



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

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

Dydd Mercher, 22 Mai 2013
Wednesday, 22 May 2013

Cynnwys **Contents**

Cyflwyniad, Ymddiheuriadau a Dirprwyon
Introductions, Apologies and Substitutions

Y Bil Trawsblannu Dynol (Cymru): Cyfnod 2—Ystyried y Gwelliannau Human
Transplantation (Wales) Bill: Stage 2—Consideration of Amendments

Grŵp 1: Hyrwyddo Trawsblannu (Gwelliannau 25 a 26)
Group 1: Promotion of Transplantation (Amendments 25 and 26)

Grŵp 2: Adolygu'r System Gydsynio (Gwelliant 27)
Group 2: Review of System of Consent (Amendment 27)

Grŵp 3: Cydsynio i Roi Organau (Gwelliannau 22, 1, 4, 32, 33, 14 a 42)
Group 3: Consent to Donation (Amendments 22, 1, 4, 32, 33, 14 and 42)

Grŵp 4: Cynrychiolwyr Penodedig (Gwelliannau 28, 29, 2, 30, 3, 31, 35, 5, 6, 7, 8, 9, 10, 40,
41, 11, 13, 15, 16)
Group 4: Appointed Representatives (Amendments 28, 29, 2, 30, 3, 31, 35, 5, 6, 7, 8, 9, 10,
40, 41, 11, 13, 15, 16)

Grŵp 5: Cydsyniad Datganedig—Cysylltiad y Rhai sydd mewn Perthynas Gymhwysol
(Gwelliannau 23 a 34)

Group 5: Express Consent—Involvement of Those in a Qualifying Relationship
(Amendments 23 a 34)

Grŵp 6: Consent: Excepted Adults (Gwelliannau 36, 37, 38 a 39)

Group 6: Cydsynio: Oedolion a Eithrir (Amendments 36, 37, 38 and 39)

Grŵp 7: Rhoi Organau sy'n Ymwneud ag Oedolion Byw nad yw'r Galluedd Ganddynt i
Gydsynio (Gwelliant 12)

Group 7: Living Donation Involving Adults who Lack Capacity to Consent (Amendment 12)

Grŵp 8: Y Weithdrefn Is-ddeddfwriaeth (Gwelliannau 17, 18, 20 ac 21)

Group 8: Subordinate Legislation Procedure (Amendments 17, 18, 20 and 21)

Grwp 9: Technegol (Gwelliant 19)

Group 9: Technical (Amendment 19)

Grŵp 10: Y Gwasanaethau neu'r Cyfleusterau sy'n Ymwneud â Chael Cydsyniad
(Amendment 24)

Group 10: Services or Facilities in Connection with Obtaining Consent (Gwelliant 24)

Cynnig o dan Reol Sefydlog Rhif 17.42 i Benderfynu Gwahardd y Cyhoedd

Motion under Standing Order No. 17.42 to Resolve to Exclude the Public

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

Rebecca Evans	Llafur Labour
Vaughan Gething	Llafur (Cadeirydd y Pwyllgor) Labour (Committee Chair)
William Graham	Ceidwadwyr Cymreig Welsh Conservatives
Elin Jones	Plaid Cymru The Party of Wales
Darren Millar	Ceidwadwyr Cymreig Welsh Conservatives
Lynne Neagle	Llafur Labour
Gwyn R. Price	Llafur Labour
Kenneth Skates	Llafur Labour
Lindsay Whittle	Plaid Cymru The Party of Wales
Kirsty Williams	Democratiaid Rhyddfrydol Cymru Welsh Liberal Democrats

Eraill yn bresennol
Others in attendance

Mark Drakeford	Aelod Cynulliad, Llafur (y Gweinidog Iechyd a Gwasanaethau Cymdeithasol) Assembly Member, Labour (the Minister for Health and Social Services)
Pat Vernon	Polisi ar Ddeddfwriaeth Rhoi Organau a Meinweoedd, Llywodraeth Cymru Policy for Organ and Tissue Donation Legislation, Welsh Government
Sarah Wakeling	Gwasanaethau Cyfreithiol, Llywodraeth Cymru Legal Services, Welsh Government

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

Sarah Beasley	Clerc Clerk
Joanest Jackson	Uwch-gynghorydd Cyfreithiol Senior Legal Adviser
Sarah Sargent	Dirprwy Glerc Deputy Clerk

Dechreuodd y cyfarfod am 9.04 a.m.
The meeting began at 9.04 a.m.

Cyflwyniad, Ymddiheuriadau a Dirprwyon
Introductions, Apologies and Substitutions

[1] **Vaughan Gething:** Good morning. Welcome to members of the committee, to the Minister and to his advisers, and to members of the public who are joining us for this meeting of the Health and Social Care Committee. The meeting is bilingual and headphones can be used for interpretation from Welsh to English on channel 1, and for amplification on channel 0. I ask Members—and I am just about to do this myself—to turn off mobile phones as they interfere with the broadcasting equipment. You do not need to tap your microphones, as they will come on automatically. We have a full complement, and no apologies have been received.

9.05 a.m.

Y Bil Trawsblannu Dynol (Cymru): Cyfnod 2—Ystyried y Gwelliannau
Human Transplantation (Wales) Bill: Stage 2—Consideration of Amendments

[2] **Vaughan Gething:** Every Member will have in front of them the marshalled list of amendments and the groupings list. In the event that all amendments are not disposed of today, a second meeting is available to us on Thursday, 6 June, following the Whitsun break, to dispose of any remaining amendments. If there is a second meeting, there will be an opportunity for Members to table further amendments to any section of the Bill that we have yet to reach. The deadline for doing so will be 5 p.m. on Thursday, 30 May. In line with the deadline that we have set ourselves, we need to complete Stage 2 by 7 June.

[3] The marshalled list that you all have on the white paper, is, effectively, the sequence in which the amendments hit the Bill—sequentially through the Bill, from sections 1 to 20, and at the end. Therefore, that is the order in which we will consider those amendments. You also have a groupings list, which is, effectively, the themes of debate, according to which the amendments are arranged. Members will need to follow both papers, although I will help you and advise you when I call you as to whether you are being called to speak in that debate, or are being called to move your amendments for a decision and a vote. There will be one debate for each group of amendments. If you do not have an amendment in that group, but you wish to speak, please indicate in the usual way—by catching my eye, or the eye of a member of the clerking team—and we will ensure that you are called to speak.

[4] I will call the Minister for Health and Social Services to speak on each group. As previously, as the Minister is not a member of this committee, as Chair, I will move all of his amendments, and I will do so at the appropriate place each time. If, for some reason, Minister, you do not wish to move a particular amendment, please indicate before I do so; however, I have had no indication that you do not wish any amendments to be moved. If Members wish to take advice—or if the Minister wishes to take advice from his advisers—those discussions will not be on the record. Members can take advice as we go through if they need to; please indicate if you wish to do that, so that we can stop to do that.

[5] Is all that clear? I see that it is. In that case, we will make a start.

Grŵp 1: Hyrwyddo Trawsblannu (Gwelliannau 25 a 26)
Group 1: Promotion of Transplantation (Amendments 25 and 26)

[6] **Vaughan Gething:** The lead amendment in this group is amendment 25 in the name of Darren Millar. I call on Darren to move his amendment, and to speak to it and amendment 26.

[7] **Darren Millar:** I move amendment 25 in my name.

[8] I wish to take this opportunity, in opening this debate on group 1, to thank the Minister and his officials for the way in which they have engaged with me during the amendments process that we are about to complete today, hopefully, in respect of Stage 2. I have really appreciated that engagement.

[9] Amendments 25 and 26 deal with the promotion of transplantation activity. The proposed deemed consent system makes big changes to the ways in which organs are treated upon death. Its success will depend on whether the system is perceived as ethical and legitimate by the public. The Minister for Health and Social Services—the present Minister, and his predecessor—has said that, in order for deemed consent to be valid, people in Wales must be fully aware of the system, and I agree with the present Minister, and his predecessor, on that point. In fact, the Minister’s legal adviser stated in committee that consent could not be valid if people did not understand the system, and that it would be in breach of human rights. We have since taken further information from the Minister, which sought to clarify the advice and the statements that had been given by his legal adviser.

[10] The UK Donation Ethics Committee supported the view, however, and said that clear information about the system, and the implications of opting out—or not—is a vital component of an ethically acceptable system. The Human Tissue Authority also said that there needed to be a continuous communication campaign, so that those who have made a decision in the past are able to revisit it on as regular a basis as possible. The HTA also had questions about the finances that have been attributed to that campaign in the explanatory memorandum.

[11] The Bill puts some duties on Welsh Ministers to promote organ donation, but these amendments that I have tabled seek to take that one step further. When the Health and Social Care Committee did its report at Stage 1, we acknowledged that, on the basis of international evidence, by itself, a change in the law of the sort proposed in the Bill is unlikely to be decisive in driving up the rate of organ donation. I do not think that the current provisions on the face of the Bill will enable the Minister to meet the test of ensuring that people are fully aware of the new deemed consent system. We know that populations are transient, and that people move in and out of Wales, and I think we would be foolish to assume that the current suggestions on the face of the Bill will reach the whole population. I want a commitment on the face of the Bill, which is what amendment 25 seeks to introduce, for an annual campaign to promote transplantation, especially given that I have tabled another amendment further on in today's proceedings, amendment 36, that proposes a 12-month residency criterion instead of the current proposal of six months. So, this runs in conjunction with that other amendment.

[12] Amendment 26 relates to a requirement for an annual report. I note the Minister's intention to produce an evaluation strategy for monitoring the effectiveness of the campaign, and to publish an attitude survey as the campaign progresses. However, there needs to be more of a concrete commitment to make sure that awareness-raising levels are working well, and the information collected by the Minister should be brought before the Assembly so that the effectiveness—or otherwise—of that information can be properly scrutinised. That is why amendment 26 seeks to place a duty on Ministers to report annually to the National Assembly for Wales. These two amendments go hand in hand, and will ensure that there is a regular way to evaluate the success of the promotional activity that the Minister undertakes.

[13] **Vaughan Gething:** Thank you, Darren. Do any other Members wish to speak to either of the amendments in this group, amendment 25 or 26? I see that Lindsay wishes to do so, and then we will have William Graham.

[14] **Lindsay Whittle:** Has Darren Millar costed this pan-Wales awareness-raising activity, and is it budgeted for?

[15] **Vaughan Gething:** Darren will get an opportunity to reply, so he can respond to that at the end of the debate. William Graham is next.

[16] **William Graham:** I wish to speak in support of my colleague. The Bill states that the Welsh Ministers must promote transplantation. We accept that entirely. The Human Tissue Authority states that communication will be vital in ensuring the legitimacy of a system of deemed consent. We think that that would be better provided through these amendments. The Minister for health has already said that consent could not be valid if people do not understand the system. Clearly, that is vital. We think that our amendments aid that. In terms of amendment 26, a communications campaign would be subject to monitoring, but we think that more information should be provided by the Minister, and this amendment seeks to achieve that.

[17] **Vaughan Gething:** Are there any other Members who wish to speak to either of these amendments? I see that Elin Jones wishes to do so.

[18] **Elin Jones:** Hoffwn ddweud fy mod yn gweld diben rhoi rhywbeth ar wyneb y Bil a fydd yn sicrhau bod Gweinidogion Cymru yn rhoi cyhoeddusrwydd i'r system newydd yng Nghymru. Rwyf yn siŵr bod gan y Gweinidog fwriad i wneud hynny, er efallai nad ar wyneb y Bil. Credaf fod gwelliant 25, **Elin Jones:** I would like to say that I understand the purpose of placing something on the face of the Bill to ensure that Welsh Ministers publicise the new system in Wales. I am sure that the Minister intends to do that, although perhaps he would not state that on the face of the Bill. I believe that amendment

sy'n gofyn am nodi'r broses honno ar wyneb y Bil, yn ddigon derbyniol, gan fod hwn yn newid go sylweddol i'r system yng Nghymru. Er hynny, ni welaf werth mewn rhoi ar wyneb y Bil ofyniad am adroddiad blynyddol gan Weinidogion Cymru. Mae'r Gweinidog yn atebol i'r Cynulliad drwy'r amser a thrwy'r flwyddyn. Felly, mae modd i Aelodau a'r cyhoedd graffu ar waith y Gweinidog ar y materion hyn, a hynny heb fod angen rhoi'r byrdwn hwnnw ar wyneb y Bil. Bydd y ddeddfwriaeth hon yn ei lle ymhen 10 mlynedd ac, o bosibl, ymhen 20 mlynedd. Mae cael gofyniad am adroddiad blynyddol ar wyneb y Bil, felly, yn orfodaeth sy'n mynd gam yn rhy bell, yn enwedig yng nghyd-destun y ffaith bod y Gweinidog wedi rhoi gwybodaeth inni am y modd y mae ef yn rhagweld y bydd y system hon yn cael ei gwerthuso, a dyna sy'n bwysig: gwerthuso'r ddeddfwriaeth hon dros y cyfnod cychwynnol.

15, which asks for that process to be noted on the face of the Bill, is perfectly acceptable, given that this is a very significant change to the system in Wales. However, I do not see any value in placing on the face of the Bill a requirement for an annual report from Welsh Ministers. The Minister is accountable to the Assembly all of the time and throughout the year. Therefore, Members and the public can scrutinise the Minister's work on these issues without there being a need to place that on the face of the Bill. This legislation will be in place in 10 years' time and, possibly, in 20 years' time. Having a requirement for an annual report on the face of the Bill, therefore, is a requirement that goes a step too far, particularly in the context of the fact that the Minister has provided us with information on how he anticipates this system will be evaluated, and that is what is important: evaluating this legislation in the initial period.

[19] **Vaughan Gething:** Thank you, Elin. I now bring in Kirsty Williams.

9.15 a.m.

