



Cynulliad Cenedlaethol Cymru **The National Assembly for Wales**

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

Dydd Iau, 7 Chwefror 2013
Thursday, 7 February 2013

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Cofnodir y trafodion yn yr iaith y llefarwyd hwy ynddi 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 Antoniow	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
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

Y Parchedig/Reverend Aled Edwards	Prif Weithredwr, Cytûn—Eglwysi Ynghyd yng Nghymru, ac Ysgrifennydd Cyngor Rhyng-ffydd Cymru Chief Executive, Cytûn—Churches Together in Wales, and Secretary, Inter-Faith Council for Wales
Geraint Hopkins	Swyddog Polisi, Cytûn—Eglwysi Ynghyd yng Nghymru Policy Officer, Cytûn—Churches Together in Wales
Saleem Kidwai	Cyngor Mwslimiaid Cymru Muslim Council of Wales
Joyce Robins	Patient Concern
Yr Athro/Professor John Saunders	Cadeirydd, Pwyllgor Materion Moesegol mewn Moddion, Coleg Brenhinol y Meddygon Chair of Royal College of Physicians' Ethical Issues in Medicine Committee
Y Parchedig/Reverend Carol Wardman	Cynghorydd Esgobion ar yr Eglwys a Chymdeithas, yr Eglwys yng Nghymru Bishops' Adviser on Church and Society, Church in Wales
Y Parchedig Ddoctor/Reverend Dr Stephen Wigley	Llywydd, yr Eglwys Fethodistaidd yng Nghymru Moderator, the Methodist Church in Wales

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

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

*Dechreuodd rhan gyhoeddus y cyfarfod am 10.03 a.m.
The public part of the meeting began at 10.03 a.m.*

Cyflwyniad, Ymddiheuriadau a Dirprwyon Introduction, Apologies and Substitutions

[1] **Mark Drakeford:** Bore da, agorwn y cyfarfod yn awr, ond rydym yn aros i'r tyst gyrraedd fel ein bod yn gallu parhau ag eitem 3 ar ein agenda. Rydym wedi derbyn ymddiheuriadau oddi wrth Darren Millar; nid yw'n gallu bod gyda ni heddiw.

Mark Drakeford: Good morning, the meeting is now open, but we are waiting for the witness to arrive so that we can continue with item 3 on our agenda. We have received an apology from Darren Millar, who cannot be with us all day today.

10.05 a.m.

Bil Trawsblannu Dynol (Cymru): Cyfnod 1—Sesiwn Dystiolaeth 8 Human Transplantation (Wales) Bill: Stage 1—Evidence Session 8

[2] **Mark Drakeford:** Croeso i chi i gyd. Dyma'r wythfed sesiwn o dystiolaeth ar y Bil Trawsblannu Dynol (Cymru). Mae'n bleser gennyf groesawu Joyce Robins, un o sylfaenwyr Patient Concern, sy'n ymuno â ni heddiw i'n helpu yn ein gwaith. Diolch yn fawr i chi am ddod. Fel arfer, rydym yn gofyn a oes unrhyw sylwadau agoriadol byr gennych i dynnu sylw at yr hyn a ddwedoch chi yn eich dystiolaeth ysgrifenedig. Ar ôl hynny, trof at aelodau'r pwyllgor i ofyn eu cwestiynau.

Mark Drakeford: Welcome to you all. This is the eighth evidence session on the Human Transplantation (Wales) Bill. It is my pleasure to welcome Joyce Robins, one of the founders of Patient Concern, who joins us today to help us with our work. Thank you very much for coming. Usually, we ask if you have any brief opening remarks to highlight what you have said in your written evidence. After that, we will turn to committee members to ask questions.

[3] So, thank you very much for being with us today. I invite your opening remarks and then we will turn to questions.

[4] **Ms Robins:** Thank you very much. My problem with this Bill is that it seems to be based on a falsehood. It is pretending that you have agreement to something, when you have no such thing. I heard the Minister earlier in the week, in your hearing, saying that, apart from the assumption of consent, the Bill changes nothing. In our view, it changes everything. The whole concept of a gift is changed and it deprives would-be donors of the opportunity to exclude certain organs, which you can currently do on the donor form—I think that eyes are a fairly common exclusion.

[5] When this was originally debated in Westminster several years ago, the proponents were very clear that it would change the nature of the conversation with relatives. You would no longer be asking, 'May we take these organs?', but you would be saying, 'We plan to take these organs.' To me, that has a slight element of coercion and is unacceptable. Basically, that is where I stand.

[6] **Mark Drakeford:** Thank you very much. Before I turn to Members, it would be helpful for us if you very briefly told us a bit about Patient Concern as an organisation and how you draw the views of your members together.

[7] **Ms Robins:** It is not a membership organisation, as such. It is an independent voluntary organisation. We have an advisory board with lawyers, ethicists and such like. No-one in our organisation owes their living to the health service. We set it up 13 years ago, because we felt that there was a need for a completely independent organisation. That is what we try to do.

[8] **Mark Drakeford:** Thank you very much indeed. Who would like to start off? Vaughan?

[9] **Vaughan Gething:** Coming back to your fundamental discomfort and disagreement with the Bill, you said in your opening remarks that it would take away the right to opt in or out of elements of donation. Correct me if I am wrong, but would it not still be the case that you could request to opt in or out?

[10] **Ms Robins:** I am sorry, could you repeat that?

[11] **Vaughan Gething:** You could request to opt in or out. On a consent form at present, you can opt in or opt out to donate certain organs; that does not change under this Bill, does it, unless I have missed that somewhere?

[12] **Ms Robins:** I do not think that that is actually so. At the moment, you sign on to the donor register, or you do not. If you are not on the donor register, then you are not a donor. I do not think that it has been spelt out exactly what the position will be, but it has always been said that you will be able to opt out. I have not seen any proposals for a form where you can either opt in or opt out. That would be more acceptable. We are much more for the idea of a sort of mandatory choice, but you have dismissed that out of hand.

[13] **Vaughan Gething:** Mandatory choice is interesting. Will there not be a range of people who would have even greater concerns about mandating everybody to make a positive choice, one way or another? That is where I would start.

[14] I am interested in your view that there is a fundamental ethical problem with the Bill, because we had evidence last week from a range of medical ethicists who said that there was not a fundamental ethical problem with a presumed consent system, but their concerns were rather more practical around whether or not people would understand the choice that they were making. Is your concern really that people cannot make a choice or are you of a fundamental view that presumed consent is unethical?

[15] **Ms Robins:** There is no other area of life that I know of where the absence of refusal means consent, as such. Of course, you say that everyone will understand that they can opt out, but it is not my experience that that is ever so; it certainly was not so in the examples that we have had so far, for instance, with summary care records. People do not know, they do not understand and it does not matter what publicity you have. You have here some 80 pages of an explanatory memorandum for a Bill, for the people who can read a Bill, but how will folk out there understand what this is about and understand their choices? I do not think that they will.

[16] **Vaughan Gething:** At the point of choice, as it were, under the Bill, if someone has not opted out and expressed their formal wishes, you will have heard what the Minister said about any member of the family in a qualifying relationship—of course, a qualifying

relationship is not just family, because a friend of long standing has a qualifying relationship—are you saying that you do not accept the Minister’s statement that, in practice, if anyone in a qualifying relationship objected to a donation, that would mean that a donation would not go ahead is what would happen?

[17] **Ms Robins:** That is not what your new law says. At the moment, you can opt in and say that you want to be a donor, but if your family objects, that can be overridden. I do not approve of that. If you say that you want to be a donor, you should be able to be a donor. That is how it works, in that doctors will not do it if someone objects. That may be the way under your new law, but I do not see anything in the Bill that says that. I think that it says that relatives should be significantly distressed, and someone will assess that—I do not know which clever person will assess that, but I do not like the sound of it at all.

[18] **Ms Robins:** May I go back to mandatory choice? I can see that there are problems with mandatory choice, but I do not see a problem with—I do not understand why it has not been done for years—asking you every time that you access healthcare whether you wish to be a donor or not. That can be recorded on your notes, and it is there. It is so simple; it does not take £8 million to do it. I do not understand why it is not done—just like you are asked who your next of kin is. It seems so simple.

[19] **Vaughan Gething:** On the question that I asked—you went back to a different question.

[20] **Ms Robins:** I did. I got my little say in about that.

[21] **Vaughan Gething:** I have even forgotten the question that I asked myself; that is embarrassing. Is this really about the fact that, even though it is not on the face of the Bill, you do not accept the practice that already exists where even if there is expressed consent and there is an objection that the donation does not go ahead? Is this really about the fact that you do not trust that, even with presumed consent, if someone in a qualifying relationship objects, that may happen anyway? Is this a matter of trust or is it simply that, if it was on the face of the Bill, that is what would happen. Would that allay your concerns?

[22] **Ms Robins:** It would certainly be a lot better if it was on the face of the Bill. If it said that if your relatives said ‘no’, that would be ‘no’, that would ease my mind considerably. It is not what the Bill says.

[23] **Vaughan Gething:** No, it is not what the Bill says.

[24] **Mark Drakeford:** Mick has a point on this, and then I will go to William, Lynne and Lindsay.

[25] **Mick Antoniw:** I want to clarify what your real objection is in the light of what you said. If it were the case that the educational campaign and so on were such that you were satisfied that the Welsh Government had satisfactorily communicated the whole process, so that people understood that if they did not want to donate, they would have to opt out, you would not have any objection to it. Is your objection really about the fact that you do not think that it is possible to have adequate communication and education? Is that what it boils down to?

[26] **Ms Robins:** There are two things there. The first is that I do not think that it would be adequate. I sat in front of a parliamentary select committee when we were going to upload summary care records and I made the same objections then, namely that people would not understand and know that they could opt out. Everyone said ‘Oh yes, there’s a letter to every house. It’s a wonderful campaign. Everyone will know’. Up went the summary care records,

and the various audits that were carried out after that showed that hardly anybody knew it was happening, and I think the same thing is going to happen again on something far more important.

10.15 a.m.

[27] Also, even if you do spread the word, the usual inertia, ignorance and inability to confront the idea of death all come in, and therefore people do not do what you are saying they can do. At the moment, that works the other way around—you do not get as many donors as you should because of these various things. So, what you are planning to do is turn the law around so that you get it your way, and I do not think that that is ethical.

[28] **Mark Drakeford:** I will go to William, Lynne and Lindsay, and then there will be more, I know.

[29] **William Graham:** Could you tell the committee what you believe are the most common reasons for relatives refusing consent?

[30] **Ms Robins:** To a large extent, it is because the approach is not right. Spain has conquered this, and now has only a 10% refusal rate. We have 40%, plus 75% in ethnic minorities, which is horrendous. It is my view that, if the system worked properly, and you had someone who really worked with you at such a sensitive time for you to reach the decision that was right for you, then we would not get all of those refusals, which we do not want any more than anyone else does. Spain has managed it; why can we not manage it?

[31] **William Graham:** Have you any suggestions for how that could be achieved?

[32] **Ms Robins:** It is being achieved under the taskforce's recommendations. Enormous improvements have been made already. Obviously, it takes time. Also, there are a lot of religious objections on the part of relatives, and that is the most common reason given—because, although every religion, except possibly Islam, says that, yes, they are for transplantation, an awful lot of religious folk are not. They think there is some desecration about it, which I do not go along with, but that is one of the big reasons. Also, of course, there is the shock at the time. It is a terrible moment to be approached about that. That is why it needs to be done properly.

[33] **Rebecca Evans:** I want to press you on that, because I have had lots of correspondence from deeply religious people who are extremely in favour of transplantation, so I was just wondering where the evidence is that people who hold a faith are more likely to object when it comes to that moment.

[34] **Ms Robins:** Simply that that is given as the most common reason at the bedside. Whether it is honest or not, I cannot tell you. However, that is the most common reason given, apparently—religious objections.

[35] **Lynne Neagle:** I just wanted to go back to this issue of understanding, because you have said that your organisation's work with patients shows that, as a concept, opting out is poorly understood, and you have referred to the problems with the records. I wonder whether that was the only thing that you were basing that assertion on, or whether you have done any work consulting with any networks that are involved with your organisation on that issue.

[36] **Ms Robins:** Yes, and opting out is a rather foreign concept to us. We are just not used to doing that. To opt in to something is informed consent. What is being proposed now is that, if you do not opt out, then you have agreed—there is nothing informed about that. Polls are constantly quoted showing that x number of people are in favour of transplantation; it is

not informed consent if you tick 'yes' in the street. All that I can say is that we get enormous abuse because people do not understand that, because you say that you are for informed consent, you are not against transplantation. We get enormous abuse, and name-calling every time we say that publicly, and I am used to that, but the ordinary folk are not, and a lot of people think, 'Oh no, if I opt out then I am going to be a bad person, and I am going to be discriminated against'. I do not agree with that, but there is quite a lot of feeling out there.

[37] **Lynne Neagle:** So it is kind of anecdotal, from the patients you work with, rather than any formal piece of work.

[38] **Ms Robins:** Yes; most things related to patients are anecdotal. There is also the evidence of the summary care record. We were told that it would be quite different, just as I am being told now, and it was not, and it still is not. Millions of records are up there. You ask people in the street and hardly anybody knows that their record is up there.

[39] **Kirsty Williams:** I am quite interested in the concept of consent and what constitutes consent. I am interested in what you regard as the crucial elements of consent, and whether you could ever have a system in which you could provide enough information to enough people to establish that not opting out really would mean consent.

[40] **Ms Robins:** Oh.

[41] **Kirsty Williams:** I know, and it seems in some ways petty to have these discussions, because they are esoteric, and we are talking about something very practical, but if a Government is deeming the consent of its population, for me, as a Liberal, these are important concepts. So, I wonder what you would regard as consent and whether you could ever educate and provide enough information to establish consent within a population.

[42] **Ms Robins:** It is difficult within a population. It is an individual matter, obviously. We did a lot of work with the Government in the early 2000s, after the Bristol scandal, the Alder Hey scandal and endless other scandals, and it had an enormous consent initiative, and informed consent became the order of the day. It is now wafting away, interestingly enough—the mid Staffordshire thing might bring it up again.

[43] In one sense, I suppose that you could argue that you can never give enough information, but you can make sure that any individual who makes a choice understands the choice they are making. I do not think that, on a deemed basis, you can possibly do that. Deemed consent is fake consent.

[44] **Mark Drakeford:** I am going to go to Lindsay next, but before that, Ms Robins, you say in your evidence that in no other walk of life is the absence of refusal regarded as consent. What if someone were to say to you that that is quite the reverse of the truth and that the way that we navigate and negotiate our daily lives is almost always on the basis of deemed consent rather than anything else.

