Cynulliad Cenedlaethol Cymru
The National Assembly for Wales

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

Dydd Iau, 24 Ionawr 2013
Thursday, 24 January 2013

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

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

Aelodau'r pwyllgor yn bresennol
Committee members in attendance

Mick Antoniw	Llafur (am ran o'r cyfarfod) Labour (for part of the meeting)
Mark Drakeford	Llafur (Cadeirydd y Pwyllgor) Labour (Committee Chair)
Rebecca Evans	Llafur Labour
Vaughan Gething	Llafur (am ran o'r cyfarfod) Labour (for part of the meeting)
William Graham	Ceidwadwyr Cymreig Welsh Conservatives
Elin Jones	Plaid Cymru The Party of Wales
Lynne Neagle	Llafur Labour
Gwyn R. Price	Llafur (yn dirprwyo ar ran Mick Antoniw am ran o'r cyfarfod) Labour (substitute for Mick Antoniw the part of the meeting)
Jenny Rathbone	Llafur (yn dirprwyo ar ran Vaughan Gething am ran o'r cyfarfod) Labour (substitute for Vaughan Gething for part of the meeting)
Lindsay Whittle	Plaid Cymru The Party of Wales

Eraill yn bresennol
Others in attendance

Mick Antoniw	Aelod Cynulliad, Llafur, yr Aelod sy'n Gyfrifol am y Bil Adennill Costau Meddygol ar gyfer Clefydau Asbestos (Cymru) Assembly Member, Labour, Member in Charge of the Recovery of Medical Costs for Asbestos Diseases (Wales) Bill
Fiona Davies	Gwasanaethau Cyfreithiol, Llywodraeth Cymru Legal Services, Welsh Government
Paul Davies	Aelod Cyswllt o Athrofa Iechyd a Gofal Cymdeithasol Cymru Associate of Welsh Institute for Health and Social Care
Grant Duncan	Dirprwy Gyfarwyddwr y Gyfarwyddiaeth Meddygol, Llywodraeth Cymru Deputy Director, Medical Directorate, Welsh Government
Vaughan Gething	Aelod Cynulliad, Llafur Assembly Member, Labour
Lesley Griffiths	Aelod Cynulliad, Llafur (y Gweinidog Iechyd a Gwasanaethau Cymdeithasol)

	Assembly Member, Labour (the Minister for Health and Social Services)
Dr Rachel Iredale	Cyfarwyddwr y Tîm Cefnogaeth Canser, Tenovus Director, Cancer Support Team, Tenovus
Joanest Jackson	Uwch-gynghorydd Cyfreithiol, Comisiwn y Cynulliad Senior Legal Adviser, Assembly Commission
Sally Johnson	Cyfarwyddwr, Rhoi Organau a Thrawsblannu, Gwaed a Thrawsblaniadau’r GIG Director, Organ Donation and Transplantation, NHS Blood and Transplant
Glyn Jones	Cyfarwyddwr Cynorthwyol Cyllid (Gweithrediadau), Bwrdd Iechyd Lleol Aneurin Bevan Assistant Director of Finance (Operations), Aneurin Bevan Local Health Board
Mark Osland	Dirprwy Gyfarwyddwr Cyllid, Iechyd a Gwasnaethau Cymdeithasol, Llywodraeth Cymru Deputy Director of Finance, Health and Social Services, Welsh Government
Yr Athro/Professor Ceri Phillips	Economegydd Iechyd, Canolfan Economeg Iechyd Abertawe, Coleg y Gwyddorau Dynol a Iechyd, Prifysgol Abertawe Health Economist, Swansea Centre for Health Economics, College of Human and Health Sciences, Swansea University
Roy Thomas	Cadeirydd Gweithredol, Sefydliad Aren Cymru Executive Chairman, Kidney Wales Foundation
Pat Vernon	Pennaeth Polisi ar Ddeddfwriaeth Rhoi Organau a Meinweoedd, Llywodraeth Cymru Head of Policy for Organ and Tissue Donation Legislation, Welsh Government
Sarah Wakeling	Gwasanaethau Cyfreithiol, Llywodraeth Cymru Legal Services, Welsh Government
Julia Yandle	Rheolwr Gwasanaethau Cyngor, Tenovus Advice Services Manager, Tenovus

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

Sarah Beasley	Clerc Clerk
Steve George	Clerc Clerk
Gwyn Griffiths	Uwch-gynghorydd Cyfreithiol Senior Legal Adviser
Joanest Jackson	Uwch-gynghorydd Cyfreithiol Senior Legal Adviser
Olga Lewis	Dirprwy Glerc Deputy Clerk
Victoria Paris	Y Gwasanaeth Ymchwil Research Service
Sarah Sargent	Dirprwy Glerc Deputy Clerk
Robin Wilkinson	Y Gwasanaeth Ymchwil Research Service

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

Cyflwyniad, Ymddiheuriadau a Dirprwyon
Introductions, Apologies and Substitutions

[1] **Mark Drakeford:** Bore da a chroeso i chi i gyd unwaith eto i’r Pwyllgor Iechyd a Gofal Cymdeithasol. Croeso eto i Gwyn Price a Jenny Rathbone, sydd yma ar gyfer ein hymchwiliad yng Nghyfnod 1 o’r Bil. Diolch i’r ddau ohonoch am ddod.

Mark Drakeford: Good morning and welcome once more to the Health and Social Care Committee. Welcome back to Gwyn Price and Jenny Rathbone, both of whom are here for our Stage 1 inquiry of the Bill. I thank you both for coming.

[2] Rydym wedi derbyn ymddiheuriadau heddiw oddi wrth Darren Millar. Nid yw Darren yn gallu bod gyda ni drwy’r dydd. Mae William Graham yn rhedeg ychydig yn hwyr, ond mae ef ar ei ffordd i mewn. [*Torri ar draws.*] Diolch i Lindsay Whittle am ddod—annwyd a phopeth. Dyma ni; awn ymlaen ag eitem 2.

We have had apologies today from Darren Millar. Darren is unable to be with us throughout the day. William Graham is running a little late, but is on his way in. [*Interruption.*] Thanks to Lindsay Whittle for coming in—cold and all. Right, let us move on to item 2.

Bil Adennill Costau Meddygol ar gyfer Clefydau Asbestos (Cymru): Cyfnod 1—Sesiwn Dystiolaeth 8
Recovery of Medical Costs for Asbestos Diseases (Wales) Bill: Stage 1—Evidence Session 8

[3] **Mark Drakeford:** Mae’r pwyllgor yn dal i wneud ei waith ar Gyfnod 1 o’r Bil. Am yr awr nesaf, bydd y Gweinidog Iechyd a Gwasanaethau Cymdeithasol, Lesley Griffiths, gyda ni. Croeso unwaith eto i’r pwyllgor, Weinidog. Gyda Lesley heddiw y mae’r swyddogion Mark Osland, y dirprwy gyfarwyddwr cyllid yn yr adran iechyd a gwasanaethau cymdeithasol, a Fiona Davies o’r Gwasanaeth Cyfreithiol.

Mark Drakeford: The committee is continuing with its work on Stage 1 of the Bill. For the next hour, the Minister for Health and Social Services, Lesley Griffiths, will be with us. Welcome once again to the committee, Minister. With Lesley today are her officials, Mark Osland, deputy director of finance in the health and social services department, and Fiona Davies from Legal Services.

[4] Fel arfer, Weinidog, gofynnaf i chi a oes gennych sylwadau agoriadol byr, ac wedi hynny, byddaf yn troi at aelodau’r pwyllgor am gwestiynau.

As is customary, Minister, I ask you whether you have any brief opening remarks, and then, I shall turn to committee members for questions.

[5] **The Minister for Health and Social Services (Lesley Griffiths):** Thank you very much, Chair. I would just like to say that I am very grateful to the committee for the opportunity to discuss the Recovery of Medical Costs for Asbestos Diseases (Wales) Bill. When Mick Antoniw made his legislative statement in Plenary on 5 December, I expressed my support for the Bill’s policy intentions, and the Government’s position in respect of the Bill remains one of support.

[6] I should probably stress at this point that as it is a Member-proposed Bill, I have not as yet had detailed discussions, as to do so would not be correct.

[7] As Members are aware, the Bill would allow for Welsh Ministers to recoup some of the costs incurred from the NHS treatment provided to victims of asbestos-related diseases. It would place a duty on Welsh Ministers to ensure that, in the allocation of the funds recovered, they must have regard to the care and treatment of all services for asbestos-related disease

victims and their families. I wholeheartedly support this proposal. The awful effects of asbestos-related diseases are seen all too commonly, and I know that the committee has heard some very powerful evidence from some of those who have been affected. I believe that the Bill proposes a relatively simple, but effective, regime that offers the prospect of providing a real improvement in the services for sufferers and will make a very positive difference to the people of Wales.

[8] **Gwyn R. Price:** Good morning, Minister. You say that the money that you recover will go towards the sufferers et cetera. How specifically would you carry out this duty to make sure that the families and sufferers get the money directly?

[9] **Lesley Griffiths:** Again, we have not had those detailed discussions and it would not have been appropriate to have given any Government resources to such discussions. We would have to have detailed discussions with suffers and their families as to where that money would be put.

[10] **Rebecca Evans:** Following on from Gwyn’s question, would you be minded to report to the Assembly as to how that money had been spent?

[11] **Lesley Griffiths:** Absolutely. The one thing we have to be is very transparent and open, as we are right across Government, not just in health. So, yes, I would be very happy to do that if the committee felt that it was appropriate as part of your report on general principles. I would obviously have to put in an amendment to the Bill in order for that to be done.

[12] **Rebecca Evans:** You are in favour of the general principles of the Bill; what is it about asbestos-related diseases that make them particularly suitable for this kind of legislation?

[13] **Lesley Griffiths:** We have known about the dangers of asbestos for many years and we know that the cause of exposure can be identified with sufficient certainty, which can then give rise to compensation. It is right that the compensator rather than the taxpayer should bear some of the cost of certain medical treatment. Mick decided on asbestos-related diseases because of that certainty. It is relatively clear, for example, that mesothelioma is almost always caused by exposure to asbestos, and we are seeing the number of cases in relation to asbestos-related diseases increasing. Looking at the evidence that the committee has seen, we can expect that number to certainly increase over the next decade. So, although this principle could be applied much more broadly across other diseases, the reason why Mick chose asbestos-related diseased is because of the certainty.

[14] **Mark Drakeford:** Thank you. Minister, to be absolutely clear for the record, it is Elin who has been raising with other witnesses an idea of an amendment to the Bill to place a duty on Welsh Ministers to provide an annual report on the amount of money raised through the Bill and how that money has then been applied. That principle has generally been much welcomed by supporters of the Bill. Did I understand in your answer to Rebecca’s first question that you do not have any objections to that idea?

[15] **Lesley Griffiths:** Absolutely. I would be very happy to put down an amendment in relation to that point.

[16] **Mark Drakeford:** Thank you very much; that is really helpful.

[17] **Jenny Rathbone:** How much of this Bill, if it becomes an Act, would be a circulator of money within the public sector? The Welsh Local Government Association is saying that most of the liabilities would then fall on NHS local authorities and that there would be a huge

bureaucracy involved in what would effectively be a paper exercise.

[18] **Lesley Griffiths:** I know that Mick will be appearing later before the committee and you can ask him a bit more about that. However, I had a discussion with him about that and I know that Thompsons Solicitors have done some research for him on that. It looked at 165 cases, and fewer than 10% of cases came from the public sector. I have forgotten the breakdown, but, as I say, Mick or someone from local government could probably tell you. I do not think that there were any from the NHS in this sample of 165 cases. I think that there were a few from local government and a few from Government. I do not think, therefore, that it is a huge issue. Why should it not apply to the public sector, as with the private sector, if it is at fault? While I acknowledge that not all public sector bodies would be liable under the Bill, or would have third-party insurance, I do not see why we should differentiate between different categories of employers.

[19] **Elin Jones:** I want to ask you about the practicalities of assessing what costs would be liable under asbestos-related diseases. Some of the evidence that we have received shows the difference between this legislation, and how it would be considered and challenged, compared with the legislation on the recovery of costs in relation to road traffic accidents, given that it is very easy to assess the injuries resulting from road traffic accidents. However, with asbestos-related diseases, there are often other diseases linked, or there is comorbidity, with older people having diabetes and heart problems. The insurance industry in particular seemed to suggest that it would not see that all costs in a hospital setting would be related to asbestos-related diseases and, therefore, it would end up challenging and triggering the appeals system. What assessment have you made of the likely burden on the Welsh Government in having to work through the appeals process that is part of this legislation? If insurance companies end up challenging through the appeals process what costs are related to the asbestos-related disease and what costs, at hospital, could be related to other diseases not related to the asbestos-related disease?

[20] I also want to ask you about the cost of this legislation. In your evidence, you say that you would want to undertake more detailed discussions with the compensation recovery unit on the costs of administering the scheme. Given the fact that the explanatory memorandum states that the moneys raised or recovered would be around £2.03 million, what level of cost for the public purse would you consider significant enough to warrant this legislation being done?

[21] **Lesley Griffiths:** I will hand over to Mark to give a substantial answer. A lot of the work will be done around the tariff scheme; we would really need to do more work around that. As I mentioned in my opening remarks, with it being a Member-proposed Bill, we have not done a great deal of work at this stage. It would not have been right to provide Government resources at this stage.

[22] In relation to the CRU, we have a service level agreement with it at the present time, through the Department of Health, in relation to other schemes. I know that Mark has had preliminary discussions with the CRU, so he can say more about the administrative burden, which we do not think would be great and would not preclude us from having this Bill.

[23] **Mr Osland:** I will come onto the administration costs in a moment. First, I will touch briefly on the question of comorbidity and the identification of the disease. It is a valid point to some extent. It was quite heavily debated when the Health and Social Care (Community Health and Standards) Act 2003 came into force, and it was one of the reasons why, at that point, diseases were left out of the compensation recovery arrangements. Here, it is somewhat different because mesothelioma, as the Minister has already said, is almost always caused by exposure to asbestos. Therefore, the causal link between the disease and the exposure is much clearer. That is why we think that the recovery of costs in relation to this particular disease

would be much more easily identified than if it is was extended to all other diseases.