[20] **Kirsty Williams:** Thank you, Chair. Darren Millar raises valid and important points in these amendments. We were clear as a committee about the need to ensure strong, coherent and pan-Wales campaigns to not only raise awareness of the change in the law, but positively promote the idea of people positively opting in to the system. I can understand the concerns that, in the way the Bill is currently drafted, that may not be strong enough. However, I would like to reiterate Elin Jones's point: we are legislating not just for 12 months or the first five years of this scheme; this is legislation that is supposedly designed to stand the test of time. If this Government's policy is to be successful, I would like to think that we will move to a situation in which organ donation and the system are widely understood and we will have achieved a cultural step-change in how we view organ donation. I hope that we will get to a stage when my children, for instance, will wonder why this has been as controversial and testing as it has been. Therefore, I wonder whether it is appropriate to be so prescriptive about not only the publicity campaign but annual reporting in the longer term. We are all clear, and the Minister, in fairness, has been clear, about the necessity of undertaking those publicity campaigns. However, it is a question of balance with regard to whether we need to be as prescriptive as to put that on the face of the Bill, which would then require a change in primary legislation, if, in years to come, the need for such prescriptive publicity and reporting would no longer be necessary, as I hope would be the case.

[21] **Vaughan Gething:** I see that no other Members wish to contribute, so I call the Minister.

[22] **The Minister for Health and Social Services (Mark Drakeford):** Thank you, Chair. I will begin by thanking the mover of the amendment for his opening remarks. Communication is central to the Bill. The Government has always said that, and there is a duty on Welsh Ministers to promote transplantation in the Bill that goes beyond anything that has previously existed in legislation. It has always been the Government's intention that there should be pan-Wales communication activity in order to make sure that people know of the

change that the Bill introduces and are aware of what it means for them. For that reason, I have no difficulty with making an extra commitment in the Bill of the sort set out in amendment 25. However, we have some minor drafting concerns with regard to how the amendment is drafted, which I will come back to. It would always be the intention of Ministers to make an annual statement, or more frequent statements, about progress under the Bill. That statement would set out the nature of the communication campaign and how it had been given effect across Wales. The evaluation strategy refers to that in some detail. I understand exactly the points, however, made by Elin and Kirsty about whether that needs to be embedded in the legislation. Once it is there, it is there for the very long term. I will make a suggestion to the mover of the amendment, which I hope he will be willing to consider. If he were to not to proceed with these amendments at this stage, the Government will certainly come forward with an amendment at Stage 3 to put on the face of the Bill our commitment to annual pan-Wales communication activity. We will consider what other Members have said in relation to whether there is a need to put on the face of the Bill a requirement for an annual statement from Ministers in relation to that activity. I am happy to share with the Member drafts of the Government amendment that we would bring forward at Stage 3. If the Member wishes to put it to the vote, as he is entitled to, we would have to resist the amendments as currently drafted. However, I make that commitment in terms of what the Government would do at Stage 3.

[23] **Vaughan Gething:** I call on Darren Millar to reply to the debate.

[24] **Darren Millar:** Thank you, Chair. I am grateful for the Minister's response to these amendments. The purpose is not to put a straitjacket on either him or future Ministers in Wales in terms of promotional activities; it is simply to clarify that there ought to be an annual campaign mentioned on the face of the Bill, to tie in with the 12-month residency criterion, which has been tabled in amendment 36.

[25] Picking up on some of the issues that Kirsty and Elin mentioned, yes, there is currently a duty for Ministers to promote transplantation activity and, yes, that could be considered to be promotional activity throughout the year. However, there is nothing that states on the face of the Bill that that ought to be pan Wales. This amendment seeks to make that situation very clear. Also, there will be a need, I think, for at least an annual campaign, given that people are moving constantly in and out of Wales, many of them from places that will not have a deemed consent system in operation. So, while I accept that many people around this table may want to change the culture and the attitude towards organ donation in Wales, that is not going to change the culture or attitude of people in other parts of the United Kingdom or overseas, who may come to Wales and, therefore, not have the opportunity to benefit from the promotional activities that are currently on the face of the Bill. I very much welcome the Minister's commitment to bring forward a Government amendment at Stage 3 in respect of pan-Wales promotional activities on an annual basis, as well as his consideration of the points that have been made around a report on those promotional activities. When I say that there must be a report, it need not be a fully written, brochure-type approach to reporting to the National Assembly; it could simply be a report within the other reporting mechanisms that already exist within the Assembly. I am simply saying that there ought to be some formal mechanism whereby Members of the Senedd can scrutinise that promotional activity, to ensure that it is in line with the commitments that have been given previously by the Minister for health and his predecessors. On the basis that the Minister is going to bring forward his own amendments, I will withdraw amendment 25 and not move amendment 26.

[26] **Vaughan Gething:** The Member has indicated that he is prepared to withdraw amendment 25. The committee needs to endorse the withdrawal of the amendment. Does any Member object to the withdrawal of amendment 25? I see that there are no objections.

Tynnwyd gwelliant 25 yn ôl drwy ganiatâd y pwyllgor.

Amendment 25 withdrawn by leave of the committee.

[27] **Vaughan Gething:** Does any Member wish to move amendment 26? I see that no-one does.

Ni symudwyd gwelliant 26.

Amendment 26 not moved.

Grŵp 2: Adolygu'r System Gydsynio (Gwelliant 27)
Group 2: Review of System of Consent (Amendment 27)

[28] **Vaughan Gething:** The only amendment in this group is amendment 27 in the name of Darren Millar. I call on Darren to move and speak to his amendment.

[29] **Darren Millar:** I move amendment 27 in my name.

[30] This amendment is in respect of the system of consent. It is a very simple amendment that asks on the face of the Bill for a report within a period of three years from the commencement of the new system. There has been a commitment in the explanatory memorandum by the Minister to monitor and evaluate the new system once it is in place, but I think that there is some merit in placing that on the face of the Bill. The explanatory memorandum estimates that approximately 15 more donors will be found each year as a result of the activities under the deemed consent system. Indeed, the committee recommended that the Minister prepare a contingency plan to respond to greater-than-anticipated numbers. However, if the number of organs available was much lower than anticipated, and the awareness campaigns were unsuccessful, we need to be able to evaluate that properly and the Minister needs to make a conscious decision about whether the deemed consent system should proceed.

[31] We know that there have been concerns about unintended consequences in relation to the Bill. People have advised this committee and individual Members around this table, and surveys have clearly demonstrated, that there are some people who are currently on the organ donation register—albeit a small proportion—who would remove themselves from the organ donation register if a system of deemed consent were in place in Wales. We need to know whether any increase that we might see in organ donation in the future is directly as a result of the deemed consent system that is in operation, or whether it is due to other factors, such as increased critical care capacity, an increase in road-traffic accidents or whatever else might be out there that has an impact on organ-donation rates.

[32] We know that Spain has seen a significant increase in organ donations, and it has been much lauded around Wales for its organ-donation system, but we have been told as a committee, receiving evidence from Professor John Faber and others, that the system that is in operation in Spain is not a deemed consent system at all, and that it is not a presumed consent system; the law may say that there is a presumed consent system, but it is clear that that system has never been enacted. So, there are all sorts of reasons why different countries around the world have significantly better organ-donation rates than Wales. We need to make sure that the monitoring and evaluation of this system is able to demonstrate why there is a difference in organ donation post the implementation of the Bill. That is why I have suggested that, rather than just accept the commitment that has been given in the explanatory memorandum, there needs to be a clear commitment and a requirement on the face of the Bill that Welsh Ministers ought to review the system and decide whether the system ought to continue after three years of implementation.

[33] **Vaughan Gething:** A number of Members have indicated: Rebecca Evans, then Lynne Neagle, then Elin Jones and then Kirsty Williams.

[34] **Rebecca Evans:** I share Darren's concern that the system should be closely monitored and evaluated, but I have two particular concerns about this amendment. The first is that I feel that it is unnecessary, given the clear commitment in the explanatory memorandum that the system will be subject to review. So, it is unnecessary to add it to the face of the Bill. My other concern about this three-year timetable is that I feel that the first two years will be dedicated to the awareness raising and education part of the campaign. So, essentially, your proposal would be to make an analysis of just one year of the Bill in practice, in terms of how it would affect transplantation. So, I feel that that would not be long enough to make any concrete judgment as to whether it is having an impact.

[35] **Lynne Neagle:** I have similar comments to make. I support the need to review the operation of the legislation, but I do not think that three years is an appropriate timescale.

[36] **Elin Jones:** I speak, in part, in support of this amendment and, in part, against a part of it. It is probably appropriate to put on the face of the Bill that there is a timescale for a formal review from commencement, but as others have already expressed, three years does not, perhaps, allow for enough time. It is okay to place on the face of the Bill the commitment to review, but my particular concern about this amendment, and my reason for objecting to it as it is drafted, is that I do not support how the amendment concludes, where it says

[37] 'with a view to considering its continued operation'.

[38] I think that a review should be open, without needing to express as clearly as that an intention to continue to assess whether it should be continued in operation as a system. It could have the effect of raising an expectation that, in three or five years, whenever that review happens, this could be completely dropped. I accept that that could be a conclusion that a Minister draws at that time, but I do not think that it should be worded in such a way that there is a risk that it raises an expectation out there that, after three years, the legislation could be dropped.

9.30 a.m.

[39] **Kirsty Williams:** In the same way as for other members of the committee, it was quite clear to me from the evidence that we received that any thinking Minister, undertaking such a controversial and, in some ways, risky policy decision, would want to review the effectiveness of the legislation. I have not seen any evidence that we have heard that three years is the appropriate timescale for that review. It seems pretty arbitrary to me. While I accept that a three-year time limit would not prevent a Minister from reviewing it in the meantime, or subsequent to that three-year period, I think that it is arbitrary. There is no evidence to suggest that, after three years, you would be in a position to fully assess the impact of this legislation or any other actions by the Government to increase the number of donations. Elin is quite right. Darren's views on this Bill are based on principles and are well-known, but there is a presumption here that could lead people to believe that this is an opportunity to subvert the system—a system with which Darren does not agree. I accept that—he does it for principled reasons and because he does not believe in it—but this is, potentially, a way of trying to undermine the stated goal of the legislation. Therefore, I will not be able to support it.

[40] **Vaughan Gething:** Do any other Members wish to speak? I see not, so I call on the Minister.

[41] **Mark Drakeford:** The mover of the amendment started by saying that any Minister would want to make a conscious decision about the success or otherwise of the Bill, and that is a proposition, of course, to which we would sign up and which we would support. In the

wider literature about the Bill, it is often described as a natural experiment, with something happening in Wales and not in other parts of the United Kingdom, and there would be a great deal to learn from it as it moves forward. There are three objections, however, to the amendment.

[42] The first is the issue of whether it is necessary to have this on the face of the Bill. The Government thinks that it is not. We have a clear commitment, in the explanatory memorandum, to a full evaluation strategy. That evaluation strategy was circulated to members of the committee on 1 May. I think that you can see that it is a comprehensive document and a comprehensive approach. It has qualitative and quantitative aspects of the evaluation. The quantitative aspect, which will measure whether or not the number of donations has moved as a result of the Bill, will not be carried out by the Government itself. The strategy makes a commitment to that being carried out independently of Government. So, there are reassurances there.

[43] The second reason why we cannot accept the amendment is the timescale issue. The first two years post commencement of the Bill are dedicated to education and communication. So, in a three-year time frame, there would be only one year—the first year at that—of experience of deemed consent. The explanatory memorandum and the evaluation strategy set out a five-year time horizon, which we think is a more sensible, proportionate way of assessing whether the Bill has succeeded.

[44] Thirdly, in an unintended way, I have no doubt, picking up on Elin Jones's and Kirsty Williams's points, a three-year time horizon in the terms set out in the amendment could be taken by some people as a rallying point to continue to oppose the Bill and to try to engineer its failure, rather than, as the amendment—I know—set out to do, which is to take a more neutral and balanced view of whether it has succeeded, or not. For those three reasons, we would resist the amendment.

[45] **Vaughan Gething:** I call on Darren Millar to reply to the debate.

[46] **Darren Millar:** Thank you, Chair; I am grateful for the opportunity to reply. I have to say that, having listened to the arguments in respect of the three years, I accept them. I accept that three years is probably too short a time period for a review to take place, given that the publicity and communications campaign will take place over two years, followed by implementation. I would be quite prepared to see an amendment tabled at Stage 3 in order to amend my amendment, should it be successful when I put it to the vote—I will want it to go to the vote, if that is okay.

[47] I understand the concerns about the way in which the amendment is worded. I do not accept Kirsty Williams's assertion that I am attempting to subvert a system with which I disagree in principle. It is not a wrecking amendment at all. It is clearly an amendment that simply asks the Minister, given that he has already made a commitment to undertake a review, to put that commitment on the face of the Bill. That is all.

[48] It is asking the Minister to undertake to fulfil a commitment that he has already given previously. We know that this Minister has given a clear commitment. We do not know what future Ministers might do in terms of a review of the system and that is why I think that it is really important, given the concerns that have been raised, and given the controversy surrounding this Bill and the strong passions that it has aroused among those people who have given evidence to the committee, that there is a clear commitment on the face of the Bill for a review to take place that will consider whether the Act, in terms of the way that it is working, once it is implemented, should continue. I know that the Minister has given that commitment already, but that is not on the face of the Bill, and I am seeking to ensure that it is actually there. So, I will want to move to a vote.

[49] **Vaughan Gething:** Darren has indicated that he wishes amendment 27 to proceed to a vote. The question is that amendment 27 be agreed to. Does any Member object? I see that there are objections. Therefore, I call for a vote.

