomes law, whether the Bill will make your job easier or harder. You will, obviously, do your best under whatever circumstances you face. However, at the end of this process, we will all walk away, but you will not be able to do so—you have a job to do. I am interested in whether this will help or hinder you.

[225] **Mr Walton:** The communication and education package that comes with the Bill and the change in legislation will mean that organ donation is spoken about in the home more often and more readily than at present. One of the most agonising and difficult positions in which we are placed as specialist nurses for organ donation is that of watching a family agonise over a decision to which it does not know the answer, and watching a family that is acutely bereaved and does not know whether a loved one would have supported organ donation or not. If this package is going to ensure that families are talking about organ donation regularly, and that they know whether or not the patient has actively opted in or out of the register, it will make our job a lot easier. Giving the option of opting out gives us clarity, which makes life easier.

[226] **Rebecca Evans:** In your experience, for what reasons might family members object to donation?

[227] **Mr Walton:** I will have to give a breakdown here. There is an increasing trend, currently, of a known wish; 21% of donors since April of this year have said to their loved ones before they have had a conversation with a SNOD or clinician that they would not want to be donors. There are circumstances where we can explore that a little further. Sometimes, it is not appropriate to do so with a family, depending on how the family feels at the time. However, it is nice for us, as SNODs, to try to understand the reasons why they might have said ‘no’ and how they have come to that conclusion. That is an ongoing piece of work. If your next question would be whether it is to do with the legislative change, we have not had a lot of feedback from donor families to say that that is the case currently. We have had two conversations in the last four or five months with donor families in which the opt-out system has been brought up, but it has not been the deciding factor.

[228] **Rebecca Evans:** So, for 21%, the reason given was ‘unknown wish’. What about the other 79%?

[229] **Mr Walton:** No, just to be clear, that was a ‘known wish’ of the patient not to donate.

[230] **Rebecca Evans:** Ok. So, with the others, what are the reasons that families may give?

[231] **Mr Walton:** They are that the family was unsure and so did not want to make the decision, so, to be safe, decided to not donate. Some felt that the patient had suffered enough, and some felt that the donation process was going to be too long. Those are the top four or five reasons.

[232] **Rebecca Evans:** We have heard evidence recently that in 75% of the cases where families object, the reasons given have been on religious grounds. Is that something that you would recognise?

[233] **Mr Walton:** On religious grounds, no.

[234] **Darren Millar:** It seems to me, Mr Walton, that what you are saying is that the most useful thing that this piece of legislation does is to allow people to register a wish to opt out of organ donation and to withdraw their consent for any organs to be removed after death. Is that the case? In your mind, is that the really useful thing about this piece of legislation?

[235] **Mr Walton:** It provides more clarity for the family in making a decision. So, from the family's point of view, I would say that it is most useful. As long as the clinicians are identifying and referring the patients to the specialist nurses and we are able to have access to those families and to go to speak to them and give them all the information that they require to make an informed decision, that will be what affects the donation rates significantly. For us to get access to those families would make a big difference, but for those families to have clarity from their loved ones is where the benefit of this Bill comes in.

[236] **Darren Millar:** In terms of the communication that you have with family members when someone is in a position where there may be an opportunity for organ donation, that is the key to driving up the organ donation rates, is it not, as opposed to any legislative change? In fact, this could actually reduce organ donation rates, could it not, if someone has the ability to opt out, but the family may have given permission previously? This has the potential to reduce organ donation, does it not?

[237] **Mr Walton:** I guess that it has the potential—

[238] **Darren Millar:** Do you expect it to increase or reduce organ donation rates? What is your personal opinion?

[239] **Mr Walton:** I honestly do not know. I am really supportive of the fact that in Wales we are trying something brand new in the UK that is raising the profile of organ donation. Every home is going to be speaking about it and every home is going to get information on organ donation, which they have never had before. In one night, last Wednesday, we saw a massive hit rate on the organ donor register site. That was in one night. So, a concerted effort on an education and communication plan across Wales would make a massive difference. There will be people who will opt out, but there will also be people who will have conversations to say that they would like to be a donor, and that is a good thing.