9.15 a.m.

[24] On the administration costs, the Minister mentioned that we have actually met with the CRU. We did indeed have an initial visit up to the north-east, which is where it is based, in October, I think. It was just to have initial discussions about the unit's potential to help us to administer the scheme. We envisaged from the outset that this should be something that we should pursue because the unit clearly has the experience, the knowledge, the contacts and the systems in place. It has been doing this sort of thing for many years. It proved to be very positive. There were no detailed discussions; it was generally a broad principle about what we were trying to do, and whether or not the unit could help. The unit was very keen and positive. The staff explained how their systems work and they saw no reason, at that time, why they could not help us. Of course, there would need to be some changes to the systems that they currently operate. The IT systems that they have are very automated for the whole process around how the unit operates. It has direct links with the NHS bodies in England and Wales, and it has direct links with the insurance companies; so, there would be some tweaking—if that is the right word—to the IT systems to reflect the nature of this recovery in relation to a disease. It was a very positive visit, and we think that that is something that we will be pursuing in more detail following the scrutiny process.

[25] The overall costs, I think, are very minimal in the overall sort of recovery costs that we are talking about. We are potentially estimating an ongoing annual administration cost that covers all of the work that the local health boards may have to do around this. Of course, they already have processes in place to recover costs in personal injury. In those instances, we are talking of 20,000 cases per year. So, there is already a fairly well-established process. However, there will be some slight increases because this is an additional process that they would have to administer. That, put together with the potential extra costs that we have estimated for insurance companies, and our relationship with the CRU, is estimated to be around £29,000 per year on an ongoing basis which, I would suggest, is relatively small compared with the extent of the recoveries that we are talking about.

[26] **Elin Jones:** [*Inaudible.*]—recovery that you have given, but on the issues that I raised regarding your anticipation of appeals and challenges as a result, and maybe linking it to the issue of comorbidity. The insurance companies gave us evidence that they thought—and I do not think that they quantified this in any way; I cannot recall them doing so—that there could well be plenty of challenges that a particular hospital stay had been put down for an asbestos-related disease, but that they thought it was because that patient had low blood sugar levels and had to be admitted to hospital. So, they were telling us that they thought that this would trigger a lot of challenges within the system and a lot of appeals. How do you assess the likely impact of this legislation on the number of triggered appeals that would happen, and how does that relate? Is it already factored into that £29,000?

[27] **Mr Osland:** We have estimated that there may be a small element of appeals, but we envisage that to be very small. The reason for that, as I outlined a few moments ago, is because the relationship between the disease itself and the causes of it is much clearer in the case of asbestos. We do not envisage there being many circumstances where the actual disease itself is complicated in terms of trying to identify the cause of it. So, we do not think that it will be an issue for us.

[28] **Mark Drakeford:** May I just ask as well, to make sure that I have understood it correctly, that if there are appeals, the appeals will be against the award of compensation? They will not be against the decisions that come from this Bill. The point that the insurance companies were making is that, because of the effect of this extra money that they would have to pay as a result of compensation awards, there may be more appeals.

[29] **Lesley Griffiths:** Shall we have a legal opinion on that?

[30] **Mark Drakeford:** Go on, Fiona, tell us.

[31] **Ms Davies:** Liability will be determined at the point when the compensation payments are made. There is an opportunity to appeal, under the Bill, the certificate of charges that has been issued, but that will be heavily tariff-based, and so we are not anticipating much debate on that, because it will be clear, objective and factual.

[32] **Elin Jones:** Yes, but the insurance companies are telling us that they would challenge that on the basis that there would be some kind of analysis as to whether a particular hospital stay that would trigger a tariff payment would have been related to a cardiac aspect of the person's care that could be linked to his or her—it is usually his, I hear—asbestos-related disease. So, they were telling us that they would challenge the tariff aspect. That is what I understood.

[33] **Ms Davies:** We would only attribute costs under the tariff if the stays were related to the asbestos-related disease and the medical notes would make it clear what the reason for the hospital stay was. Under the regulations, those who are issued with certificates will be entitled to ask about the basis on which calculations have been made. So, there will be scope for them to investigate and satisfy themselves that the costs are in relation to asbestos-related disease and not to other conditions.

[34] **Elin Jones:** I understand all that. The point that I am making, and the point that I think that the insurance companies were making, is that this is more complicated and more likely to be open to challenge than the road traffic legislation, which is more clear-cut. A lot of the people involved in that are younger people who have no other conditions. A lot of people with asbestos-related diseases will be older people who have already existing chronic conditions. So, I am raising the point that it could be more complex and could trigger more appeals than you have factored in to date.

[35] **Lesley Griffiths:** I can see the point that Elin is making, but, as Fiona has just said, the hospital records would show clearly why a person had been admitted.

[36] **Rebecca Evans:** I would like to move on to look at the scope of the Bill. It is confined to recovering those costs that have been incurred in secondary care. Do you think that the Bill gets it right in confining those costs to secondary care? In addition, can you give us a picture of the kind of breakdown of costs to the NHS because of asbestos-related diseases between primary and secondary care?

[37] **Lesley Griffiths:** Most of the costs would be within secondary care, because, for instance, if you have cancer, you would want to be treated quickly, and most of that treatment would take place in secondary care. So, we think that the breakdown is predominantly in secondary care and not in primary care. Is there anything else that you want to add to that?

[38] **Mr Osland:** I think that you are right. The evidence that we have looked at, particularly the 12 cases specifically cited in the explanatory memorandum, indicates that only around 1% to 5% of the total cost of the treatment for these sufferers was considered to be a cost incurred in the primary care setting. That proves that the majority of costs would be in the secondary care setting and, therefore, covered by the tariff that we intend to adopt.

[39] **Rebecca Evans:** With moves in the future to deliver more care closer to people's homes, in the community or in primary care, do you think that the Bill ought to provide power to Welsh Ministers to extend the scope of the Bill, of the recovery of costs in future, in order

to account for the transfer of care into the community?

[40] **Lesley Griffiths:** It is certainly something that we can look at, because the primary care costs are not included in the tariff at present.

[41] **Mr Osland:** It is a fair point. One of the principles around this Bill is that we want to try to make it as simple and cost-effective as possible and to keep the administrative burden as low as possible. If we were to pursue the avenue of trying to identify all the costs incurred throughout the whole process, in primary and secondary care, the whole thing might become overly complex and unnecessary in terms of the extent of the administration costs incurred. That is another reason we perhaps have not gone down that road.

[42] **Lesley Griffiths:** In answer to the specific question that you raised, it could be something that we should keep under review because, as you say, as care and treatment changes, it would have to be kept under review.

[43] **Mark Drakeford:** That is the point that has been put to us. People have not argued that the Bill should be changed to allow primary care costs to be recovered now. In terms of futureproofing the Bill, the question put to us was whether the Bill ought to be amended to provide Welsh Ministers with a power in the future, should they think it sensible to do so, to extend the recovery of costs to primary and community settings on the basis, as Rebecca said, that the long-term shift in healthcare is out of secondary care and towards primary and community care. So, it is not to be used now. Should the Bill be futureproofed in that way?

[44] **Lesley Griffiths:** I would say that, certainly, as medical practice changes, we should think about it and keep it under review.

[45] **Jenny Rathbone:** Last week, we heard from Marie Curie Cancer Care It looks after people with mesothelioma. Some of its referrals come from secondary care: the hospitals do not need to keep the patients, so they transfer them to Marie Curie. However, other people either self-refer or are referred by their GP. How would you define ‘secondary care’, using Marie Curie as a specific example, as there will be other providers? A referral may have come from secondary care, but they are actually in the room next door to somebody who has come from primary care.

[46] **Lesley Griffiths:** When we have looked at palliative care costs, we have seen that many of them are in the third sector, such as Marie Curie.

[47] **Mr Osland:** Again, the Bill does allow us to recover those costs at this time. The work that has been done so far—as explained in the explanatory memorandum—is based only on in-patient care treatment in a secondary care setting. However, we still have work to do in identifying how the tariff system will work in detail and in practice. Indeed, we may consider that, if a fair amount of cost has been incurred in a hospice setting, for example, which the NHS has paid for, it could form part of a tariff system. However, we have yet to really work out all of the details.

[48] **Ms Davies:** One issue is that, with CRU looking to administer this scheme, the more changes we make to the way in which the current process works under the 2003 health and social care Act, the more likely it is to become extremely costly. So, the cost of changing the CRU’s process would maybe swallow up any extra benefits that would be achieved. Whether it would be practicable would therefore be subject to further conversations with the CRU.

[49] **Jenny Rathbone:** On the way the CRU handles the recovery of costs for road traffic accidents, does the money go to the Department of Health, or does it go to the specific hospital where the victim of the road traffic accident was dealt with?

[50] **Ms Davies:** It goes to the specific hospital.

[51] **Jenny Rathbone:** Right, but in this case, it would come directly back to the health department. That is a change in the method of distribution.

[52] **Ms Davies:** Yes. It is because so much less is going to be recovered under this Bill that it was considered better to take the view that, if we get all the money collected together, we could look at how best to spend it at that stage. One LHB could maybe have one case, and that would not be enough money to make a difference, but if you collect the money together and take a view at that stage on what it would be better to spend those funds, we could take a view on how to achieve the greatest impact.

[53] **Rebecca Evans:** Do you have any views on how costs could be recovered to the NHS in Wales in instances where the claims are determined outside Wales and England—in Scotland, for example—but the cost have been incurred by the Welsh NHS? How would you go about recovering those costs?

[54] **Lesley Griffiths:** Again, this is not a wholly new issue. Provided that the medical treatment was provided and funded here in Wales, the provisions of the Bill will apply, even if the exposure took place outside Wales, or even if the compensation payment was made outside Wales.

[55] At the present time, foreign compensators, or those outside Wales, are required to register a claim with the CRU in the same way as a UK-based compensator. So, if the Bill is passed by the Assembly, we will ensure that, as part of the implementation process, those affected by the Act are aware of the legislative changes that are going through. Again, if we use the compensation recovery unit, its experience would help us to identify how best we could inform compensators not based in the UK. Mark will probably back me up on this, but I think that it would largely mirror the current process that we have for injury cases where the compensator is outside Wales.

9.30 a.m.

[56] **Mr Osland:** Yes, the compensator obviously has a legal duty to inform the CRU when a claim is lodged with them, irrespective of where they may reside. So, the CRU will be aware that a claim is in process and therefore the system begins, so it does not matter where that has originated.

[57] **Rebecca Evans:** We heard an interesting argument from insurance industry representatives around human rights: that is, that this would be against their human rights and they consider the retrospective nature of the Bill to be fundamentally unfair because these risks could not have been known about many years ago when premiums were calculated, charged and collected. What is your response to that human rights argument?

[58] **Lesley Griffiths:** I would be very disappointed if that were the case. I do not think that it would be significant. It would be quite limited. Again, the 2003 Act has a retrospective effect in that it provides that, when an insurance policy covered a compensation payment made to an injured insured person in consequence of any injury, that policy would also cover the NHS costs incurred in treating the injured person. I do really think that it would be only a marginal proportion of overall premiums and payments of insurance companies. Certainly, the evidence that we have had is that it would not have a huge impact. I know that you have heard conflicting evidence, but insurance is a risk business and it would be extremely disappointing if that were the case. The insurance industry has to take into account the risks, both seen and unforeseen, when it sets its premiums. So, I would really question whether any

extra costs would be incurred.

[59] **Ms Davies:** I would also add that the Presiding Officer has already decided that the provisions in the Bill do not breach convention rights, and we agree with that view.

[60] **Elin Jones:** You have referred a few times to the 2003 Act, and I think that you referred earlier, Mr Osland, to the fact that a decision was taken by UK Ministers at the time not to include diseases as part of the recovery process in that Act. Do you think that anything has changed within the administration of the NHS to make this an easier process to deal with now than it was when that decision was taken by Ministers in 2003?

[61] **Mr Osland:** Excuse me if I am repeating what I said earlier, but the decision that was taken in 2003 was primarily based on the practicalities of including all industrial diseases. They were not isolating specific diseases and saying that one would not be included but another would—it was all diseases. As we know, diseases are very complex and there are many factors involved, so you can understand that decision. However, here we are talking about a specific, identifiable disease, the cause of which is much clearer. That is why we think that this is a completely different decision from that which was taken in 2003. It is much easier in practice to administer and we believe that it will be workable.

[62] **Elin Jones:** Is it your view then that, if this legislation is enacted, those working on other industry-related diseases may want to champion the cause for their own recovery-of-costs legislation in Wales? Have you scoped the landscape to see whether there are other equally suitable diseases that could trigger a request to Welsh Government for legislation of this type?

[63] **Mr Osland:** The direct answer to your question is ‘no’. We have not scoped the extent of the possibility of coming forward to work in this way with regard to other diseases. There is no intention of that at the moment. We would not completely ignore the possibility of that happening, but it has not been taken under consideration.

[64] **Gwyn R. Price:** You say that implementation could be in 2014-15. Is that a realistic target?

[65] **Lesley Griffiths:** Yes, I think that it is realistic. To bring it into effect in 2014-15, we would have to consult on regulations in the autumn of this year, probably. It would be quick, but we think that we could do that.

[66] **Mark Drakeford:** I have a small number of questions just for the record, taking up points made by other witnesses, and then I will see whether Members have any further questions. I think that you have answered this question already, but, just to be completely clear, I will ask it. The explanatory memorandum to the Bill rehearses four different possibilities as to how the scheme could be administered. It concludes that using the CRU is the preferred method. Is that a conclusion that you share?

[67] **Lesley Griffiths:** Yes, I think that the CRU would be the preferred option for administering this scheme. As you say, there are other options in the explanatory memorandum, but we already have a relationship with the CRU and a service level agreement, which has been very successful. You heard Mark say before that he has had a preliminary meeting with it, which was very positive. So, it would be the preferred option. That is the current position, but, as I said, there have been only very preliminary discussions at this stage, and that is most appropriate.

[68] **Mark Drakeford:** Thank you. The Bill sets up a tariff-based system for recovery costs. Some have suggested to us that the tariff mechanism should appear on the face of the

Bill. Do you think that there is any merit in that?