*Gwelliant 27: O blaid 2, Ymatal 0, Yn Erbyn 8.
Amendment 27: For 2, Abstain 0, Against 8.*

Pleidleisiodd yr Aelodau canlynol o blaid:
The following Members voted for:

Graham, William
Millar, Darren

Pleidleisiodd yr Aelodau canlynol yn erbyn:
The following Members voted against:

Evans, Rebecca
Gething, Vaughan
Jones, Elin
Neagle, Lynne
Price, Gwyn R.
Skates, Kenneth
Whittle, Lindsay
Williams, Kirsty

*Gwrthodwyd gwelliant 27.
Amendment 27 not agreed.*

**Grŵp 3: Cydsynio i Roi Organau (Gwelliannau 22, 1, 4, 32, 33, 14 a 42)
Group 3: Consent to Donation (Amendments 22, 1, 4, 32, 33, 14 and 42)**

[50] **Vaughan Gething:** I have already indicated that Members may be called to speak twice during this debate, depending on how the debate proceeds. The lead amendment in this group is amendment 22 in the name of Elin Jones. I call on Elin to move and speak to her amendment and the other amendments in this group.

[51] **Elin Jones:** I move amendment 22 in my name and with the name of Darren Millar in support.

[52] The purpose of amendment 22 is to ensure that the distinction between life-saving and novel forms of organ donation is on the face of the Bill, and to ensure that deemed consent does not apply to novel forms of transplantation. In our scrutiny session, as a committee, it was clear that there was a consensus developing that deemed consent should not apply, in the first place, to novel forms of transplantation. The committee's recommendation was that this could be a matter that would be left to the code of practice. However, it is my view, on reflection, that this could be placed on the face of the Bill. The public discussion, to date, and the work done by Government in particular on this Bill have been around the life-saving properties of organ donation and the increase in the numbers of organs that could result from this Bill for life-saving purposes, and internal organs in particular. This Bill, as it is currently drafted, has only very few exceptions to the deemed consent system, which are in section 16.

[53] We know, from evidence and from information from all parts of the world, that novel transplantations of face, hands and other parts of the body are becoming possible and will, in all likelihood, increase. We heard evidence to this committee from those who have spent years considering the ethics of organ donation that, possibly at this first stage, deemed consent should not be applicable to novel forms of transplantation. I believe that the Government is also of this view. The purpose of this amendment is to ensure that this is on the face of the Bill, and I have been advised that this is the way to draft this amendment and to ensure that novel transplantations—or composite transplantations, as I have been advised to term them for the purpose of the Bill—should not be included within deemed consent on the face of the Bill.

[54] **Vaughan Gething:** I now call Darren Millar to speak, and then I will open the debate to other Members who do not have amendments in this group.

[55] **Darren Millar:** I want to speak in support of the amendment tabled in the name of Elin Jones. I will also wish to move the other amendments in this group that are tabled in my name. The issue of novel transplantation was discussed at some length during Stage 1 in committee. It was quite clear that very different ethical issues arise when considering novel transplantations as opposed to essential life-saving transplantations. For that reason, I certainly want to support what Elin Jones has said about the need for a clear statement on the face of the Bill that those novel, or composite, transplantations would not be included within the scope of the deemed consent system.

[56] The other amendments in this group that I have tabled relate to the family role in decision making and what I feel needs to be done to ensure that the role of the family is properly safeguarded through the legislation. This is perhaps the most contentious area of debate today. We have had extensive discussions on this matter around this table at Stage 1, and indeed outside this chamber, privately with people with whom we have discussed the deemed consent system. This Minister has made it quite clear that he wants the practice that emanates from this Bill to line up with the provisions on the face of the Bill. What I have sought to do in my amendments 32 and 33 is ensure that the practice that we have understood as a committee that will emanate from the Bill is actually there on the face of the Bill in practice.

[57] We know that families have a much closer relationship with their loved ones than the state ever will, and I feel that they are best placed to relay the views or likely views of the deceased in the event of a decision being taken to remove their organs as part of a transplantation activity. Even if the deceased has not expressed a particular view about donation, the family may well have an intricate knowledge of that person's values and beliefs, and is better placed than any Government of any colour to make a decision about the removal of organs. That is why it is really important that the family is there as a point of information about the known views of an individual, which is what the Minister's amendments seek, but my amendments go a little further than the Minister's—which is why I will not be able to support the Minister's, I am afraid—and suggest that the likely views of the deceased should also be taken into consideration when the transplantation activity is proposed. I have no objection to the Minister's suggestion about issuing further guidance. That is absolutely essential in terms of a code of practice, et cetera. I fully support amendments that relate to that. However, these two particular issues in terms of novel transplantation and the role of the family need to be on the face of the Bill and very clearly understood. That is why I have tabled these amendments.

[58] **Vaughan Gething:** We now move to a debate for every other member of the committee. I have Lindsay Whittle to start and then Kirsty Williams.

[59] **Lindsay Whittle:** Like one or two members of this committee, I am old enough to remember the world's first heart transplant. I think that it was around 1967—I have not researched this—when Professor Christiaan Barnard transplanted a heart into a man whose name, I think, was Louis Washkansky, and he lived for 17 days. It was very controversial at the time; I remember the investigative journalist David Frost interviewing him on television, and there was a lot of public backlash. However, at the end of the day, it was a life-saving operation, and that is what we must not lose sight of. Now, 50 or 60 years on, we have advanced considerably with these life-saving operations.

9.45 a.m.

[60] I know that Elin Jones is not happy with this word ‘novel’, because face transplants and hand transplants are not novel—they are attempting to improve people’s quality of life. I have a feeling that we will be revisiting this in some years to come. However, as a committee, we have not received evidence that we are significantly progressed in this field, and that is why I am supporting my colleague with regard to this amendment. We have not yet sufficiently progressed, but I am sure that whoever will be here in five or 10 years’ time will be coming back to this.

[61] **Kirsty Williams:** I too think that it is important to make the distinction of novel transplantation clear. There was a consensus on this and the views expressed to the committee at Stage 1 were quite clear. This is an evolutionary process, and one that is not without controversy. If we start the presumed consent process on the basis of organ donation that is generally understood and expected, that will be the first step to embedding that change in culture that I think we would all like to see, and to increasing the numbers of donations. The added complication of putting in issues such as hands and faces just makes it even more difficult, and therefore I am supportive of moves to separate out novel forms of transplantation in the Bill at this stage. However, like Lindsay, I expect that, as medical techniques move along, what we regard today as being novel will become much more commonplace. However, that will be a matter for another Health and Social Care Committee to consider.

[62] **Lynne Neagle:** I agree on the issue of novel transplantation. We do not want to have people worrying about that, but I am satisfied that the Government’s amendment 1 deals with that in a more appropriate way. It is my understanding that Elin’s amendment 22 would go further than we would want, and would potentially outlaw all novel transplants in Wales, including those to which someone had given express consent.

[63] I just want to say, on Darren Millar’s amendment 32, that I am opposed to that. We had a lot of discussion in the committee about the need for clarity, particularly for the health professionals who may be dealing with people in very difficult circumstances. I feel that to talk about the likely views of a donor would muddy the waters and cause confusion, so I am opposed to that.

[64] **William Graham:** I speak in support of amendments 32, 33 and 42. In terms of amendment 32, this amendment precludes the consent of the deceased from being deemed. This is based on the fact that a person in a qualifying relationship knows the likely views of the deceased.

[65] In terms of amendment 33, we remain concerned about emotional relationships. Stakeholders have confirmed that the role of the family should be clearly defined in the Bill to minimise any confusion or distress.

[66] In terms of amendment 42, once again, qualifying relationships should be ranked to provide clear guidance for what happens if a family disagrees and to avoid confusion for clinicians. That is a direct reference to our committee meeting on 30 January. The clinical ethics committee of Abertawe Bro Morgannwg University Local Health Board said,

[67] ‘it is not clear what should be done in the likely event of disagreement between people with qualifying relationships. Such disagreements are common and there is often uncertainty about who knows best...A formal hierarchy or ranking of kinds of qualifying relationship might make things clearer.’

[68] Our amendment 42 supports this.

[69] **Vaughan Gething:** Thank you, William. As indicated, I will move around the table

to see whether other members of the committee want to have a second round on what has been said or to make any comments that have not been made about this whole group of amendments. Darren Millar has already indicated, but do any other Members want to speak to any of the other amendments in this group?

[70] **Elin Jones:** As a point of clarification, when will the Government amendments be proposed and spoken to? Is that right at the end?

[71] **Vaughan Gething:** They are in this debate, even—

[72] **Elin Jones:** Yes, I know, but when are they explained and proposed to the committee? Is it only when the Minister speaks right at the end?

[73] **Vaughan Gething:** Yes. I am happy to call the Minister now, then have another round of discussion for the committee and then bring the Minister back in again before we respond to the debate. There is no reason why I cannot do that.

[74] **Lynne Neagle:** Is that not how we did it in relation to the Recovery of Medical Costs for Asbestos Diseases (Wales) Bill? Did we not have two opportunities to speak?

[75] **Vaughan Gething:** If I call the Minister now, then I will move around to the rest of the committee again, and then the Minister will have another opportunity to respond to the debate, and you can respond to the whole group as well, Elin.

[76] **Mark Drakeford:** Thank you, Chair. This is an important group of amendments, dealing with two significant parts of the Bill. I hope that you will forgive me if I set out some views in greater length than I would otherwise do in order to reflect the importance of the issues. In some aspects, but not in all, our debate is about the means rather than the ends. We agree on what we want to achieve, and then we sometimes have different views about the best way to achieve them, but we are often not much divided on the object that we want to achieve, and that is true of some parts of this group, certainly.

[77] I will deal first of all with the role of the family, which is covered in this group of amendments. You know that I gave a commitment on behalf of the Government during the Stage 1 debate to bring forward an amendment that would make it clear that where family members, at the point when donation was being considered in a deemed consent context, were able to say that they knew the views of the potential donor, those views would prevail. That is what the Government amendment does. It makes it certain in law and for families that, where someone has not expressed consent and their consent is being deemed, if a family member knows that that person would not have wished donation to go ahead, donation will not go ahead. That will now be secured on the face of the Bill by the Government amendment. It is an important amendment and has been widely welcomed by organisations and individuals who have engaged and commented on the Bill as it proceeds.

[78] Darren's amendment 32 goes a step beyond that. Families would now be able to object, not on the basis of the known views of the potential donor, but on the likely views, and, for us, that is a step too far away from the fundamental principle of this Bill, namely that the views of the donor should prevail, and it pushes the decision a bit too far into families being able to bring their own views into the discussion rather than the known views of the donor. For that reason, we think that amendment 32 departs a shade too much from the fundamental part of the Bill, which many Members previously were—and in some further amendments still are—committed to, namely that the known views of the donor should be the most significant of all.

[79] I have thought hard about amendment 33, because I am sympathetic, in many ways,

to what it sets out to achieve. This is one of those ones where the discussion is not about what we want to achieve, but about how we should achieve it. Amendment 33 puts on the face of the Bill a test that clinicians would have to navigate about the undue distress of family members. The Government's view, having thought it through, is that this is better dealt with in the statutory code rather than on the face of the Bill. When it is on the face of the Bill, it pushes clinicians into making a legal determination rather than a clinical determination about the family and the position that the family finds itself in. To remind Members, as you will know well, the code of practice will be a statutory code, it will be provided for in primary legislation, it will be consulted upon and it will be subject to an affirmative procedure on the floor of the National Assembly. So, Assembly Members will be able to pursue the aim of the amendment that Darren wants to achieve through the code, and the Government's view is that that is a more appropriate place for this important area to be set out and pursued.

[80] To turn for a moment to the second matter in this group of amendments, namely that of novel forms of transplantation, the Government's position on this has altered as a result of the committee's Stage 1 consideration and the committee Stage 1 report. The original position, which my predecessor took, was that the Government would set out our agreed position with the mover of the amendment, namely that novel and composite forms of transplantation should not be covered by deemed consent—that is absolutely common ground between us—but that they would be covered by directions. The committee felt—and you said so in your report—that it would be more appropriately dealt with by regulations, and that those regulations should be made under the superaffirmative procedure. The amendments that the Government brings forward today in this group and in group 8 do exactly that. We absolutely agree that composite forms of transplantation should not be covered by deemed consent. We will set that out in regulations; those regulations will be consulted upon, and they will come back to the floor of the Assembly for a vote.

[81] Why do we think that that is preferable? Well, there is a risk, in an unintended way, I imagine, that the current amendment, as drafted, would not simply prevent deemed consent from applying to forms of composite transplantation, but that even if somebody had given an expressed form of consent, that would not be lawful in Wales as a result of this amendment. I do not think that we would want to see that.

[82] There is also an issue that Members have rehearsed already about how you deal with the changing nature of transplantation. To give you just one example, in 1987, the first ever example of small bowel transplantation took place. By the beginning of the 1990s, there were just two places across the world where that form of novel transplantation was possible. In the last two years in the United Kingdom, more than 40 such transplantations have taken place. Something that was novel not that long ago has now become much more widely available. If you deal with that through regulations, they are a more flexible way—even though they would still be subject to the affirmative procedure and so on—of keeping the Bill in line with emerging practice. The amendment, which we agree with in what it wants to set out as far as deemed consent is concerned, means that it would be much more difficult, and we would be in the position, as I think other Members have said, of having to come back to amend primary legislation each time practice moves ahead and something that is novel today becomes much more mainstream tomorrow. For that reason, we are unable to support Elin's amendment 22.

[83] Finally, amendment 14, a Government amendment, is the amendment that would require a Human Tissue Authority code of practice to give practical guidance on how to assess information provided by relatives and friends. This is our way of dealing with the debate that some of us had post Stage 1, where we again met faith groups, medical ethicists and others to talk about what would happen under the Government's first two amendments, where two members of a family turn up, both having a legitimate claim in being able to say that they knew the views of the individual, but that those views are different. How do clinicians resolve that position? Well, the code of practice will provide guidance under

amendment 14 to clinicians to do that, by developing, not a hierarchy of relationships, but a hierarchy of information. It will help clinicians to decide which of those two competing pieces of information is more likely to have validity. Amendment 14 sets out how that would be accomplished through the code.

[84] **Vaughan Gething:** Thank you, Minister. I now look to Elin and Darren, again, and then to other Members. Afterwards, if there is a further round of debate, I will then ask the Minister and Elin to close the debate. So, effectively, everybody gets an opportunity for another comment, if they wish. Elin, of course, you do not have to speak now, but you may if you wish.