[45] **Ms Robins:** Could you give me an example?

[46] **Mark Drakeford:** Well, in the unlikely event that I was to be selected for the Assembly cricket team, nobody would say to me, 'Are you sure that you've signed up to the intricacies of the LBW rule?' If I buy a ticket for the theatre, nobody says to me, 'Are you certain now that you are signing up to the fact that that ticket will only allow you to sit in a particular seat, and that you will be expected to not stand up and start talking to people around you in the middle of the performance?' My consent to the rules that operate in such contexts is deemed. So, most of the way in which we understand our normal, daily lives is done on the basis of deemed consent, and what the Nuffield bioethics people said to us was that this

would be no different; it would simply be a different convention and a different set of rules that people would understand and abide by. Deemed consent is not poor-man's consent; that is what they said to us.

[47] **Ms Robins:** Well, I would not agree with them. In the instance that you have given, in which you buy a ticket, you have chosen to buy the ticket; you know that you want to go to that show. The fripperies of where you sit and so on are immaterial, really. If you are put into a cricket team, you do not get there, put your pads on and say, 'I didn't really want to come'. You have consented to go. This is what we are talking about here. You are talking about whether someone can take your organs when you are dead. You are not talking about how they do it or when they do it; you are saying, 'Yes, you may do it'. I do not see those examples as parallels at all.

[48] **Lindsay Whittle:** Good morning, and thank you for coming to give evidence to us today. We listen to opinion polls, and they tell us that there is a reasonably good majority of people in Wales who are in favour of this new Bill. I would be interested in your opinion on that.

[49] You mentioned Alder Hey and the appalling treatment of people who had lost loved ones and how organs were taken without consent. Obviously, I would hope that that would never happen in Wales. I want to ask about the new code of practice, because I carry an organ donation card and have done so for very many years, and I believe with a passion that if anybody wants any of my organs, then they should please use them. I have spoken to my loved ones and told them, should anything tragic happen to me, to not object. However, of course, they could object at the time because, I would like to think, they would be distressed; but I hope that they would not be that distressed. Do you think that the new code of practice should be strengthened so that we can capture the permission of the person whose organs we are going to use? For me, that is more important than the relatives' permission. I know that sounds controversial.

[50] **Ms Robins:** I agree with you. At the moment, the law is that relatives cannot override your expressed decision. It happens because doctors will not push the body past the relative picket line, as they call it. We do not agree with that. If you have made your decision, that is your decision, and relatives should not be able to override it. However, we are talking about something different here where you may not have made a decision.

[51] As far as support for the Bill goes, I understand that it has dropped substantially in the past few months, and that the majority of Welsh people are no longer in favour of it, possibly because they now know a bit more about it. However, opinion polls are not something I value terribly, because what you are asked out on the street is not necessarily what your considered decision would be.

[52] As far as the code of practice is concerned, if this horrible Bill goes through—I am sorry to put it like that—the code of practice should be very strong and say that relatives have the right to overrule if you have not specifically said that you want it, and presumably you will not have done; it will have been assumed, deemed, or whatever.

[53] I am sorry; have I missed something in your question?

[54] **Lindsay Whittle:** No, I think that you have captured most of it. I have not seen the new opinion polls that you mentioned.

[55] **Ms Robins:** I am told that support fell from 63% in March to 49% in October, according to the Welsh Government's poll.

[56] **Lindsay Whittle:** That is interesting. So, at least people in Wales are having the debate, which can only be a good thing.

[57] **Ms Robins:** Yes, it has to be a good thing.

[58] **Lindsay Whittle:** You mentioned in your oral evidence that many religious groups are opposed to this. From my point of view, I would fully respect those people's wishes; heaven forbid that we would not do that. I hope that that will be safeguarded in this Bill.

[59] **Ms Robins:** It is certainly not in the way that it is laid out at the moment.

[60] **Vaughan Gething:** To follow up, you refer in some of your remarks to Alder Hey and mid Staffordshire. Is that not a bit of a red herring? What happened in those instances was that the families were not even informed, but that is not what this Bill is suggesting, and that is not the practice that is being laid out. The practice that the Minister has been very clear about and the practice that we expect to see being directed in the code of practice is that a discussion has to take place, as happens already, including in the case of people who are not expressly opted in on the register, where there can still be a discussion with relatives. I want to be clear about what would happen in those instances. Surely, you are not trying to equate that with the deemed consent process that this Bill suggests?

[61] **Ms Robins:** I am not trying to draw a parallel between what happened at Alder Hey with what you propose in your Bill; that would not be sensible. What I am worried about—this is probably where I may not have made myself clear—is that I think that there will be mistakes in the way that you are going. It may well be that once organs have been removed, some cross family members will come up with evidence that should have been considered that this person did not want their organs to be removed.

[62] The media, rightly or wrongly—I have a lot of dealings with the media, and I have some very ambivalent feelings about them—will blow it up like mad. We have some experience, as a few of you will remember, of mistakes made by NHS Blood and Transplant in relation to what donation forms said and that organs were taken that should not have been taken. This is the type of thing that I am worried about. That went global, and I was quoted all over the world as saying what a dreadful thing this was.

[63] Once a Bill is passed, consent is deemed and mistakes are made, you might confront a whole load of trouble, which would be very bad for the whole transplantation process. I would hate to see it, but I think it is likely to happen.

[64] **Vaughan Gething:** I have another question, but it leads to a different point, which someone else may want to ask about.

[65] **Elin Jones:** I want to ask you about deeming consent for all organs and tissues. On the face of this Bill, consent is deemed for everything, with the exception of a very short list in section 16. We have had discussions in this committee around the fact that the population at large would probably understand this Bill in the context of solid organs, or possibly life-saving organs, whereas transplantation now is going into the fields of face transplantation and hand transplantation. If this Bill is to proceed, do you have any view on whether the face of the Bill should be more specific as regards the relevant material where consent is deemed?

10.30 a.m.

[66] **Ms Robins:** I certainly do. Funnily enough, just as I was leaving and had my coat on to come here from London, one of your local journalists telephoned me to talk about this particular point. I had not thought of it. I think I said something—and it may well be quoted

this morning—that many people who would be willing for their heart or lungs to be taken would not be willing to have bits of their face taken, and that they might well be prepared to have organs taken for a life-saving procedure but not for a cosmetic one. I do not know what particular things you are thinking about, but I was quite shocked to think that I might sign up to a donor register without thinking of these things and to not have them excluded. The short answer is ‘yes’; the face of the Bill should be clear as to what we are talking about.

[67] **Mick Antoniw:** As part of the ethos point that you raised in relation to the nature of consent, is there a follow on from the position that you have adopted that patients should be able to say not only which organs they are prepared to allow, but where and to whom those organs go? What is your view on that?

[68] **Ms Robins:** No, we have never a system where you can pick and choose where your organ goes. I think that it would be quite wrong.

[69] **Mick Antoniw:** Why?

[70] **Ms Robins:** All sorts of racial issues might come in, along with things that, on the whole, we find unacceptable.

[71] **Mick Antoniw:** Does it not follow on naturally from the position that you are adopting about informed consent?

[72] **Ms Robins:** No, I do not think so, because you are informed. You know that you cannot choose where your organ goes. If you feel terribly strongly that you would only want it to go to X, Y or Z, you will not sign up; except that, under your Bill, you would have signed up—your consent will be deemed.

[73] **Mick Antoniw:** Is that not a form of deemed or presumed imposition?

[74] **Ms Robins:** I am sorry; I missed that.

[75] **Mick Antoniw:** Is that not a form of deemed imposition on the individual?

[76] **Ms Robins:** No, I do not think so, because you are aware that that is the system. I do not think that there is anyone who may not understand much about transplantation but does not know that you cannot pick and choose where your organs go. You sometimes see a fuss about it, where someone wants an organ to go to a particular person. However, that is not the system.

[77] **Rebecca Evans:** Do you think that there might be any implications in terms of the patient’s relationship with their clinicians, or the patient’s family’s relationship with the clinicians during receipt of treatment?

[78] **Ms Robins:** Yes, I do. I think that this whole idea rather eats away at trust. People might well feel that they are much more valuable as a donor than they are as a live, extremely ill patient. That is not really how we want to see it.

[79] **Rebecca Evans:** Do you have any concerns about the pressure it might put on clinicians if they are dealing with deemed or presumed consent? What sort of confidence could they have that they would be acting in the best interests of that patient?

[80] **Ms Robins:** Exactly. The last poll that I heard of among intensivists showed that 50% of them were against this particular way of going. They did not like it. They did not feel that they would be confident that they really had the consent of the people whom they were taking

organs from.

[81] **Rebecca Evans:** I have a question on a different issue. The Government suggested that it would have £50,000 per annum for ongoing communications with people. I think that that would include people when they turn 18, for example. Do you think that £50,000 a year would be sufficient to get the message out there about deemed consent?

[82] **Ms Robins:** It is most unlikely, I would have thought. Obviously, in my view, it would be wasted money. It is not the way that we should be going. It seems to me that the whole £8 million would far better spent in other ways, but there we go.

[83] **Rebecca Evans:** If you had that £8 million and a blank sheet of paper, what would you do with it?

[84] **Ms Robins:** Do you mean with regard to this Bill?

[85] **Rebecca Evans:** No, with regard to organ donation; if you had £8 million and wanted to realise the goal of doubling the number of organs, what would you do with it?

[86] **Ms Robins:** I would spend it in the way that the taskforce is now spending the money, namely on training co-ordinators who can work with families to ensure that if they want to say 'yes', they can do so. I hear from people who have been asked at this point to allow their family member to donate and who have said 'no', and have regretted it, which is sad. However, I also hear from people who have agreed and have regretted that because of how they were then treated. That is perhaps by the by, but there are better ways of spending the money. I do not have the figures on intensive care beds in Wales, but I know that ours are absolutely dreadful. They are right at the bottom of the international tables.

[87] **Kirsty Williams:** Ours are worse.

[88] **Ms Robins:** Yours are worse? There you go. On the whole, you cannot do much in this field without intensive care beds because that is where the people who can donate the organs will die. So, you are possibly wasting your money on informing people about this if you do not have the wherewithal to do it.

[89] **Vaughan Gething:** I want to go back to the comment that you made in response to my follow-up question on your concern that presumed or deemed consent would lead to more mistakes being made in terms of organs being transplanted when subsequent evidence would suggest that someone objected. Do you have any evidence to support that concern because other healthcare systems have a soft opt-out system?

[90] **Ms Robins:** You mean that other countries have it.

[91] **Vaughan Gething:** Yes.

[92] **Ms Robins:** Yes, but other countries do not have our history of Alder Hey Children's Healthcare Hospital. I do not know how much that impinged in Wales. I know that you had problems, but it was mainly—

[93] **Vaughan Gething:** But I thought that we had just established that Alder Hey was a different matter, where there was no attempt at getting consent.

[94] **Ms Robins:** I am talking about people's heads and not the actual facts of the matter. What happened was that organs were taken without consent and if it is shown again that that is sometimes done without consent, the media will make much of it. I am not necessarily

saying that it is so or that the media should make much of it or that there is a complete parallel, but I know the media—I know what I say to the media and what comes out in the media. You have to be very careful and I think that we should be more careful about this because of history.

[95] **Vaughan Gething:** So you are saying that our history is unique and that similar issues are not arising in Belgium or Spain where they have a soft opt-out system.

[96] **Ms Robins:** As far as I know, our history is unique. I do not know of it in other countries. Furthermore, Belgium, for example, has a soft opt-out system, where, if the relatives say ‘no’ to organ donation, then it is a ‘no’; that is not what is currently being proposed. It has been said around this table that that might be the case, but it is not what is currently proposed. Spain does not have a working presumed consent law, although it is often quoted as having one; it does not work there. There is no opt-out register there—it has never been used. It all depends on what the relatives say. Spain is at the top of the transplant league; in second place is the USA, which has never had a presumed consent law. It does not have to be that way. It states in the memorandum, I think, that this is the only way to do it, but it is not. Other countries have done it successfully and so could we.

[97] **Vaughan Gething:** So, just to be clear about the question that I asked: there is no objective evidence that states that there will be more mistakes, but you are concerned that there could be more mistakes—that is what you said earlier. You said that you were concerned that more mistakes would be made.

[98] **Ms Robins:** Yes, that some mistakes would be made.

[99] **Vaughan Gething:** What I do not understand is why you are saying that there would be more if this law were passed.

[100] **Ms Robins:** I do not think that I said that there would be more; I said that there would be mistakes because you are assuming something that you do not have, namely consent.

[101] **Vaughan Gething:** I would like to go back to an alternative point because that is not what any of the clinicians have put to us so far. One point that has been made is that new arrangements might make clinicians more cautious in terms of stating and authorising consent and that having the list of relatives drawn up, where anyone from a qualifying relationship can object, would make it more difficult to authorise and obtain consent. Their concern was that rather than this helping—in a way that you think may be unethical—it might make things more difficult.

[102] **Ms Robins:** That is an interesting point, because the way that I read the Bill, you have to be extremely distressed before anyone is going to take any notice of you as a relative. On the face of the Bill, it does not say that you can object and that that objection will be taken on board. There has been some suggestion here that that is what it will say, but it is not what it says now. You make an interesting point; I had not thought of it in that way.

[103] One thing that I welcome, if the Bill goes through as it is, is that you can nominate someone to make the choice for you. That is good, except that when I think about my family, I would have to be very careful about which particular person I nominated in terms of the answer that would be given.

[104] **Vaughan Gething:** They would not have to be a family member.

[105] **Ms Robins:** This part of the Bill is to be welcomed. I like the idea; it is the only thing

that I do like.

[106] **Vaughan Gething:** Finally, on the group of relatives and long-standing friends, one question that we have generally asked other people is whether they agree that anyone on that list should potentially be able to object or whether they favour a ranking system, where a category of relatives would be considered—spouse and parents, for example—and other people being ranked after that.

[107] **Ms Robins:** I would favour a ranking system, assuming that the Bill went ahead.

[108] **Rebecca Evans:** We have heard some concerns regarding the nominated person, namely that there is a window for these operations and that it might be difficult to find that person in time. Is there a danger that that could mean that organs that could, potentially, have been used willingly would not be used in the end because the nominated person could not be found?

[109] **Ms Robins:** That is possible, so I guess that you would have to have a ranking system of nominated people. It gets very complicated, does it not? That is how life-saving operations work at the moment, so I suppose that it might work.

[110] **Mark Drakeford:** The Bill provides certain safeguards for people who are thought not to have the capacity to provide consent of any sort. Do you think that the Bill is adequate in the safeguards that it provides in those circumstances?

[111] **Ms Robins:** I think that the honest answer to that is that I do not really know; it is not really my field.