[69] **Lesley Griffiths:** No, I think that the most appropriate place for the tariff would be in regulations, and we would have to consult widely on that.

[70] **Mark Drakeford:** Thank you. My final question is about the stop-the-clock approach that the Bill takes, in that it ties the recovery of NHS costs to the point at which the compensation claim is settled. Some witnesses have suggested to us that this could lead to significant NHS costs not being recovered because the compensation claim is settled but the person continues to be ill and to receive treatment, and those costs are not recoverable in the mechanism set out in the Bill. Is that a significant omission, or do you think that the administrative simplicity, which is the case that the Member in charge put to us for the stop-the-clock mechanism, outweighs any disadvantages?

[71] **Lesley Griffiths:** Yes, I think the latter. As I said before, if you have cancer, for instance, your treatment is very quick, so we think that the stop-the-clock mechanism is the most appropriate way forward.

[72] **Jenny Rathbone:** Would you consider adding a sum for palliative care to that? We know that that is not the most expensive element, but it is about nursing care.

[73] **Lesley Griffiths:** No, not at the moment, but it is perhaps something that we could look at as we go forward.

[74] **Mark Drakeford:** Do Members have any final questions for this session?

[75] **Elin Jones:** If the CRU ended up refusing to be part of this, what other options would you consider at that point if you were still in favour of the legislation?

[76] **Mr Osland:** The two alternative options would be to have a team in the Welsh Government to directly administer this, or it could possibly be administered by the NHS itself. We have identified the estimated costs, if that were to be the case, in the explanatory memorandum.

[77] **Mark Drakeford:** Minister, diolch yn fawr iawn—thank you very much. We have moved swiftly through a large number of the points that have arisen in the evidence that we have taken from other witnesses in this stage of the Bill's investigation, so we are very grateful to you for helping us this morning.

Gohiriwyd y cyfarfod rhwng 9.40 a.m. a 9.52 a.m.
The meeting adjourned between 9.40 a.m. and 9.52 a.m.

Bil Adennill Costau Meddygol ar gyfer Clefydau Asbestos (Cymru): Cyfnod 1—Sesiwn Dystiolaeth 9
Recovery of Medical Costs for Asbestos Diseases (Wales) Bill: Stage 1—Evidence Session 9

[78] **Mark Drakeford:** Bore da a chroeso. Diolch i chi i gyd am fynychu'r cyfarfod y bore yma. Symudwn ymlaen at ein nawfed sesiwn dystiolaeth ar y Bil Adennill Costau Meddygol ar gyfer Clefydau Asbestos (Cymru) ac mae panel o dystion yn ymuno â ni ar gyfer y sesiwn hon.

Mark Drakeford: Good morning and welcome. Thank you for attending the meeting this morning. We move on to our ninth evidence session on the Recovery of Medical Costs for Asbestos Diseases (Wales) Bill and a panel of witnesses is joining us for this session.

[79] Croeso i Dr Rachel Iredale o Tenovus, i'r Athro Ceri Phillips o Ganolfan Economeg Iechyd Abertawe, Coleg y Gwyddorau Dynol a Iechyd, Prifysgol Abertawe ac i Glyn Jones o Fwrdd Iechyd Lleol Aneurin Bevan.	I welcome Dr Rachel Iredale from Tenovus, Professor Ceri Phillips from the Swansea Centre for Health Economics, College of Human and Health Sciences, Swansea University and Glyn Jones from the Aneurin Bevan Local Health Board.

[80] I will go straight to Members for questions. I will ask them to say whether they have questions that they particularly want to direct at any individual member of the panel. We have 45 minutes for this session. Hopefully, we will have some time at the end of questioning, so, if there are points that you think are important for Members to take away from the session that we have not managed to cover in questions, you will have a few minutes to ensure that you leave those points with us. We will go straight to Members; Gwyn Price has the first question.

[81] **Gwyn R. Price:** Good morning. Perhaps the witness from Aneurin Bevan Local Health Board could answer this: do you have an idea in your mind of the timetable you feel that there should be for treatment for which the costs can be recovered?

[82] **Mr Jones:** On a timetable for recovering the costs, if you look at the impact assessment that was undertaken, that demonstrates that the treatment period for these types of cases tends to be fairly short, at around 12 to 18 months. Our experience of recovering costs through the current injury cost-recovery scheme is that it is usually a matter of weeks. Clearly, with these matters, there may be a slightly longer timetable, so we could be talking about longer than just a matter of weeks, which is what is normally the case with the current injury cost-recovery scheme. We have not undertaken any detailed work to look at what the typical timetable would be, but, given the system that has been proposed in the Bill, we would expect cost recovery to be fairly quick once the compensation claims have been established. So, we are probably talking about weeks, maybe months, but certainly not longer than that.

[83] **Lynne Neagle:** How confident are you that any costs recovered will be used for the benefit of people who are ill as a result of asbestos exposure?

[84] **Mr Jones:** Would you like me to answer that?

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

[86] **Mr Jones:** Looking at how it is proposed that the system will work, clearly the intention is for the money to be recovered and to go back to the Welsh Government. We, as a local health board, would be keen to work with the Welsh Government to discuss how that money could potentially be routed back to local health boards and trusts. As a local health board, our responsibility is to commission, plan and, in a lot of cases, provide those services. So, we would be keen to work with the Welsh Government to agree a clear and practical mechanism for ensuring that that cost recovery is routed back to local health boards and trusts to enable us to build that into our planning of services, particularly those related to asbestos-related diseases.

[87] **Mark Drakeford:** Dr Iredale, Tenovus's evidence, which is broadly supportive of the Bill, created some anxieties that money collected via the mechanism set up by the Bill might displace rather than supplement money that is currently available through the NHS. Would you like to tell us a bit more about that?

[88] **Dr Iredale:** Yes, thank you, Professor Drakeford. We have had quite a lot of experience of the needs of people who have asbestos-related diseases, particularly

mesothelioma. We have done a kind of quick-and-dirty analysis of the last 50 or so of our clients who have come to the third sector for our services. May I give you a quick profile of those clients?

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

[90] **Dr Iredale:** Of the last 54 clients I looked at, 30 came from Cardiff and Vale University Local Health Board and 15 from Abertawe Bro Morgannwg University Health Board. However, we do have clients as far as Anglesey. Forty six of those 54 were male, and eight were female. The age range was from 58, going up to 91 years of age. Sixty-five per cent of those people wanted short-term advice on benefits that they needed immediately, such as, carers' allowance and disability living allowance, as well as advice on how to go through Government compensation schemes and pursue civil compensation schemes. So, advice on short-term benefits was something that they immediately required. The other third needed things such as counselling support on issues such as how to talk to their kids about the condition and how to deal with it within their families. We also offered a lot of bereavement support and signposted people to other social services. So, that gives you an idea of the sorts of needs we are seeing and where we think money should be spent in future.

[91] **Mark Drakeford:** I want to check one thing with you. In our earlier session with the Minister, she indicated that she had no objection to a suggestion that other witnesses have put to us that the Bill should be amended to place a duty on Welsh Ministers to report annually on the amount of money recovered as a result of the Bill, and how that money is applied. Would that offer any comfort to bodies such as Tenovus?

[92] **Dr Iredale:** At Tenovus, we would always be in favour of the Minister reporting and accountability for any aspect of cancer, and having a transparent process to see how those funds were spent.

[93] **Mark Drakeford:** Thank you very much. Lynne and Elin are next.

[94] **Lynne Neagle:** On that point, Tenovus has said that it thinks that there should be checks and balances. In your mind, would that be a sufficient check and balance to secure that sort of change?

[95] **Dr Iredale:** Yes, providing that we pursued the principles around 'Together for Health', so that we were working together for the benefit of cancer patients and that there was some third sector involvement where necessary. We have a lot of these systems in place. In the last two years, we have managed to access more than £600,000 in benefits for our clients. There is no need to reinvent the wheel, and lots of other cancer charities are doing this as well. So, I think it would be important to work with us to roll out this sort of system.

[96] **Mark Drakeford:** Thank you. Elin, is your question on this point?

[97] **Elin Jones:** No.

[98] **Jenny Rathbone:** Is it the assumption, within the Bill, that benefits advice is part of the overall care, or is it strictly confined to NHS costs? I appreciate that there is a stop-the-clock approach, but the counselling—

[99] **Dr Iredale:** We see our role as complementary to the clinical needs that patients will have. So, you can look at a condition such as mesothelioma in two ways: there is a clinical side and the psychosocial support that charities can offer is aligned with that.

[100] **Jenny Rathbone:** So, the cost of caring support that you and other charities offer

would not be recoverable.

[101] **Dr Iredale:** We would hope that, from that fund that the Minister had, some of it would be diverted to those psychosocial issues.

10.00 a.m.

[102] **Professor Phillips:** There needs to be a degree of caution, in the sense that I firmly believe that there should be a separation between the recovery of costs to the NHS and the damages to the individual. The damages that are paid out to the individual should, in a sense, cover the benefits, the counselling and the psychosocial support. In terms of the NHS, the fact that the NHS has to treat patients as a result of asbestos-related diseases means that it cannot provide care, treatment and support for others at that point in time. There has to be a distinction between the two when we are talking about the recovery of costs. We are talking about the recovery of treatment costs to the NHS and we are also talking separately about damages to which patients would be entitled.

[103] **Mark Drakeford:** I welcome Julia Yandle.

[104] **Ms Yandle:** I am sorry I am late.

[105] **Mark Drakeford:** You are not late at all; you are exactly on time. We have run slightly ahead of ourselves this morning. Julia is the advice services manager for Tenovus and I am grateful to her for joining us this morning. We will go to Elin Jones for our next question.

[106] **Elin Jones:** I have a question for the health board. We have had evidence from the insurance companies to say that many older people in particular who may be hospitalised for asbestos-related diseases will also have other diseases; they may be diabetic or have heart conditions that may not be related to their asbestos-related disease. The insurance companies have told us that they could well challenge the allocation of costs under the tariff system and trigger the appeals process in the legislation. The Minister said in her evidence this morning that it would be quite easy for the health boards to clearly allocate whether a hospital stay was due to an asbestos-related disease. Do you think it is as straightforward as the Minister said, is it as complex as the insurance companies portrayed, or is it possibly in between?

[107] **Mr Jones:** If you look at the system that is proposed, it tries to strike a balance between being a very practical system and one that obviously tries to, as far as possible, recover the true costs of providing the treatment and care for this disease. As the system is proposed, what it is suggesting is that it identifies the treatment directly related to things like mesothelioma. In a practical sense, that is fairly easy to trace back; so, when you look at the impact assessment that looks at the administration costs for local health boards, that would involve somebody within the local health board looking through medical records where we could clearly identify those treatments related to mesothelioma as distinct from any other comorbidities. In that respect, the proposal put forward is fairly practical, and generally, it would be quite easy to identify those treatments specific to asbestos-related diseases.

[108] **Elin Jones:** Would the health boards be willing to put the system in place to administer such recording of an assessment of medical records? Would that be reasonably straightforward and would you expect Welsh Government to fund you to put that system in place?

[109] **Mr Jones:** Again, if you look at the system that is proposed, particularly the one around the compensation recovery unit, there is a fairly well-established system in terms of an overall process from the compensation claim to identifying the particular individual and

tracking back the treatments that were provided. Given that the system also proposes the recovery of costs primarily around secondary care and not primary care, again, we have fairly good information systems and medical records for individuals that would allow us to do that relatively easily. There would probably be a small, incremental administration cost involved in looking through those patients' notes to clearly track that the treatment was provided in relation to an asbestos-related disease. By and large, the system and the infrastructure are there within the local health boards, but there would be that incremental administrative cost, which has been broadly identified in the impact assessments.

[110] **Elin Jones:** I want to ask another question to Professor Phillips about the paper provided; I just want to understand it better. You have referred to the study that was done in 2000 and the estimate, on a UK basis, that hospital costs for mesothelioma would equate to £23.3 million in real terms. I do not know whether you could estimate what the Welsh part of that would be. If it was done on the basis of the Barnett formula—though I am sure that the Barnett formula is not in any way applicable for mesothelioma—then the hospital costs would be around £1 million or slightly more. The explanatory memorandum that we have in front of us estimates that the cost would be over £2 million. Do you have anything to say about that difference?

[111] At the end of your paper, you talk about net benefits gained of £7.8 million. I have not been able to follow how that relates to the hospital cost of asbestos-related diseases and whether that is the net benefit for the NHS from recovery of costs or whether it is a lot more general.

[112] **Professor Phillips:** In terms of technicalities, the report was accurate. The £7.8 million recovery of costs is the net benefit that society as a whole would receive. Then, if you discount future benefits—we are not just talking about the recovery of costs at a single point in time, but over time; a five-year perspective was taken in the impact assessment—then that would translate, in current terms, to a net benefit of just under £7 million. On the issue as to what that constitutes relative to the cost, we have to separate those. The cost prediction in the paper looked at 120 cases in Scotland. We then multiplied that through to the UK population and came up with £16 million, which, if you talk in terms of current prices, would be the £23 million that you refer to. Then, you divide that by the proportion of people in Wales relative to the UK population and you come up with a figure of between £1 million and £1.5 million. The paper itself acknowledges that those figures are a gross underestimate because of what was included in the cost. It looked at 120 treated cases in Scotland and was very direct in terms of the costs that were incurred in providing treatment for those, but acknowledged that a number of conditions were not included, which would add to the costs. Putting that in the context of the impact assessment, there was a five-year perspective taken. So, looking at 80 cases each year in Wales and translating what they would cost each year for five years gives you the net benefit of £7.8 million. Then, the actual discounting of future costs and benefits gives you a figure of £7 million. I do not know whether I have explained it as you wanted.

[113] **Elin Jones:** I did an economics degree a long time ago and it is obviously a really long time ago. [*Laughter.*] When you say that the net benefits gained would be £7.8 million or £7 million, then that is not money to the Welsh exchequer—

[114] **Professor Phillips:** It is money. It is reflecting the actual costs of administering the scheme, the costs incurred in recovering those costs and the actual moneys gained that would come back to NHS Wales. Perhaps some of the difficulties arise from the impact assessment, in that they took what is called a societal perspective, where there is no money gain. However, if you took the perspective simply of the NHS, which is what NICE takes and is not the societal perspective, then those gains would be financial to NHS Wales. That is the point that I think is important.