[85] **Elin Jones:** I will speak at the end.

[86] **Vaughan Gething:** Okay, fine. Darren?

[87] **Darren Millar:** I have just three points, if I may. I am very grateful that the Minister has given some consideration to my amendment 33, which deals with this issue of undue distress. It was very clear that nobody at this table, or any of the witnesses that appeared before the committee at Stage 1, wanted a donation activity to take place where undue distress was being caused to a family. That is why we tabled this amendment in my name, because we feel very strongly—I feel very strongly—that the face of the Bill ought to match the practice that we all think should emanate from it. The Minister has been very strong in making the case for the face of the Bill to match up with the practice, and leaving it all to a code of practice, particularly when we have a clear understanding of the intention, is unwise. There is no reason why there should not be an amendment in relation to undue distress on the face of the Bill.

10.00 a.m.

[88] In terms of amendment 32, which introduces the concept of the likely views of the deceased, I really cannot understand the objections that have been brought forward by both Lynne and the Minister, because the issue here, surely, is that the Minister and the Bill suggest that the state is going to be best placed to know the likely views of the deceased and there are assumptions being made about the views of the deceased through the system of deemed consent. So, surely, the family members who are close in relationship—the people in those qualifying relationships—are far better placed to know the likely views of the deceased where no view has been discussed or no view is known to the family. There is a need, desperately, to ensure that those likely views are given proper consideration by clinicians and other people when a decision about a transplantation activity is being considered. I understand that the legislation is a deemed consent system, but you are making big assumptions about the views of the deceased, assuming that they are happy to have their organs removed following their death, by not opting out of the system. That is a huge assumption to make, and I would charge you, Minister, to have a look at this issue again at Stage 3. If you are not happy with the amendment, or the wording of my amendment, then please take a moment to think about what has been said in the past, about the role of the family in knowing and understanding the views of their loved ones much better than any of us around this table would if we were not related to those deceased people.

[89] I failed earlier on, Chair, to mention my amendment 42, which introduces a ranking system. This ranking system seeks to eliminate the possibility of disagreement where there are two members of a family in a qualifying relationship who have a different view of what they believe were the known views of the deceased. The Minister is introducing a ranking system where an appointed representative cannot be found, so that people in a family relationship are ranked, and they can be asked their views as to whether there was consent in place, or not. I cannot for the life of me understand why it is okay to have a ranking system

that is mentioned on the face of the Bill for a situation where an appointed representative cannot be found, but it is not okay to have a ranking system where there is a dispute between different people in qualifying relationships. To me, there is an issue of consistency here. There is a need to be absolutely consistent in terms of the way that people's views are determined when there is an appointed representative, or when there is no appointed representative. The system has to be consistent. It is not at the moment, and that is why I tabled that particular amendment. We know that the Human Tissue Authority said that there could be confusion in the event that two people in a qualifying relationship have a different view, and a clear hierarchy and ranking system as part of the decision-making process would help to support and facilitate a greater level of organ donation.

[90] **Vaughan Gething:** Thank you, Darren. I see that Kirsty Williams wants to speak. I will then see whether other members of the committee wish to speak.

[91] **Kirsty Williams:** Chair, I would appreciate some legal advice over the definition of 'undue distress', on whether that is a legal term that is currently in common usage in legislation, and on the legal consequences for clinicians in trying to establish 'undue distress'. I would like some legal advice about whether there is such a concept in the law of England and Wales.

[92] **Vaughan Gething:** Given that the legal advice for the committee will not be on the record, we will take a short recess to have that advice provided to the committee and we will then return on the record.

[93] **Kirsty Williams:** Sorry.

[94] **Vaughan Gething:** You are perfectly entitled to ask for it; this is the whole point of me doing my job properly. I will then move on to Rebecca Evans. We will now take a short break.

*Gohiriwyd y cyfarfod rhwng 10.05 a.m. a 10.25 a.m.
The meeting adjourned between 10.05 a.m. and 10.25 a.m.*

[95] **Vaughan Gething:** Thank you for your patience while we had that brief interlude. We are now returning to the debate on group 3 on consent to donation. The next Member who has indicated that she wishes to speak in this debate is Rebecca Evans.

[96] **Rebecca Evans:** I want to put on record that I share Lynne's concerns about the effects of Elin's amendment, particularly the effect of banning all novel transplantation. Perhaps in your response to the debate, you could outline whether that was the intention of the amendment, even in cases where people had expressly consented to that. In addition, I have been persuaded by the Minister's argument that the code of practice is the best place to deal with family distress, so that clinicians are able to make a clinical judgment rather than a legal judgment as you said.

[97] **Vaughan Gething:** Do any other Members wish to speak in this general debate? If not, I will call the Minister.

[98] **Mark Drakeford:** Thank you, Chair. I will just deal with the three points that were raised by Darren Millar in his second contribution. To begin with, thank you to Darren for raising the ranking issue, which I had not covered. I am glad to have a chance to clarify it now. From my perspective, the way in which the Bill deals with ranking is entirely consistent and understandable, and it goes like this: in all issues of deemed consent, the Bill prefers an unranked list, because, in deemed consent, what family members are doing is contributing information. Where there is express consent, families are not contributing information; they

are making a decision. When you are making a decision, it is important to know whose responsibility it is to make the decision. There is then a ranked list, so it is clear to whom the decision falls. That is consistent throughout the Bill. Wherever we are dealing with deemed consent, we have unranked lists, and wherever we are dealing with express consent, we have ranked lists. The Bill makes that distinction clear between information giving and making a decision. I hope that that clears up why we opt for the one list in one part of the Bill and the other sort of list in another part.

[99] Moving on to deal with the ‘likely’ issue, what we heard from Darren when he was making the case for being able to act on the likely views of the family is his previously, and perfectly properly, expressed objections to the whole idea of deemed consent. Darren’s idea of deemed consent is that, somehow, it is an act of assumption on the part of the state that they know what somebody’s views are. That is not my view of deemed consent, nor is it the view of deemed consent that runs through the Bill. Deemed consent is an absolutely equally valid form of consent as either saying, ‘No, you do not want to’, or, ‘Yes, you do’. In Wales, you will have three choices: you can opt out, you can opt in, or you can choose to have your consent deemed. As the Nuffield Bioethics Institute said when it came here, deemed consent is not a poor person’s consent. It is every bit as valid a consent as any other form of consent. We know that Darren does not accept that position, and his reason for wanting to introduce the likely views of someone in the family is that it sort of gets around that objection in another way. It is a very slippery concept as well. I wrote down—unfairly, I know, because we are all speaking off the cuff rather than from script here—what the Member said in his very final remarks on the likely views. He said that where the family knows what the person’s views are, it ought to be able to say so. I completely agree with that. That is why our formula is ‘known’, rather than ‘likely’, and that is the difference between us there.

10.30 a.m.

[100] I believe that the undue distress issue, on which you have heard further, is more closely balanced. As I said, I have thought very hard about amendment 33, and, in the end, it is a matter of judgment. Is that subjective test, which becomes a legal test and which requires clinicians to think in that legal sort of way, better on the face of the Bill, or is it better dealt with in the statutory code, where the judgment is more clinical and revolves around a clinical assessment of the condition that the family might be in? It is our judgment that it is better dealt with in that way. We both want the same result in ensuring that family distress is properly recognised in that very difficult set of circumstances, where donation is being considered.

[101] **Vaughan Gething:** Thank you, Minister. I now call on Elin Jones to reply to the debate.

[102] **Elin Jones:** I am glad that we have heard this morning that the Government, as well as the majority of committee members, believes that a deemed consent system should not include novel forms of transplantation from the commencement of the legislation, and that there is a difference of opinion on how that could be delivered. That is in front of us this morning. I believe that it should be on the face of the Bill, and the Minister believes that it should be done via regulations under the affirmative procedure. I have listened to what the Minister and others have said, which is that there could be unintended consequences to the amendment that I have tabled, in its current drafting, and that it could include within its scope those novel forms of transplantation where there had been express consent for novel transplantation. It was not my intention to include that. I will therefore withdraw the amendment for the purposes of this morning’s consideration, and I will further reflect on whether a redrafting would not include express consent for novel transplantation. I will consider bringing that at a further stage. Therefore, for this morning’s purposes, I wish to withdraw this amendment, but I will be voting against the Government’s amendment in order

to ensure that I am able to hear legal advice of my own on whether a redrafting of the amendment is appropriate, for the purposes of the next stage.

[103] **Vaughan Gething:** Thank you, Elin. The Member has indicated that she wishes to withdraw amendment 22. Does any Member object to the withdrawal of that amendment? I see that there are no objections. Amendment 22 is therefore withdrawn.

*Tynnwyd gwelliant 22 yn ôl drwy ganiatâd y pwyllgor.
Amendment 22 withdrawn by leave of the committee.*

[104] **Vaughan Gething:** We now move to dispose of amendment 1. I formally move amendment 1 in the name of the Minister. The question is that amendment 1 be agreed to. Does any Member object? I see that there are objections. We therefore move to take a vote by a show of hands.

*Gwelliant 1: O blaid 6, Ymatal 0, Yn erbyn 4.
Amendment 1: For 6, Abstain 0, Against 4.*

Pleidleisiodd yr Aelodau canlynol o blaid:
The following Members voted for:

Evans, Rebecca
Gething, Vaughan
Neagle, Lynne
Price, Gwyn R.
Skates, Kenneth
Williams, Kirsty

Pleidleisiodd yr Aelodau canlynol yn erbyn:
The following Members voted against:

Graham, William
Millar, Darren
Jones, Elin
Whittle, Lindsay

*Derbyniwyd gwelliant 1.
Amendment 1 agreed.*

Grŵp 4: Cynrychiolwyr Penodedig (Gwelliannau 28, 29, 2, 30, 3, 31, 35, 5, 6, 7, 8, 9, 10, 40, 41, 11, 13, 15, 16)

Group 4: Appointed Representatives (Amendments 28, 29, 2, 30, 3, 31, 35, 5, 6, 7, 8, 9, 10, 40, 41, 11, 13, 15, 16)

[105] **Vaughan Gething:** We will now debate the amendments in group 4, which deal with appointed representatives. The lead amendment in this group is amendment 28, in the name of Darren Millar. I call on Darren to move amendment 28, and to speak to it, as well as the other amendments in this group.

[106] **Darren Millar:** Thank you, Chair. I move amendment 28, tabled in my name within this group.

[107] My amendments seek to set out the removal of the ability of an individual to appoint more than one nominated representative. I fully support the principle of nominating a representative to take a decision and to act on someone's behalf. However, I am concerned that there is currently very little recourse, when time is of the essence, and I am concerned that a dispute might arise between more than one nominated representative. When multiple representatives have already been appointed, as is currently the case, I am not looking to reverse those decisions that have already been taken, and we would need to protect the existence of a number of nominated representatives where they already exist. However, I think that, for the purposes of clarity, it would be a much better way forward to have just one single nominated representative in the future under our new system.

[108] We were told by various witnesses who came to give evidence at Stage 1 that, under the current drafting, if an appointed representative could not be found, those in a qualifying

relationship would not be asked; the transplantation activity simply would not go ahead. So, I will be supporting the Government's amendments in this group, because it is sensible that, where a nominated representative cannot be found, there is still an opportunity for transplantation activity to go ahead by asking those in a qualifying relationship and those people who are close to the deceased. So, I will support the Government's amendments, but it is important that there is only one nominated representative in the future in order to avoid any confusion that might arise, and the potential for a transplantation activity not to go ahead where two appointed representatives have opposing views.

[109] **Vaughan Gething:** I now call other Members to speak on the debate on the whole group of amendments. The first Member to have indicated is William Graham.

[110] **William Graham:** I speak in support of amendment 28 in particular. It is very important that there should be the complete elimination of the possibility of disputes arising between nominated representatives. Therefore, one representative is our preference.

[111] **Vaughan Gething:** Are there any other Members who wish to speak in this debate on this group of amendments on appointed representatives? I see that there are not. Therefore, I will move to the Minister.

[112] **Mark Drakeford:** I will first explain the Government amendments in this group and then I will say something on the amendments brought forward by Darren Millar. The Government amendments give effect to recommendation 7 of the committee's report regarding appointed representatives. As you know, the Bill, as originally introduced, meant that, if an appointed representative or representatives could not be found, donation could not go ahead and that would be the end of the matter. The committee recommended that the Bill should be amended to bring it back closer in line with the provision in the Human Tissue Act 2004 in which, if an appointed representative cannot act, for example because they cannot be found, then it is possible to revert to the family to have the decision made. The Government amendments make that possible. Amendments 2, 3, and 5 through to 10 alter the cases in the tables in sections 4 and 5 of the Bill to make it clear that, where an appointed representative is unable to act, consent then passes to a person in a ranked qualifying relationship. Amendment 11 sets out that, if it is not reasonably practicable to contact an appointed representative within the time available, the clinician can judge that he or she is unable to give consent; that mirrors the wording in the 2004 Act. Amendments 13, 15 and 16 are consequential changes. Just to reinforce a point that I made in the debate on the last group, the reason that the decision passes to family members in a ranked list is because they are being asked to make the decision. That is why they are in that way.

[113] Darren Millar's amendments would make it obligatory for people to appoint only one representative, as opposed to one or more. There are persuasive arguments that he put forward, in a practical sense, as to why it would be easier for specialist nurses and so on dealing with this difficult issue at the point where a decision is being made—it would be clearer and simpler, and so on. I have not been able to obtain final advice, however, as to whether or not moving in that direction might have some unintended consequences. I have asked my advisers to go back to the debate that surrounded the 2004 Act. In Hansard, at that time, the Minister responsible for bringing the 2004 Bill forward set out a series of policy reasons as to why it was important that more than one representative could be appointed. I have asked my advisers to go back to those tests to see whether, over the passage of time, they have turned out to be real concerns and, therefore, that more than one representative is an important thing to have, or whether they have turned out to be concerns that, in the practical world, really have not applied.

[114] What I want to do is test whether there are any unintended and unforeseen reasons why we should not move to a single representative for the purposes of clarity and simplicity.