[112] **Kirsty Williams:** Do you have any comments to make on different ethical concerns with regard to transplants from patients who are brain-dead or who have suffered circulatory death? We had a suggestion last week from some professionals that, as a first step, the Bill should apply only to patients who are deemed to be brain-dead and not in cases of circulatory death. Do you have any views on that?

[113] **Ms Robins:** We were asking earlier why people refuse to donate, and a number refuse because they do not believe in our category for brain death anyway, which complicates it even more, does it not? Our criteria for brain death are less rigorous than in many countries. Again, as far as your question is concerned, I am not sure that I am qualified to answer it.

[114] **Kirsty Williams:** You say that the way in which we classify brain death is not as rigorous. Please forgive my ignorance, but in what way is that the case?

[115] **Ms Robins:** There are various tests that we do not apply. Again, I am not a medical person, and I do not have the tests in my head at the moment. However, I know that there are a couple of very strict criteria that many countries apply, and we have decided that they are not necessary; that is, our top specialists have decided not to apply them. Some of the doctors with whom we have corresponded about this have made this great point. I am not a medical person, so I cannot delve into the matter in detail, but it seems to be the case that we are not as rigorous.

[116] **Kirsty Williams:** I will ask the specialists.

[117] **Ms Robins:** Please do.

[118] **Mark Drakeford:** In the last minute or two that we have for this session, I would like to give you an opportunity to go back to the preferred option that you set out in your paper. If

I have understood it correctly, it is a kind of soft mandated choice model. Your model would not require people to declare themselves, but you would put that choice in front of them regularly enough so that in the end, they would declare a view.

10.45 a.m.

[119] **Ms Robins:** I am not sure that they would, necessarily, if they were strong-minded. However, yes, you would be asked who your next of kin was, whether you would like to be an organ donor or not, and whether you would like to leave the decision to your family. Every time you go to the doctor or the hospital, it should be one of the things on the form. It seems so simple to me and I do not know why we do not do it. There has been some argument that that might be a bit scary for people; it is no more so than having to say who your next of kin is, which only applies if you are dead, as does this.

[120] **Mark Drakeford:** Would you repeat that question every time, or is it—

[121] **Ms Robins:** Every time that you access healthcare—unless you have already made a decision, or you want to change your decision, or whatever. On the famous electronic notes that are going to be introduced, it would get flagged up and there would be no more problems.

[122] **Mark Drakeford:** I just want to make sure that I have really understood this point. I present myself; I am asked the question; I know my view, so I say what it is and it is recorded. I am not asked the next time I present myself, am I? Not every time?

[123] **Ms Robins:** You are not asked for your next of kin every time. I would have thought that some doctors, depending on their viewpoints, might ask whether that was still your decision, but if you had made your choice and you were not saying that you wish to make another, then, no, you would not be battered by this each time.

[124] **Mark Drakeford:** That is what I was trying to clarify.

[125] **Mick Antoniw:** You say that it sounds simple, but I can see a lot of people going in perhaps with a bit of chest pain and so on, and the first question that they are asked is, 'Do you want to be an organ donor?' It is not quite as simple as that, is it?

[126] **Ms Robins:** Again, you say that you can publicise things and let people know, but this is on a one-to-one basis—'We will now ask this question, it does not mean anything sinister to you—it is the same as asking who your next of kin is'. I think that an explanation of this will soon percolate through. This is someone you trust—your personal doctor. Most of us trust our personal doctor; I do so—much more than I trust any deemed consent.

[127] **Mark Drakeford:** Thank you very much. It has been a very interesting three quarters of an hour. Thank you for answering all the questions that we put to you and taking the trouble to come to help us with our inquiry this morning. Diolch yn fawr iawn.

[128] **Ms Robins:** Thank you. I have enjoyed it very much.

[129] **Mark Drakeford:** Fe gawn ni egwyl **Mark Drakeford:** We will now take a short yn awr. Diolch yn fawr. break. Thank you very much.

*Gohiriwyd y cyfarfod rhwng 10.47 a.m. ac 11.04 a.m.
The meeting adjourned between 10.47 a.m. and 11.04 a.m.*

Bil Trawsblannu Dynol (Cymru): Cyfnod 1—Sesiwn Dystiolaeth 9
Human Transplantation (Wales) Bill: Stage 1—Evidence Session 9

[130] **Mark Drakeford:** Bore da a chroeso i chi gyd. Diolch yn fawr am ddod. Rydym yn bwrw ymlaen gydag eitem 4 ar ein agenda. Mae panel mawr gennym, fel y gall pob un weld, felly gofynnaf i Aled i gyflwyno aelodau'r panel. Os oes unrhyw sylwadau agoriadol cryno gennych, gallwch eu gwneud ac ar ôl hynny, byddaf yn troi at aelodau'r pwyllgor i holi cwestiynau.

Mark Drakeford: Good morning and welcome to you all. Thank you very much for joining us. We will continue with item 4 on our agenda. We have a large panel of witnesses, as everyone can see, so I will ask Aled to introduce the members of the panel. If you have any brief opening remarks that you wish to make, please do so, and after that I will turn to committee members to ask their questions.

[131] **Y Parch Edwards:** Diolch yn fawr am y gwahoddiad i roi tystiolaeth i'r pwyllgor. Rydym yn ei werthfawrogi yn fawr yn Cytûn ac, os caf ddweud, yng Nghyngor Rhyng-ffydd Cymru. Bydd hynny yn awgrymu i chi ein bod, yn yr ystyr honno, yn gwasanaethu amrediad eang o gyrff ond nid yn eu cynrychioli. Clywsoch y bydd ein lleisiau yn dod o elfennau arbennig yn nheulu'r cymunedau ffydd yr ydym yma i'w gwasanaethu. Yn hynny o beth, bydd fy nghydweithiwr, Geraint Hopkins, yn rhoi crynodeb i chi, os ydych yn fodlon, o safbwyntiau nifer o eglwysi. Mae yntau'n gwasanaethu Cytûn. Mae Carol Wardman o'r Eglwys yng Nghymru. Mae hithau'n gynghorydd i esgobion yr Eglwys yng Nghymru, a hi fydd yn rhoi safbwynt Mainc yr Esgobion i chi. Mae gennym gydweithiwr arall yma, sef Saleem, sy'n gyd-aelod o'r cyngor rhyng-ffydd. Bydd ef yn rhoi barn Cyngor Mwslimiaid Cymru yn benodol. Yn derfynol, y mae un arall o'm cydweithwyr, sef cadeirydd Synod Cymru yr Eglwys Fethodistaidd. Os ydych yn fodlon, fe awn ni drwy bethau yn y drefn honno. Yr ydym yn rhydd, wrth gwrs, i chi ofyn cwestiynau, a byddwn yn hyblyg fel yr ydych chi, Gadeirydd, yn dymuno i ni fod.

Rev Edwards: Thank you for the invitation to give evidence to the committee. It is very much appreciated by us in Cytûn and, if I may say so, by the Inter-faith Council for Wales. That will suggest to you that we, in that sense, serve a wide range of organisations without representing them. You heard that our voices come from particular elements in the family of faith communities that we are here to serve. In that regard, my colleague, Geraint Hopkins, will provide you with a summary, if you are willing, of the perspective of a number of churches. He works for Cytûn. Carol Wardman is from the Church in Wales. She is an adviser to the bishops of the Church in Wales, and she is here to present to you the view of the Bench of Bishops. We have another colleague here in Saleem, who is a fellow member of the inter-faith council. He is here specifically to provide the opinion of the Muslim Council of Wales. Finally, there is another of my colleagues, namely the chair of the Wales Synod of the Methodist Church. If you are content, we will go through things in that order. We are open, of course, to any questions you have, and we will be as flexible, Chair, as you wish us to be.

[132] **Mark Drakeford:** Grêt. Diolch yn fawr. Geraint, a ydych am ddweud rhywbeth cryno?

Mark Drakeford: Great. Thank you. Geraint, do you have any brief remarks?

[133] **Mr Hopkins:** Yes. Thank you, Chair and Members, for the opportunity you have provided for faith communities to make representations on the Human Transplantation (Wales) Bill. My name is Geraint Hopkins, and I am the policy officer for Cytûn—Churches Together in Wales—which is an ecumenical body that has as full members 12 national Christian denominations in Wales: the Baptist Union of Wales, the South Wales Baptist Association, the Methodist Church, the Church in Wales, the German-speaking Lutheran

Church, the Salvation Army, the United Reformed Church, the Roman Catholic Church, the Union of Welsh Independents—the Annibynwyr, the Congregational Federation, the Presbyterian Church of Wales, and the Religious Society of Friends, more commonly known as the Quakers.

[134] Welsh churches have shown a long-standing interest in and concern for the work of the Assembly and for the wellbeing of the people of Wales, whom you represent. We believe that the Assembly has done much to enhance the quality of life for people in Wales and that it continues to articulate across party lines a clear and demonstrable desire to see Wales's social, economic, cultural and political life improved for the benefit of all the people. We have been grateful for the several opportunities provided by the Welsh Government and the Assembly to make representations on the principles and concepts underpinning the Bill, both in writing and in attending consultation events run by the department.

[135] The issues raised by the Bill, like so many, have been approached by the churches from a variety of opinions held with a good conscience. While some denominations have, through their different methods of decision making, come to a view on the matter, I think that it is fair to say that no denomination could pronounce on the ethical and moral questions with unanimity. There is differing opinion within our denominations on the matter, and it is fair and proper to highlight to you at the outset that fact. Faith communities are in the business, I suppose, of discussing difficult ethical questions, where the concept of what is right and what is wrong is difficult to discern easily, and we live in a time where the approach taken to political and ethical questions in our media does not always allow much room for reasoned and quiet contemplation.

[136] The first thing that I want to say is that I think it would be a fair and reasonable reflection to say that all the denominations that have expressed a view on the Bill support organ donation. Indeed, they would, by and large, unite around the view that organ donation, and, indeed, the donation of blood, is a Christian duty. It is an expression, we say, of love that the one ought to have for the other in society. The Archbishop of Wales and the Archbishop of Cardiff, along with other faith leaders, have made this point very clearly, and it is reiterated here today as a first principle.

[137] On the question of the Bill and the proposals put forward by the Welsh Government, there is a difference of opinion that is not restricted to the churches, of course. It is fair to say that these ethical nuances have been reflected to the debates within the Assembly itself and throughout civic society in Wales. Furthermore, it is a debate that is being watched and studied carefully across the United Kingdom, not only for the lessons that can be learned from Wales, but also for any cross-border implications that the new regime might have. So, without wishing to take up too much time, I would summarise the two positions that we have experienced as follows. There is a view held by many within the Christian community, and, indeed, the Jewish, Muslim and other faith communities, that what is proposed represents a shift in emphasis that goes too far in allowing the state to presume the wishes of an individual concerning their own bodies after death. This view has been articulated by the two archbishops and Carol, to my right, will be able to explore that further. It is also a view taken by many in the Jewish community, and as Saleem will no doubt explain, would be highly representative of the Muslim community also. They would be concerned that the positive ethos of donation as a free gift is endangered by an ill-judged if well-intentioned proposal to move from voluntary donation to presumed consent. Opinion has been expressed that the belief that changing from an opt-in system to an opt-out system would improve the rate of transplantation is not justified by the available evidence, and it should not be taken for granted that changing the law to a system of opting out would increase the availability of organs for transplantation. They would articulate that the most effective way to increase rates of both organ donation and family agreement to donation is to encourage people to sign the organ donation register, and to talk about the issue with relatives and those close to them. The

White Paper calls for a soft opt-out system in which the relatives will be consulted, but the ideas of consultation or being involved in the process are ambiguous, and the law needs to state in perhaps a more positive way whether relatives will be able to refuse permission for the removal of organs.

[138] On the other hand, a number of denominations have discussed the Bill and come to a different outlook. Within the Presbyterian Church of Wales's church in society department there has been considerable support for these measures, which are intended to save lives, although, again, opinion is strong on both sides. The Religious Society of Friends—the Quakers—recently considered the ethical and practical implications of the Bill. They realised that not everyone will support the intentions of the Bill, feeling that an opt-in method, as currently available, best protects individual and communal sensibilities. However, overall, they feel that there is nothing to impede their support for the Bill, and, given the finality of our physical being and the possibility that our remains might assist others to lead fuller, longer lives, this is a matter of showing compassion with those who are in ill health, where the availability of organ transplantation is a solution to their predicament, giving them and their families hope in the light that it will offer consolation to many. The offering of an organ is both a gift and a legacy. The Bill gives truth to the fact that we all belong to the one society of which we are part, and its outcomes should not be seen as a desecration of long-held views, and may lead to people gaining a clearer understanding of their own deaths, and mortality. So, it is essential to give people time to come to terms with the legislation if it is passed, so that the concept is familiar to everyone. The needs of those moving to live in Wales are worthy of close attention. They are particularly sensitive to the demands and challenges that the legislation might give to some professionals, especially those who on grounds of conscience do not support its intentions. Indeed, on that last point, it is worth noting that, through the extensive chaplaincy and other support services provided by the churches throughout the national health service in Wales, churches would be keen to continue to be involved in the process beyond the legislation in ensuring that whatever system emerges operates in the most effective way, sensitive to the spiritual needs of the families and close friends of those who are affected. Essentially, the debate within churches is very similar to the questions you are posing yourselves in conscience. The legislature, the state, deems consent unless one has opted out. To what extent are we as a nation willing to allow that for the common good?

11.15 p.m.

[139] **Mark Drakeford:** Diolch yn fawr. Thank you very much indeed for setting out some of the real complexities that this issue gives rise to in such a balanced way. I am going to allow the other three witnesses to briefly present the particular view that they represent. I know that committee members will have lots of questions and we have only an hour altogether. Caroline, we will go to you next with that in mind.

[140] **Rev Wardman:** I would be very happy to just take questions. The paper that has come forward from the Church in Wales, the Roman Catholic Church and the Orthodox Church has been agreed within the Church in Wales by the bishops; it has not been discussed by the governing body of the Church in Wales, but it does represent its unanimous view.

[141] The main thing that I wanted to say up front—I am quite happy to take questions—is that, as Geraint said, we are totally in favour of organ donation. I was a little disappointed when I heard some of the comments made about the church's views on this; that some of the church's objections on ethical grounds and very finely nuanced points are rather being conflated with some of the scaremongering that has gone on about some of the effects of the Bill. We would see organ donation as being very much a part of a Christian duty of self-giving love, mandate to heal, and all that kind of thing, and solidarity extending to even beyond the grave. We all want to do the same thing, which is to increase the amount of organs available for donation.