[115] **Elin Jones:** But they would be indirect gains, would they not? If a hospital is not treating someone with an asbestos-related disease, it would be treating someone else with another condition.

[116] **Professor Phillips:** No. There is the opportunity cost, which is a different issue. My view is that if you look at the actual treatment costs of the 80 cases per year and seek to recover those from the offending organisations and/or their insurers, those will be the actual moneys that will come back into NHS coffers.

[117] **Mark Drakeford:** I am really reluctant to tiptoe into this with two economists at the table. May I just put it to you in this way to see whether I have understood it correctly? The explanatory memorandum describes net present value by stating, ‘This is the amount of money that will come to the NHS, but that amount of money will be lost to the insurance companies’. So, you have to take the one away from the other and, as a result there is no figure of positive public benefit that they come up with. Your figure at the end of your paper suggests, ‘Actually, if you think of just what the NHS will get out of this, you come up with that figure of £7.8 million or £6.9 million once you have factored in inflation’.

[118] **Professor Phillips:** That is exactly it. The tendency, perhaps, in terms of cost-benefit analysis has been to look at the societal perspective; so, to look at the private sector, the NHS, the public sector, and if there is gain in one side, the private sector would have to compensate. I think that we are in a different era now when budgets are so important, so organisations are managed and, in a sense, assessed in terms of how they manage their budgets. Perhaps we do need to look at what I would call a partial societal perspective along the lines of NICE. NICE does not look at the drugs that it is assessing from a societal perspective. It does not include certain aspects of costs and benefits; it simply looks at the impact on the NHS.

[119] **William Graham:** We were told previously in evidence by the lawyers that they anticipated that the number of cases would reduce for reasons of which you will be well aware. Would you subscribe to that view?

[120] **Professor Phillips:** To go back to the point about tariffs, I think that, in Wales, we perhaps need to do a little bit of work to make those tariffs explicit; there are tariffs in Wales, but they are not used as they are in England because of the way in which hospitals are funded. We may have to be slightly careful in terms of deriving the cost estimates, but if we can do that and they are explicit I do not see a reduction in claims because I think that the companies themselves would be aware of the consequences and they would factor that into their costs.

[121] **Mark Drakeford:** I want to go to Rebecca next, but because this is a point that Tenovus also comments on, perhaps I will rehearse this question one more time. It is one on which we have had very different views from different witnesses. Some witnesses say that the effect of the Bill will be to make the settling of claims more difficult. Due to the fact that there are now extra costs riding on the settling of compensation claims, it will make the industry fight them even harder, drag them out even longer, and make it more difficult and complex for claimants. I think that this is an anxiety that Tenovus raises. However, other witnesses have said to us, including lawyers who work directly for the insurance industry, ‘You have completely misunderstood the way that the industry operates’. The stop-the-clock mechanism means that they will want to speed up the settlement of these claims because the sooner that they settle them the more costs that they avoid in terms of recovery of NHS costs. When Tenovus rehearses that anxiety, Dr Iredale, is it just something that you are worrying about or is it something that you have evidence on, so you really think that this will make things more difficult? I am interested in Professor Phillips’s view in an econometric sense. How do you think that this Bill will impact on the speed with which claims are settled?

[122] **Dr Iredale:** It has not been our experience to date. We hear that clients can take up to

two years to settle compensation claims. That is the here and now of what we are dealing with.

[123] **Mark Drakeford:** So, they are fought now quite hard and it is difficult to claim, and you think that the Bill might make that more difficult.

[124] **Ms Yandle:** It was speculation, I think, that it was a possibility.

[125] **Mark Drakeford:** Yes, that is what I was wondering. Of course, none of us here know.

10.15 a.m.

[126] **Professor Phillips:** I take the point. I think that what we are dealing with here, again, is something separate. We are not dealing with individual damage claims against organisations; we are dealing with the recovery of costs. If the Bill comes to fruition and you seek to recover the costs that are likely to be incurred where there is a recognition that these diseases cost x number of pounds to treat, then that will be a factor that insurers and employers will be fully aware of. We know that in other claims to recover costs for the NHS, from injuries incurred in road traffic accidents, for example, that is accepted—because the tariff is known, people factor it into their decisions.

[127] **Rebecca Evans:** Thinking about the scope of the Bill, does the Bill get it right in terms of confining the recovery of costs to those that have been incurred in secondary care? That question is to anyone.

[128] **Professor Phillips:** Shall I start? When you try to cost treatment for conditions and diseases it gets very difficult. We have already been asked, ‘What about people who have other diseases as well as the asbestos-related diseases? When they go to their GP, for example, do they go about their asbestos-related condition or about their heart condition, or whatever?’ It becomes an exercise in estimation rather than trying to be exact. The costs at hospital level are more explicit. As Glyn alluded to, the tariffs are based on a system whereby the procedures are costed and then there is a different tariff for those people who have got the disease plus complications. Obviously, you cannot devise a system of costings to cover all eventualities. We have to categorise patients, and there is a degree of heterogeneity across patients, but nevertheless, that is a piece of information that the health system is aware of and that others, such as employers and insurers, can also be aware of. If we started costing presentation at GPs, phoning the GP for advice, et cetera, then we would get into a different ball game where we would increase the cost. It can be done, and where patients rely on primary care as opposed to secondary care, then perhaps the NHS will suffer as a result if we cannot factor those costs in. However, it is a difficult exercise to do that.

[129] **Mr Jones:** Just to follow up the points that Professor Phillips has made, and to build on some of the questions asked earlier about whether, if you make this more complex, it could be open to more claim and contention, I think the system that is proposed strikes quite a good balance in terms of making it fairly practical to administer. Generally, the in-patient costs of treatment when we talk about hospital in-patient stays, chemotherapy and, to a certain extent, the out-patient stays, are probably the more expensive or costly parts of the treatment and care. So, I think that it captures the more significant costs involved.

[130] **Rebecca Evans:** If there is a greater move towards care being delivered closer to people’s homes, in primary care or in the community, would it be sensible for the Bill to provide the powers to Welsh Ministers to extend the scope of the Bill in future to reflect that?

[131] **Professor Phillips:** We discussed earlier the way in which the insurance companies

would perhaps fight that. If we attribute the reason for a consultation to a specific disease, I think that would open up the challenges. If one can keep it tight, in the sense that this is what the disease costs, even if that is not accurate, but is something that is explicit, then that would probably limit the amount of legal challenges that one would have. If we did open it up to try to accurately specify and attribute the consultation with the professional, and try to get every penny back, as it were, that would make it much more complicated and much more open to scrutiny from the legal profession.

[132] **Elin Jones:** This question is to the health board: would you have information on the numbers of people suffering from asbestos-related diseases possibly over the last five years in each health board area? I ask that question to seek your view because this legislation is based on the presumption that it does not matter where in Wales the treatment occurs, the money will go to the Welsh Government, and it could be likely that post-industrial areas in south Wales are treating greater numbers of people with asbestos-related diseases, but that will not be reflected in this legislation at all. So, it is on a different basis to the cost recovery for road traffic accidents, which goes directly to the hospital that incurred the cost, I think. Do the health boards support the fact that this money will go to the Welsh Government and not to the health boards incurring the cost?

[133] **Mr Jones:** To answer the first part of your question around the assessment, I am not aware that local health boards have done an assessment of the cases relating directly to asbestos-related diseases. To a certain extent, under the retrospective system that is proposed, part of the administrative cost would be to physically trace those cases back to identify where treatment was provided. We have not, to my knowledge, undertaken that assessment and would not necessarily know, historically, where all those cases have fallen.

[134] To answer your point about how the cost recovery would be routed, it is different to the current system for injury cost recovery, where that money flows directly back to the relevant trust or local health board. I think that we would be keen to work with the Welsh Government to look at the best way of allocating the money that is recovered. I guess that we would be particularly keen to have a degree of certainty. So, if we are talking about, potentially, £2 million of cost recovery across Wales, if there is more certainty around where and how that money might flow back to local services, as a local health board, that will allow us to plan and commission services more easily, particularly around asbestos-related diseases, going forward. We would certainly welcome a dialogue with the Welsh Government at the right time about how that would be done to give us better information about how we could best plan our services going forward.

[135] **Jenny Rathbone:** If somebody from England goes for a weekend to Swansea and ends up in the accident and emergency department, you recharge the home health trust, do you not, for the care that they have received while in your Swansea hospital?

[136] **Mr Jones:** I am sorry, if one of our—

[137] **Jenny Rathbone:** In relation to the way in which the NHS recharges at the moment, if you treat somebody from England in A&E with unexpected care, their home health authority would be recharged, would it not?

[138] **Mr Jones:** Yes, there are certain types of treatment, particularly emergency treatment, where that would apply. If somebody was to come to a local A&E to receive treatment and care, we would recover the cost either through the existing service agreements that we have with other local health boards or, if it was somebody who lives in England, we would currently recover the cost from a primary care trust. So, there are currently mechanisms for recovering some of those costs. Some of them are probably more sophisticated than others, I would also point out. However, there is an element of cost

recovery and recharging between health bodies at the moment.

[139] **Elin Jones:** To follow on from that, it could be quite straightforward, therefore, if this committee decided that it might prefer to suggest the use of the model where the health board or the hospital that treats is the one that recovers the costs. In terms of your own administration—this is not a policy view—that would be a reasonably straightforward way to implement this legislation, rather than the way that is proposed. Administratively, it would not pose a problem for health boards to do it in that way.

[140] **Mr Jones:** I do not think that it would be a significant problem. As I said before, we are talking about a relatively small number of cases, particularly when compared with the injury cost recovery scheme that is currently in operation. It would be a fairly small incremental administrative cost to us to do that.

[141] **Mark Drakeford:** I have one follow-up question on this point for Professor Phillips and Mr Jones, then I have a question for Tenovus. I will then look to see whether there are any further questions from Members, after which we will just check whether there are any final round-up points that any member of the panel wants to make.

[142] My question for Professor Phillips and Mr Jones is related to the last one. You may not have a view on this, but do you believe that the Bill is clear enough, as currently drafted, about the position of the following two sets of circumstances? The first is where the origin of the disease—the event that triggered the disease—happened outside Wales, but the NHS treatment is in Wales. The second is where a patient of a Welsh local health board is receiving treatment outside Wales, wherever that would be. Is the Bill clear enough about how those cases would be navigated?

[143] **Mr Jones:** I will answer first. As local health boards, we have two roles, if you like. One is to commission and plan services, which means that, potentially, we could be funding and picking up the costs of services that are delivered in a trust in England. Therefore, ultimately, the cost of the treatment and care would fall to the local health board. The second role is as a provider of services, whereby we would pick up the cost of providing the service directly. It probably is important that the Bill is clear that it would cover both of those instances. So, if it could make it clear that it covers the treatment that we fund in other trusts, albeit that they may be in England, that would be really helpful.

[144] **Professor Phillips:** Given what we have heard today on the radio and seen in the press about cross-boundary issues, I think that as much clarity as possible should be included in the Bill. I firmly believe that, in the case of people who suffer the disease as a result of work in England and who are treated in Wales, the NHS in Wales is entitled to chase those organisations, irrespective of where they are located. Indeed, it would often be the case that, even if those people had been working in Wales, the employers would have their headquarters in England and so on. So, that is a point that perhaps needs to be tightened.

[145] On those issues to do with patients being treated in England, the same principle applies. The relevant health board would have to pay for the treatment in England, and therefore would be entitled to seek recovery of the treatment costs.

[146] **Mark Drakeford:** Lovely. Thank you very much indeed.

[147] This next question is for either or both of our Tenovus witnesses. The evidence that you provide puts a particular emphasis on making sure that the voice of victims and support groups should, as you say, be at the forefront of discussions about how any money derived through the Bill should be deployed for their benefit. Their views, you say, should be given weight above all others with an interest in the process. Might you be able to help us by saying

a little bit more about that and about how you think the voice of people who have suffered from the disease can be strengthened in the way that the Bill sets up its mechanisms?

[148] **Ms Yandle:** When we talk about how the money is going to be reallocated, that would be a good starting point. Certainly, it would be interesting to see whether there would be any plans to give any financial support to groups that support victims and give them a better platform to voice any concerns that they have. That is certainly something in which I would be interested in seeing more accountability on when the money goes to the central pot of the Welsh Government.

[149] **Mark Drakeford:** Most of the evidence that we have received so far has rather assumed that the money coming in through the recovery of NHS costs would be redeployed in the NHS. Are you suggesting something slightly broader than that and that there are other needs that victims have, such as extra help to support them through the compensation claim process, and so on, and that this money should be looked at more widely in terms of its application for the benefit of victims? Have I understood that right?

10.30 a.m.

[150] **Dr Iredale:** We probably see 3,500 to 4,000 people with cancer every year in Tenovus who try to access our services, whether through our mobile unit or our support line, for a variety of reasons. Their clinical needs and going through their cancer treatment is just a small part of how they need to be supported. So, from a third sector point of view, we would be keen, if there were an opportunity to do it, for patients, their families and other organisations to have some say in how that money was to be reallocated. That would be a very positive thing. However, we understand the narrative of the quid pro quo process that might take place, whereby the NHS spends the money and gets it back. We are just trying to put it out there in terms of what the patients whom we see are coming to us for.

[151] **Mark Drakeford:** That is a very useful point.

[152] **Lynne Neagle:** Professor Phillips and Aneurin Bevan Local Health Board have picked up on the point that a significant number of these claims could be against public sector organisations. We had evidence during the last meeting that that could make up about 40% of cases. Do you have any comment to make further to your observations on that in your evidence? Does that alter your view of the effectiveness of this Bill as a piece of legislation?

[153] **Professor Phillips:** I agree that it is a different circumstance. I made the point earlier about perspective, and it does not really make sense for the Welsh Minister for Finance to pay out from the budget into the NHS. However, given the budgets and the way in which organisations are funded and assessed in terms of performance, I think that even public sector organisations that cause the problem should compensate other public sector organisations. The way in which we conduct cost-benefit analysis now has to be narrower, and therefore I believe that the same principles should apply.