We will need to raise this with the Department of Health as well. The committee's original recommendation 7 moved our Bill back closer to the 2004 Act and, therefore, minimises differences in a cross-border context. Darren's amendment opens up another area of difference between Wales and England. Given that we have an agreement on a four-nation basis to have a single UK register, I would need confirmation from the Department of Health that it does not feel that opening up another area of difference would create a different kind of difficulty for us. I cannot offer anything more to the mover of those amendments today, other than a commitment to consider this matter further and to see whether the Government could bring forward an amendment at Stage 3. However, I cannot make a decision on that until I have the further advice that I need. Therefore, for today, the Government would wish to resist the amendments in this group in Darren Millar's name.

[115] **Vaughan Gething:** I call Darren Millar to reply to the debate.

[116] **Darren Millar:** I am grateful for the Minister's response that he will go away to look at this in more detail in terms of my amendments to reduce the number of nominated representatives, or restrict the number to a single nominated representative. I am a little surprised that he has not already had some advice on that, given that these amendments were tabled last week. That said, I am grateful for his remarks about considering this further in the future. I think that, when he looks at the discussions that took place in the UK Parliament, he will find that the rationale for having more than one nominated representative was that, under the current system, if a nominated representative cannot be found, the donation transplantation activity cannot go ahead. Therefore, the more nominated representatives there were, the greater the possibility of a donation taking place. Under this system of deemed consent and the amendments that the Minister has tabled, in terms of what happens where a nominated representative cannot be found, it introduces a system that ought to make transplantation activity more likely to go ahead, because family members and those immediately involved in a qualifying relationship would be asked to give their consent or otherwise. I am hopeful that the Minister will be able to support these amendments. I will push them to the vote today. In the absence of any further amendments from the Government at Stage 3, if my amendments fall, I will give a commitment to retable them or something similar at that stage, and once the Minister has taken his advice.

[117] **Vaughan Gething:** The Member has indicated that he wishes to proceed to a vote on amendment 28. I should inform Members that, if amendment 28 is not agreed, consequential amendments 29, 30, 31, 35, 40 and 41 will fall automatically.

[118] The question is that amendment 28 be agreed to. Does any Member object? I see that there is objection. We will therefore move to a vote on amendment 28. We will take a vote by a show of hands.

*Gwelliant 28: O blaid 2, Ymatal 0, Yn erbyn 8
Amendment 28: For 2, Abstain 0, Against 8*

Pleidleisiodd yr Aelodau canlynol o blaid:
The following Members voted for:

Graham, William
Millar, Darren

Pleidleisiodd yr Aelodau canlynol yn erbyn:
The following Members voted against:

Evans, Rebecca
Gething, Vaughan
Jones, Elin
Neagle, Lynne
Price, Gwyn R.
Skates, Kenneth
Whittle, Lindsay
Williams, Kirsty

Gwrthodwyd gwelliant 28.

Amendment 28 not agreed.

*Methodd gwelliant 29.
Amendment 29 fell.*

[119] **Vaughan Gething:** We now move to dispose of amendment 2. I move amendment 2 in the name of the Minister. The question is that amendment 2 be agreed to. Does any Member object? There are no objections. In accordance with Standing Order No. 17.34, I therefore declare amendment 2 agreed.

*Derbyniwyd gwelliant 2.
Amendment 2 agreed.*

*Methodd gwelliant 30.
Amendment 30 fell.*

[120] **Vaughan Gething:** We now move to dispose of amendment 3. I move amendment 3 in the name of the Minister. The question is that amendment 3 be agreed to. Does any Member object? There are no objections. In accordance with Standing Order No. 17.34, I therefore declare amendment 3 agreed.

*Derbyniwyd gwelliant 3.
Amendment 3 agreed.*

*Methodd gwelliant 31.
Amendment 31 fell.*

[121] **Vaughan Gething:** We now move, in line with the marshalled list, to dispose of amendment 4, which was debated as part of group 3 on consent. I move amendment 4 in the name of the Minister. The question is that amendment 4 be agreed to. Does any Member object? I see that there is objection. We will therefore take a vote by show of hands.

10.45 a.m.

*Gwelliant 4: O blaid 8, Ymatal 0, Yn erbyn 2.
Amendment 4: For 8, Abstain 0, Against 2.*

Pleidleisiodd yr Aelodau canlynol o blaid:
The following Members voted for:

Evans, Rebecca
Gething, Vaughan
Jones, Elin
Neagle, Lynne
Price, Gwyn R.
Skates, Kenneth
Whittle, Lindsay
Williams, Kirsty

Pleidleisiodd yr Aelodau canlynol yn erbyn:
The following Members voted against:

Graham, William
Millar, Darren

*Derbyniwyd gwelliant 4.
Amendment 4 agreed.*

[122] **Vaughan Gething:** That also means that amendments 32 and 33 will fall.

*Methodd gwelliant 32.
Amendment 32 fell.*

**Grŵp 5: Cydsyniad Datganedig—Cysylltiad y Rhai sydd mewn Perthynas
Gymhwysol (Gwelliannau 23 a 34)
Group 5: Express Consent—Involvement of Those in a Qualifying Relationship
(Amendments 23 a 34)**

[123] **Vaughan Gething:** The lead amendment in this group is amendment 23 in the name of Elin Jones. I call on Elin to move and speak to her amendment and the other amendment in the group.

[124] **Elin Jones:** I move amendment 23 in my name.

[125] The purpose of this amendment is to ensure that people who opt in to organ donation cannot have their wish to donate overridden by a family member. We have already debated in this committee this morning the complexity of that bedside discussion relating to the known or likely views of the deceased. The ‘known known’ in this system is where an individual has opted in to organ donation in a deemed consent system. That is the clearest demonstration of the view and the will of the individual. They want their organs donated and they have expressed this prior to death, even though they would have known that they lived in a country where consent was deemed. I would hope that the Government will continue to promote organ donation, the register and opting in, even once this Bill comes into force, so that individuals in this country can know and can have the assurance that, should they opt in, that wish will be recognised, by the country and by their family. I would not wish, once this Bill becomes law, that the view of the individual can be overridden by a family member. So, this places on the face of the Bill the supremacy and sovereignty of the individual’s view as expressed clearly by opting in to a system of organ donation in a country where deemed consent has been accepted as the legislative framework.

[126] **Vaughan Gething:** I now call on Darren Millar to speak in this group debate. Then, I will move to Lindsay Whittle and Kirsty Williams.

[127] **Darren Millar:** It may appear at face value that my amendment and the amendment that has been tabled in Elin Jones’s name are identical. However, they are not. They seek to achieve the same, I think, and I am pretty sure that we agree, in principle, where we want to see a provision on the face of the Bill in respect of someone’s active and conscious decision to give their express consent not being overridden. The amendment that has been tabled by Elin Jones, which I am afraid I will have to oppose, only protects a person’s decision to opt in from being overridden. It does not protect a person’s decision where they have made a conscious decision to opt out of the organ donation register. I think that it is really important that we protect the express consent, or non-consent, of an individual. My amendment takes it a little bit further than Elin’s, by respecting the wishes, whether they are to opt in or out of the organ-donation system, rather than simply to protect the wishes of those people who want to opt in.

[128] **Lindsay Whittle:** I do not think that these amendments are a million miles apart. My views have become well known in the process of this Bill: the wishes of the individual and the ability to do what you want with your organs when you die are absolutely sacrosanct. In the case of tragic events, it can probably—I do not say ‘actually’, because I do not know and I have never experienced such a tragic event—ease the grieving process as well, and would, perhaps, give some solace and comfort to the grieving families and friends. I am not so sure that these two amendments are a million miles apart, but, for me, this is vital. I know what I want in the hopefully unlikely event that I have a tragic accident next week. I know that I want my organs, if they are suitable, to be used for donation. I hope that that would be respected fully by my family and my friends. I am sure that the committee will vouch for that.

[129] **Elin Jones:** We will be there at your bedside. [*Laughter.*]

[130] **Lindsay Whittle:** That is a great comfort.

[131] **Kirsty Williams:** I appreciate that one of the most difficult pieces of evidence that we heard is that a number of potential organs are lost every year, despite the fact that the potential donor was carrying a donor card and had opted in, because relatives objected to that donation going ahead. That is a source of regret, and it must be very difficult for clinicians in those circumstances to be faced with that. However, given the debate that Darren has just had about undue distress in one situation, I wonder why the same does not apply to relatives of people who have opted in, because you could have a situation where somebody has opted into the system and, for very understandable reasons, those relatives, in the tragedy of that moment, are extremely distressed, even though they are quite clear about what their relative's views are. They may be very distressed indeed, and we have heard from clinicians who have said, in those circumstances, they have a duty of care not only to the individual who is a potential donor, but to the wider family. I would hate to be in a situation where we would compel clinicians to take organs in the face of a very distressed family, especially—and we have heard a lot of evidence about this as well—given that we have to have high levels of confidence in this system. Potentially, you could undermine confidence in the system if families objected to what had happened, even if somebody had expressly said that they wanted their organs to be given. It is impossible, and guidance should be given to clinicians on this matter in a code of conduct. They already have ethical and professional codes by which they have to abide, and I just think that it would be wrong to put on the face of the Bill a compulsion for clinicians to act in a way that they, in that situation, would feel very uncomfortable with. Also, there is the other side of the argument. Should they decide, in the face of that undue distress, not to proceed, there is the issue of the potential organ recipient who becomes aware of the fact that their chance of a kidney, a lung or a heart has been lost because a clinician, in the face of those relatives, said, 'I'm not going to proceed'. At the heart of this, we also have to think about the clinicians and their standing. Therefore, while I understand that there is huge frustration about losing organs in this way, I do not think that this is an appropriate way in which to proceed.

[132] **Vaughan Gething:** Rebecca is next, then I will allow Darren to come back in very briefly on the point Kirsty raised, and then I will call Ken Skates.

[133] **Rebecca Evans:** I echo everything that Kirsty has said, but to build on the point that she made about putting clinicians in a difficult position, it would actually put them in a legally difficult position, and you could envisage situations where people might try to bring legal cases against clinicians who had failed to take organs from somebody because they felt that it was the wrong thing to do, despite what the law told them. It is so important that the duty of care remains with family members. It is distressing; we have heard so much evidence on this. It outlines why the code of practice is so important, and I know that this committee will take a great interest in seeing that develop as well. My final point is that, if one of these amendments were to be passed and there was a case where organs were taken in the face of strong family upset and opposition, I believe that that would irreparably damage organ transplantation and confidence and faith in the system, which would undermine everything that we are trying to achieve in terms of increasing donation in Wales.

[134] **Vaughan Gething:** I said that I would allow Darren to come back in, briefly.

[135] **Darren Millar:** I want to draw a distinction between protecting the express consent that somebody might have given and deemed consent, which is a distinction that Kirsty Williams, given her remarks, does not recognise. Where somebody has given express consent, I think that we all feel that that ought to be observed where absolutely possible. Deemed consent is quite a different concept. The Minister has drawn the distinction between the two in terms of there being a hierarchy of people to make a decision in the absence of a nominated

representative. The system here must, therefore, recognise that, where an individual has given express consent, that ought to take priority over the consideration of anybody else's views, and, if transplantation activity is appropriate, then it ought to go ahead.

[136] I am very surprised to see people around this table arguing that the express consent or otherwise of an individual prior to their death should not be followed up. It is a pretty extraordinary argument for people to make. Yes, I accept that there might be distress caused to family members as a result of a decision a person might have made before their death. That is normal in life, full stop. No doubt provisions in people's wills can be distressing to family members, but it is more important to fulfil the wishes of the individual than those of others who might take a different view, even if that causes distress to a family member.

[137] **Vaughan Gething:** Thank you, Darren. Kenneth Skates is next and then I will allow Kirsty to come back in.

[138] **Kenneth Skates:** Thank you, Chair. It is not just about the distress to the family. As Rebecca Evans and Kirsty Williams have said, it puts the clinicians in an incredibly difficult, and potentially legally compromised, position. However, death is never simple and, while I recognise that the express will of somebody who is dying should be observed as much as possible, the loss of control that a family has when somebody dies could be compounded by a blanket decision to observe their expressed will, and I think that we need to be a bit more flexible, or offer clinicians more flexibility on this matter.

[139] **Kirsty Williams:** I want to respond to Darren, who said that he is making a distinction between forms of consent. This comes back to Mark Drakeford's point earlier. Presumed consent is not a poor man's consent. Darren makes a distinction, because he does not agree with the concept of presumed consent. In this system, although there is an option to expressly consent, by not opting out, your consent has been given. That is why it is impossible to make the distinction between—*[Interruption.]*

[140] **Vaughan Gething:** Darren, there is no need to try to talk over her.

[141] **Darren Millar:** I am not talking over her.

[142] **Kirsty Williams:** You are trying to make a distinction between distress in different consenting situations, but I do not accept that there are different consenting situations, because, as we have heard repeatedly, presumed consent is consent and it is not a lesser form of consent.

[143] **Vaughan Gething:** I see that no other Members wish to speak, so I call on the Minister.

[144] **Mark Drakeford:** Thank you, Chair. Fundamental to this Bill is that the known views of the donor should prevail. So, I start from exactly the same point as Elin Jones when she moved her amendment. Are we concerned about the number of donations that do not go ahead when the known views of the donor were that they were in favour of donation? Yes, we are. It happens too often.

[145] NHS Blood and Transplant, the organisation responsible for drawing up the five-year strategy, has succeeded in increasing the number of donations quite dramatically across the United Kingdom and is about to publish its new strategy for up to 2020. You can see the draft on its website. When the final discussions on it are concluded, the hope is that it will be signed by health Ministers from all four UK home nations. That strategy specifically identifies reducing the number of occasions when the known views of the potential donor are in favour of donation but donation does not go ahead. It sets out a series of ways in which that

number can be further eroded. I am very keen that we in Wales should be associated with that strategy, and with those actions.

11.00 a.m.