[142] Our main issues about the proposed legislation are that we are a bit concerned about the fact that deemed consent is not really consent, and that it breaks the link between free-will donation and something that is not a donation but just a presumption. There is a concern about the very considerable scope of the people who would be affected by this legislation: anybody who has lived in Wales for six months, including migrant workers, temporary workers, students and even prisoners. There is a real issue about that and about how you inform people.

[143] There is also a requirement for an enormous and continuous education and awareness-raising campaign to make sure that you constantly bring the legislation to the attention of the people whom it will affect, and the resources that that will require. Surely it would be better to put those resources into a thoroughgoing and continuous education campaign to raise the level of voluntary donation, which is already going up because of all the publicity, so we know that that works.

[144] **Mr Kidwai:** I am the secretary-general of the Muslim Council of Wales, an umbrella body representing mosques, Muslim organisations, charities and schools across Wales. I am submitting these views and comments as an overview of the responses that we have received from the Muslim community and our affiliates regarding the issue of presumed consent and organ donation.

[145] I would like to express my thanks to the Welsh Government and the National Assembly for being engaged in the conversation with a variety of faith groups regarding the contentious and difficult issue of presumed consent. The 2011 census showed that the majority of people in Wales still follow a faith tradition, and questions about the treatment of the deceased are inexorably linked to the faith of the deceased, thus no faith organisation should be excluded from these discussions. The announcement of changes to organ donation has been distressing to members of the Muslim community in Wales, and I am pleased to have been able to reassure them that the Welsh Government and the Assembly have been listening to the views of faith organisations and their leaders.

[146] Before I discuss the position of the Muslim Council of Wales and the Muslim community on presumed consent, I believe that it is important to clarify the nature of our objection. Our objection is not about the theological permissibility of organ donation, but rather about the wisdom behind introducing such a significant piece of legislation where other less drastic measures may suffice, or, indeed, be more successful, especially as the proposed legislation significantly affects the rights of every individual in Wales.

[147] In chapter 5, verse 32 of the Koran, God says that whoever saves a life, it is as if he has saved all mankind in its entirety. Due to this divine instruction to preserve life, the overwhelming majority of Muslim scholars have declared it permissible and praiseworthy to donate organs, both during life and after death. There are of course provisions relating to what constitutes death, the way in which organs are removed and the wishes of the immediate family, but these are not the subject of discussion today. In general, Muslims can and indeed have been organ donors under the current UK system of donation.

[148] Much like our partners from other faith traditions, we believe that organ donation is a good thing, and we are committed to seeking ways in which donation can be encouraged. We do not believe, however, that presumed consent is the answer as it leads to more difficulties than solutions. There are legal challenges to be overcome before presumed consent can be introduced. There are concerns about the implication of presumed consent in terms of the relationship between the individual and the state. There are also ambiguities regarding the implementation of presumed consent in the context of the devolved Assembly.

[149] In addition to the aforementioned, there is also an ethical concern about the way in

which presumed consent will impact on organ donation itself, namely that it should be just that: a donation given freely and willingly by one individual for the direct benefit of another. A civilised society can be judged upon the way in which it treats its dead and the priorities that it gives to human dignity both in life and in death, and the respect given to the wishes of the dead. Presumed consent undermines those.

[150] It is important that, as a Welsh society, we do not allow a situation to arise in which even a single organ can be used without the true, full and proper consent of the individual to whom it belonged. As Muslims, the sanctity of deceased bodies is absolutely essential. We have therefore been campaigning about the use of a CT scan rather than the post-mortem procedure, which is the normal course of things.

[151] Islamic teachings regarding the treatment of the dead are detailed and many. Muslims believe that the soul is conscious of the body after death until burial. In this regard, it would be immensely distressing for the Muslim family if organs were taken from the body of a relative without the deceased's clear and express consent prior to death. A failure to opt-out prior to death should not be understood to mean that the person has consented to organ donation and I believe that the majority of the people in Wales share this view.

[152] We wholeheartedly support the statement made by the Welsh churches in January 2012 that,

[153] 'the positive ethos of donation as a free gift is being endangered by an ill-judged if well-intentioned proposal to move from voluntary donation to presumed consent.'

[154] The Muslim Council of Wales is conscious, however, that there are people waiting for organs and that the wait for these organs can at times be fatal. We recognise that there is a need for a greater number of organ donors in Wales and we wholeheartedly support campaigns to increase that number.

[155] When speaking directly with the members of the Muslim community, we found that they were concerned and distressed. The number of letters received was evidence of that fact. Although there were just over 2,000, the sentiment expressed was that of the majority.

[156] We also found out that many were willing to donate organs, but were unaware of how to do so. This willingness among the Muslim community and the wider Welsh community is reflected in the 49% increase in organ donors since 2008. Thus we strongly believe that education and an awareness of the need for organ donors and how to become an organ donor can much more effectively increase the number of organs available in Wales, while avoiding the legal, ethical and moral quagmire of the presumed consent system.

[157] If there is a desire to introduce a new law on organ donation, we would argue that the mandated consent choice system, rather than the presumed consent system, would be more effective. We note that Patient Concern and other groups have already argued in favour of the mandated consent choice system and we would agree with them. I understand that Professor Saunders and Professor Steve Edwards from Swansea University also advocate that choice.

[158] In conclusion, I would humbly request, on behalf of the Muslim community in Wales, that you reconsider the concept of presumed or deemed consent. I believe that it may have a negative impact on our communities and instead of increasing organ donors, it may decrease the number. I also suggest that the resources may be provided to raise awareness among our communities.

[159] We, as the Muslim Council of Wales, have brought together a team of young people who have received organ transplants, along with people from the medical profession, who

will go out into the community to make presentations to raise awareness of the need for organ donation. The young people will be role models whose lives have been changed and will make a powerful case. We feel that the Muslim community could do a great deal more to promote organ donation with your help. It has to be a system of voluntary donation and not deemed or presumed consent, which is not real consent.

[160] Briefly, before I close, the day before yesterday, we received an e-mail through a social network that a lady from the south-Asian community desperately needs a kidney. The message came on Monday night and this morning I was informed that six people have contacted the medical authorities as possible donors. So, that is a way to increase donation, rather than this Bill.

[161] **Mark Drakeford:** Mr Wigley, do you have anything to say quickly?

[162] **Rev Dr Wigley:** Yes. I will try to be brief; I know that I am the last.

[163] I am Stephen Wigley; I am chair of the Wales Synod of the Methodist Church. The Methodist Church is a cross-border British church, with Scotland and England as well as Wales. Part of my reflection picks up on that factor. I echo what has been said from the Anglican, Catholic and Orthodox position. We do not have a fixed position as yet because we are a British church and this happening in Wales is triggering us to have to think ahead about our position elsewhere across Britain. However, we support the principle of organ donation and want to encourage it. We recognise the concerns that have been expressed clearly about the importance of gift and donation and the theological issue about presuming that there is a right to someone's body after death. That is a concern. We also recognise the concerns expressed about whether what is being proposed is actually the most effective way of increasing donation.

[164] There are two things I would like to say. First, being a cross-border church, we recognise that there are cross-border issues about how this works and how records are kept. Wales is a very mobile society; we experience that as part of our church. There is an issue about how this will work and how far it can work separately to what is happening across the borders in England and Scotland. Secondly, on behalf of my colleague who has just spoken, as I read the presentation documents, one of the particular areas of concern is that there are more acute needs for donation in Asian and Caribbean communities, and that is where donation rates are currently lowest. So, if one has a process or a policy that seems to trigger anxieties and concerns in those communities, it seems to me that that policy as a whole runs the risk of falling down in the place where it is most needed. That is part of the general, wider, ecumenical concern that I would like to represent on behalf of colleagues and other faith traditions.

[165] **Mark Drakeford:** Thank you all for those opening statements. I am glad that we have had a chance to get those views on the record. I will turn to questions from Members. I ask Members to direct their questions to specific members of the panel. I will have to restrict the number of people who can answer any one question, because there are lots of people who want to ask questions in the next half hour. I will call Mick first, then Rebecca and William.

[166] **Mick Antoniw:** Thank you for your contributions; it is obviously right that religious bodies express views on social issues. The last Archbishop of Canterbury had very strong views on doing so and felt it was an obligation. However, as I understand it, what you are collectively saying is that there is no fundamental element of your various religious views that says, 'No, this is contrary to either our religious teachings or our beliefs'. The core issue for you is whether this will actually deliver and achieve an improvement in donation rates, which is something that we all support. The question that I would put to you is this: if it were possible to satisfy you that the consequence of this Bill would be that it would lead to an

increase in donation rates, and therefore an increase in the number of lives saved or improved, would your view be supportive or contrary to it?

[167] **Rev Wardman:** I think that I would still have some reservations because it breaks a link in the change from something that is a voluntary donation and a free-will gift to something that is an obligation, which is very important. The human body is very important within Christianity: the incarnation demonstrates that. We believe that God took on a human body, so respect for the body is very important. We also recognise the emotional attachment of relatives to the body. We would not want to go as far as to say that relatives should have a veto if the deceased person wanted to donate, but I think that I would still have some reservations about that, because it breaks that important link.

[168] **Mr Kidwai:** I agree. However, we would still have concerns because we believe that there should be a choice. That is why we would go for a mandated consent choice system, because that involves people saying 'yes' or 'no', saying whether they want to donate or not. In my view, it may be difficult in my community, because people will feel pressured and, because they do not know what organs would be taken, they will think that it is better to say no. It would be a much more positive contribution to raise awareness of it, and to educate and train them, to increase the organ donors and to serve the purpose.

11.30 a.m.

[169] **Mark Drakeford:** If the practicalities could be overcome—

[170] **Rev Dr Wigley:** Most of the faith traditions say that they support the principle of donation, but there are concerns about presuming that; it ceases to be a donation at that point, and it becomes a kind of requirement. There is concern about that. So, I do not think that there is agreement that that is a good thing, leaving aside the practicalities, although the practicalities are also important.

[171] **Rebecca Evans:** We heard this morning from our previous witness that when family members object to organ donation under the current system, 75% are objections made on religious grounds. Is that a figure that you recognise, coming from your various faith perspectives?

[172] **Mr Hopkins:** It is not a figure that I would recognise, and I think that that would come as a surprise and, perhaps, a disappointment to many of us within the faith communities, since the teaching across all our respective denominations and faiths would be that organ donation was a profoundly godly act, if I can put it that way, and I think that that is the consistent teaching across all the faith communities.

[173] **Rev Wardman:** There is a series of leaflets, which I have contributed to, produced by NHS Blood and Transplant, from religious perspectives, and all of them state that organ donation is more than acceptable and is very much encouraged. Unfortunately, some people may use that as a reason for not giving because they have other personal reasons about it; it is not something that faiths that we recognise would endorse.

[174] **Rebecca Evans:** You said that the faith perspectives have not been correctly portrayed in the media, and there has been talk that opposition to presumed consent has come as part of an orchestrated campaign. Is there anything about that that you are concerned about? Does taking part in a campaign make those views any less sincerely held?

[175] **Mr Kidwai:** According to Government records, over 2,000 letters were sent yesterday from our community, using a template letter. That was the only way to express it, because from the point of view of education and effort it would not otherwise have been

possible. In two of the meetings that we had in the faith forum with the First Minister, the way it was presented suggested that it did not matter how many people had written because it is the same letter. Am I right?

[176] **Rev Edwards:** Experience would suggest, taking the breadth of the issue, faith communities will seek understanding and avoid, when we go into the public domain, the things that the press and media sometimes desire, which is simplicity and conflict. We will strive, in this case in particular, to seek the common good by developing understanding. So, any view that is portrayed through misrepresentation or inaccuracy would be problematic for most faith communities, because, essentially, what we strive for in these things are truth and understanding. Whatever the views would be, those would be the aspirations that most faith communities would have. So, if anybody was misrepresenting an issue or the positions of those faith communities, that would be problematic for us.

[177] **Mr Hopkins:** I will be a little more explicit in that: when the Archbishop of Wales spoke out last year on this matter, the colour of the coverage in the Welsh media and elsewhere was that he was anti-organ donation, even though that may not have been explicitly said, that would have been what many people may have read. That is clearly not the case. He has made it perfectly explicit that it is a Christian duty to give organs and blood. That is an example where the media can sometimes colour things in an unhelpful way. As I said in my opening submission, faith communities, just like the Assembly, are trying to discuss a complex issue, where there is no black and white, but many shades of grey, if I can put it that way, and the media are not always extremely helpful.

[178] **Rev Dr Wigley:** In my experience, most blood donation and requests for marrow and all the other things happen in church halls and church schools up and down Wales. That is where I give blood. You have to recognise that that is part of the fabric of who we are and how people engage with things. There is a commitment to that, but there are concerns about particular aspects of what is being raised.

[179] **Rev Edwards:** With your leave, Chair, the other dimension that is important to us is that we provide chaplains to the health service, who will be alongside people and who have to hold conversations on these issues and what is right. We are mindful of providing them with informed valuable support as they seek to counsel and help families who turn to those chaplains.

[180] **Mark Drakeford:** Mr Kidwai, just to make sure that we have it on the record properly, I think that you were making the point, in answer to Rebecca, that for Muslim communities, issues of language and literacy and so on sometimes mean that a standard letter that someone signs is just the most practical way that they have of making their views known.

[181] **Mr Kidwai:** Yes; exactly.

[182] **Mark Drakeford:** Thank you very much. I have a long list of people who want to ask questions. William is next and then Kirsty.

[183] **William Graham:** Thank you, Chair. Is it your opinion collectively, that the resources behind this Bill would perhaps have been better expended on communication to raise the number of organ donors?

[184] **Mr Kidwai:** Yes, certainly. In July 2012, a few officials from the Welsh Government came to see me and mentioned this and said that they were going to start the programme in September. I asked them for some literature about organ donation, so that we can start the programme, which they mentioned. To date, we have not received any response from the Welsh Government on that. However, we have started this programme with our limited

resources and it has made a difference with regard to awareness and education and getting people to realise its importance. Young people who have had transplants talk about how their lives have changed. On Monday night, I talked about a lady who needed a transplant and, today, six potential donors are going to have the medical check-ups to see if they are compatible for her. So, education can make a lot of difference.

[185] **Mark Drakeford:** Does anybody want to dissent from the proposition that Mr Graham put to you that you think that the money could be more effectively spent in a different way to raise the number of organ donors?

[186] **Rev Edwards:** That might be a conviction within the faith communities that we serve. I think that it would be problematic for us to give the impression that it is our collective view, because we would be more nuanced and serving of the communities rather than representative of them. However, it is a conviction that would be heard within faith communities. As my colleague, Geraint implied earlier on, a counter view might also be heard, and it is difficult for us to give you the impression that that would be a uniform view on our part.