[154] **Mr Jones:** I am not sure what the basis is for that 40% figure; I have not done my own assessment of what the figure would be. I would probably support Professor Phillips' point, in that we recognise our responsibilities as an employer as well. If we are found culpable, we would have to accept that, potentially, there could be some costs moving from the local health board back into the NHS, albeit that it could even be back into some of our services and so you might argue that, in that particular case, it is not a particularly useful approach, but I think that it would, generally, probably be in the minority.

[155] **Dr Iredale:** Some of the data that we used to extrapolate these figures are about six or eight years old. When we have examined our data, although we have a small dataset, we

are seeing small shifts in the number of women coming forward with mesothelioma, and also with regard to occupations where you would not traditionally expect to see this type of condition. I know that a lot of work is going on about the extent to which asbestos is in public sector buildings and, to be facetious, if I may, we work in a building that was formerly Government-owned, which is now in private hands but occupied by a third sector organisation, and which has asbestos in every single window sill, every ceiling tile and every stairwell. If you adopt the principle of the polluter pays in that instance, who is the polluter? Each of the sectors have been involved in that structure, and, going forward, we are starting to have a trickle of cases through from non-conventional industries, from women and from places such as schools and hospitals.

[156] **Mark Drakeford:** Thank you very much. I see that there are no further questions from Members. I will just check with each member of the panel whether there are any points that you feel have not emerged with sufficient strength or clarity in the discussion that we have had and you want to make sure you leave with us as part of this Stage 1 consideration. Mr Jones, I will go to you first. You do not have say anything—there may not be anything.

[157] **Mr Jones:** I do not think that I have anything to add. Thank you very much for the opportunity to be here.

[158] **Mark Drakeford:** Dr Iredale?

[159] **Dr Iredale:** I am Irish, and we always have to have the last word. [*Laughter.*] It is possibly beyond the scope of the Bill, but I would say please give some consideration to futureproofing and the wider needs of patients. Third sector organisations such as Tenovus have acquired considerable expertise_in dealing with patients over the years, so we would be happy to help in any way going forward.

[160] **Mark Drakeford:** Diolch yn fawr iawn i chi i gyd. Dyna ddiwedd y sesiwn.

Mark Drakeford: Thank you all very much indeed. That is the end of the session.

[161] Thank you very much for your help this morning.

[162] Cyn i ni droi at yr eitem nesaf, hoffwn ddweud ein bod wedi derbyn ymddiheuriadau oddi wrth Kirsty Williams am gyfarfod y bore yma, ond bydd Kirsty gyda ni yn y prynhawn yma.

Before we turn to the next item, I would like to say that we have received apologies from Kirsty Williams for the meeting this morning, but Kirsty will be with us this afternoon.

Cynnig o dan Reol Sefydlog Rhif 17.42 i Benderfynu Gwahardd y Cyhoedd o'r Cyfarfod ar gyfer y Canlynol: Eitem 5

Motion under Standing Order No. 17.42 to Resolve to Exclude the Public from the Meeting for the Following Business: Item 5

[163] **Mark Drakeford:** Cynigiaf fod

y pwyllgor yn penderfynu gwahardd y cyhoedd o'r cyfarfod ar gyfer eitem 5, yn unol â Rheol Sefydlog Rhif 17.42(ix).

Mark Drakeford: I move that

the committee resolves to exclude the public from the meeting for item 5, in accordance with Standing Order No. 17.42(ix).

[164] Gwelaf fod Aelodau'n fodlon.

I see that Members are content.

Derbyniwyd y cynnig.
Motion agreed.

Daeth rhan gyhoeddus y cyfarfod i ben am 10.35 a.m.
The public part of the meeting ended at 10.35 a.m.

Ailymgynullodd y pwyllgor yn gyhoeddus am 11.02 a.m.
The committee reconvened in public at 11.02 a.m.

Bil Adennill Costau Meddygol ar gyfer Clefydau Asbestos (Cymru): Cyfnod 1—Sesiwn Dystiolaeth 10
Recovery of Medical Costs for Asbestos Diseases (Wales) Bill: Stage 1—Evidence Session 10

[165] **Mark Drakeford:** Croeso nôl i'r Aelod sy'n gyfrifol am y Bil, Mick Antoniw, a phawb arall sydd yn ôl gyda ni heddiw.

Mark Drakeford: Welcome back to the Member responsible for the Bill, Mick Antoniw, and everyone else who is back with us today.

[166] Welcome back to all our witnesses for this follow-up session with Mick as the Member in charge of the Bill. Since we heard from you at the very start of the Stage 1 proceedings, as members of the committee, we have heard from a range of other witnesses. What members of the committee will want to do in the next hour is follow up those key points that we think have been raised with us and put them to you, Mick. Lynne, would you like to lead off?

[167] **Lynne Neagle:** One of the things we talked about in our earlier session was whether sufficient consideration had been given to, rather than the money coming back in centrally to the Minister, giving it back to the relevant health board where the costs had been incurred. Elin made the point that there is a likelihood that these cases will be concentrated in industrial areas, and therefore there is an issue of fairness as well. I wondered why you have decided on this particular mechanism of it going back to the Minister and her deciding from there.

[168] **Mick Antoniw:** The view that we have taken is how do we get the maximum effect from the moneys that are recovered across a range of additional support to asbestos victims and their families. So, you might be looking at issues relating to hospices and counselling for the families and the individuals themselves, and that sort of support. Of course, there are third sector bodies that provide a certain amount of specialist support already. If you are really going to get the maximum benefit and want to engage with not only those who are suffering, but the families and the other bodies that are involved, and with the health boards themselves, in identifying the best strategy when you have several million pounds to spend, we asked ourselves, 'How could it be used most effectively?'. For example, if there were an area of research that could benefit, it would clearly be more advantageous to have a collective pool in order to undertake that research from which everyone might benefit. The same might apply to technology.

[169] It is also worth making the point that, in many of the cases, and certainly in the case of mesothelioma, the treatment is carried out in certain specialist hospitals, where there are specialist units to deal with it. So, you will have a high preponderance of people who may be travelling specifically for that treatment to certain areas from outside their own health board area. The logic might be to say that all that money should go to them but, in fact, those people live in different areas and the support that they would require might come from another health board elsewhere. So, this is really about knowing the best way of using this money collectively. My thinking is that it would be better to have the pot and then to work out how to use it strategically so that it maximises the overall benefit for everyone.

[170] **Mark Drakeford:** I wish to pursue one point with you that Lindsay Whittle raised during our sessions. You mentioned research as a potential use for the money. Are you satisfied that the drafting of section 16 in the Bill sufficiently clearly allows for research to be one of the purposes for which this money could be applied or would it, for purposes of clarity, be better specifically to amend the section to identify research as one of those purposes?

[171] **Mick Antoniw:** Reading section 16, I think that it is fairly broad. It was described last time as being a bit woolly because it says,

[172] 'The Welsh Ministers must have regard to the desirability of securing that an amount equal to that reimbursed by virtue of section 2 is applied, in accordance with the National Health Service (Wales) Act 2006, for the purposes of treatment of, or other services relating to, asbestos-related diseases.'

[173] That incorporates research because research is part and parcel of evaluating what sort of treatment is used and how you treat individuals. As I mentioned the last time I gave evidence, I support in principle the idea of making annual reporting clearer and more accountable, along with the need for greater confidence in how it is used. I do not in principle have a problem with amendments that seek to strengthen that particular part of the Bill. I heard the Minister's evidence earlier, during which she gave a commitment to that effect. However, the specific answer to your question is that I think that it does incorporate that. It is sufficiently broadbrush, but I do not object to this aspect of the Bill being tightened up, if that is appropriate.

[174] **Jenny Rathbone:** Another aspect of the Bill that requires some clarification is exactly which aspects of care are covered in the compensation and which are not. Marie Curie gave evidence to us. At what point would the cost of NHS-funded care given by Marie Curie be recoverable, because some of the referrers are secondary carers, some are self-referred and others are GP-referred. It is clearly a service in a hospital, but it is a hospice. What is the definition of secondary or tertiary care, or how will you exclude primary care?

[175] **Mick Antoniw:** Primary care is excluded by the Bill itself. On the compensation element that you mentioned, it is important to distinguish and separate the compensation element because the Bill is not about the compensation. Although, for example, family members who provide care can form a part of the civil compensation claim by virtue of gratuitous care. So, there is provision within all of that.

[176] In terms of the money that will be recovered, the stage that we are at is that, after the civil action—because the civil action triggers the recovery—it is about what provision can be made on top of what might already be available. That might be through the third sector or the NHS itself—whether it is counselling, specialist additional nurse care, purchase of a particular item of technology and so on. Those are matters that the Minister will need to consult on in order to come up with the best strategy.

[177] **Jenny Rathbone:** In the case of an NHS hospital that wishes to commission care from a third sector organisation, because it thinks that that is the best place for a patient, that is commissioned by the NHS board and is a way of ensuring that people are not unnecessarily in the hospital. Will that be deemed as primary care?

[178] **Vaughan Gething:** This is about the administrative issue. At what point do you draw the line between the cost and the benefit that you recover? This is something that we took advice on in terms of the tariff. It would probably be helpful if Paul deals with this point. There is a wider issue here about primary care as well, about what the Bill does and does not seek to recover and why.

[179] **Mr Davies:** We looked specifically at 11 cases in detail. We went through their medical records from the onset of their diseases to their deaths and there were some instances of hospice care. None of the cases that we looked at were funded by the NHS, so they did not come within NHS costs. However, the Bill is proposing that, for the purpose of organisational fit and efficiency, we would apply the in-patient tariff. When we calculated the costs using the in-patient tariff, it equated to within 1% of the actual costs incurred. So, by using only the in-patient tariff, which does not include hospice care—only secondary and tertiary admissions—that is £720 per day and an average of £23,000 per case. The actual cost of every case, which included all care—including primary and hospice care—came to within 1% of the figure. So, we are saying that, by applying the tariff, it incorporates all the costs. If we ventured into a system of identifying all the actual costs involved in the recovery process, I think that we would have a major problem in terms of trying to get recovery. The tariff is the key.

[180] **Jenny Rathbone:** I understand that, but perversely, it might force the NHS to keep patients in hospital longer than might be in their best interests, because it would not be able to recover the cost of commissioning a third sector organisation to provide in-patient care.

[181] **Vaughan Gething:** I do not think that the Bill would change the way that clinicians treat patients or how the NHS commissions care. The reality is that this is about recovering money that the NHS has already spent. So, those costs will be incurred anyway. Looking back at the 1989 Act in relation to NHS recovery of costs and at the 2003 Act, which broadened that to all areas of personal injury apart from disease, that has not changed the way in which clinicians have made decisions about the best care for their patients and it has not changed the way that the NHS has commissioned care in England, Wales, Scotland or Northern Ireland, where Bills have been introduced and enacted. So, looking at the reality of how the changes will be made, I do not think that the Bill will change those decisions. This is just about being effective: do we want to recover the costs, and what is the most administratively efficient way to recover those costs? That is why we have come to this decision.

[182] **Mark Drakeford:** Thank you. Rebecca and Elin have questions on this point.

[183] **Rebecca Evans:** In terms of the change in methods of service delivery in the NHS and the move to offer people more care closer to home and in community and primary healthcare settings, would you wish to see the Bill amended to provide Welsh Ministers with the powers to extend the scope of the Bill in future, as more care is delivered closer to home?

11.15 a.m.

[184] **Mick Antoniw:** The provision in the Bill is fairly broad already and includes, for example—and I know that it has already been mentioned—hospice care and things like that. The question is: what is the most effective way of maximising the amount recovered in the most cost-efficient way? So, I think that those powers are there. If it were the case that the Welsh Government were to look at this and say, ‘We think that, because there was a change in provision, we should actually move away from the tariff system and not develop it’, then that possibility is there. In terms of bringing forward a system now, we have to look at what happens at the moment, and particularly at what happens with the mesothelioma cases, which are the most serious ones, and which are over a very narrow period of time, and also—to answer the point that you raised—cases where the majority of care, in fact, is normally provided by family members because that is what families wish. I think that that was evidence that was given by one of the support groups at one of the last sessions.

[185] **Elin Jones:** I would like to raise two issues. First, you have said that there is provision in the Bill to move away from the tariff system. Can you just explain to me a little bit about that because one of the strengths that you have advocated and that I recognise of this Bill is the tariff system itself? I just want you to explain how you think that a Minister may, in

future, want to move away from the tariff system.

[186] I am still slightly confused about how hospice care triggers the recovery of cost for NHS treatment in this context, because Marie Curie Cancer Care representatives told us in evidence that they are commissioned by the NHS to provide palliative services, that funding does not follow the individual, and that different hospices in Wales would have a different percentage of their income coming from the NHS and from voluntary organisations. Can you explain to me again how a referral from a hospital to a hospice for end-of-life care would trigger the recovery of NHS costs, or whether it may not at all?

[187] **Mr Davies:** It would not because, under the tariff system, the in-patient day tariff is a hospital tariff. So, whether it is secondary or tertiary care, that is the currency. Hospice care is not the currency even though the patient would have been referred from the NHS. The actual costs would certainly have to be included in total, but the assumption is that, at the moment, based on the cases that we have looked at, the tariff is sufficient to secure that money in total.

[188] **Elin Jones:** So, the hospice care part of it is sort of built into the hospital in-patient tariff.

[189] **Mr Davies:** It is a national UK tariff and it has been set up by the Department of Health. As has been already highlighted, it is uprated every year and so on. It is currently £755 per day. A lot of work has been done to try to work out the totality or composite figure that understands what the nature of the NHS is as a whole. Strictly speaking, it is not the cost of an in-patient stay in a hospital, because it would include out-patients and a variety of examinations such as scans.

[190] In terms of hospice care, I do not know whether that is fully a part of it. As I said, in the study that we looked at there was no instance of NHS-funded hospice care, so it was not included. There was little or no palliative time; the patients more or less died within 12 months.