[146] Why, then, are we against these two amendments? I associate myself entirely with the points that Kirsty Williams has already made about the family, which others have made, but there is a further reason why I would wish to resist these amendments. I think that this reason is entirely consistent with the arguments that the mover of the amendment has made. Imagine a situation in which someone has opted in and put their name on the register some years ago, has heard the debate about the organ donation Bill, has changed their mind—we have heard of examples of this in the evidence that the committee heard in Stage 1—and no longer want to be a donor, but have not got around to removing their name from the list, or have not had time to remove their name from the list, because, having had a discussion with their family and having changed their mind, they leave their home and they are involved in some catastrophic accident. If these amendments are agreed, the position would be that, in the room where donation will happen, the family will know that that person does not want donation to go ahead, and clinicians will know that that person does not want donation to go ahead, but far from that person's views, as Elin said, having supremacy or being, as Lindsay said, absolutely sacrosanct, under these amendments, donation would have to go ahead, despite the fact that it is known that that is exactly what that person would not have wanted to happen.

[147] So, I think that the amendment is a straitjacket. I am absolutely sympathetic to what it wants to achieve; I want the known views of the donor to prevail. I am anxious, however, that, in a very small number of cases, but describable cases, the effect of the amendments would be to ensure exactly that that would not be the case. So, I prefer to go down the route of the NHSBT's new strategy in order to achieve what the amendment in Elin's name sets out to achieve.

[148] **Vaughan Gething:** I call on Elin Jones to reply to the debate.

[149] **Elin Jones:** Thank you, Chair. It pains me to say this, but I agree with Darren Millar that his amendment is better than mine, in that the principle that I have sought to achieve in amendment 23 should apply equally to those people expressing an opinion and registering their opting out of organ donation. So, I will withdraw my amendment, but I will support amendment 34. I have heard what those people who are opposing amendments 23 and 34 have said about undue distress being caused at the bedside if amendment 34 were agreed. One concern that I have, in general, if this legislation is enacted, is that there is a very real possibility that the number of people opting in or opting out of the register may decrease. By having a very clear purpose on the face of the Bill for opting in or opting out, that ensures, in my opinion, that Government has a continued responsibility to promote opting in and opting out, even in a deemed consent system, that individuals can see a real value to opting in and opting out, and that their express view will be accepted if organ donation is contemplated following their death.

[150] Therefore, I will withdraw my amendment, but I will support the principle of that amendment included within amendment 34, and the principle included for opting out as well as opting in.

[151] **Vaughan Gething:** The Member has indicated that she wishes to withdraw amendment 23. Does any Member object to the withdrawal? I see that there are no objections. Amendment 23 is therefore withdrawn.

*Tynnwyd gwelliant 23 yn ôl drwy ganiatâd y pwyllgor.
Amendment 23 withdrawn by leave of the committee.*

*Methodd gwelliant 33.
Amendment 33 fell.*

[152] **Vaughan Gething:** Darren, would you move amendment 34?

[153] **Darren Millar:** I move amendment 34 in my name.

[154] **Vaughan Gething:** The Member has already indicated that he wishes amendment 34 to be put to a vote. The question is that amendment 34 be agreed to. Does any Member object? I see that there is an objection, so we will move to a vote.

*Gwelliant 34: O blaid 4, Ymatal 0, Yn erbyn 6.
Amendment 34: For 4, Abstain 0, Against 6.*

Pleidleisiodd yr Aelodau canlynol o blaid:
The following Members voted for:

Graham, William
Jones, Elin
Millar, Darren
Whittle, Lindsay

Pleidleisiodd yr Aelodau canlynol yn erbyn:
The following Members voted against:

Evans, Rebecca
Gething, Vaughan
Neagle, Lynne
Price, Gwyn R.
Skates, Kenneth
Williams, Kirsty

*Gwrthodwyd gwelliant 34.
Amendment 34 not agreed.*

*Methodd gwelliant 35.
Amendment 35 fell.*

**Grŵp 6: Consent: Excepted Adults (Gwelliannau 36, 37, 38 a 39)
Group 6: Cydsynio: Oedolion a Eithrir (Amendments 36, 37, 38 and 39)**

[155] **Vaughan Gething:** The lead amendment in this group is amendment 36 in the name of Darren Millar. I call on Darren Millar to move and speak to that amendment and the other amendments in this group.

[156] **Darren Millar:** I move amendment 36 in my name.

[157] I will deal with amendment 36 first in this group. This amendment simply seeks to extend the residency criteria attached to the deemed consent system so that someone will have had to have been ordinarily resident in Wales not for a period of six months, as is currently the case on the face of the Bill, but rather for a 12-month period. This is to take into account what will undoubtedly be, as we have heard today, an annual programme of campaigning by the Welsh Government or Welsh Ministers to promote organ donation and transplantation. It seeks to address what I feel is the potential that some people may not be fully aware of organ transplantation before their consent might be deemed. I hope that the Minister might be able to support that amendment, as well as other members of the committee.

[158] My other amendments relate to those groups of people who would be resident in Wales—sometimes ordinarily resident perhaps. I would be interested to hear what the Minister has to say on this. These are not necessarily people who are here on a voluntary basis, but who would be in Wales on a different basis to those people who would be ordinarily resident. Amendment 37 seeks to exclude prisoners from the deemed consent system—those people who have been imprisoned in Wales and have not ordinarily been

resident prior to their imprisonment. Amendment 38 makes it clear that those people who are involved in armed forces activities and have not ordinarily been resident in Wales prior to their death would be excluded from the system, along with their extended families, who are very often located in Wales as a result of the posting of their spouse or family member. My amendment 39 seeks to exclude students who are in Wales for the purpose of their education alone, whether they are from other parts of the UK or are international students, given that they may not be familiar with the system of deemed consent.

[159] I have to say that if my amendment 36 is supported by the Government, it would go some way to addressing my concerns around students, because I feel that, over a 12-month period, there may be an opportunity for students who are here for the purposes of their education to be exposed to promotional activity. I encourage Members to support all these amendments, to put these things beyond any doubt.

[160] **Vaughan Gething:** We now have the general debate for all Members. Kirsty Williams is first, then Elin Jones and then Lynne Neagle.

[161] **Kirsty Williams:** There is merit in moving to a 12-month residency period, especially given the Government's ongoing commitment to an annual publicity campaign. It seems to me that people living here for a year would have been caught by that campaign, and there is sense in moving to that.

[162] We had long discussions in the committee about whether someone should qualify only as a result of wanting and actively choosing to be in Wales or whether those people would qualify who happen to find themselves in Wales, potentially against their wishes—I suppose that that is the wrong way to describe it—in terms of being in prison and also in terms of armed forces personnel, because they are required to be here as part of their jobs and they have no opportunity to object to being posted here. As Darren said, their families often come here too and I would hate to be in a situation where, if people felt very strongly about these laws, they felt that they could not come here with their spouse or partner. Therefore, I will be supporting the amendments with regard to prisoners and armed forces personnel.

[163] I think that the situation is different for students. Students can actively choose to be in Wales and, therefore, I think that the arguments there are different. However, I will be supporting moves to a residency period of 12 months and the exception of prisoners and armed services personnel.

[164] **Elin Jones:** I can also see the merit of extending the residency basis to 12 months, and aligning that more closely with an annual programme of promoting the system of organ donation in Wales, although I will wait to hear whether the Minister has any views on why a six-month residency would be preferable to a 12-month residency. So, I will decide after hearing the Minister's view on that.

[165] I agree that amendments 37 and 39 as drafted provide protection for prisoners and armed forces personnel in their residency in Wales in relation to this Bill.

[166] On students, we have discussed this in this committee a number of times, regarding students living in Wales for possibly only a short period. I represent two universities in my constituency, and I have had no representations from student bodies or individual students as to their desire to be exempted from this Bill. So, I do not think that there is a reason to exempt students from this legislation. The point made by Darren Millar in terms of aligning a 12-month residency period with an annual promotional campaign may well ensure that students are given a clear steer within their first 12 months of residency as to whether they would need to opt in or opt out of the system in Wales, and that the system in Wales may differ from the one where they live as permanent residents.

[167] **Lynne Neagle:** I favour a 12-month residency period as well. I think that that will sit nicely with the annual publicity programme. We had lengthy discussions in this committee about what to do with people who move around a lot. I feel a lot more comfortable with a residency period of a year. That has also reassured me in relation to students. I would have been more worried about students had we stuck with the proposed six-month period.

[168] **Rebecca Evans:** I would also like to welcome amendment 36 regarding the 12-month minimum residency. I think that it is eminently sensible, Darren, and I am grateful to you for bringing it forward.

[169] With regard to amendment 38, my understanding is that it would cover all Welsh students in Welsh universities and their families, which could potentially be an unintended consequence of your amendment. Perhaps you could respond to that in your comments.

[170] **Kenneth Skates:** Could I ask what is the legal definition of ‘ordinarily resident’, and whether that would apply to armed forces personnel?

[171] **Vaughan Gething:** You can, but we need to move into private session to give that advice. It should not take very long. We will have a brief break and move into private session.

*Gohiriwyd y cyfarfod rhwng 11.14 a.m. ac 11.28 a.m.
The meeting adjourned between 11.14 a.m. and 11.28 a.m.*

[172] **Vaughan Gething:** Welcome back, Minister, and welcome to your advisers. We will now move to a contribution on this area of debate from William Graham.

[173] **William Graham:** I speak in support of amendment 37, but would welcome your clarification on part of that, if I may. I am concerned about the elements regarding prisoners on remand, who might be on long-term remand and who might have consented to that remand, sometimes for reasons of protection.

[174] **Vaughan Gething:** Do any other Members wish to contribute and make a point before the Minister speaks?

[175] **Kenneth Skates:** I seek clarification on the question of whether adult family members of armed forces personnel are voluntarily resident in Wales.

[176] **Vaughan Gething:** I call the Minister to speak.

[177] **Mark Drakeford:** I will deal with amendment 36 first. The Government is happy to support amendment 36, which extends the period of residence from six to 12 months. It is consistent with the first group of amendments, where we talked about an annual campaign. The reasons for moving to 12 months have been rehearsed already in front of the committee. There is one other reason why I am happy to support it. In taking the Bill through the Assembly, one of my ambitions for it has been to build into it a number of confidence-building measures. We have heard in evidence that there are people who are very keen to increase the level of organ donation, but who have some anxiety about some aspects of the Bill. For example, in bringing forward the family amendment earlier, and in this case as well, knowing that you have to be resident in Wales for 12 months before deemed consent applies helps to build confidence among those people who have had some anxieties about the practical operation of the Bill. So, I am very happy to accept that on behalf of the Government.

11.30 a.m.

[178] In relation to amendments 37 and 39, which talk about prisoners and the armed forces, I am very committed to the principle that anybody who is not voluntarily in Wales should be removed from the ambit of deemed consent. Is that best done in the way that the amendments do it, by picking up some particular groups of people and making specific exemptions in their case, or is it better to rely on the ‘ordinarily resident’ test, which is on the face of the Bill? My position is that there is case law: in a test case, Lord Scarman, in a judgment involving Shah and Barnet London Borough Council, set out exactly what ‘ordinarily resident’ means for the sake of the law. In his judgment, he said that

[179] ‘“ordinarily resident” refers to a man’s abode in a particular place or country which he has adopted voluntarily’.

[180] So, if you are not covered by that principle, then you are not brought within the ambit of deemed consent. My position is that it is better to rely on the principle and to have the principle in the Bill, which can then be tested in the individual sets of circumstances that the committee has been thinking about this morning and has put to me, as those individual circumstances arise. If we go down the road of trying to specify each time, separately, where we think a group is covered by that principle, then the Bill will become very complex. I will give you a different example that is not covered by either amendment. What about someone who is detained, against their wishes, under the Mental Health Act 1983 and is in a facility that is located in Wales? In my view, they are caught by the ‘ordinary residence’ test and their consent could not be deemed, but they would not be covered by either amendment. So, my position in front of the committee today is that, rather than attempting to cover off each of these individual situations by amendment, we should rely on the principle of the ‘ordinary residence’ test that is on the face of the Bill. We should remember that there are two separate tests that will have to be faced. First, you would have to have been in Wales for 12 months, and then you will need to be ordinarily resident here. If you are not here voluntarily, then ‘ordinary residence’ will not apply. On that basis, the Government resists amendments 37 and 39.

[181] We resist amendment 38 in relation to students for a different reason, which is that we think that students are here voluntarily. They have chosen to come to study in Wales. They are entitled to be brought within the deemed consent regime. How will they be protected? Their interests are protected in a number of ways. We are working hard with higher education institutions in Wales, student unions and so on to make sure that students will be specifically covered during the 12-month campaigns that we will now have. Where students are within the deemed consent regime, I remind Members that donation in a deemed consent context cannot go ahead without the family being involved. So, you will remember—given that the committee has debated this a number of times—the position regarding an overseas student who comes to Aberystwyth who is involved in some sort of accident and is a potential donor under deemed consent. If you cannot contact their family, it cannot go ahead. In addition, where the family has been contacted and is now able to say, under the amendments that we have agreed already, that that person would not have wished donation to happen, it will not go ahead. So, students have a double lock on their position under deemed consent. For those reasons, we do not believe that amendment 38 is necessary and we resist that as well.

[182] **Vaughan Gething:** I call on Darren Millar to reply to the debate.

[183] **Darren Millar:** I am grateful for the contributions that everybody has made to this discussion. I have to say that I am not convinced by the Minister’s arguments. This ‘ordinarily resident’ test absolutely would apply, as I understand it, only to those people, as the Minister put it when he quoted whoever the person was who made the ruling, whose abode in a particular place is ‘adopted voluntarily’.

[184] We know that, as the Bill currently stands, all prisoners, regardless of whether they were previously resident in Wales ordinarily, would be excluded from the deemed consent system. I feel that that is inappropriate and that some prisoners, who were previously ordinarily resident, ought to continue to be included within the deemed consent system, should one exist. The Minister, in rejecting my amendment, is slimming the pool of people who could be available to donate their organs by not accepting the amendment. It would be interesting to know whether the Minister had given consideration to that particular point prior to his decision to resist the amendment today.