[240] **Darren Millar:** You seem to be reinforcing the message that this is really about communication and that it is communication, not necessarily legislative change, that is the key. So, as you quite rightly said, we have had this big increase just last week, without any change in the law whatsoever, simply because we are encouraging people to talk about the issue, to discuss it as a family and find out each other's views so that they can either register themselves or at least have an understanding among family members of what their wishes might be. So, would it not be more appropriate for the Government to concentrate on an effective communication and education campaign, rather than simply changing the law?

11.00 a.m.

[241] **Mr Walton:** I do not know the answer to that, sorry. What I do know is that, since April, we have had 10 families who have said ‘no’ because they did not know the wish of their loved ones. We find scenarios where the family wants to sit on the fence—that is perhaps not the right phrase, but you get my meaning—because they do not know and so they are not sure. If we have presumed consent or deemed consent legislation, the safe option may default to, ‘Well, they had the chance to opt-out and they have not, so they should donate.’ That is the other side—that is the flipping of the default setting. So, instead of keeping safe and not doing anything, they will know that their family member will have had the opportunity to opt out and may want to donate.

[242] **Elin Jones:** You mentioned in your list of reasons of why families may reject organ donation that the process was too long. Will you explain, for my understanding, the practicalities? How long can the process of organ donation take?

[243] **Mr Walton:** The process of organ donation is a little bit separate to the process of the patient’s stay in hospital, so we have to take it in its entirety. For example, a young man falls off his motorbike on a Thursday afternoon or evening, say, gets admitted to hospital and has a few days of treatment. He is treated on Friday and Saturday and has an assessment on Sunday. We get to Monday, and there is a full ward round, the specialist nurses are in and there is a referral. Already, that family has been in hospital—there have been loved ones by the bedside—for three or four days. They have not been sleeping, eating, going home or showering. Their whole world has been turned upside down. Then we get to the point of futility or brainstem testing. Continuing treatment is a futile gesture, so we start talking about end-of-life care and then the topic of organ donation is broached. So, the topic of organ donation might be broached about three or four days after admission. That is an extended period of time for any family to go through. Part of the transparency and clarity that we provide as specialist nurses is to go through every part of the process and what that involves. For a DCD donor we know that, from the point of referral through to going into theatre, we are looking at about 11 and a half hours in addition to what they have already experienced. For a DBD donor, it is about three or four hours more than that, so 15 or 16 hours. The family then have a choice of, ‘Do we it end now, so we can draw a line under things, go home, grieve and be a family together, or do we extend this a little bit longer for the benefit of somebody else?’ That must be an extremely difficult decision to make as a family. I think it is understandable that families might say that the process is too long.

[244] **Mark Drakeford:** I have one more question on this area, Mr Walton. We know that a large percentage of donations made currently are from individuals who are not on the organ donation register. They have not opted in. Does the nature of the conversation that you, as a specialist nurse, will have if you are working with a family where someone has opted to be on the register—so, their views are known—differ from the conversation you will have with regard to someone who has not taken that step?

[245] **Mr Walton:** Yes, absolutely. It is part of the process of assessing suitability. Ideally, we would try not to approach a family if the loved one does not fit the criteria for being an organ donor, that is, they have a past medical history that means they could not be a donor, for example, a history of cancer or something such as that. Part of assessing suitability would be to check whether they are on the organ donation register. If they are on the register, we would get a print-out of their entry on the register. In going to speak to the family, then the conversation is a little subtle. Instead of asking for the family’s permission for donation to proceed, we would ask the family to support the wishes of their loved one who has already stated that they would like to be a donor. So, it is subtly different, but, yes, it is different.