[191] **Elin Jones:** On the issue that I raised with Mick about moving away from a tariff-based system and the Minister having the freedom to do that—

[192] **Mick Antoniw:** If there were changes in medical technology, medical treatment and so on, or changes that meant that the in-patient system was not effectively recovering the majority of costs, I would have thought it reasonable for the Welsh Government to want to look at an alternative. However, according to all of the information that we have, a tariff system—which is, again, a fairly broad-brush approach—would, at the moment and for the foreseeable future, recover the majority of those costs.

[193] **Mark Drakeford:** I think that Elin is asking where that flexibility in the Bill would be found. If a future Welsh Government wanted to move away from that system, where does the Bill give them that freedom?

[194] **Mick Antoniw:** It is in section 3, is it not? Section 2 is the liability to pay charges—

[195] **Vaughan Gething:** If you look at the way that the Bill is structured, you will see that the Bill does not require a tariff system, but, in reality, it has been predicated on there being a tariff system, and the explanatory memorandum makes that clear, because we think that it is the best way. It is about how the certificate for charges is generated. On the face of the Bill, in section 3(6)(a), primary care is excluded, but if you look at the paper that Members have had today from Paul Davies, you will see that primary care costs in the cases examined were only 1% to 5% of the cost. That is a point about administrative efficiency. If you try to gear up a system that looks at those costs and tries to recover them as well, you will spend more money

than you will receive. So, if Ministers wanted to move away from a tariff system, they could use their regulation-making power, but we do not think that that would be the most effective way forward at this point in time, because, as I said, it is the production of the certificates that generates the basis for the recovery of payment.

[196] **Mick Antoniw:** Specifically on that point, section 2 is the liability to pay charges, while section 3(5) mentions ‘treatment or other services’ in broad terms and, of course, in those sections the only exclusion is primary care. So, all the other payments that are made are covered by this legislation and that gives the Government flexibility. When you bring the tariff system into that, it is a question of whether that is the most effective method of recovery, but the powers are within that section and the information is again provided in section 6.

[197] **Mark Drakeford:** One last time, because I am not absolutely sure that I have followed all of this. Your answer to Elin’s question about how the Welsh Government could respond to changing patterns of services in the future is that, while the Bill is predicated on a tariff system, the word ‘tariff’ does not appear anywhere on the face of the Bill, and that section 3 gives the Government enough leeway to do it differently in the future if it thought that that was a better way of doing this.

[198] **Mick Antoniw:** Yes.

[199] **Mark Drakeford:** However, Rebecca asked you whether the Bill ought to be amended to give Welsh Ministers the power in future to recover costs in primary care, if, for example, a lot more care was being provided in that setting, yet section 3 specifically excludes primary care. So, they would not be able to do that.

[200] **Mick Antoniw:** They would not in respect of primary care. The reason why we excluded primary care was because we thought that the efforts to try to recover primary care costs would complicate and increase massively the administrative cost. As the paper that has gone around will also show, the primary care costs are a very small proportion. They also suffer increasingly from the question of why someone attends—comorbidity issues and so on. So, we felt that the simplest way of presenting this was to exclude primary care and to include all the others, but then to look at the system that might be the most efficient.

[201] **Elin Jones:** Do you have any objection to reference being made on the face of the Bill to regulation-making powers for the Minister to consider primary care and to remove the exclusion?

[202] **Mick Antoniw:** I do not have a problem with that, in principle. In fact, the reason why we excluded it was in response to the introductory debate, where quite a lot of emphasis was placed on the complications and the costs of recovering, so we felt that we should present something in response to that. However, I have no problem with that at all.

[203] **Mark Drakeford:** So, you could futureproof it in that way.

[204] **Mick Antoniw:** Yes.

[205] **Vaughan Gething:** When discussing the Bill at the outset, we discussed whether primary care should be included or not, and there is a simple practical point. The point of principle, as the Law Commission sets out in its evidence, is that there should be the ability to recover costs. In lovely legal language, it essentially says that there is ‘an unjust enrichment’ if somebody causes injury that results in compensation and they do not then have to pay the NHS costs that flow from that injury. So, the principle is there, and it does not exclude disease or any other acts; it is just a practical point about whether it is efficient and sensible to

try to recover those costs. However, there is no objection if Members want to suggest an amendment to the Bill to allow that.

[206] **Mark Drakeford:** Just to be clear, I do not think that any member of the committee is quarrelling with the point that you make about it being too complicated in current circumstances to pursue the recovery of costs in primary care. The problem is in looking ahead to a time when more treatment might be provided in the community and in primary care. Ought Ministers not have a regulatory power that would allow them to revisit this issue without having to remake primary legislation? That is the point.

[207] We will move on to William and then to Rebecca.

[208] **William Graham:** I thank Paul Davies for his useful additional papers for today. My questions are about the number of cases. You will have heard in evidence that your colleagues and practitioners suggested that the number of cases is likely to fall as time goes on, and that was more or less confirmed by Professor Phillips this morning. That makes your Bill all the more timely, but we have heard as a committee that there seems to be greater discovery of asbestos, so are there not potentially more asbestos-related diseases, which means that it is likely that the number of cases might actually increase in the longer term?

[209] **Mick Antoniw:** It is quite a difficult question because of the nature of the research and empirical evidence available. What we do know is that by around 2016 to 2020 the number of mesothelioma cases should start to plateau for a period. We currently have historical legacy cases from, by and large, heavier exposure, particularly industrial exposure and so on. We also know, however, that cases of asbestosis—which is a fibrosis of the lungs normally caused through fairly consistent and regular exposure—do not occur that often, so you are getting towards the end of the legacy of cases of those proportions, and I would say that we will probably see a reduction in those types of cases. There will be a period where it plateaus. I have seen it suggested that we have underestimated the number of mesothelioma cases and that they will probably increase for a couple of years more. The figures are not massive, but they are not insignificant. Then, after 2020, the overall number should be reducing. Of course, asbestos is not used anymore, although it is present in a lot of premises, so the question arises: will that trigger future cases or an increase in cases? I think the numbers will go down because the presence of asbestos in buildings normally means very limited exposure, provided it has been monitored and sealed and that measures have been taken over a period of time before the planned removal. There will undoubtedly be some cases, but I think after 2020 the number will start to go down. We will still have significant numbers of mesothelioma cases for at least the next two decades.

[210] **William Graham:** Have you been able to speculate in terms of treatment? Have you any evidence to suggest that treatment will get better in the period you discuss?

[211] **Mick Antoniw:** At the moment there is effectively no treatment for mesothelioma. Sometimes there is surgical intervention to relieve pain, but basically it is about the management of the final days of the process. There is some medication and there had been some questions marks over the availability of certain forms of medication; they are effectively all resolved, but of course new medication might come along. There might also be other technology related to radiography, because one of the problems with radiotherapy treatment of the lungs is that they are moving parts; how do you therefore focus the ray et cetera? There are considerable advances taking place there, but we are still in the very early days. However, in two or three years' time there might be something. My thinking is that if a very impressive but expensive piece of equipment suddenly came along that could actually treat mesothelioma, then that could be considered an appropriate use of this money.

[212] **Rebecca Evans:** I wanted to put to you the argument that we have heard from the

WLGA and the insurance industry and others, which is that what we are creating is a system whereby money is moved around the public sector. The insurance industry has suggested that 40% of cases receive their exposure to asbestos within the public sector, but the Minister suggested this morning that you might have different figures.

11.30 a.m.

[213] **Mick Antoniw:** I was surprised when I heard that, because it seemed to appear out of thin air in response to a question; it does not seem to be based on evidence, and I have not seen any other evidence for it. So, I did my best to carry out my own research on it, and I went to Thompsons Solicitors, which is a firm that I used to be with and one of the largest handlers of personal injury claims in the country. It took its last 165 settlements from the last 12 months and did an analysis of against whom the claims had been brought. Of the 165 cases, seven were against local authorities, eight were against Government departments—those are not necessarily Welsh Government departments, they could be UK Government departments—and none were against NHS trusts, although I know that there have been cases brought against NHS trusts in the past. That amounted to 9.09%. I remember, after I heard that 40% figure, wondering what, from my experience, I would have expected the figure to be, and, off the cuff, I actually said at the time that I thought it would be around 10%, so that seems to fit very much within that. So, there will be a certain number of local authority cases, but it will certainly be well below 40%. If anything, the statistics that I have been given are somewhat biased towards the higher end for the public sector, because of where the work comes from through to Thompsons, which is from public sector unions and so on.

[214] **Rebecca Evans:** We have also heard from the GMB that, although we expect a fall in the overall level of cases over time, within that, there would be a growth in the number of cases from the public sector. What is your response to that?

[215] **Mick Antoniw:** There is certainly a noticeable change beginning to occur in the sorts of people coming forward. In the past, you would have had the insulation workers—commonly known as laggers—and people working in heavy industry and on pipe work, where there is lagging, and so on. Those are the cases that are beginning to clear through, because of the latency period. What you are getting now are more cases from working in premises where there is asbestos, for example, electricians called in to work on a building’s ducting, around which is insulation. You are getting those kinds of cases, which involve a lot more maintenance workers, a certain number of people working in construction, and even a certain number of cleaners and so on. There is a shift away from cases of traditional heavy industry exposure to cases among maintenance/construction-type workers who come into contact with asbestos less significantly, but from time to time. Of course, those types of exposure are supposed to be controlled by the management of asbestos regulations in terms of monitoring, ceiling removal and so on.

[216] **Rebecca Evans:** What is your assessment of the level of insurance that exists within the public sector currently? Of the cases that you mentioned that Thompsons was handling, how many were unable to recover money from the public sector? Is there sufficient insurance?

[217] **Mick Antoniw:** All of them would have recovered money, because they had a judgment and a decision, and they were settled. Those are the settled cases. I do not have any figures for cases that were not settled or not proceeded with for one reason or another, but, of those, a very small number involve a local authority.

[218] **Elin Jones:** Do you have any views on whether the legislation could provide an exemption from the recovery of costs in cases against the Welsh public sector, so that we avoid this issue of the money turning in the same pool?

[219] **Mick Antoniw:** In principle, I would be opposed to that. If you start from the basis that it is right to recover the costs from the employers that are to blame, that should apply across the board, unlike the days when we had systems of Crown immunity or exemptions et cetera to protect particular interests. I think that that is wrong, and it goes against the theme of the legislation, which seeks fairness across private and public sectors. If you have negligently exposed somebody to asbestos, and that has resulted in disease and that results in a settlement, then that triggers an NHS entitlement to recover those costs for the purposes that the Bill and the explanatory memorandum have set out.

[220] **William Graham:** For clarity, are the cases that you considered all cases that you could trace, not just those that have entered the judicial system?

[221] **Mick Antoniw:** Sorry, what do you mean by ‘all cases that we could trace’?

[222] **William Graham:** In terms of compensation, not just those that are—

[223] **Mick Antoniw:** I know that the question has been raised as to how you identify a case. One of the attractions of using the CRU is that anyone who makes a claim, or any insurer who is dealing with a claim and wants to settle it, has to notify it. So, in fact, all of the cases that we are concerned with, wherever the exposure has occurred, because there is a settlement, agreement, judgment or whatever that has resulted in a payment of compensation to the individual, will already be registered with the compensation recovery unit.

[224] **Mark Drakeford:** How would the Welsh NHS know if a compensator did not seek the certificate from the CRU that the Bill states it ought to seek?

[225] **Mick Antoniw:** The answer is that it would not. However, it is an offence not to provide that information, and the practice is well established in terms of procedures in that, the moment that a claim is notified, the first thing that happens is that the CRU is notified. I have no evidence of any avoidance of notifying the unit. It would also be quite difficult to do, because there are often other reasons why an insurer would particularly want to make sure that the CRU knows about it, which relate to the repayment of benefits to the UK Government and sometimes off-setting some of them against some of the items of compensation. So, there is no real incentive for an insurer to want to avoid notification of such cases.

[226] **Mark Drakeford:** So, in reality, you think that it will happen in the way that is set out.

[227] **Mick Antoniw:** Yes.

[228] **Mark Drakeford:** Elin, do you want to pursue the issue of comorbidity?

[229] **Elin Jones:** Yes, I do. Thank you, Chair, for reminding me.

[230] We have had evidence from the insurance companies that, because this is very different from road traffic accidents, given that individuals who suffer from asbestos-related diseases are, on the whole, older and may well have other chronic conditions such as heart conditions, they might then challenge the tariff trigger on something not being an asbestos-related disease and as being something that could well be related to another disease. The Minister for Health and Social Services told us that her view is that it is quite clear in hospital records as to whether something is asbestos related, and that may well be quite clear in mesothelioma cases, but other asbestos-related diseases are far more difficult to assess and to relate to asbestos. I want to hear your views on whether you think that there could be a lot of use of the appeals process that you have put in your Bill for challenging costs that should be

recovered simply on the basis of being related to asbestos.

[231] **Mick Antoniw:** You are right to say that mesothelioma is not affected by this, because asbestos is the only known cause of it and, once it is diagnosed, the pathway becomes very clear. In respect of the lower end, the pleural thickening cases, they normally do not cause significant disabilities and are mainly scanned and then monitored, and are normally subject to some sort of provisional settlement, which might act as a trigger at a later stage.

[232] With regard to the question of whether there might be complications in respect of asbestosis in terms of comorbidity issues, there are some comorbidity issues with regard to asbestosis and asbestos-related lung cancer—that is, non-mesothelioma lung cancer—the biggest of which, obviously, is smoking. However, there is provision within the Bill that, when someone achieves a settlement, they will normally have a proportion knocked off if they are a smoker, which allows for that. So, there would be a proportionate identification. So, that will be clear on the face of the settlement with regard to the proportion of the cost that would be recovered. Where there are other comorbidity issues, it is normally fairly clear, when someone attends hospital as an in-patient in hospital, what that is for, because it normally involves radiography and a deterioration of the respiratory condition. I do not think that any other comorbidity issues will be a significant factor, probably no more than the comorbidity that occurs even in the case of accidents, where someone may have a back problem and suffer damage to the spine. There are proportionate comorbid factors that would cause that.

[233] In terms of appeals, the CRU’s experience of appeals is that 0.1% to 0.2% of 20,000 claims a year result in appeals. What you tend to have much more of is a mathematical challenge of the calculation and application of the costs, which are normally dealt with by means of a review. Again, there is provision within the Bill for the Welsh Government to amend the certificate, but what normally happens in practice is that a letter is sent in saying, ‘No, these figures are wrong for reasons A, B, C—will you please review them?’ The majority of them are dealt with that way, because they are predominantly to do with mathematical calculations.