[187] **Mr Hopkins:** As Mr Graham is talking about raising awareness, I think that an extended point would be that, whatever the outcome of these discussions or of the legislation, there will need to be an extensive ongoing public awareness campaign to ensure that everybody in Wales is made aware of the new regime and that informed choices can be made.

[188] **Rev Edwards:** If I may, Chair, for many faith communities it would be strongly in their aspiration to be supportive of that endeavour.

[189] **Mark Drakeford:** Good. Thank you. Kirsty is next, then Vaughan, then Elin.

[190] **Kirsty Williams:** Good morning. Several times this morning, you have spoken about people being compelled to donate organs, and the inference being that this law would compel people to donate. Of course, the law does allow people to opt out of that system. I am trying to understand why you would feel that perhaps people would feel compelled to donate when there is a system that would allow them to express that that was not their wish. Given the points that you made, Reverend Wardman—I agree completely about the role of the family in this and how important the body is to the family in all religious cultures—would some of your concerns be alleviated if the need to consult relatives and the role of the relative was explicitly written on the face of the Bill? The Minister has said that if a family member objects, the organ donation will not go ahead, but that is not how it is currently written in the Bill. Would some of your concerns be alleviated if it was clearly stated in the Bill that that was the case?

[191] **Rev Wardman:** I will go back to the first point first. I do not think that I did use the word ‘compel’; I said that it is presumed that people would want to donate. The issue is that with something as important as this, it is not like filling a form or ordering something and you are required to tick the box if you do or do not wish to receive any further information. There will not even be a point at which people will be obliged to make that choice. I think that some kind of guarantee that there would be a point in someone’s life where they would have to indicate that choice would be better than nothing at all and just leaving it to people’s random choice as to whether they ring a hotline, tick a box, go on a website, or whatever. There is a subtle change between something being a voluntary donation and being something that is accepted.

[192] In terms of the role of the family, some denominations, such as the Roman Catholics, for example, are very keen to have a stronger role for the family. It possibly would be better if the role of the family was more clearly spelled out in the actual Bill, rather than in the

guidance. The guidance can be changed at any point, and if it was in the Bill there would be something there. This is a bit of a personal view because it is not something that has been widely discussed. I am not sure that the use of the term ‘family veto’ is helpful either. If a person has made a decision, I think that that decision should stand. If it was written into the legislation rather than the guidance, that would probably be helpful.

[193] **Mark Drakeford:** Do you wish to add anything, Geraint?

[194] **Mr Hopkins:** No, I do not think so.

[195] **Rev Dr Wigley:** It is the language of presumption, is it not? If you like, it requires that you have to answer that question. The state has a right to ask you that question at a time in your life when all kinds of things may change to which you have to give a response that commits you and others. That is quite a big presumption to make. As I understand it from the evidence, most of the people in situations where organs are donated are actually people who have not registered to do it, but that is where people choose to give and it brings life to others. That is what we want to affirm, but starting from the basis that you can presume to ask that question and require an answer, which commits people to things, is quite a big presumption to make.

[196] **Vaughan Gething:** I am interested in Mr Kidwai’s view on this particular topic. You were the strongest in your statement about wanting an expressed consent system only. Of course, at present that is not what we have. Some people do donate organs despite having not made any expression of their wishes before they die; so, the family in that instance already donate organs. I am interested to know whether that presents problems in terms of recipients from the Muslim community where they cannot know whether someone has given expressed consent already. So, people may well already be the recipients of organs, but expressed consent has not been given. I am especially interested in your response to the point that Kirsty raised about whether or not you would feel more comfortable if the role of the family was expressly on the Bill in some form, about there being a soft opt-out, where the family must be consulted, and whether that would change or soften your view.

[197] The second question is more for Reverend Wardman. I am interested in the point about qualifying relationships. The Bill sets out a range of people, and the Minister’s current view is that anyone who has a qualifying relationship can object. I am interested to know whether you have a view about whether those qualifying relationships should be ranked. On a practical level, we have had evidence that having anyone on that list being able to object has led some medics to be concerned that that would decrease the level of donation, as well as some rather more practical points about how close you really should be to a person before you are able to override the view of someone who is potentially closer; for example, a half-brother who turned up at the bedside being able to override the wishes of a wife at the bedside. So, I am interested in hearing your view. The first question is to Mr Kidwai on those points.

11.45 a.m.

[198] **Mr Kidwai:** When we had the focus or working groups with members of the community, these were the points that I brought to their attention. They said that they have it on record. I have not heard it, but they have heard it on television—the Minister has expressed views that the medical group or the Minister can override the consent of the family. Also, the Bill means that if someone wants to opt out and does not want to do it, there should be two witnesses. Section 3 means the Minister can overrule or override the wishes of the family. If it is specifically mentioned that family consent will be taken, that would soften it, but it not would change the concept of presumed consent, and ‘presumed’ is the word that we are disagreeing with. What I mentioned is that, if the law has to be made, then mandated choice consent would be better than presumed consent, because that means that people would

at least be making choices.

[199] I agree with you, because I know a lot of families who have given consent for a donation where a family member was not a carrier of a donor card. As I said, it is divine in our religion to save a life—if you save a life, you save humanity, and on that basis people do give consent. However, in response to the question Ms Evans asked, I have dealt with a few people who have suffered the loss of family members, and nobody asked them if they could take any organs at the hospital, so they have never had to make a choice, but if they had been asked, they would have given consent.

[200] **Rev Wardman:** The list of people in a qualifying relationship seems to me to be pretty comprehensive and fair. I have to say again that this is not something that has been discussed within the Church in Wales, so this is my personal opinion. The Bill refers to the list of people in a qualifying relationship being the same as in the Human Tissue Act 2004, and that actually specifies a ranking of relationships, so that somebody further down the hierarchy of relationships will not be able to override the views of somebody higher up and closer to the person. That might be a sensible thing to adopt. I could see all kinds of family feuds and mayhem breaking out if, as you say, you take the views of somebody who is not as close to the deceased person and who might have a different view to somebody who was closer. Perhaps it would be helpful if the ranking was retained in the same way as it is in the Human Tissue Act.

[201] **Vaughan Gething:** It is helpful to have your view on that.

[202] **Rev Wardman:** On a practical level, it would also be incredibly difficult, because if you have not been able to trace people further down that list, and then somebody pops up afterwards and says, ‘Oh, I would have objected if I had been consulted, but I wasn’t’, how would you deal with a situation like that?

[203] **Mark Drakeford:** I will go to Elin next and then to Lynne.

[204] **Elin Jones:** I have two questions in two different areas. All of you in your evidence have spoken of your support for organ donation for the purposes of saving lives. This Bill, as it is drafted currently, deems consent for the transplantation of all organs and tissues with the exception of a very short list. Would you have any views on whether the Bill, if it progresses, should be more specific on the organs to be transplanted—for example, deemed consent for solid organs? We have situations where novel transplantations now involve faces, hands and limbs. Do you have any views that you have gathered from your various organisations and churches on whether there is an understanding that this Bill, as currently drafted, includes everything, with the exception of a short list, or have your discussions been specifically around solid-organ transplantation for life-saving purposes?

[205] Secondly, some of us have had representations from individuals who have told us that they currently opt in and they are registered as donors, but if there is a deemed consent system in Wales, because of their in-principle objection to the deemed consent system, they would demonstrate their objection by opting out. Do you recognise that as a school of thought among some of your members? Is it something that we should take seriously?

[206] **Rev Wardman:** It is something that we should take seriously. I have heard it mumbled about. I would not say that there was such a huge groundswell of opinion among Christians or members of the Church in Wales that means that they are all saying, ‘Well, if this comes in, we’ll all opt out.’ However, it certainly has been said, as it has been said among the general population. It is something that you need to take seriously. It would be an unfortunate unintended consequence, doing the opposite of what you intend, if that were to happen. I sincerely hope that it does not happen, and, as a church, we would do our best to

make sure that it did not. Our position would still be to promote signing up on the voluntary register and then you will not have any problems, will you? Nobody can object to that.

[207] With regard to the first bit about which kind of organs and tissues can be donated, I know that people have some emotional views about different parts of the body. That has not come up as a theological question at all. Parts of the body are not ranked in any hierarchical order, and I cannot imagine any theological objection to any particular part of the body versus any other. However, again—I am not quite sure how you would do this, and maybe it is something for the guidance—that should be carefully monitored and it should be made clear to relatives and the general public, if they are signing up to the register, what that might mean. It might mean the face, hands or other parts, and as medical science is constantly advancing, it is likely that the range of body parts that can be reused will increase over time. That needs to be part of the education campaign so that people are aware of that.

[208] **Mr Kidwai:** During our workshops and focus groups and when we were talking to the committee, it came up, because when we give something as a donation, we expect benefits in kind from God in the afterlife, but if it has been taken without our consent, that is not a donation, it is a sort of tax that you are paying. People were saying, ‘If this law comes in, then we will opt out.’ That is why I said that there could be negativity rather than positivity in this case.

[209] As far as the organs are concerned, I am not a theologian or an expert on this, but the majority of the schools of thought say that organs save lives, whereas plastic surgery is just cosmetic and may not be allowed. That is my understanding, but I cannot give an expert opinion on that.

[210] **Elin Jones:** Given what you said about some of your members discussing the possibility of opting out to demonstrate that objection, can you foresee a circumstance in which any of your churches or faith groups would advocate that position rather than it just being allowed for your members?

[211] **Mr Hopkins:** Absolutely not. Having listened to the last five minutes, I am concerned that the committee should not go away putting too much emphasis on the discussions about people demonstrating their opposition by opting out. That is certainly not the position of any of our communities, and it would be explicitly opposed by any of the leaders of the communities that we represent. The encouragement is to donate with willingness at the moment, but there would certainly be no move along those lines afterwards.

[212] May I say something about your first point about the type of organs, Miss Jones? Those organisations that have expressed a concerned view about the Bill so far would not yet have gone beyond their principled objections. So, their position is that presumed consent is undesirable, never mind what organs we are talking about. Those organisations that have expressed some support for the Bill might want to go away and discuss that issue further, and we can take that to them.

[213] **Y Parch Edwards:** Fel mae fy nghyfeillion wedi mynegi, nid wyf yn credu bod unrhyw ddyhead diwinyddol, strwythurol eglwysig nac o fewn y gymuned ffydd i greu’r math hwnnw o gonsŷrn ynglŷn â hyn. Yn ddyfnach na hynny, rwy’n credu y byddai sawl ffydd yn dweud—yn nhermau’r ffydd Gristnogol, beth bynnag—mai ein gobaith yw bwrw allan ofn. Mae’r math hwnnw o ymateb greddf—sef dweud, ‘Rydym yn optio

Rev Edwards: As my colleagues have said, I do not think that there is any structural theological aspiration within the church or within the faith community to create that type of position on that matter. Going deeper than that, I think that many faiths would say—or at least in terms of the Christian faith—that we hope to cast out fear. That type of instinctive response—saying, ‘We are opting out’—is more likely to be based on a lack of

allan’—yn fwy tebygol o fod yn seiliedig ar ddiffyg gwybodaeth ac ofn afresymol. Fel cymunedau ffydd yn gyffredinol, byddem yn dyheu bwrw allan camddealltwriaeth ac ofn. Dyna beth fyddai’r farn o ran ein greddfau ni fel cymunedau ffydd yn y math hwnnw o ddeialog.

information and irrational fear. As faith communities in general, we would aspire to get rid of misunderstanding and fear. That would be our instinctive opinion as faith communities in that type of dialogue.

[214] **Mr Kidwai:** We will not be going out to ask, but it is our responsibility to educate our community, to tell people what the choices are and what the law says. It is up to the individual to decide what they want to do. We will not be running a campaign for people to opt-out. It is our responsibility to educate our community, because that is what is needed in both ways.

[215] **Rev Dr Wigley:** We are talking about a relatively small number of events, in quite acute situations—it is not easy for anyone to face those—and at a time when the real question is about trust. What makes things happen is people trusting that what they are doing at a really difficult time is making a difference. It is about the things that conspire to support that trust and make people feel that they are doing things to help it. If things appear to undermine that trust or raise questions about it, they do not make those decisions in those acute situations any easier. That is the concern that is being expressed.

[216] **Mark Drakeford:** I want to put the same question to you in a slightly different way. When the Minister was here giving evidence, she was at pains to emphasise her wish that for those people who wished to opt out, the system should be as clear and as simple as possible for them to do that. Where there may be concentrations of individuals who have ethical troubles about it, she will want to make special efforts to make sure that this opportunity is known to them. While I understand that you are all saying that there is no sense of a campaign to do this, but where you are able to assist in making sure that people understand that there is an easy and simple way for them to declare their wish to opt out of the system, am I right in thinking that you would all make a contribution of that type?

[217] **Rev Wardman:** I am sorry that you have taken the view that we might be trying to get people to opt out. I have said several times that we will do everything we can to get people to opt in, and that is what we will do. However, if you say to people that there is a way in which they can register their wishes, then, obviously, that is equal on both sides. I think that the Church in Wales will be weighting its advice towards telling people to get their name on the donor register, because that is what we want people to do. However, it is part of our civic duty to point out that you can opt out as well.

[218] **Parch Edwards:** Un o’r elfennau y dylem fod yn ymwybodol ohoni yw ein bod yn aml iawn yn cysylltu rhai cymunedau ffydd efo cymunedau ethnig. Mae trosglwyddo gwybodaeth i rai o’r cymunedau hynny yn anodd iawn. Mae’n fwy tebygol y bydd pobl yn gwneud y math hwnnw o benderfyniad ar sail ofn neu ddiffyg gwybodaeth, yn hytrach nag unrhyw gymhelliaid diwinyddol. Fel yr wyf i a fy nghydweithwyr wedi ceisio’i danlinellu, byddai’r rhan fwyaf o’r cymunedau ffydd sydd gennym yn gwbl ymroddedig i roi gwybodaeth gadarn, gywir i bawb fel eu bod yn deall y goblygiadau. Fodd bynnag,

Rev Edwards: One of the aspects that we should be aware of is that we very often associate some faith communities with ethnic communities. It can be very difficult to convey information to some of those communities. It is more likely that people will make that type of decision based on fear or a lack of information, rather than for any theological motive. As I and my colleagues have tried to emphasise with my colleagues, most of the faith communities that we have are completely committed to giving robust and accurate information to everyone so that they understand the consequences. However, we would at the same time wish to have the

byddem ar yr un pryd yn arddel y rhyddid i ddweud nad ydym yn gyfforddus efo'r syniad hwn o ragdybio caniatâd. Byddem yn rhoi gwybodaeth, heb, os mynnwch, gollu ein *integrity* a'r safiad moesol ynglŷn â pha un a ddylech gymryd neu roi organau fel rhodd.

freedom to say that we are not content with this notion of presuming consent. We would give information, without, if you will, losing our integrity or our moral standpoint on whether you should give or take organs as a gift.