[246] **Darren Millar:** My question is on the same track. I will see whether I can join it up. In terms of the approach that you might make as a specialist nurse, or your team might make,

does that approach happen in every single case where organ donation is possible? What proportion of approaches would be made? Is it in 70% of situations that the question would be posed to a family? Is it 50%, or, in every single case where there is a possibility of donation, are specialist nurses involved in approaching the families and asking for a decision?

[247] **Mr Walton:** Specialist nurses are not always involved—sometimes for logistical reasons. For example, we offer an on-call service and, on a Sunday, there are two specialist nurses on call for the whole south Wales region, which covers from Bronglais in Aberystwyth to Hereford and all those hospitals underneath, so covering 12 to 14 hospitals. If the SNOD that is on call is based in Cardiff and you get a call from Bronglais, it is probably a little unfair to keep that family waiting when there has already been a decision that continuing treatment is futile, so that conversation may be had by a clinician there. That is done under guidance, to be fair. There is a telephone conversation about the key messages to get across and key things to talk about with the family. Therefore, the answer is ‘no’. Not all approaches to potential organ donors and their families would be made by a SNOD.

[248] **Darren Millar:** How confident are you that a request will always be made by clinicians to a specialist nurse to attend and support a family in making a decision? Are you confident that every opportunity is being taken up under the current arrangements?

[249] **Mr Walton:** We know from our key performance indicators that there are situations when the SNOD is not involved. Sometimes donors are not identified at all. Those are classed as missed cases.

[250] **Darren Millar:** What sort of percentages are we talking about?

[251] **Mr Walton:** There might be a case every couple of months where a patient could have been brainstem tested and was not referred, or where a patient was brainstem tested and was not referred. There are cases where patients have had treatment withdrawn and have not been referred. We would see that about once a month, at least.

[252] **Darren Millar:** So, that is a possibility of at least 12 new donors, potentially, if the system were able to close those gaps.

[253] **Mr Walton:** We have made significant progress in the last four and a half years, but we do not have a perfect system in place at the moment. Our role as SNODs—working in collaboration with the clinical leads for organ donation, the chairs and the committees—is to ensure that the organ donation taskforce recommendations and the NICE guidelines that came out in 2011 continue to be followed at a local level and that local policies in those health boards reflect those policies from the nationwide guidance. We continue to build that momentum.

[254] **Darren Millar:** What is going to have a bigger impact on donation rates? Will it be closing those gaps that we have just talked about or changing the law?

[255] **Mr Walton:** I think a combination of both will see a significant increase. If all patients who are having life-ending treatment and all patients who have brainstem tests are referred to the SNODs—so, a 100% of cases are referred—we will be approaching more families, although more families will, by definition, say ‘no’. Then, if you have a law passed, working alongside that, I am sure that you will see a difference.

[256] **Darren Millar:** Do we need more SNODs to accomplish that?

[257] **Mr Walton:** The donation potential that we have is funded and we have the right establishment for that currently. If we see an exponential rise in organ donation, we would

have to look at that.

[258] **Darren Millar:** You are telling me that, at the moment, you might be missing potential donors as it is under the current arrangements, so do we need more SNODs?

[259] **Mr Walton:** We are funded for our potential; that includes the missed cases.

[260] **Darren Millar:** Okay. I just wanted to clarify that.

[261] **Kirsty Williams:** As you say, for perfectly legitimate logistical reasons, there might not be a specialist nurse available to have those conversations with families. You said that you provide advice to clinicians that are on the spot about what they should do in those circumstances. Has any work ever been done to look at success rates for people like you, who are specifically trained to do this work, as opposed to those of other clinicians asking families, when it is not their usual job? What is the fall-off rate, or is there one? If you ask, because you know what you are doing and you do it all the time, you are likely to get a higher success rate than a clinician who has had some telephone advice because, legitimately, we do not have a specialist nurse there. Is there a fall off?

[262] **Mr Walton:** Yes; those data exist. The SNOD consent rate is classed as the SNOD-collaborative-approach rate, which means that if a SNOD is present in a room with a clinician, the success rate is around 70% to 75%. If it is a consultant-only approach it is around 50%.