[185] On amendment 39, which deals with the armed forces, the Minister is quite right: servicemen and servicewomen who are posted to Wales would not be ordinarily resident, but there are people who may join those servicepersons on their journey to Wales on a voluntary basis who are family members. They would be regarded as being part of the deemed consent system as a result, but of course the reality is that they would be here simply because of the posting that their partner or spouse had been allocated. Amendment 39 is necessary to ensure that the wider household of the individual, who is not ordinarily resident, is also considered to be not ordinarily resident for the purposes of the deemed consent system.

[186] In relation to amendment 38, while I accept that the 12-month residency criterion will go some way to addressing my concerns about students being familiar with the deemed consent system if they choose to come here for their education, I think that the ‘double lock’, as the Minister described it, is not completely there, because there are situations where somebody may come to study and bring their family—particularly if they are an adult learner, or an older person going into education—and they may be given some information on enrolling within their higher education institution, or FE institution or whatever, but they may not necessarily share that information with the other members of their household, who may therefore not be exposed to the information that might be necessary in order to meet the information test for people prior to being considered to be part of the deemed consent system. It is also worthy of note that many people, when they come to study, do so for short periods of time and then return to their place of origin. They may come to study in Wales from Newcastle and disappear back to Newcastle at certain points in the year when the promotional activity and campaigns that you might envisage as part of your communications strategy take place, and thus not have the opportunity to be exposed to the necessary information in order to have their consent deemed.

[187] Of course, anybody in these categories could opt in to this system, and quite rightly be included within the transplantation system, but I do not think that you have given proper consideration to those prisoners who are ordinarily resident prior to their imprisonment, or to people in the armed forces who are not ordinarily resident prior to their posting in Wales, or indeed to their extended families. Likewise, in terms of students, their ability to fall without the communications campaign because of their temporary periods away from Wales has not been fully considered, and nor has the fact that they may be accompanied by their families, and the need to communicate with the family members is just as critical. So, I want to move these to the vote.

[188] **Vaughan Gething:** The Member has indicated that he wishes to proceed to a vote on amendment 36. The question is that amendment 36 be agreed to. Does any Member object? I see there is no objection, and so amendment 36 is agreed in accordance with Standing Order No. 17.34.

*Derbyniwyd gwelliant 36.
Amendment 36 agreed.*

[189] **Vaughan Gething:** I call on the Member to move amendment 37.

[190] **Darren Millar:** I move amendment 37 in my name and with the name of Elin Jones in support.

[191] **Vaughan Gething:** The question is that amendment 37 be agreed to. Does any Member object? I see that there is objection. We will therefore move to a vote.

Gwelliant 37: O blaid 5, Ymatal 0, Yn erbyn 5.

Amendment 37: For 5, Abstain 0, Against 5.

Pleidleisiodd yr Aelodau canlynol o blaid:
The following Members voted for:

Graham, William
Jones, Elin
Millar, Darren
Whittle, Lindsay
Williams, Kirsty

Pleidleisiodd yr Aelodau canlynol yn erbyn:
The following Members voted against:

Evans, Rebecca
Gething, Vaughan
Neagle, Lynne
Price, Gwyn R.
Skates, Kenneth

Gan fod nifer y pleidleisiau yn gyfartal, defnyddiodd y Cadeirydd ei bleidlais fwrw yn unol â Rheolau Sefydlog Rhif 6.20(ii).

As there was an equality of votes, the Chair used his casting vote in accordance with Standing Orders No. 6.20(ii).

*Gwrthodwyd gwelliant 37.
Amendment 37 not agreed.*

[192] **Vaughan Gething:** I invite Darren to move amendment 38.

[193] **Darren Millar:** I move amendment 38 in my name and with the name of Elin Jones in support.

[194] **Vaughan Gething:** The question is that amendment 38 be agreed to. Does any Member object? I see that there is objection. Therefore, we will move to a vote.

Gwelliant 38: O blaid 3, Ymatal 0, Yn erbyn 7.

Amendment 38: For 3, Abstain 0, Against 7.

Pleidleisiodd yr Aelodau canlynol o blaid:
The following Members voted for:

Graham, William
Millar, Darren
Whittle, Lindsay

Pleidleisiodd yr Aelodau canlynol yn erbyn:
The following Members voted against:

Evans, Rebecca
Gething, Vaughan
Jones, Elin
Neagle, Lynne
Price, Gwyn R.
Skates, Kenneth
Williams, Kirsty

*Gwrthodwyd gwelliant 38.
Amendment 38 not agreed.*

[195] **Vaughan Gething:** I invite Darren to move amendment 39.

[196] **Darren Millar:** I move amendment 39 in my name and with the name of Elin Jones in support.

[197] **Vaughan Gething:** The question is that amendment 39 be agreed to. Does any Member object? I see that there is objection. We therefore move to a vote.

*Gwelliant 39: O blaid 4, Ymatal 1, Yn erbyn 5.
Amendment 39: For 4, Abstain 1, Against 5.*

Pleidleisiodd yr Aelodau canlynol o blaid:
The following Members voted for:

Graham, William
Jones, Elin
Millar, Darren
Williams, Kirsty

Pleidleisiodd yr Aelodau canlynol yn erbyn:
The following Members voted against:

Evans, Rebecca
Gething, Vaughan
Neagle, Lynne
Price, Gwyn R.
Skates, Kenneth

Ymataliodd yr Aelodau canlynol:
The following Members abstained:

Whittle, Lindsay

*Gwrthodwyd gwelliant 39.
Amendment 39 not agreed.*

[198] **Vaughan Gething:** In line with the marshalled list, we now move to dispose of amendments 5 through to 11. These amendments were debated as part of group 4.

[199] I move amendment 5 in the name of the Minister. The question is that amendment 5 be agreed to. Does any Member object? I see there is no objection, therefore amendment 5 is agreed in accordance with Standing Order No. 17.34.

*Derbyniwyd gwelliant 5.
Amendment 5 agreed.*

[200] **Vaughan Gething:** I move amendment 6 in the name of the Minister. The question is that amendment 6 be agreed to. Does any Member object? I see that no Member objects, therefore amendment 6 is agreed in accordance with Standing Order No. 17.34.

*Derbyniwyd gwelliant 6.
Amendment 6 agreed.*

[201] **Vaughan Gething:** I move amendment 7 in the name of the Minister. The question is that amendment 7 be agreed to. Does any Member object? I see that no Member objects, therefore amendment 7 is agreed in accordance with Standing Order No. 17.34.

*Derbyniwyd gwelliant 7.
Amendment 7 agreed.*

[202] **Vaughan Gething:** I move amendment 8 in the name of the Minister. The question is that amendment 8 be agreed to. Does any Member object? I see that no Member objects, therefore amendment 8 is agreed in accordance with Standing Order No. 17.34.

*Derbyniwyd gwelliant 8.
Amendment 8 agreed.*

[203] **Vaughan Gething:** I move amendment 9 in the name of the Minister. The question is that amendment 9 be agreed to. Does any Member object? I see that no Member objects, therefore amendment 9 is agreed in accordance with Standing Order No. 17.34.

*Derbyniwyd gwelliant 9.
Amendment 9 agreed.*

[204] **Vaughan Gething:** I move amendment 10 in the name of the Minister. The question is that amendment 10 be agreed to. Does any Member object? I see that no Member objects, and therefore amendment 10 is agreed in accordance with Standing Order No. 17.34.

*Derbyniwyd gwelliant 10.
Amendment 10 agreed.*

*Methodd gwelliannau 40 a 41.
Amendments 40 and 41 fell.*

[205] **Vaughan Gething:** I move amendment 11 in the name of the Minister. The question is that amendment 11 be agreed to. Does any Member object? I see that no Member objects, therefore amendment 11 is agreed in accordance with Standing Order No. 17.34.

*Derbyniwyd gwelliant 11.
Amendment 11 agreed.*

**Grŵp 7: Rhoi Organau sy'n Ymwneud ag Oedolion Byw nad yw'r Galluedd
Ganddynt i Gydsynio (Gwelliant 12)
Group 7: Living Donation Involving Adults who Lack Capacity to Consent
(Amendment 12)**

[206] **Vaughan Gething:** This group contains one amendment, amendment 12, which is in the name of the Minister. I move amendment 12 in the Minister's name and invite the Minister to speak to his amendment.

[207] **Mark Drakeford:** Amendment 12 amends section 8 of the Bill and gives effect to a commitment made by my predecessor to the Constitutional and Legislative Affairs Committee. This section of the Bill deals with specific cases involving living adults who lack capacity to consent to donation. In the original Bill, there was the possibility that donations in such circumstances could be carried out other than on the basis of that donation being made in the best interests of the person who lacks capacity. The amendment makes it clear that the only ground upon which donation could go ahead in such circumstances is on that best-interests test. The Constitutional and Legislative Affairs Committee believed that it was proper for the Government to set out in greater detail than was possible by simply having the best-interests test on the face of the Bill the circumstances in which such a donation could proceed. For that reason, amendment 12 means that the circumstances in which a living donation by someone who lacks capacity only on the grounds that it would be in their best interest will be set out in regulations. Those regulations, if the amendments in group 7 and group 8 are agreed to today, will be made through the superaffirmative procedure.

11.45 a.m.

[208] As far as I am aware, there is only one set of circumstances in which it is plausible to argue that donation could be made by someone lacking capacity on the basis that it is in their interest, and the example most often given is when someone is being cared for by somebody else, and their care and their future depend upon that person. If the carer falls ill and requires a kidney, which could be given by the person who is being looked after, it could be argued that it is in that person's best interest to make a donation in order to allow their care to continue. May I be clear that, if that case were to be made, it would not be being made in the circumstances that we have discussed with regard to other parts of the Bill, under the pressure of a sudden emergency need to make a decision? Such a decision would have to go directly to

the Human Tissue Authority. It would have to be heard by a panel of the Human Tissue Authority, and that panel would decide whether the case made that it was in the best interest of the person without capacity could be upheld.

[209] So, this is a rare set of circumstances. If this amendment is carried, the way in which it will happen in practice will be set out in regulations, which will be consulted upon and of which the Assembly will have the final approval through an affirmative vote. It is on that basis that the Government brings it forward in order to give effect to the recommendations of the CLA committee.

[210] **Vaughan Gething:** Does any Member want to take part in this debate? I see that no Member does. Minister, I take it that you do not wish to respond to your own debate and I assume that you wish to proceed to a vote on amendment 12.

[211] **Mark Drakeford:** Yes, please.

[212] **Vaughan Gething:** The question is that amendment 12 be agreed to. Does any Member object? I see that no Member objects, therefore, amendment 12 is agreed in accordance with Standing Order No. 17.34.

*Derbyniwyd gwelliant 12.
Amendment 12 agreed.*

[213] In line with the marshalled list, we will now dispose of amendments 13, 14, 15 and 16 in the name of the Minister. These were debated as part of groups 3 and 4. I move amendment 13 in the name of the Minister. The question is that amendment 13 be agreed to. Does any Member object? I see that no Member objects, therefore amendment 13 is agreed in accordance with Standing Order No. 17.34.

*Derbyniwyd gwelliant 13.
Amendment 13 agreed.*

[214] I move amendment 14 in the name of the Minister. The question is that amendment 14 be agreed to. Does any Member object? I see that no Member objects, therefore amendment 14 is agreed in accordance with Standing Order No. 17.34.

*Derbyniwyd gwelliant 14.
Amendment 14 agreed.*

[215] I move amendment 15 in the name of the Minister. The question is that amendment 15 be agreed to. Does any Member object? I see that no Member objects, therefore, amendment 15 is agreed in accordance with Standing Order No. 17.34.

*Derbyniwyd gwelliant 15.
Amendment 15 agreed.*

[216] I move amendment 16 in the name of the Minister. The question is that amendment 16 be agreed to. Does any Member object? I see that no Member objects, therefore amendment 16 is agreed in accordance with Standing Order No. 17.34.

*Derbyniwyd gwelliant 16.
Amendment 16 agreed.*

Grŵp 8: Y Weithdrefn Is-ddeddfwriaeth (Gwelliannau 17, 18, 20 ac 21)
Group 8: Subordinate Legislation Procedure (Amendments 17, 18, 20 and 21)

[217] **Vaughan Gething:** The lead amendment in this group is amendment 17 in the name of the Minister. I move amendment 17 in the name of the Minister and call on him to speak to this amendment and the other amendments in this group.

[218] **Mark Drakeford:** All the amendments in group 8 give effect to undertakings that I gave at the Stage 1 debate on the floor of the Assembly, and they all arise from recommendations made by the Constitutional and Legislative Affairs Committee. In that committee's report, it stated that it believed that an additional set of safeguards was needed in the Bill so that, where regulation-making powers fell to Ministers, they would be carried out in a way that provided additional levels of oversight and scrutiny by the National Assembly. Each of the amendments in this group does exactly that; they raise up by a level the degree to which the National Assembly will scrutinise these regulation-making powers.

[219] So, amendment 17 ensures that Welsh Ministers are required to conduct public consultation on any Order to be made to alter the ranking of qualifying relatives set out in section 27(4) of the 2004 Act, in other words, to bring that procedure within the superaffirmative ambit of the Assembly.

[220] Amendment 18 reverses the position in relation to the code. The code is subject to the negative procedure under the 2004 Act in Parliament. In Wales, if this amendment is agreed, then any code of practice produced by the Human Tissue Authority will now be subject to the affirmative procedure on the floor of the National Assembly. Amendment 20 introduces the superaffirmative procedure in four different circumstances: organs to be excluded from deemed consent, going back to the debate we had earlier about novel and composite forms of donation; people who may not act as an appointed representative; circumstances in which the consent of a living person who lacks capacity may be deemed—the amendment in the previous group; and identifying those who can be on the list of qualifying relations. All of those are covered by amendment 20. Amendment 21 is consequential to amendment 20.