[219] **Mark Drakeford:** Diolch. Y pwynt a wnaeth y Gweinidog oedd, lle mae pobl o fewn rhai cymunedau yn becsu ac y mae ganddynt ofn am yr hyn y bydd y Ddeddf yn ei wneud, ei bod hi am gyflwyno cam arall er mwyn bod yn glir gyda nhw bod ffordd syml o optio allan o'r system. Dyna'r pwynt yr oeddwn yn ei godi. Felly, er enghraifft, os bydd gan y cyngor Mwslimaidd rôl o safbwynt helpu pobl i ddeall, dyna'r ffordd o ddelio gyda'r ofn, os ydych yn dal i bryderu am y Ddeddf yn y dyfodol.

Mark Drakeford: Thank you. The point that the Minister was making was that, where there are people within certain communities who are concerned and who are fearful of what the Act will do, she wants to introduce an extra step in order to be clear with them that there is a simple way of opting out of the system. That is the point that I was making. So, for instance, if the Muslim council is to have a role as regards making sure that people understand, then that would be the way of dealing with the fear, should you remain concerned about the Act in the future.

[220] 12.00 p.m.

[221] **Lynne Neagle:** We have previously heard concerns about whether the Bill is sufficiently clear in its definition of death, particularly in the way it affects donation in the case of circulatory death. Do you have any particular comment to make on that?

[222] **Mr Kidwai:** The Muslim perspective is divided in its schools of thought. Some think that brain stem death is an acceptable indicator, whereas for others, the heart is the thing. That is why I made a point of saying at the beginning that I cannot make a statement on that, because there are different schools of thought.

[223] **Rev Edwards:** I think that you should foresee a Jewish contribution on that. I am sure that our colleagues will convey that to you with clarity, because I know that it is an element in their thinking.

[224] **Mark Drakeford:** Does anybody else have a point to make on this? It has been put to us—Kirsty raised it last week with a witness from the UK ethics committee—that the Bill ought to begin by deeming consent only in the case of brain stem death and not presume consent in the case of circulatory death, but that, potentially, would be a step too far ethically.

[225] **Rev Wardman:** This is getting into one of the great technicalities, and I am not an expert on medical ethics, and less still on medical issues. What struck me when this point was raised earlier on, in preparation for this meeting, was that the definition of death seems to change over time, and as medical advances come along, we tend to move further away from the presumption of death. People have been known to come round from conditions that were previously thought to be completely without hope, such as persistent vegetative state, locked-in syndrome and so forth. Again, it is a question of education and allaying fear to make it very clear that the most up-to-date techniques will be used to assess death and to be flexible about it. For that reason, I might be a little bit wary about trying to define death in the Bill, because, if some medical advance appears next year and changes the definition, you might find yourself with an outdated definition of death. So, perhaps that is not something to enshrine in law, but then, if medical ethicists have a different view, they might know better than I.

[226] **Mark Drakeford:** Does anybody else want to contribute on this point?

[227] **Vaughan Gething:** I note the point that the Rev Aled Edwards made, but we have written evidence from a representative of the Jewish community that sets out the issues they have about the various definitions of death, so that evidence is something that we have already considered. It is unfortunate that that representative could not be with us, but I know that Members will have read that evidence. It is not something that we have not thought of and is not in our minds.

[228] **Mark Drakeford:** Yes. Thank you for that.

[229] **Mr Hopkins:** I think that Mr Soffa, whose evidence you refer to, has offered to come at a later stage if that would be helpful to the committee. However, I understand that that may be subject to the pressures of time.

[230] **Mark Drakeford:** We have something in our formal timetable, but even if we are not able to offer him a chance to appear in this sort of forum, we will find a way in which members of the committee can meet him, so that he can explain to us orally what we have already had in the very clear written evidence from him.

[231] **Kirsty Williams:** Just to clarify, you do not have such feelings about the definition, or the differences, or the ethical issues that are raised with regard to brain death and circulatory death, do you? Is it particularly relevant to the Jewish community, and therefore not so relevant to your community?

[232] **Rev Wardman:** I do not know that I would say more or less relevant, but they obviously have a very clear way of defining it, I do not think that there is similar clarity in the Christian tradition.

[233] **Kirsty Williams:** Okay.

[234] **Mr Kidwai:** In the Muslim community, there is a school of thought on both sides.

[235] **Mr Edwards:** I would add that it must be borne in mind—I think that I have already hinted at this—that, at the very best, faith communities would want to be alongside science in this issue, and alongside ethical as well as scientific developments. I think that you will find that, on the whole, people in faith communities—particularly, if I may say so, people of faith who work in medicine and science—would wish to remain up to date and to develop their ethics on this issue according to the science. I think that that would be a key element in many faith communities, alongside those traditional views of how those things take place.

[236] **Mark Drakeford:** Diolch yn fawr i chi i gyd am ddod i'n helpu ni'r bore yma. Rydym ni mas o amser yn awr. Rydym yn ddiolchgar iawn i chi am eich tystiolaeth a'r ffordd yr ydych wedi ein helpu ni'r bore yma gyda phwnc mor ddwfn a chymhleth.

Mark Drakeford: Thank you very much for coming to help this morning. We are out of time now. We are very grateful to you for your evidence and for the way in which you have this this morning with what is a deep and complex issue.

[237] We are very grateful to you for your help in this complicated and ethically challenging area. It has been a great help to us to have your evidence on the record here today.

[238] Diolch yn fawr iawn i chi i gyd. Thank you all very much.

12.05 p.m.

Trafod Llythyr y Pwyllgor Busnes ynghylch Amserlenni'r Pwyllgorau
Discussion of Business Committee's Letter about Committee Timetables

[239] **Mark Drakeford:** Trown at eitem 5 ar yr agenda. Mae pob aelod o'r pwyllgor wedi cael copi o lythyr y Pwyllgor Busnes am amserlenni'r pwyllgorau. **Mark Drakeford:** We will now turn to item 5 on the agenda. Each committee member has received a copy of the Business Committee's letter on committee timetables.

[240] You will all have seen the letter that the Presiding Officer has written to us. There is also a supporting paper from the clerks to the Business Committee. It sets out a proposal that, as you see, originates primarily from the Chair of the Public Accounts Committee. Members will understand what the proposal involves. I am entirely agnostic about the proposal from the Chair, but I need, in a factual way, to say to Members that, given the current legislative load before the committee, the plans that we have made to report against the various deadlines that we have could not be met in the short run if we were to move to having, in effect, one third fewer sessions over a fortnight compared with what we have now. Beyond the summer, when our timetable is not as fixed, things could be different. However, even if Members were very keen to make the move, I do not think that we would be able to agree to shift before the autumn, because of the amount of work that we have and the need to report within specific deadlines. So, I will now ask you for your views on this.

[241] **Lynne Neagle:** We have looked at this in the Children and Young People Committee also and I do not agree with what is being proposed. I am a little puzzled as to why we seem to be revising the whole committee timetable at the behest of one individual Assembly Member. I think that things are working as well as can be expected given the current workload, so I think that we should stay as we are.

[242] **Elin Jones:** I agree.

[243] **Mark Drakeford:** Is anyone going to dissent from that?

[244] **Vaughan Gething:** I have a slightly different point. I know that part of the rationale for the Public Accounts Committee meeting on a Monday was the need to have a Minister or an official attend, who may otherwise be at a Cabinet meeting on a Tuesday morning. If there is a need to be flexible to accommodate that, and we were due to meet on a Wednesday and could shift our meeting to the Tuesday, I would not have a problem with that. I know that members of the Finance Committee have had a conversation about whether or not the Thursday slots that it does not use could be used to accommodate the Public Accounts Committee. However, I am deeply hostile to the proposal of the Chair of the Public Accounts Committee, because I think that it would disrupt our work as a committee and make us much less effective.

[245] **William Graham:** The Business Committee has tried, on many occasions, to accommodate that no single committee should always meet on a Thursday afternoon. It has not proved successful, and that has been the case in previous Assemblies also. That was the main rationale, namely to try to achieve an equal distribution of committee time, but it has not proved possible and various solutions—inventive solutions, shall we say—have been suggested by the secretariat, none of which found favour with the majority of the Business Committee. That is why it was decided to ask the Chairs of committees that would be directly involved.

[246] **Kirsty Williams:** We have severe reservations about this. I am not convinced that we spend enough time as it is looking at some of this legislation, which has profound effects on how Wales will be governed. The prospect of having even less time to look at that legislation

fills me with horror. Perhaps we can suggest that if the Chair of the Public Accounts Committee does not wish to be in Cardiff on a Thursday, he resigns from the Chair and gives it to someone who is prepared to be in Cardiff on a Thursday. However, I suspect that he will not.

[247] **Mark Drakeford:** Mick, did you want to say something?

[248] **Mick Antoniw:** No.

[249] **Mark Drakeford:** I think that the views of the committee are clear. If you look at the figures, you will see that this committee has used every single Thursday afternoon slot allocated to us, apart from one. I cannot remember why we did not use that one, but we are not a committee that routinely gives up our Thursday afternoon slots by any means. As Vaughan said, if there were very specific one-off reasons as to why, by being flexible, we could contribute to the greater good of the Assembly, I suppose we would be prepared to consider that. However, changing the whole system, which is what we are being asked to do, is something completely different.

[250] **Mick Antoniw:** These things are all linked, because we are all on different committees and so on. It is almost impossible to do, unless you are planning 12 months ahead.

[251] **Kirsty Williams:** I certainly was not aware that we had not signed up to being in Cardiff bay on a Thursday afternoon.

[252] **William Graham:** No, it is about every committee meeting—the committee always meeting on a Thursday afternoon. We do not always meet on a Thursday afternoon.

[253] **Elin Jones:** No, we do so every two weeks.

[254] **Mark Drakeford:** Yes, we do not meet every Thursday afternoon.

[255] **William Graham:** We do every two weeks. However, the Public Accounts Committee has the opportunity to meet every Thursday afternoon.

[256] **Mark Drakeford:** I think that it is clear, from what people are saying, that we think that we need the time currently allocated to us to do the job we need to do. Therefore, we would not be able to agree to the change that is floated here.

[257] I will mention, while we have a minute, that our report of the one-day inquiry that we held on stillbirths has been drafted. I have had a chance to look at it and have worked on it a little. It will be circulated to Members later today. At the moment, it is a real struggle to find time to discuss things in committee. So, I hope that Members will be willing to look at it and provide written comments and we will see how far we can go in that way. Of course, if we hit a point where we need to discuss things orally to resolve the matter, we will do that. However, the more progress we can make on paper and by e-mail, the easier it will be in terms of timetable problems and the sooner we will be able to get the report published too.

12.12 p.m.

Papurau i'w Nodi Papers to Note

[258] **Mark Drakeford:** A yw pawb yn hapus gyda chofnodion y cyfarfodydd blaenorol? Gwelaf eich bod. Diolch. **Mark Drakeford:** Is everyone content with the minutes of the previous meetings? I see that you are. Thank you.

[259] We have a short break now. I hope that as many of us as possible will manage to get across to say hello to the advisory committee at 12.30 p.m., which is at the meeting in the Pierhead. It is doing it in the way in which we asked it to; it is not just standing around and chatting. The beginning will be a more formal bit, when the committee members will tell us who they are, what work they hope to do and how they hope to interface with what we do. There will be a chance after that, if people are able and want to stay, to have a more informal discussion with members.

[260] **Elin Jones:** So, the formal bit is at 12.30 p.m., at the start?

[261] **Mark Drakeford:** Yes. Then, people understand that we need to get back to our offices and do other things before we meet again, back here in this room, at 1.30 p.m. for three quarters of an hour. In this room, at 2.15 p.m., there will be a briefing by the NHS Confederation and others on the Francis report, which is not a formal part of the committee's proceedings. The committee will have adjourned at that point, but Members are very welcome to stay and that is also open to other Members of the Assembly, so other people may join us. It will be in this room; we will stay here, we will not have to move.

[262] **Elin Jones:** Is it just for Members, or can staff come?

[263] **Mark Drakeford:** I think that staff can come. If there is not enough room in this room, the gallery will be open and translation and all the normal facilities will be available.

[264] **Kirsty Williams:** May I ask in what capacity is Professor Saunders addressing us later?

[265] **Mark Drakeford:** He is here in a combination of capacities: partly as a clinician himself in this field, partly for his academic credentials, and also because he has held various prominent positions in national committees that have a relevance to the transplantation field. He comes with a variety of credentials.

[266] **Kirsty Williams:** He is a good guy.

[267] **Mark Drakeford:** Yes. Diolch yn fawr iawn. Thank you all very much indeed.

*Gohiriwyd y cyfarfod rhwng 12.14 p.m. a 1.34 p.m.
The meeting adjourned between 12.14 p.m. and 1.34 p.m.*

Bil Trawsblannu Dynol (Cymru): Cyfnod 1—Sesiwn Dystiolaeth 10 Human Transplantation (Wales) Bill: Stage 1—Evidence Session 10

[268] **Mark Drakeford:** Croeso yn ôl i bawb a diolch am ddod yn ôl am 1.30 p.m. Croeso i'r Athro John Saunders. Diolch yn fawr am ymuno â ni y prynhawn yma. Fel arfer, rydym yn gofyn a oes gennych chi unrhyw sylwadau agoriadol yr hoffech eu gwneud i'r pwyllgor. Rydym wedi gweld y dystiolaeth ysgrifenedig yn barod. Ar ôl hynny, trof yn syth at aelodau'r pwyllgor i ofyn cwestiynau.

Mark Drakeford: Welcome back to you all and thank you for coming back at 1.30 p.m. Welcome to Professor John Saunders. Thank you for being with us this afternoon. As usual, we ask whether you have any opening remarks that you wish to put to the committee. We have had an opportunity to look at your written evidence. After that, I will immediately turn to members of the committee to ask questions.

[269] Thank you for being with us, Professor Saunders. If you are happy to offer a few

introductory points, we will then go straight to questions from committee members.

[270] **Professor Saunders:** First of all, thank you for the opportunity to come to talk to you, which is appreciated. I do not think that I have an awful lot that will radically change opinion around the table. I am broadly supportive of the Bill as drafted. There are comments about the explanatory memorandum that puts the Bill into operation. At the end of the brief paper that I have submitted to you, I stated that I was probably chiefly responsible for the evidence statement that came for the Royal College of Physicians of London. I am happy to address anything that I raised there. If I can be of help, I am pleased to be so.