[263] **Kirsty Williams:** So, your role makes a big difference in how families react to that difficult conversation.

[264] **Mr Walton:** Yes, part of our training allows us to provide clarity and detailed information about the entire process. It is done in a format that means you get the same information regardless of whichever SNOD approaches that family. We do not have control over what information a clinician would give to the family, so there would be variants.

[265] **Kirsty Williams:** There may be a better bedside manner.

[266] **Mr Walton:** I cannot comment. [*Laughter.*]

[267] **Mark Drakeford:** Mr Walton, I do not want to have a spurious certainty about numbers, but I want to pursue this conversation one stage further to make sure that I have it right in my own mind. On turning potential donors into real donors, in a case of a collaborative-SNOD approach, there is about a 75% consent rate, but if it is done without that, there is about a 50% consent rate. So, if the system is missing about one a month of people who could have been approached, and we applied the same rates to that, there would be about three or four people in south Wales in a year, who could have been real donors, who we are missing.

[268] **Mr Walton:** Yes.

[269] **Mark Drakeford:** So, that is south Wales and then there is the whole of Wales. On Darren's point about tightening up the system, if it was working at its maximum efficiency, given that the Bill intends to produce 15, we could be half way there if the current system's efficiency could be maximised. That is the point that I was trying to get to.

[270] **Mr Walton:** Yes.

[271] **Mark Drakeford:** Thank you. William is next.

[272] **William Graham:** Based on your previous answers, from your experience, do you think that the local health boards are delivering on the organ donation taskforce recommendations?

[273] **Mr Walton:** On the whole, yes, I think that they are. On some of the important aspects that required implementation, for example, the appointment of CLODS and committees, they are functioning and have policies. They all exist across our five health boards in south Wales. Each hospital has its own difficulties. There are some hospitals where the referral rate or the approach rate to families involving a SNOD is a bit lower than in others. There are some hospitals that, for whatever reason, have patients whose families consent, but they never actually get to theatre or get to donate organs. So, the localised issues are still being looked at and that will be ongoing. We are never going to be able to say that the rate is 100% in every single area, because that is just too much to expect.

[274] **William Graham:** Based on that, do you think, therefore, that now is the time to implement this Bill?

[275] **Mr Walton:** I am sorry; I missed your question.

[276] **William Graham:** Based on what you just said, do you think that now is the best time to implement this Bill?

[277] **Mr Walton:** I would not know the answer to that. I think that it has come at a time when we are approaching the end of our five-year target from the organ donation taskforce. The NHSBT is about to publish its new strategy to take us up to 2020 and this goes hand-in-hand with that. If it comes into force, we will work with it. If it does not, we will continue with what we are doing.

[278] **Kirsty Williams:** You said that sometimes a family gives consent, but for whatever reason, a donation does not go ahead and there are some particular issues within hospitals in relation to that. Could you explain what those circumstances are?

[279] **Mr Walton:** There is a variety of reasons why a potential donor might not convert to transplanting organs, or donating and then transplanting organs. We spoke about the coroner earlier; so, a coroner refusing might be one reason. The patient's health might deteriorate and they might die before we get consent. We explained earlier that there is a 10 to 15-hour period between referral and going into theatre. In that time, the patient might deteriorate and their heart might stop; there is nothing that you can do about that. You would do a profile of the patient, who may have blood chemistry that looks fine and normal, but when you get in to theatre, you might find that those organs do not look transplantable—they are not good enough to transplant. You would not take the risk of putting those organs into someone who is already not healthy.

11.15 a.m.

[280] **Kirsty Williams:** Is it possible to supply those figures on the breakdown for different hospitals? I do not know whether it is particularly relevant to the Bill, but it might be interesting to see.

[281] **Mr Walton:** Yes, we can send a note. We can prepare those data. Absolutely.