[221] **Vaughan Gething:** Thank you, Minister. Do any other Members wish to speak in this debate? I see that they do not and I see that the Minister does not wish to respond to his own debate. I assume, Minister, that you wish to proceed to a vote on amendment 17.

[222] **Mark Drakeford:** Yes.

[223] **Vaughan Gething:** The question is that amendment 17 be agreed to. Does any Member object? I see that there are no objections. Therefore, amendment 17 is agreed in accordance with Standing Order No. 17.34.

*Derbyniwyd gwelliant 17.
Amendment 17 agreed.*

[224] I move amendment 18 in the name of the Minister. The question is that amendment 18 be agreed to. Does any Member object? I see that there are no objections. Therefore, amendment 18 is agreed in accordance with Standing Order No. 17.34.

*Derbyniwyd gwelliant 18.
Amendment 18 agreed.*

Grwp 9: Technegol (Gwelliant 19)
Group 9: Technical (Amendment 19)

[225] **Vaughan Gething:** We now arrive at group 9, which is a technical amendment. There is one amendment in this group, which is amendment 19, tabled in the name of the Minister. I therefore move amendment 19 and call on the Minister to speak to this amendment.

[226] **Mark Drakeford:** Thank you, Chair. This amendment is a correction to a typographical error that appeared in the Bill on its introduction. It referred incorrectly to subsection (6) of section 36 of the Human Tissue Act 2004. It should have read subsection (5), and this amendment corrects that error.

[227] **Vaughan Gething:** Thank you for being so clear, Minister. Does any Member wish to speak in this debate? I see that no Member does. I assume that you do not wish to respond, Minister, and that you wish to proceed to a vote on amendment 19.

[228] **Mark Drakeford:** Yes.

[229] **Vaughan Gething:** The question is that amendment 19 be agreed to. Does any Member object? I see that there are no objections. Therefore, amendment 19 is agreed in accordance with Standing Order No. 17.34.

Derbyniwyd gwelliant 19.
Amendment 19 agreed.

Grŵp 10: Y Gwasanaethau neu'r Cyfleusterau sy'n Ymwneud â Chael Cydsyniad
(Amendment 24)
Group 10: Services or Facilities in Connection with Obtaining Consent (Gwelliant 24)

[230] **Vaughan Gething:** There is one amendment in this group, which is amendment 24, tabled in the name of Elin Jones. I invite Elin Jones to move the amendment and to speak to it.

[231] **Elin Jones:** Thank you, Chair. I move amendment 24 in my name.

[232] The purpose of this amendment is to ensure that the Minister and local health boards have a duty to create specialist nurse posts for the purpose of promoting organ donation. As a committee, we have heard and been persuaded of the real value and merit of the work of specialist nurses in promoting organ donation. We have discussed how any increase in the number and coverage of specialist nurses in this field, working in hospitals, could increase the number of organs available for transplantation. We could be in a position where, in the future, local health boards could take decisions to not have specialist nurses in this field, or could reduce the numbers currently working as specialist nurses on organ donation. So, this amendment would create a duty to create specialist nurse posts for the promotion of obtaining consent under the Human Transplantation (Wales) Bill, when passed. There would then be a duty on future health boards to have such posts in place.

[233] **Vaughan Gething:** Thank you, Elin. Do any other Members wish to take part in this debate?

[234] **Darren Millar:** I want to speak in support of this particular amendment. We heard very powerful arguments for the provision of additional facilities and resources, along with the need to ensure that they were adequately made available within the NHS to promote

transplantation activity, and it was not just the specialist nurses for organ donation, although they were a very critical part of the process. I seem to recall that when Phil Walton came in to speak to us, he made it clear that the success rate when an organ donation nurse approached a family to request consent was around 75%, compared with around 50% for other clinicians. So, clearly they are an important part of the landscape in terms of organ donation in Wales. We should do everything that we can to ensure that those people are in place.

[235] However, looking more generally at the facilities and other services available within the NHS to support organ donation, we heard that Wales's critical care capacity was among the lowest in Europe. I will again refer to Spain, where they have a significantly higher donation rate, but they also have a significantly higher number of intensive care beds per million of the population than we do here in Wales. There is a clear lesson for us about our critical care capacity, especially given that we were told that there have been times when people have been suitable to be candidates for organ donation, but because of a lack of critical care beds, unfortunately, an opportunity to proceed with the transplantation activity has been prevented. So, I very much support this amendment, and I hope that other Members will support it too.

[236] **Kirsty Williams:** It is clear that unless we get the infrastructure surrounding this legislation right, this Bill will be for naught. The new legislation will put an increasing importance on the role of specialist nurses in taking families through decisions about their loved ones at such a difficult time. As has been repeated, the differentiation in success when a specialist nurse has a conversation with the family, as opposed to other medical professionals, was plain to see. I support the principle of trying to increase the number of specialist nurses that are available. It was also clear that, on occasions, there were not enough specialist nurses to go around the system, and that was causing problems. Therefore, I support the principle of what the amendment is trying to achieve.

[237] It begs the question of whether we should move to legislate for staffing levels across the whole range of healthcare services. The same argument could be applied to lots of other specialisms. That is an interesting debate to be had at a later stage. I am not aware, from my reading of this, that there is anything technically wrong with this amendment. As I said, I will wait to hear what the Minister says about the technical drafting of it, but I very much support the principle of what Elin Jones is seeking to achieve with the amendment.

[238] **Vaughan Gething:** Are there any other Members who wish to contribute? I see that there are not. Therefore, I call the Minister to speak.

[239] **Mark Drakeford:** First, I will deal with the issue of critical care capacity that Darren Millar raised, which Kirsty echoed, and which is important to the Bill. I gave an undertaking, which I will repeat today, that the Government will publish a critical care plan that will explicitly address the interplay between critical care capacity, transplantation and the Bill. We hope to be able to do that very shortly. On Monday this week, I met a group of clinicians drawn from across Wales—intensivists who are directly involved in this field and who are working on that plan. I feel confident as a result of my discussions with them that the plan will provide a way forward that they will be prepared to sign up to and to support and which the Government will be committed to as well. I asked them whether they would be prepared, when the report is published, to meet Members in order to brief them on the content of the plan and to explain how they see it working over the coming years and how they see its relationship with this Bill. They agreed that they would do that. Members will then be able to decide for themselves whether they are satisfied with the explanations that the clinicians will have provided. However, I recognise Darren's point that there is clear interplay between the two things.

12.00 p.m.

[240] I want to address the issues that Elin raised in relation to specialist nurses. I entirely agree with what she said about the pivotal importance of specialist nurses in raising the level of organ donation and the role that they will be asked to play in the future. The Government resists the amendment, however, for two reasons. The first is a general objection. The existing section 3 of the National Health Service (Wales) Act 2006, which this amendment seeks to amend, is a very general section indeed. For example, it places duties on Welsh Ministers under section 3(1)(a) to secure hospital accommodation. That is the whole of the paragraph. Under paragraph (c) of that section, they have a duty to secure:

[241] ‘medical, dental, ophthalmic, nursing and ambulance services’,

[242] and under paragraph (f), to secure:

[243] ‘such other services or facilities as are required for the diagnosis and treatment of illness’.

[244] In other words, the section really is pitched at that high level of generality, under which all services are subsumed. As Kirsty Williams said, this amendment leads us down a very different sort of legislative path. Instead of placing general duties on Ministers to secure services, you have very specific requirements, and I do not think that it is consistent with the way in which the 2006 Act was drafted or is intended to operate.

[245] I have a second and much more specific objection to the amendment as drafted. Wales has 15 specialist nurses in this field and Scotland has 17. I do not think that there is any case to make that Wales is somehow deficient in the numbers that we have. It is very important to be aware that these nurses are not employed by LHBs. So, Elin’s anxiety, which I would share, is that, in the future when money is increasingly short, LHBs might look to use this part of their budgets to make savings. However, specialist nurses are employed by NHSBT, which is a body over which Ministers have the power of direction. So, in a way, the amendment sets out to solve a problem that does not exist in the way that the amendment thinks that it does.

[246] How could we make sure that we secure the sort of services from specialist nurses that we need in the future? I think that there are interesting lessons to learn from elsewhere. I remember very well the point that Phil Walton made when he gave evidence about being on duty by himself one weekend—as you would expect—and he found himself in Carmarthen attending to a potential donation when another potential donation came up in Bridgend. He could not be in both places at once, so one of the donations was likely to be lost. There are other ways in which it is possible to make provision against such circumstances—for example by training up other members of staff who are likely to be on duty at a hospital; it would not be something that they do all of the time, but they would share in the skillset of specialist nurses and would be able to be brought in as a reserve to make sure that we do not lose donations when they are potentially available.

[247] So, I have a lot of sympathy with what, I think, lies behind the amendment. I heard very little in what Elin said with which I would disagree in terms of what she wants to achieve. I do not think that the amendment is necessary, or that it quite does what is necessary, and we will resist it for those reasons.

[248] **Vaughan Gething:** I call on Elin Jones to reply to the debate.

[249] **Elin Jones:** Thank you for the responses to the amendment. I am pleased that the Minister has reiterated his intention to produce a critical care plan, which is important to achieve an increase in organ donation. I have heard what the Minister has said on the general

and specific part of my amendment, and I am pleased that he accepts the value of specialist nurses. I was advised that securing a duty to create specialist nurses posts was best achieved by amending the National Health Service (Wales) Act 2006. If this amendment is not successful today, I will consider what the Minister has said on that for the next stage. I still believe that it is important that there is an opportunity for this legislation to ensure that there is a duty for specialist nurse posts to be enshrined in this legislation. I will pursue this amendment for today, but I will reflect on the comments made by the Minister if this amendment is not successful. I may well bring it back in another form at a later stage.

[250] **Vaughan Gething:** Thank you, Elin. The Member has indicated that she wishes to proceed to a vote on amendment 24. Therefore, the question is that amendment 24 be agreed to. Does any Member object? I see that there is objection, so we will move to a vote by a show of hands.

*Gwelliant 24: O blaid 5, Ymatal 0, Yn erbyn 5.
Amendment 24: For 5, Abstain 0, Against 5.*

Pleidleisiodd yr Aelodau canlynol o blaid:
The following Members voted for:

Graham, William
Jones, Elin
Millar, Darren
Whittle, Lindsay
Williams, Kirsty

Pleidleisiodd yr Aelodau canlynol yn erbyn:
The following Members voted against:

Evans, Rebecca
Gething, Vaughan
Neagle, Lynne
Price, Gwyn R.
Skates, Kenneth

Gan fod nifer y pleidleisiau yn gyfartal, defnyddiodd y Cadeirydd ei bleidlais fwrw yn unol â Rheol Sefydlog Rhif 6.20(ii).

As there was an equality of votes, the Chair used his casting vote in accordance with Standing Order No. 6.20(ii).

*Gwrthodwyd gwelliant 24.
Amendment 24 not agreed.*

[251] **Vaughan Gething:** Finally, we will dispose of amendments 42, 20 and 21, which were debated as part of groups 4 and 8. I invite Darren Millar to move amendment 42.

[252] **Darren Millar:** I move amendment 42 in my name.

[253] **Vaughan Gething:** The question is that amendment 42 be agreed to. Does any Member object? I see that there is objection, so we will move to a vote by a show of hands.

*Gwelliant 42: O blaid 2, Ymatal 0, Yn erbyn 7
Amendment 42: For 2, Abstain 0, Against 7*

Pleidleisiodd yr Aelodau canlynol o blaid:
The following Members voted for:

Graham, William
Millar, Darren

Pleidleisiodd yr Aelodau canlynol yn erbyn:
The following Members voted against:

Evans, Rebecca
Gething, Vaughan
Neagle, Lynne
Price, Gwyn R.
Skates, Kenneth
Whittle, Lindsay
Williams, Kirsty

*Gwrthodwyd gwelliant 42.
Amendment 42 not agreed.*

[254] **Vaughan Gething:** We therefore move to amendment 20. I move amendment 20 in the Minister's name. The question is that amendment 20 be agreed to. I see that there is no objection, therefore amendment 20 is agreed in accordance with Standing Order No. 17.34.

*Derbyniwyd gwelliant 20.
Amendment 20 agreed.*

[255] **Vaughan Gething:** Finally, we move to amendment 21. I move amendment 21 in the Minister's name. The question is that amendment 21 be agreed to. Does any Member object? I see that no Member disagrees, therefore amendment 21 is agreed in accordance with Standing Order No. 17.34.

*Derbyniwyd gwelliant 21.
Amendment 21 agreed.*

[256] **Vaughan Gething:** That concludes the votes on all the amendments that we had before us. All sections of the Bill have been deemed agreed by the committee today. Under Standing Order No. 26.27, I propose that the Minister prepares a revised explanatory memorandum, given that the Bill has been substantially amended as a result of today's proceedings. Are Members in agreement? I see that Members are.

[257] As Stage 2 has been completed today, Stage 3 begins tomorrow. Members will be able to table amendments to the Bill with the Legislation Office for consideration at Stage 3 from tomorrow. Thank you. I should say, Minister, that you are released and that you are free to go with your advisers. Thank you for your attendance today.

12.09 p.m.

**Cynnig o dan Reol Sefydlog Rhif 17.42 i Benderfynu Gwahardd y Cyhoedd
Motion under Standing Order No. 17.42 to Resolve to Exclude the Public**

[258] **Vaughan Gething:** I move that

the committee resolves to exclude the public for items 1 and 2 from the meeting of 6 June 2013 in accordance with Standing Order No. 17.42(vi).

[259] I see that Members are content.

*Derbyniwyd y cynnig.
Motion agreed.*

[260] **Vaughan Gething:** Finally, I thank all of you for attending and for contributing today. It was a particularly important and well-worked Stage 2. We next formally meet on 6 June, when we will undertake further consideration of the Social Services and Well-being (Wales) Bill. I formally close the meeting, but if Members wish to stay behind, there will be an informal meeting to look at a couple of small items. Thank you all very much.

*Daeth y cyfarfod i ben am 12.09 p.m.
The meeting ended at 12.09 p.m.*