[271] **Vaughan Gething:** Thank you for coming to see us today, Professor Saunders. I am interested in a particular view that you flag up. You favour the move from the term ‘presumed consent’ to ‘deemed consent’. Other witnesses have seen that move as a problem; they would prefer the term to be ‘presumed consent’. Can you explain why you see ‘deemed consent’ as being a preferable choice of language?

[272] **Professor Saunders:** In public advocacy, particularly where politicians in general are highly suspected by large numbers of the public, I think that it is crucial that we are honest in our language and in what we mean. The concept of presumed consent is, to me, as nonsensical as talking about a square circle. It is crucial to consent that it represents the autonomous choice of an individual—it is not something that can be presumed. In fact, presumption is the very opposite of what consent stands for. In my view, there is no such thing as presumed consent—it is a complete conceptual nonsense.

[273] By contrast, in the use of language, in deeming something of somebody, we are saying ‘You do not have it, but we will treat you as if you have it’, or, in the case of deemed consent, ‘We accept that this is being done non-consensually, but we are going to treat you as if you had consented’. That is what is being proposed. I do not have a problem with that. Non-consensual removal is justifiable in moral terms. I think that the use of the term ‘deemed consent’ is closer to what we are actually doing. Honesty in language is important. Otherwise, you would immediately be accused of a coercive use of language in pretending something is what it is not.

[274] **Vaughan Gething:** In the morning session, we heard from Patient Concern, which had a pretty clear view that it objected to the concept of deeming consent in any event, whether it was called presumed or deemed consent. The representative of Patient Concern viewed it as being unethical. We have had other evidence from medical ethicists that disagrees with that. One thing that we have discussed with people from faith communities is the varying reasons why some people are unhappy about this not being a genuine positive donation. We asked them whether some sort of reference to the soft opt-out option, if it appeared on the face of the Bill, rather than in a code that may accompany it—as mentioned by the Minister in her statement—would, effectively, make it more acceptable. Is that something on which you have a view?

[275] **Professor Saunders:** I am not sure that I follow your question.

[276] **Vaughan Gething:** The Minister has been clear in stating that even though it says on the face of the Bill that expressed consent is not needed where none has been given, in reality, if members of the family object, donation will not go ahead. However, that is not what the Bill says. So, essentially, even after consent has been deemed, would having a reference to family members and to the soft opt-out option somewhere on the face of the Bill—we have not looked at the wording—help with regard to allaying some of the fears that exist? Given the evidence that you have given and the paper that we have seen, is that something that you would support?

[277] **Professor Saunders:** It probably is. The problem with this is that, in the process of seeking organ retrieval at present, when somebody goes to talk to the grieving family, the way that this is usually approached is not, ‘Do you know whether this person had any particular wishes?’. The usual approach, as I understand it, is to ask, ‘Do you know whether this person has any particular objections?’. So, the ordinary approach in the intensive therapy unit side room, or wherever this conversation is conducted, is one of asking, ‘Do you know whether there was an objection?’. That is not so far away from what is going on with a soft opt-out system because it is enabling the family to come back to say, ‘We believe that there is an objection.’ If you water it down too much, the danger is that you will lose any potential advantages in the legislation. You will be pushing the practice in the Bill towards what is currently already happening, which means that there cannot be any particular advantage to it. The closer you are to ordinary practice, the less benefit there is in passing the legislation. I am not opposed to what you suggest, but I worry that we would lose something in it.

[278] **Vaughan Gething:** Finally, some of the other practitioners who have been before us were concerned about the statement that any member of the family or those with a qualifying relationship—which is more accurate because they do not all have to be a family member—could object, which in reality would prevent the donation from going ahead. One view put to us was that that would make things more difficult because, at present, you do not have to get unanimity from a group of people, therefore, would it not be preferable to have a ranking system, taking people in order, as it were? You would not then need a room full of people all agreeing on a donation going forward before it could happen. Rather, you could say that a clear majority view on what the deceased would have wanted was for the donation to be made and therefore it would be.

[279] **Professor Saunders:** You are asking how we handle family dissent, which is an occasional but genuine issue. That is quite subtle because of the nature of the relationship. In a ranking order, the distance between No. 1 and No. 2 may be huge; No. 2 may be the son who has flown in and has not seen the person for 20 years and No. 1 may have looked after the person very closely for many years. On the other hand, they may be two people who have been looking after that individual very closely. I would imagine that most clinicians would probably have a preference—and my opinion is not worth more than anyone else’s on this—and would weigh the difference accordingly. For example, if a remote family member is putting up the objection and the others are quite strongly in favour, then the latter group should certainly win out. Any objection from no matter how distant a family member should not negate the donation.

[280] **William Graham:** In your paper, for which we thank you, you say,

[281] ‘The problems with the Bill are the hazards it creates for damaging the present programme of transplantation.’

[282] You go on to say that a ‘mishandled opportunity’ and a ‘modified register’ could cause potential confusion. Could you enlarge on that?

[283] **Professor Saunders:** Yes. These are practical issues with an ethical dimension. They are not primarily ethical issues, but they do have that dimension. First, you can imagine the plea of ‘I did not understand this registration process.’ There is no longer one single register—there are two: there is a register for Wales and a register for the UK—so where do these things come together? That may be quite easy for you and me to understand, but we are interested in the subject and are inevitably better informed. We somehow have to get this message across to the entire resident population of Wales and that is quite a tough nut to crack. You have to keep the register up to date because people forget, move and die, and so on. So, it is an enormous practical difficulty.

[284] I worry about the inevitable: no human system is ever perfect. I worry about the fact that if someone were on the register, that would not be picked up and their organs would be taken and then that story would get picked up by one of our glorious tabloids. You then have the effect that the famous *Panorama* programme had on the transplant programme around 30 years ago—it is a long time ago, but it is always much quoted and much remembered because of the damage that it did. Those are my concerns. They are essentially practical concerns, but practical concerns, if you can see them coming, clearly have a moral dimension to them.

[285] **William Graham:** Could you suggest any other way of enhancing the programme without this particular measure?

[286] **Professor Saunders:** Enhancing the information?

[287] **William Graham:** To put it another way, as I have asked others: do you think that the resources would be better used for education and promotion of the programme generally?

1.45 p.m.

[288] **Professor Saunders:** I suppose that the one-word answer to that is probably 'yes'. I am not a transplant doctor, you understand; my background is as chair of the ethical issues in medicine committee at the college. However, we have looked at this over a number of years now. So, we have discussed it and read around it. At the moment, if you were to ask me what my prediction would be and what my crystal ball gazing would reveal, I would say that I do not think that this will damage the situation. I do not think that there will be a great fall-off in transplants. However, I am not convinced that there will be an increase. I suspect that we will be much where we were beforehand. You could say—and this brings one of the points that I have made quite a lot of to the forefront—that that is quite an important discovery: if we were to learn that from a population of approximately 3 million in Wales, that would be a tremendous lesson for the rest of the UK. You might say that that is a lesson worth learning. It is true, after all, that we have been successful in Wales with organ registration. We have been ahead of the rest of UK for 10 years, and I gather that the latest figure is 37%, which is a staggering proportion. People always put this word 'only' in front of it. Why do you use this word 'only'? A percentage of 37% buy-in is tremendous. With that buy-in, and the rising success in retrieving organs at the moment, I think we shall be lucky to see a really significant increase; well, I hope that I am wrong.

[289] **Kirsty Williams:** Good afternoon, Professor Saunders. Are there different ethical issues to consider with deemed consent when looking at brainstem death or circulatory death? It was suggested to the committee last week that perhaps you could start with a system of consent for brain death, rather than circulatory death. On a practical issue, we heard last week from Peter Matthews, representing intensive care doctors, and he was very critical of the low numbers of ITU beds and the possibility that if this law did come into being, it would not make a difference due to a lack of capacity in ITU departments in Wales to be able to do this work. Do you have a view on that?

[290] **Professor Saunders:** I will deal with the second question before the first, because you have pressed a button on the first one, and you may have to shut me up. The second one I can almost side step, by washing my hands of being an intensivist. What I see in my own hospital in Nevill Hall is an ITU that runs at just about 100% capacity all the time. It is never empty. It is quite astonishing. I think that they are wonderful. I always say, 'If I am sick, get me into Nevill Hall please, and I will go into the ITU; I would be happy with that'. However, they are under intense pressure. You know the health service tradition: people make do, and you somehow find the bed because you take out the ITU patient who can best be managed on the wards or, in the case of Gwent, we have had occasions when we have transferred patients up from Newport to Abergavenny, which is pretty distressing for families, to go from one

ITU to another. So, ITUs are under pressure, but I am not an intensivist and, in a way, you are asking an amateur on that particular issue. Anyway, I will put that to one side.

[291] Your first question is one that fascinates me. Chairman, indulge me for a couple of minutes on this. When I was a medical student or a junior doctor—it is a long time back of course—the concept of death as being death of the brainstem was first being widely promulgated. As you know, the UK opted for a brainstem definition of death and not a whole-brain definition of death, as the Americans do. The chief protagonist or apostle of that was an anaesthetist from Hammersmith Hospital. His teaching was very simple. He used to say that the ethical and philosophical conception of death is death of the person as a whole, and what integrates the person and makes them a person as a whole are the functions of the brainstem. Therefore, the death of the person as a whole is the death of the brainstem, therefore we need to test the brainstem, and therefore we have to have reliable brainstem tests. We started with a philosophical concept and moved through to a physiological function, to an anatomical localisation and to a way of testing it. That was perfectly logical. He went on to say that this was not a new definition of death. When your heart and lungs stop permanently, your brainstem dies. That is what death has always been. Brainstem death is just a new technique of diagnosing it. True death has always been the death of the brainstem, we just did not realise it as such. I think that we all bought into that. Indeed, I do buy into it; I think that it is correct. There have been arguments about the accuracy of brainstem death testing by one or two medical heretics. However, basically, that is the doctrine that most of us believe in.

[292] It seems to me that the difficulties with death defined as circulatory death run as follows: patients who are likely to die shortly will die a controlled death, often with removal of supporting measures in the intensive care unit, and after a period of circulatory arrest they will be defined as dead. The time deemed safe to define them as dead has varied from the shortest—five minutes—up to 10 or 15 minutes. The problem is that the use of this definition of death is directly related to the transplant programme. That is why we have got interested in it. It was done first of all with neonates, new-borns, in the United States. It was published in the *New England Journal of Medicine* and caused an outcry because among the organs taken for transplant was the heart. Conceptually, you sit back in your chair at that point and say, ‘You are saying that death is death of the circulation. What keeps the circulation going? Well, for goodness’ sake, isn’t it the heart? And, you are saying that this person is dead and I can take their heart out and start it in another patient’. Intuitively, putting science to one side, it did not feel very comfortable.

[293] However, that is the argument that surrounds donation after cardiac death. The conceptual problem I raise is this: if we have a five-minute definition of circulatory arrest, and we say that somebody is dead after that, can we be completely certain that the brainstem is then dead? That is almost tantamount to saying, ‘Have you ever done a resuscitation of a cardiac arrest on the wards in the ordinary way, with a five-minute window, and the patient survived? Well, I have to say that I think you have’. So, if that is the case, what you are saying is that death is what is defined by the Academy of Medical Royal Colleges—that document having now been accepted—but you really have two different types of death: cardiac death and brainstem death. The Pallis doctrine—the doctrine of the anaesthetist Chris Pallis—is no longer true. I know that there are a number of anaesthetists who are not very happy about this; we have one or two in our hospital. You can see the controversy.

[294] I do not claim to be an expert on the physiology in this area, and you may get others to contradict me, but if I am right in what I am saying, I can see how that could be contorted as seizing organs from people who may be dead in two minutes’ time, but who are not dead at the exact point at which the organs are taken. What do those two minutes matter? Morally, there are arguments around that, that maybe they do not if death is imminent. Nevertheless, that is a change in our thinking, which I do not think has been as widely discussed as it might have been.

[295] The same argument—I do not want to go on; I know that you are indulging me, Chairman: you must stop me—has gone on in cases of permanent vegetative state. People have asked why we do not draw the definition of death there, because such people cannot enjoy a life, not in the sense of a biological life, but with any sort of social interaction. However, the line has never been drawn there. As a footnote, death has always been what doctors say it is. Although I am no expert on Catholic theology—I am not a Catholic—I gather that even the papal statement is that death is what the professionals say it is. So, there are conceptual difficulties around the definitions of death. Sorry.

[296] **Mark Drakeford:** Thank you. It is an issue that we have been pursuing. Last week, the ethical issue that was put to us in relation to the Bill was that if you have opted in—if you have taken the conscious step of putting your name on a register—ethically, those two minutes around DCD can be accommodated, because part of what you wanted to happen to you at the point of death was that your organs were to be used for transplantation, so taking actions to keep those organs viable for transplantation is ethically proper. As it was put to us, can you claim the same level of ethical probity for people who have not opted in, but whose consent is being deemed, around a DCD-type of donation?

[297] **Professor Saunders:** I think that the argument is slightly different, and it comes back to the moral justification for removing organs without consent for transplantation. As I said in my paper, it is ultimately about whether you save a life, give food to the worms or substance to the fire. Crude though that sounds, that is the reality: our organs will decompose or be burnt when we all die. That is what happens to all of us. If that can save not one life, but several and improve the quality of many, that seems to me to be a powerful moral argument in itself.

[298] **Mark Drakeford:** That is a sort of moral calculus that you refer to in your paper, which trumps these other smaller, rather ethical sideshows, compared with that.

[299] **Professor Saunders:** I think that that is fair.

[300] **Mark Drakeford:** That has been very helpful.

[301] **Mick Antoniw:** Thank you, Professor Saunders; I found that very helpful in some ways, although I am not sure if ‘helpful’ is the right word. I have an additional question to what I really want to ask you about, and that is whether there is an ethical issue with regard to people making living wills, where they are effectively saying, ‘I don’t want you to resuscitate me in the event that I get into certain circumstances’, and whether that overrides any of those ethical concerns. Perhaps you could just deal with that and then I will go on to what I really want to ask.

[302] **Professor Saunders:** I am a supporter of living wills/advanced directives. They give guidance in situations that are often hugely complex. Often, the living does not fully match the situation. However, at least in principle it is better than guessing, because it gives you some idea of the patient’s wishes. My personal view is that we should be much more active in encouraging patients to write living wills when they have conditions for which their eventual death is all too likely. I am a hypocrite on this because I have not written a living will myself, but I am fortunate enough at the moment to not have a condition. Like 40% of the British population, I am probably going to drop with cardiovascular disease because that is what most of us die from; it is the most likely diagnosis. If I developed a chronic neurological complaint such as motor neurone disease, severe advanced chronic pulmonary disease or advanced cardiac failure, as a result of which, having got it, the overwhelming probability is that I am going to die from it, there are very strong reasons for writing a living will about the future treatment that I might request.