[282] **Kirsty Williams:** Thank you. That would be interesting to see.

[283] **Mark Drakeford:** Yes, it would. Thank you very much. I wanted to ask you a

question, unless anyone has one immediately, as to whether, in the conversations that you have with families, you detect a difference between donations that are for life-saving purposes and those that do not have a life-saving component to them. Cornea transplant is a pretty routine thing now, but it is not life-saving in the way that a heart transplant might be, for example. Do families make that sort of distinction in the discussions that you have with them?

[284] **Mr Walton:** Discussions that we have normally take place in two conversations. The first conversation that we would have would follow on from a conversation with a clinician who would have delivered the bad news. So, that is a separate conversation about the fact that their loved one is not going to survive. After a period of time, as SNODs, we will make our first approach to the family to talk to them specifically about organ donation. In that conversation, the specific details of which organs and the type of donation are not really explored in that much depth; it is just about the general principle and general feeling about whether they feel that organ donation is something that they would want to do. If they require more information during that conversation, we will gladly provide that. We will talk about the information that they require to make that decision. If they go ahead and say 'yes', a second conversation happens a little while later, during which we will go through the formal paperwork. We need to get consent for each and every organ that they are willing to donate. So, we will discuss the kidneys, heart, liver, small bowel, corneas, pancreas et cetera. At each point, we would provide information about the type of patient that that would help, for example, someone who is on dialysis would receive a kidney, someone who has cystic fibrosis, perhaps, could receive the lungs and be free from disease in that respect, and someone who is not living independently and has poor eyesight, or might even be completely blind, would have their independence reinstated by having a corneal transplant, which would make a massive difference. It might not be life-saving, but you cannot measure that. So, we provide that level of information. Families do say 'no' to corneas. There is a social and cultural stigma, I guess, attached to removing the eyes. We see that a lot and that is something that we work with.

[285] **Mark Drakeford:** Thank you. That is very interesting. Rebecca has a question on this.

[286] **Rebecca Evans:** That was my question, really, whether there were particular organs that families did object to as you went down that list. You have mentioned corneas because of the social and cultural reasons, but are there other organs that cause concern?

[287] **Mr Walton:** On the whole, I would say 'no'. From my personal experience, I have had a few occasions where families have said 'no' to the heart and lungs. The reasons for that are because the heart is symbolic. There is symbolism attached to the heart; it is the symbol of love and those sorts of things. So, they would not like to think of them buried without their heart or, in a more basic thought, they would not like to think of them buried completely empty. So, the heart and lungs are occasionally declined. As for abdominal organs, that is not normally the case.

[288] **Rebecca Evans:** I have a question on a different issue.

[289] **Mark Drakeford:** Yes. Go ahead. Elin also has a question on a different issue.

[290] **Rebecca Evans:** Nurses are people too, and you will all have your own personal views, beliefs, moral compasses and so on. Could this Bill potentially put nurses in a difficult position, those who have a personal ethical objection to the idea of deemed consent?

[291] **Mr Walton:** I do not know how to answer that question. I guess if somebody had a very strong ethical objection to the concept of deemed consent, then perhaps it would, but that would be for the individual to raise, and it would be for me as a team manager, or for the

organisation, to work with that individual to see how they would go forward. Knowing the team that I work in, and that works for me, we are supportive of the legislation, and we are quite happy to work alongside the Welsh Government to implement it if it comes through. So, as it stands today, I do not foresee a problem with that.

[292] **Elin Jones:** I just wanted to ask whether organ transplantation surgery always occurs in the hospital where the patient is dying.

[293] **Mr Walton:** We do not move patients for the purpose of transplantation. That is probably an ethical step too far.

[294] **Elin Jones:** Okay; good.

[295] **Kirsty Williams:** In your experience, do families ever proactively approach the issue of organ donation? Is it always a conversation that you have to raise or are there examples where families proactively raise the subject with the clinicians? Also, is there ongoing aftercare for that family? What services and support are available for the family of the deceased after that process has taken place? In your experience, do families regret making the decisions that they have made?