[234] In terms of more complex legal challenges, I have never really come across one. I am aware of one right at the beginning of 1999 when the system came in, but beyond that I do not think that there is great scope for appeals other than on the calculation side, potentially.

[235] **Elin Jones:** I guess the reason I am asking the question is because the insurance industry may want to continue to challenge and use the appeals process, and that would be more costly to the Welsh Government, in having to answer letters and go to appeal, than envisaged in your explanatory memorandum. The insurance industry may well do that on the basis that it wants to prove that the system does not work, because it does not want it enacted in other places. So, I am looking for some confidence that the appeals process is likely to be used only in a very small minority of cases.

[236] **Mick Antoniw:** I think that the best evidence comes from the experience of what has happened with the 1999 and 2003 Acts, and also from looking at similar submissions that were made when the 2003 Act went through its consultation process. Do you want to add something on that, Vaughan?

[237] **Vaughan Gething:** I have had a look at the summary consultation that was undertaken before the 2003 Act, and very similar points were made about making the system more complex, added costs and additional burdens on insurers, in particular. Unsurprisingly, the Association of British Insurers was one of the organisations that made those submissions—it is a matter of public record. So, it is not a surprise to see similar arguments being made now. However, the 2003 Act in particular was implemented to cover all forms of

personal injury apart from disease, and there has not been a significant increase in premiums that anyone can identify, even the ABI. There has been no change in the way in which cases are run and fought from a legal point of view. The defendant lawyers acknowledge that, as well as the claimant lawyers. When you look at the number of additional CRU certificates and recoveries that have been made since the 2003 Act, there is a remarkably low appeal rate of 0.1% to 0.2%. So, there is a fairly large canon of evidence that you do not get appeals.

[238] With regard to the insurance industry and how it chooses to spend its money, when you think about it, would it really go down the route of trying to challenge certificates, and would it really be sensible to say, ‘We may not act reasonably if you pass this legislation’?’ I hope that that is not what it was saying, but there is no evidence to suggest that there will be a large number of very costly appeals.

[239] **Mark Drakeford:** William is next on this, and then I will go to Rebecca and Jenny for questions.

[240] **William Graham:** You say that there has not been a significant increase in premiums. Have we any evidence to suggest that the excesses have increased?

[241] **Vaughan Gething:** No. When the ABI was asked that, it was not able to provide you with any evidence to suggest that there had been an increase in premiums after the 1999 and 2003 Acts, or any change in the way that insurance policies were dealt with. That is for the ABI to put to you, because we are not aware that that happened at all. Of course, we cannot disprove something that does not exist.

11.45 a.m.

[242] **Rebecca Evans:** You said that fairness is the driving principle behind the Bill. In relation to what Vaughan has just said, the ABI told us that the retrospective impact of the Bill makes it fundamentally unfair for its members, particularly because it differs in that way—for them—from the 2003 Act. What do you make of the ABI’s position?

[243] **Mick Antoniw:** The legal position partly relates to the points raised on competence. The competence issue has been dealt with by the Presiding Officer, and I think that the Minister has also dealt with it. Part of that view is also based on the fact that the issue of retrospectivity and the human rights issue—which I know has been raised—were well-canvassed in the AXA case, when there was an insurance industry challenge to the decision in Scotland to legislate on the pleural plaque issue. I believe that the Welsh Government was represented in that case as well. That case has basically overridden this and made some points about retrospectivity very clear. Retrospectivity already exists in the 2003 Act. Insurance is always about uncertainties in the future, so I do not think that that argument has real validity there either. This issue has already been canvassed legally, which supports this legislation. This legislation has the precedent of the 2003 Act, as well as the support of the Scottish decision, which confirmed that the social objective justified dealing with issues of retrospectivity and the infringement of the right-to-property argument as well. Ultimately, we rely on the fact that the Presiding Officer has confirmed that this is within competence.

[244] **Mark Drakeford:** Joanest, would you like to add something?

[245] **Ms Jackson:** Yes. I would like to stress that the Bill applies only to settlements made after the Bill comes into force. It will have no effect on settlements that have already taken place. That was canvassed in the AXA case. While the 2003 Act is often referred to in relation to road accidents, it goes considerably beyond road accidents and relates to any industry. It would therefore apply to any catastrophic accident that occurred—for example, a blast furnace exploding due to any negligent act. To repeat the point: yes, the wording in the

2003 Act and the Bill before you is identical in applying to insurance policies that were in place prior to the 2003 Act coming into force and to the Bill.

[246] **Mark Drakeford:** That is very helpful. Thank you.

[247] **Jenny Rathbone:** I want to go back to the possibility of increased numbers of appeals in relation to the four types of conditions that trigger compensation, or the recovery of costs, and the 165 cases that were recently settled by Thompson Solicitors. Do you have a breakdown of how many of those cases involved mesothelioma and how many of them involved the other three conditions?

[248] **Mick Antoniw:** I do not.

[249] **Jenny Rathbone:** I can see complications arising. If you have pleural thickening or asbestosis, which are chronic conditions that are not necessarily terminal, at what point do you need to seek compensation for asbestos exposure?

[250] **Mick Antoniw:** When someone starts having problems, such as any form of respiratory problem including coughing, and is sent for radiography, which clearly identifies the presence of asbestos, that does not necessarily confirm that there will be any resulting disability. The reason why pleural plaque was excluded was that, although there is scarring of the lungs, there is no evidence of disability associated with it. I do not have a breakdown of these 165 cases. If I was to hazard a guess, I would say that probably a third of them are mesothelioma cases and two thirds are not. My main concern at that time was to identify the breakdown of the defendants at the time. If it would help, I could obtain that information. However, I am not quite sure whether it would add anything.

[251] **Jenny Rathbone:** Okay, that is fair enough. I was just trying to test whether insurance companies would be more tempted to challenge whether an injury was asbestos related or not. However, you are saying that it is categorical that in all these cases the presence of asbestos could be identified through medical tests.

[252] **Mick Antoniw:** Yes.

[253] **Mark Drakeford:** I have two questions, and then I will look to see whether there are any final questions from other committee members.

[254] I will ask about the CRU. The explanatory memorandum explores four different options for the administration of the system and it comes down in favour of the CRU. We tested that with most witnesses that have been before us, and almost all of them agree with the choice that the EM proposes. Do you envisage, assuming that the Bill moves into further stages of its consideration by the Assembly, that there will be any firming up of the view of the CRU in relation to its willingness to play the part that is being proposed for it?

[255] **Mick Antoniw:** There is no reason why the CRU would not do that. It already has a clear relationship with the Welsh Government in respect of road traffic and other personal injury cases that come forward. There have been discussions—I saw the Minister give evidence earlier on this—and negotiations have gone well, but they cannot be taken further forward until the legislation is in place and they can talk about a specific plan. Also, in the explanatory memorandum, you will see that certain costings have taken place. I cannot see any reason at all why the CRU would not want to do it; it is exactly what its system is set up for, so it would require purely a tweaking of the system to do it. It is there for this particular purpose, for the whole of the UK as well. So, I do not envisage that there would be any difficulty.

[256] **Mark Drakeford:** I am making a remark now, rather than asking a question, but I think that it would be fair to say that members of the committee have heard what you just said, and have heard it said by other witnesses, and, in general, understand the reasons that you are putting forward. However, there is a bit of a feeling that we are being asked to sign up to a set of administrative arrangements without yet having fully tested whether the organisations that we would be relying on would be in a position to do it. The Minister said that there had been preliminary discussions with the CRU, but that they were preliminary, and I think that there is just a bit of a feeling that as the Bill proceeds, a bit of a firmer indication from the CRU that it would be in a position to do this job would be helpful.

[257] **Mick Antoniw:** That is a point that we will try to sure up. The difficulty that I have is that I do not have any status to approach it to secure agreement.

[258] **Mark Drakeford:** I understand: you have to do it at a third-party level.

[259] My second question is a completely different one. Section 17 of the Bill says briefly and elegantly that ‘This Act binds the Crown’. Have you sought the consent of the Secretary of State on that provision?

[260] **Mick Antoniw:** I understand that there will be, or that there is normally, Government-to-Government communication. Immediately after the introductory debate, the step I took was to notify the Secretary of State for Wales of the legislation, and sent him copies of the legislation for him to raise any issues or matters that he wished at that stage. I have not had a response yet.

[261] **Mark Drakeford:** So, the Secretary of State is aware of the fact that the Bill makes that provision.

[262] **Mick Antoniw:** Yes. The Secretary of State is aware. I specifically ensured that he was made aware.

[263] **Mark Drakeford:** That is fine; thank you.

[264] I want to put this final point to you: the Presiding Officer considered whether it would be required to have the consent of Her Majesty the Queen and of the Duke of Cornwall for the Bill to be passed by the Assembly. She concluded that these consents may be necessary, and that the Member in charge has been asked to address that issue before Stage 3. Is that in hand?

[265] **Mick Antoniw:** It will be in hand. I will make the appropriate approaches to the referred-to persons.

[266] **Mark Drakeford:** I am sure that their numbers are in your phone book. [*Laughter.*]

[267] Are there any final questions that Members want to put to the team who are in charge of the Bill? I see that there are none. Thank you very much for coming back to help us explore the issues that have arisen during our Stage 1 consideration.

[268] The committee is now closed for this morning; we will reconvene this afternoon. Lindsay, I know that you will not be with us this afternoon. William, you will not be here at the beginning of the session, but you will be here after that. Diolch yn fawr iawn.

Gohiriwyd y cyfarfod rhwng 11.55 a.m. a 1.33 p.m.
The meeting adjourned between 11.55 a.m. and 1.33 p.m.

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

[269] **Mark Drakeford:** Prynhawn da a chroeso nôl i chi gyd i'r Pwyllgor Iechyd a Gofal Cymdeithasol. Rydym yn bwrw ymlaen at eitem 7 ar ein hagenda heddiw, sef y Bil Trawsblannu Dynol (Cymru). Dyma'r sesiwn dystiolaeth gyntaf yng Ngham 1 o'r broses o graffu ar y Bil, ac rydym yn mynd i dderbyn tystiolaeth gan yr Aelod sy'n gyfrifol am y Bil, sef y Gweinidog Iechyd a Gwasanaethau Cymdeithasol. Croeso, Weinidog, am yr ail waith heddiw. Mae tîm o bobl yma i helpu'r Gweinidog yn y sesiwn hon. Beth am i ni agor y sesiwn drwy ofyn i bob un o'r swyddogion i roi eu henwau a'u swyddi ar gyfer y cofnod?

Mark Drakeford: Good afternoon and welcome back to the Health and Social Care Committee. We move on to item 7 on our agenda today, which is the Human Transplantation (Wales) Bill. This is the first evidence session in the Stage 1 scrutiny of the Bill, and we will receive evidence from the Member responsible for the Bill, namely the Minister for Health and Social Services. Welcome, Minister, for the second time today. There is a team of people here to help the Minister in this session. How about we open the session by asking each of the officials to give their names and job titles for the record?

[270] We will just ask Grant and the others to put their names and titles on the record for us. We will then ask the Minister for any opening remarks and go into questions in the normal way.

[271] **Dr Duncan:** I am Grant Duncan, the deputy director of healthcare quality division.

[272] **Ms Vernon:** I am Pat Vernon, policy lead for the organ donation legislation.

[273] **Ms Wakeling:** I am Sarah Wakeling, senior lawyer in the health and food safety team in legal services in the Welsh Government.

[274] **Mark Drakeford:** Croeso i chi i gyd y prynhawn yma.

Mark Drakeford: Welcome to you all this afternoon.

[275] **The Minister for Health and Social Services (Lesley Griffiths):** Thank you very much, Chair. I am very grateful to have the opportunity to open your Stage 1 scrutiny of the Human Transplantation (Wales) Bill. You have just heard who I am accompanied by today.

[276] On average, three people die every month in Wales while waiting for a transplant. We believe that a soft opt-out system will lead to a significant improvement in the prospects of people on waiting lists in the future. We know that transplant surgery extends lives, improves the quality of lives and is cost-effective. Donor families find comfort in knowing that the death of a loved one provided such benefits to others. I hope that, as you scrutinise this legislation, you will keep those benefits as well as others in your minds.

[277] This is evidence-based policy. Studies have consistently shown that countries with opt-out systems for organ donation generally have higher rates of donation per head of population. It really is all about clarifying people's wishes. Research has also shown that families are much more likely to agree to organ donation when a loved one dies if they know what the deceased's wishes were. I know that you will want assurances about the safeguards that are in place.

[278] One main safeguard is our commitment to ensuring that everyone in Wales becomes aware of the new legislation and how it works. Our plans for a public-awareness campaign are absolutely unprecedented for publicity about organ donation in Wales. We are also

committing ourselves to continuing awareness raising into the future through a duty in the Bill to promote transplantation.

[279] No doubt, we will discuss in detail the role of the family of the deceased in organ donation, but, at the outset, I wish to be very clear about two guiding principles. First, the Bill starts with the principle that we must clarify and uphold the wishes of the deceased and that we alert everyone to how the legislation works and then they make a choice, including the choice to do nothing. If a person becomes a potential donor, the family can provide evidence that the deceased wished to opt out. Secondly, I am confident that every clinician in the country wishes to deal with families in an extremely sensitive manner and would not insist that organ donation goes ahead in the face of any strong opposition. This is the practical reality that applies now, even when people have opted in, and that is reported to be the case internationally whatever the law of a particular country. I am very happy to take questions.

[280] **Mark Drakeford:** Thank you for that. We will go to Lynne for the first question.

[281] **Lynne Neagle:** My first question is on the issue of family. You highlighted the fact that clinicians would not want to pressurise families into agreeing to organ donation. In the explanatory memorandum, it says that there would be sensitivity to the views and beliefs of surviving relatives and goes on to say that that means that clinical teams would not add to the distress of families by insisting on donation. It also says:

[282] ‘It is important to be clear, however, that families do not have a legal veto because the law will recognise the deemed consent of the deceased as having precedence.’