[303] I had this conversation this morning with someone who has dreadful emphysema and who is in and out of hospital. I asked whether they wanted a ventilator or not, and because it is all new, no-one had ever asked this question before. I keep saying that this should have been asked six or 12 months ago. Whatever criticisms can be brought against living wills, it revolves around the old argument of ‘Iris Murdoch is watching the *Teletubbies* and is blissfully happy; should she be kept going even though the life values of Iris Murdoch, the intellectual philosopher and author—what we often call their critical interests—seem to have no resemblance to her inner demented state’. So, is this a different person or is it the same person? Those are interesting philosophical issues that go back to John Locke in the seventeenth century.

2.00 p.m.

[304] **Mick Antoniw:** Thank you very much for that. I found that helpful. I do not think that it clarifies it any more in my mind, but it is helpful to hear you say that. In the paper that you have presented, despite all the ethical issues and the morally good issue and so on, what you seem to be saying—in almost five places in it—is that the Bill’s intention is all very well, but, frankly, the background to this Bill, in terms of it being effective, is not sufficiently well-thought-out. There is also a real question mark over it, in that, even though it ticks all the right boxes in terms of moral justification and so on, there is a real issue as to whether, actually, it might have a counter impact and it is just not going to work and is probably not necessary. That is, ‘You are doing well at the moment; why change it and risk all these different factors?’ In such circumstances, does the moral argument in support of this justify bringing forward legislation that might, frankly, put quite a lot at risk?

[305] **Professor Saunders:** The legislation will put quite a lot at risk; it is, in those terms, a gamble. The question that has never been answered to my satisfaction—I think that I have said this—relates to the fact that the organ donation taskforce sub-group that was set up during Gordon Brown’s time as Prime Minister started work with a large proportion of its members supporting a change and the sort of legislation that we are proposing in Wales. As you will know, when that group reported—I am told the Prime Minister was not very keen on the report, because it did not say what he wanted—it came out unanimously against going down this legislative path. Our own committee of inquiry here, the Health, Wellbeing and Local Government Committee, produced a report into the inquiry—you know, the purple document—which was against this sort of legislation by a majority of 2:1. So, we have had two expert inquiries, one UK wide, one Wales wide, and both have said that they do not think that this is going to help. Nobody has really explained to me why, having had that level of expertise looking at it—they were quite exhaustive inquiries, particularly the UK one—it has now been decided by the Minister that, actually, we are going to go down this road anyway. There is no real evidence that I can see that is new and that was not there when those two inquiries were meeting. The much-quoted Abadie and Gay paper is quite venerable now; I cannot remember when it was published, but the inquiries had access to that and the University of York’s material.

[306] So, without trying to be terribly negative, I cannot see why there has been such determination to press on with it. The realist in me, on the other hand, says that it was a manifesto commitment, the reasons are sincere, there is an argument, and it may be that it delivers. Let us hope that it does. The realist in me says it is not going to be pulled at the moment and, in a way, I cannot help but think that we are almost past the stage of debating whether this is a good thing. The stage we are at now, surely, is of saying, ‘Here it is; how can we improve it in the way that it operates?’ What I feel very strongly about is how we can agree in advance a measure of whether it is successful or not. My reason for saying that is the political dimension. Quite understandably, those who spend hours and days and all the rest of it of their lives putting a Bill through want to believe that it is successful. The spectacles

through which they will view the world are that any improvement in transplantation must be due to the Bill. We all know that donation rates are rising in Wales and we all know that the rates are rising in the UK, because of all those other reforms that the taskforce recommended. I think that there is the ability to cherry-pick one statistic over another after the Bill has gone through, and say that therefore it has been successful—if I were a politician, that is exactly what I would do. You do want to feel that you are doing positive things in life.

[307] I think, therefore, that there are very good reasons for trying to agree a measure of success in advance and for saying, ‘If this criterion is met and that one and that one, we will deem this successful; if those two or three are not, then it has failed.’ Then, if it has failed, rather like the legislation in, I think, Texas or Florida, it would be pretty quickly junked; I think that their mandated choice legislation was junked after one to two years, because it was thought not to be succeeding. So, I feel quite strongly about that. As I said earlier, I think that Wales is a pilot site for the rest of the UK, although I gather that the Northern Irish are about to launch forth without waiting to see how it works in Wales. If it works wonderfully in Wales, the rest of the UK will follow.

[308] **Mick Antoniw:** So, really, your position is that there are real concerns as to the capacity of it to succeed, but, given where we are with the legislative process and the commitments and so forth, what you are more concerned about now are clear success measures and an understanding that, if it turns out that those success measures are not being achieved, we should be prepared to pull the plug.

[309] **Professor Saunders:** Certainly, if the rates plummeted I think that you would want to pull the plug. Whether you would want to make any changes—

[310] **Mick Antoniw:** It was a slightly unfortunate phrase. I do apologise.

[311] **Kirsty Williams:** It is not the best phrase.

[312] **Mark Drakeford:** ‘Think again’, I think, is what you were meaning.

[313] **Mick Antoniw:** Yes, we should reappraise our position.

[314] **Professor Saunders:** Thank you. Yes.

[315] **Mick Antoniw:** Is it too late? [*Laughter.*]

[316] **Mark Drakeford:** Thank you very much. Given the time, we will move on to Rebecca.

[317] **Rebecca Evans:** We have heard some evidence that deemed consent would put medical staff in a particularly difficult position around the time of transplantation or making a decision because they would not perhaps have the confidence that they would have had had the individual whose organs will be transplanted made that positive choice. Do you have a view on that?

[318] **Professor Saunders:** I will only point out that, at the moment, it is a minority of patients from whom organs are retrieved that have given consent in advance, is it not? The number that come off the organ donation register is less than the number who do not. So, most patients at the moment who become organ donors are having their wishes interpreted through the family. They have not given advance consent in terms of going onto the organ register because, even in Wales, that is less than 40%. So, the majority are non-consensual in that way. So, I am not sure that I find that very convincing as an argument.

[319] **Rebecca Evans:** This morning I heard an argument that I had not thought of before, which was that transplant doctors and others working in that team might have personal objections to deemed consent because of their own personal views, such as religious views and so on. What impact do you think that would have on their ability to undertake their roles?

[320] **Professor Saunders:** I am not convinced of that either. Obviously, I no longer do this. When I was a younger doctor we were not so specialised; we had very few consultants. I engaged in this process myself, so I have been in the position of asking relatives for organs, but that was 15 years ago now. ITUs have got much better and there have been huge improvements. However, if this discussion hinged around the sorts of issues that I have raised over cardiac death, which are scientific, with a sort of moral dimension as to what we mean by death, I would be more concerned about what you are really pulling, which is the issue of conscientious objection. I cannot see that that arises in the sort of scenario that you are raising. Conscientious objection is a big topic in medical ethics at the moment. It is a rising one, and it will be one that we are all going to hear more about, because religious views, in particular, are more diverse in society. There have been a number of rather stormy incidents in other areas over conscientious objection, but I do not see it as a big issue here. I hope that I am not being over-optimistic or casual about it.

[321] **Elin Jones:** Do you believe that there are different ethical considerations for deeming consent for solid organs only, as this Bill, as it is currently drafted, deems consent for all organs and tissues with the exception of a very short list in section 16? I ask the question in the light of the fact that all of the public debate around the introduction of this Bill has been on deeming consent of kidneys and hearts for life-saving purposes almost, and the debate has not been about deeming consent for a wide variety of organs and tissues, and in the light of novel transplantations in particular.

[322] **Professor Saunders:** There is a huge problem with some of the novel transplantations. As you know, if we are talking about the comparison with consent for transplanting eyes—taking eyes out—that runs at 20% less than it does for solid organs, and that is because it affects, or is seen to affect, facial appearance. That is to do with our cultural understanding of the body and the way that the body relates to the person and so on. There is huge amount of literature and history on it. It becomes particularly acute when you start talking about facial transplantation and the idea of removing a face—it is experimental at the moment, but it is usually done in the context of very severe burns— and I can see that refusal rates might, very reasonably, be much higher. Claire Rayner used to talk about the ‘yuck’ factor in medical ethics. That is really saying that there are a number of things that logically do not seem to create problems—after all what is the difference between my face and my kidneys if I am dead; you could put up an argument that there is not really any difference, they are just different bits of you—but, actually, in our attitude towards bodies, they are very different. I do not see how you could comfortably ignore that. On the other hand, with a tissue like bone marrow, the idea of transplanting it is almost emotion free, is it not?

[323] **Elin Jones:** Do you have a view, therefore, that this legislation should be drafted in such a way that it lists the organs and tissues for which consent is being deemed on the face of the legislation, rather than leaving it to a code of practice, which currently is not drafted, for the purposes of this legislation?

[324] **Professor Saunders:** I think that I would almost turn the question back to you as a legislator, because my gut instinct is to say that it would be better in a code of practice than in the Bill itself, because of changing circumstances—I would not even have thought about transplanting a face 10 years ago, for example. As a jobbing clinician in a district hospital, the idea of transplanting a face would not have occurred to me, and yet, here we are, the first transplants have been done and it is possible that this may expand, although it may be a blind alley, of course. There may be other, similar things. We have had hands and fingers

transplanted—a hand was transplanted in the UK recently—which would not have occurred to me 15 years ago. Again, those transplantations alter the external appearance of the body and, therefore, come with the same potential cultural objection. As you do not think of these things in advance, I say to you as legislators that surely they could be dealt with in a code of practice that has statutory potential. I am not expert enough in legislation in Wales compared to Westminster, but the equivalent of the Westminster statutory instrument that would put it in the Minister's hands to amend things if necessary, could, I would think, deal with that effectively.

[325] **Vaughan Gething:** I do not know whether you have had a chance, in moments when you have not been able to sleep, to look at section 16, but the Bill as written refers to 'relevant material' for transplant, and there is a small exclusion that comes from a predecessor Act, so only a small amount of items are excluded. To pick up the point that Elin made, and I know that you said that it could be dealt with by a regulation-making power or a code of practice, would you prefer it if the Minister was required to set out in regulations where and how human body parts or relevant material from human bodies may be used or may not be used? I think that there is a point about wanting to have something that requires that, because, at the moment, the Minister does not have to do that or may not need to do that, whereas, if you had a regulation that may force whoever the Minister is to explain and set out how body parts may or may not be used, that might provide the flexibility you mentioned while, at the same time, meaning that there has to be a positive decision by a Minister to do that.

[326] **Professor Saunders:** That seems a reasonable proposal. I am all for putting that power in the Minister's hands, and the reasons for saying that are, rather as I indicated to Elin, that the situations that you find yourself in are the ones that you never predicted. It always strikes me that the glory of English common law is the way that you can adjust to circumstances. Last Tuesday, I found myself at the Department of Health, wearing my ethical issues hat again, faced with three very expert civil servants who were cross-questioning me about aspects of human rights issues arising from the Human Tissue Act 2004 and the Mental Capacity Act 2005.

2.15 p.m.

[327] The long and the short of this is that provisions in the Human Tissue Act, and the way it defines tissues, have created impossible situations for healthcare professionals who actually have needlestick injuries from incompetent patients. That was never the intention of the legislators. If only the Minister had the power to exempt certain tissues in certain circumstances, the problem would have been solved. The flexibility is not there in the Human Tissue Act, and the consequences are detrimental in various ways. So, I would put in a strong plea for the Minister to have the power to make such regulations, and to specify how far those powers extend. The Minister is not a dictator; he or she is subject, ultimately, to the Assembly and to the population, so I am not bothered about putting those powers in the Minister's hands. I support it.

[328] **Mark Drakeford:** Before we end, I will just go back one last time to a point you made in your written evidence. You have said a couple of times this afternoon that you think that it is critical that what constitutes success is set out in advance. I think that this is the first time I have heard that argument, so if we were to think about the criteria for success, and so on, what ought we to be thinking of? What would be the sort of things—

[329] **Lindsay Whittle:** Sorry, Chair—this follows on from my question. How would we quantify that success? You mentioned critical care; could critical care cope with the increase?

[330] **Professor Saunders:** Let me first of all say that I am an amateur in this, and I would not claim any great expertise, but the sort of picture I have runs roughly along these lines:

transplantation performance is improving in Wales at the moment, and indeed through the UK. So, you have an upward line. We can then start projecting from where we are at the moment how much we have improved matters after three years, five years, 10 years, or whatever it happens to be—we can ask the experts. We can extrapolate forward, and we can therefore make some sort of prediction, with the usual statistical fuzz around that prediction, which statisticians and mathematicians are used to doing, as to where we would expect to be in three years, five years, or whatever. We can then say mathematically what would be a statistically significant difference from that line upwards or downwards. How much it would have to go down and how much it would have to go up to be a significant increase on where it is. Allowing for the wobble that there is in all human systems, we could go for what in the memorandum of understanding is called ‘predicting counterfactuals’, so you have a prediction of where you would be with this and what would count as success—and of course what would count as failure.

[331] You would have to have some idea as to the time period over which you would make those measurements. Clearly, six months would be ridiculously short, and 10 years would be ridiculously long—to take some absurd numbers. The point at which you would have confidence statistically that you had made a difference would depend on how big the deviation was. People do this for all sorts of situations, and not just in healthcare. I cannot see conceptually why this has been dismissed, or has not been considered. As legislators, you would want to know whether the programme that you have put through has worked. After all, that is what you are giving your lives for as Assembly Members—to improve our lot as your constituents. In healthcare, obviously, that means those who are sick. Surely, you want to know: has what I have done really worked? If it has not, what lesson do I learn for the next time around? Is that not reasonable?

[332] **Mark Drakeford:** Absolutely. It was not whether the concept was reasonable, it was just how it might be put into operation. You have explained that.

[333] **Professor Saunders:** That is my picture of it. It is not good enough to ask, ‘Does the population like it?’ That is not because I am dismissive of opinion polls or referenda, although I am pretty sceptical about referenda—we will not get on to that. Thank God we have a National Assembly, I will say that. The population can be manipulated by one or two key people. I do not doubt that the population was pretty strongly in favour of the first world war, had you asked in 1914, just to give a historical example.

[334] **Mark Drakeford:** Thank you very much indeed—diolch yn fawr iawn. It has been a really interesting session for us, and we are really grateful to you for coming in and helping us to think through some of the very tricky, complicated issues that we have been grappling with for much of today.

[335] **Professor Saunders:** Thank you very much indeed.

[336] **Mark Drakeford:** Dyna ddiwedd y **Mark Drakeford:** That brings the formal session to an end.

*Daeth y cyfarfod i ben am 2.20 p.m.
The meeting ended at 2.20 p.m.*