[296] **Mr Walton:** Okay, there are three parts to your question. Yes, families will proactively raise organ donation at the bedside or in a conversation with the bedside nurse or clinician. It can be one way or the other. They can say, 'By the way, he is on the organ donor register', and that is fine—the SNOD will be brought in, and that is fine. There are occasions when the family will say, 'If you are going to come to us about organ donation, then don't'. That would be a case where it would be the known wish of the family or of the patient, and it would very difficult to then go to talk to that family and say, 'You've said that you don't want to talk to us, but here I am anyway'. That would not be fair or appropriate.

[297] With regard to aftercare, the family gets to know the outcome of the transplantations. So, the standard that we have in south Wales currently is that, on the night of donation, the patient would go to the theatre and the donation would happen, and the next morning the SNOD who has been part of that process, regardless of whether they have been up all night, as they know the family, would ring them at an agreed point to let them know. It may be to say, 'You agreed to donate the heart, lungs, liver, kidney and pancreas, and we could not take the heart because of this reason, but the lungs, liver and pancreas went'. So, they kind of know what happened. A month later, the SNOD will go to visit the family at home. It is generally after the funeral, when they have had time to reflect on what has happened, and we will give them the outcomes of those transplants. Generally, it is anonymous information. We cannot give names or where those people live, but we will be able to say that the organ went to a 28-year-old male from the midlands area, or something like that. That gives the family an enormous sense of comfort and relief on occasion. It can be quite an emotional conversation.

[298] In my experience, they do not regret donating. There is evidence out there to show that families, on the whole, do not regret donating organs. The evidence that is out there suggests that families regret not donating when they have had time to think on it. It is understandable why families say 'no', because they are being asked to make a decision on the worst day of their lives.

[299] **Mark Drakeford:** Mr Walton, we have been discussing in committee the particular safeguards that are needed for adults who lack the capacity to make the decision themselves, and in a deemed consent system the safeguards for people in that situation have to be even stronger than they would otherwise be. Do you have experience of donations being made in circumstances where the decision has to be made on behalf of someone because they would not have had the capacity to make that decision?

[300] **Mr Walton:** Yes, I have been involved in a few cases where there has been a donor who suffers from a learning disability condition, and the people around in the two cases that I have been a part of know the nature of that patient very well. They are loving, caring individuals who probably would have supported organ donation, so the families were really very confident in making decisions on the behalf of those patients.

[301] **Mark Drakeford:** So, the safeguards that were there to make sure that the decision was properly and ethically made were robust enough in those circumstances.

[302] **Mr Walton:** Yes, absolutely. In one case, the family was present along with the carers—both these patients were in care facilities. In one case, you had the family and the carers collaboratively making that decision, and, in the other, it was people from the care facility who were there, because there was no other family, but those people knew that patient extremely well.

[303] **Mark Drakeford:** I think that we may be at the end of the questions that Members have for this session. Thank you very much for coming here and helping us with our inquiry. It has been really helpful to us to understand how this system works in that sort of detail.

[304] Diolch yn fawr am ddod i'n helpu y bore yma. Thank you very much for coming to help us this morning.

[305] **Mr Walton:** Diolch yn fawr. Thank you.

11.26 a.m.

Papurau i'w Nodi Papers to Note

[306] **Mark Drakeford:** Mae nifer o bapurau gennym: cofnodion y cyfarfod diwethaf, y rhaglen waith o'n blaen a thystiolaeth oddi wrth yr Athro Vivienne Harpwood ac oddi wrth Sefydliad Aren Cymru.

Mark Drakeford: We have several papers: the minutes of the previous meeting, the forward work programme and evidence from Professor Vivienne Harpwood and from the Kidney Wales Foundation.

[307] Mae un peth arall gennyf i'w wneud cyn i ni droi at yr eitem nesaf ar yr agenda. Mae ychydig yn hir, ond mae angen mynd drwy'r pethau hyn. Mae'n ymwneud â memorandwm cydsyniad deddfwriaethol ar gyfer y Bil Plant a Theuluoedd. Efallai y bydd Aelodau yn ymwybodol y gosodwyd memorandwm cydsyniad deddfwriaethol ar 12 Chwefror ynghylch y Bil Plant a Theuluoedd sy'n mynd drwy'r Senedd ar hyn o bryd. Ddydd Mawrth diwethaf, cytunodd y Pwyllgor Busnes i gyfeirio'r memorandwm at y Pwyllgor Iechyd a Gofal Cymdeithasol a'r Pwyllgor Plant a Phobl Ifanc iddynt graffu arno. Cytunodd y Pwyllgor Busnes y dylai'r pwyllgorau gyflwyno adroddiadau am y memorandwm erbyn 11 Ebrill er mwyn caniatáu amser i drafod y memorandwm

I have one other thing to do before we turn to the next item on the agenda. It is quite long, but we need to go through these things. It relates to the legislative consent memorandum for the Children and Families Bill. Members may be aware that a legislative consent memorandum was laid on 12 February regarding the Children and Families Bill which is going through Parliament at the moment. Last Tuesday, the Business Committee agreed to refer the memorandum to the Health and Social Care Committee and to the Children and Young People Committee for scrutiny. The Business Committee agreed that the committees should present reports on the memorandum by 11 April to allow time to discuss the legislative consent memorandum in Plenary in April. As the

cydsyniad deddfwriaethol yn y Cyfarfod Llawn ym mis Ebrill. Gan fod y dyddiad cau yn ystod toriad y Pasg, bydd yn rhaid i'r pwyllgor gwblhau ei waith erbyn dydd Gwener 22 Mawrth. Mae cynghorydd cyfreithiol wrthi'n paratoi cyngor cyfreithiol i'r pwyllgor ar y memorandwm a bydd y clerch yn paratoi papur opsiynau ar gyfer dull y pwyllgor o ymdrin â'r memorandwm. Os yw Aelodau'n fodlon, byddwn yn neilltuo rhywfaint o amser yn ystod cyfarfod wythnos nesaf i ystyried y ddau bapur a chytuno ar y dull o ymdrin â'r memorandwm. A yw pawb yn hapus i wneud hynny felly yr wythnos nesaf? Gwelaf eich bod. Diolch yn fawr.

deadline is during the Easter recess, the committee will have to complete its work by Friday 22 March. A legal adviser is drawing up legal advice for the committee on the memorandum and the clerk will prepare an options paper for the approach of the committee towards the memorandum. If Members are content, we will set aside part of next week's meeting to consider the two papers and to agree on the approach towards the memorandum. Is everyone content with doing things in that way next week? I see that you are. Thank you very much.

11.29 a.m.

**Cynnig o dan Reol Sefydlog Rhif 17.42(vi) i Benderfynu Gwahardd y
Cyhoedd o'r Cyfarfod ar gyfer y Canlynol: Trafod yr Adroddiad Drafft
Motion under Standing Order No. 17.42(vi) to Resolve to Exclude the Public
from the Meeting for the Following Business: Consideration of the Draft
Report**

[308] **Mark Drakeford:** Cynigiau fod

Mark Drakeford: I move that

y pwyllgor yn penderfynu gwahardd y cyhoedd o weddill y cyfarfod yn unol â Rheol Sefydlog Rhif 17.42(vi).

the committee resolves to exclude the public from the remainder of the meeting in accordance with Standing Order No. 17.42(vi).

[309] A yw'r Aelodau'n fodlon â hynny? Gwelaf eich bod.

Are all Members content with that? I see that you are.

*Derbyniwyd y cynnig.
Motion agreed.*

*Daeth rhan gyhoeddus y cyfarfod i ben am 11.29 a.m.
The public part of the meeting ended at 11.29 a.m.*