[283] Those seem to be contradictory statements. How will you marry those up, particularly in the light of what you said in your opening remarks about the views of family?

[284] **Lesley Griffiths:** The situation is as it is now. There is no veto now. So, we are saying that the law is all about the deceased person’s wishes and not the family’s. However, if a family really objected, because, obviously, the clinicians have a duty of care to the family, the organ donation would not go ahead.

[285] **Lynne Neagle:** May I ask another question?

[286] **Mark Drakeford:** Rebecca just wanted to come in on this point.

[287] **Rebecca Evans:** No, my question is on a different point.

[288] **Mark Drakeford:** Okay, go ahead Lynne.

[289] **Lynne Neagle:** My other question was on the public-awareness campaign. Clearly, it is important that everyone understands how the system will operate if this becomes law in Wales. Can you provide more detail on exactly how that will be communicated to everyone in Wales?

[290] **Lesley Griffiths:** The budget for the awareness campaign is around £2.9 million, which is a huge amount of money, and the most that we have ever put towards such a campaign. We are working on how that will pan out, but we are committed to ensuring that everyone knows about the new piece of legislation. That will probably mean direct mailing. There will be a lot of focused publicity with, for example, faith groups, or hard-to-reach groups; that will be important. The law will apply from age 18 upwards, so we will need to ensure that the rising 18s are also aware of it.

[291] **Dr Duncan:** We must recognise that we need to use different methods to reach

different communities. In some communities, people might not read material, so we might need more visual material or we might need to engage with community leaders. In other cases, given that younger people access information in different ways these days, we need to access those channels.

[292] We have engaged a public relations consultancy to help us through this; so it is being dealt with by a professional communications body. The work that was done at Christmas time when the Bill was launched and the Heart to Heart touring campaign, which starts tomorrow, has already had significant coverage. It will also be subject to testing and learning as we go along. So, there will be continual evaluation of whether the message is being understood and whether we need to refine it and apply a different method. So, it is an active, ongoing system.

[293] **Lesley Griffiths:** I would also like to say that it will be a duty on Welsh Ministers to continue to promote and publicise this, even after the law is enacted. For instance, I mentioned 18-year-olds; we estimate that about 39,000 people a year reach the age of 18. So, every year, we will ensure that that group of young people is made aware of the legislation, in addition to the publicity that will go alongside it.

[294] **Dr Duncan:** Of course, there are already many other groups in the third sector who know how to engage with their communities and we are working with them as well.

[295] **Mark Drakeford:** Minister, on this point, the purpose of the Bill, as you say, is to increase the level of organ donation in Wales. I think that the Government estimates that about 15 extra donors might come forward as a result of the changes in the law that the Bill proposes. What would you say to the large number of people who have written to the committee saying that if the amount of money that you intend to set aside for publicising the Bill was invested instead in the sorts of measures that we know are effective in increasing the number of people who would join the current register, that would be a more effective way of reaching the policy objective that underlies the Bill without all the difficulties that those people envisage within a presumed consent system?

[296] **Lesley Griffiths:** I would say that that is just not enough on its own. Transplantation is an extremely cost-effective form of treatment. If we are doing it from a purely financial point of view, we know that one extra donor would prove cost-effective. We have had a detailed analysis of that. However, it is not just about finance; it is about the quality of life. I am sure that if any Member, like me, has met somebody who is on dialysis, for example, you will know that dialysis is three times a week for life. Their quality of life is greatly affected and if they have a transplant, they are taken off dialysis; it is no longer needed. So, from a purely financial point of view, it is extremely cost-effective.

[297] **Mark Drakeford:** On a slightly different note, we accept what you said about the cost-effectiveness of transplantation. However, it is more a case of, if you have £2.9 million to spend, would you get more donors for your money if you concentrated it on a better publicity campaign around the current scheme, rather than changing the law in the way that the Bill suggests and then having to spend £2.9 million to explain the new system?

[298] **Lesley Griffiths:** I do not think so. We have had very good publicity campaigns following the organ donation taskforce and its recommendations that have been implemented. So, we have tried that. Having said that, I do not think that any one thing works, even this system will not give us all the donors that we would like. It is a matter of having lots of different strings to the bow, to pull together.

[299] **Dr Duncan:** To add to that, as the Minister says, the evidence paper that we published alongside the Bill in December says that it is communication and legislation working together and that the greatest success in increasing donation rates has been in those

countries that have legislative back-up for opt-out systems.

1.15 p.m.

[300] **Lesley Griffiths:** It is also about a change in societal attitude. We need to make organ donation the norm. We do not talk about it as much as we should. In the countries where we have seen soft opt-out systems or opt-out systems, you see that much more: it is part of normal society.

[301] **Rebecca Evans:** In the report to which Dr Duncan has just referred, the Welsh Government concluded that it cannot be inferred that the increased organ donation rates that have been associated with countries with opt-out systems for organ donation are as a direct result of presumed consent. What, in these countries that have presumed consent, is raising the rate of donation? If it is not presumed consent itself, what else are they doing?

[302] **Lesley Griffiths:** As I just said, it is about making donation much more a normal part of everyday life, which it clearly is not in the UK at present, or in Wales. That is one aspect of it. Do you have anything else to add, Grant?

[303] **Dr Duncan:** I must agree with you: it is multifaceted, it is complex and in each country it is perhaps different. However, there seems to be an overriding issue that it is a matter of the clarification of individuals’ wishes. The countries that have opt-out systems have clearer mechanisms so that individuals’ wishes are known more when they are alive, and families are more inclined to be positive, to support and to consent when they know their loved ones’ wishes.

[304] **Mark Drakeford:** Lynne, would you like to come back on this point?

[305] **Lynne Neagle:** In relation to what Mark said about the numbers of people that you anticipate will become available for organ donation, some constituents who have contacted me object to the Bill and have said that they believe that it should be a gift that they are giving and that therefore, as a result, although they are on the organ register now, they will remove themselves if this becomes law. To what extent have you looked into that as part of your deliberations around this issue?

[306] **Lesley Griffiths:** We have looked into that and I have some figures, if I can find them in my briefing. I think that 60% of people who are on the organ donation register now have said that they would stay on it. Then, there is a teen percentage that said that they would remove themselves, and another teen percentage that said that they did not know whether they would remove themselves from the register. It is important to remember that people can opt out. We are giving them the choice. It is a gift. I completely agree, and I know that it is a very sensitive and emotive issue. I am very aware of that, but people can opt out.

[307] **Mark Drakeford:** Would you like to address that basic issue one more time with us, Minister? A great deal of the evidence that we have had from people who do not support the Bill, particularly from faith communities, start from that premise: that the Bill corrupts the gift relationship; that, at the moment, when people donate organs they have made a positive choice to do that, and that by removing that positive choice and making it a matter of presumed consent, the Bill erodes a very important principle. That is not the Government’s position, obviously, but perhaps you would like to set out the Government’s contrary view to that proposition.

[308] **Lesley Griffiths:** I know that it is an issue for some faith groups, and we have made a huge attempt to reach out to as many faith groups as we can during the White Paper consultation and during the draft Bill consultation. I will ask Grant to come in on this, but I

know that we have a clinician working with some specific faith groups at the moment. As I say, the underlying thing is that people can opt out. It is very important to remember that. They can opt in, they can opt out, or they can do nothing and then it would be deemed consent. Perhaps Grant would like to say more about the clinician who is engaging with the black and minority ethnic community.

[309] **Dr Duncan:** On the issue of gift, in some ways, you do not just have to opt in for organ donation to be a gift. Of the large number of people who say that they are in favour of organ donation, which, from memory, I think is around 90%, only 30% or so go on to be on the register. So, a deemed consent system is one where people say, if they so wish, ‘I express a wish positively, yes’, or decide to opt out. Equally, in Wales you will know that your organs will be available and, in some ways, it enables you to make that gift rather than the opt-in registering system.

[310] In terms of the faith groups, we have engaged a company called Cognition, which has already been working with the different groups in Wales. So far, it has met with representatives of about 50 different organisations. Part of that is for them to give us advice on the best way of engaging with these groups, and using different methods, so that we can talk to and with them and explain in a better way than we have done up to now.

[311] **Lesley Griffiths:** We accept that we have a great deal of work to do. For instance, there is one group about which one person has said that all 10,000 of its members living in Wales are against organ donation. We know that that clearly would not be the case. So, it is really important that we do that.

[312] **Mark Drakeford:** We will go to Elin next, but I have one last question that relates to the point that has been raised about publicity events. What assurances can you offer, Minister, that, in the publicity effort that will be made—the direct mailing and so on—the ability to opt out and the ease by which that can be done will be prominently included?

[313] **Lesley Griffiths:** It is absolutely vital that we do that. If we want everybody to understand the law, it is absolutely vital that everybody understands that they can opt in, they can opt out, they can do nothing, but if they do nothing, it will be deemed consent. So it is correct, right and appropriate that all three possibilities are set out.

[314] **Mark Drakeford:** I will go to Elin next and then to Mick and Rebecca.

[315] **Elin Jones:** Much of the public debate and, indeed, your Government’s justification for this Bill, has been about the life-saving potential of increased organ donation. However, other novel forms of transplantation may not be life-saving, such as, for example, face transplantation. They are not excluded from deemed consent and they are included within the scope of this Bill. Why did you choose not to specify that this was deemed consent for organ donation for life-saving activity?

[316] **Lesley Griffiths:** It is the same as what exists now. When somebody goes to register on the organ donation register, there is a list of organs and tissues, because you can partially register and include some of your organs and tissues. Not everybody wants to register for everything on the list. It will be the same now: the novel transplants, like hands, limbs and face, will not be on that list.

[317] **Ms Vernon:** As part of the communication campaign that will go ahead, we will have to make it clear which organs and tissues are covered by the deemed consent system. So, that will feed into the public’s understanding of what the consent would be deemed for. Novel forms of transplantation will not be included.

[318] **Elin Jones:** They are not included, although section 16 of the Bill says that,

[319] '"relevant material" means material, other than gametes, which consists of or includes human cells.'

[320] My face would come under that that, would it not?

[321] **Ms Vernon:** What the Minister was referring to is that the current Human Tissue Act 2004 does not specify which organs are included either. So, we would specify which organs are included within the deemed consent system in the publicity campaign, which would make it clear that we are not going to include, for example, the novel forms of transplantation that you have just referred to. You could never deem that somebody had consented to that sort of transplant.

[322] **Elin Jones:** Why would that not be on the face of the Bill?

[323] **Ms Wakeling:** It is something that has been considered. You will have noticed in the explanatory memorandum that the form of the Bill tries as far as possible to be mindful of the existing Human Tissue Act and the UK systems. This approach, in terms of the relevant material, which you picked up on, is exactly the same in the Human Tissue Act 2004. It is an interesting point on which we have focused, and I can see the point that you are making.

[324] **Elin Jones:** The point that I would make is that that Act is from 2004, and this Bill is in 2013. In terms of futureproofing legislation, these novel forms of transplantation have come in and are used more now. I am asking this question because, in the public debate, the justification that I and others have used is that this is about life saving, but this reads as if it is not only life-saving activity that could get caught up in deemed consent into the future.

[325] **Lesley Griffiths:** It is certainly something that we can look at, so that we can be more clear.

[326] **Mark Drakeford:** Thank you; that would be helpful. I am just trying to think of the difference between opting in—where you have a list of things that you can choose to opt in to, including research and so on—and deemed consent, where there would be a much more restricted list that you can have deemed to have given your consent for.

[327] **Lesley Griffiths:** It would be the same list as it is now.

[328] **Dr Duncan:** As it stands now, when you go to register it says, 'Do you wish to register?', and 'Do you wish to deselect any of the following list of organs?' People can choose if, for example, they do not want the heart or liver to be used. That would be the same—people could still opt in, but then opt out of individual organs and tissues.

[329] **Mark Drakeford:** I am sorry; maybe I am being very slow here, and not understanding, but in a presumed consent system, where you have not even seen the list, are you assumed to have opted in to the full list, or do you say that it would be a more restricted list that deemed consent would apply to? It would not apply to novel forms of transplantation, like face transplantation, and so on.

[330] **Lesley Griffiths:** The list as it stands now will be the same. If you are opting in you will tick the list. If it is deemed consent, it will be presumed that the whole of the list applies. However, that will not include novel forms of transplantation. Is that clear?

[331] **Mark Drakeford:** I think so.

[332] **Lynne Neagle:** Will it include research?

[333] **Lesley Griffiths:** No. It would just be the list of organs and tissues.

[334] **Mark Drakeford:** Elin, do you want to pursue that any further?

[335] **Elin Jones:** I am okay for now.

[336] **Mark Drakeford:** I will go to Mick next.

[337] **Mick Antoniw:** I have a few questions around the issue of consent and how the system will operate in practice. Deemed consent does not apply to those under 18—to children. However, in considering with a child the decision about whether to consent to transplant, the wishes of the child will be taken into account. I found that a little bland in the way that it is presented within the Act, because a child can be of any age. Have I got that right?

[338] **Lesley Griffiths:** Again, it is as it is now. Parents can register their child as an organ donor.

[339] **Mick Antoniw:** So, there is no issue as to how that consent is taken into account or anything. Nothing changes for the under-18s.

[340] **Ms Wakeling:** No. The law in relation to under-18s is the current law, as set out in the Human Tissue Act 2004. That is largely replicated in the Bill.

[341] **Mick Antoniw:** As it stands, where there is a family dispute involving an adult or a child as to whether consent should take place, even if someone has opted in, if a member of the family objects, irrespective of the opt-in with the card, and so on, no transplantation would take place. Is that right?

[342] **Lesley Griffiths:** It would not go ahead. That is the case now, and that will be the case under this piece of legislation.

[343] **Mick Antoniw:** In terms of the way that the Bill will operate, there is provision within the Bill on consent—I am looking particularly at section 7—where a person may, for example, appoint individuals to be their representatives, who may already have an indication from the individual with regard to the wishes of that individual, and so on. It seems to me that this is the sort of area where you start getting into potential areas of argument or confusion. So, the first thing I wish to ask is: who will take responsibility for saying, ‘Yes, I’m satisfied that these people are appropriately appointed and that this individual has consented in writing or otherwise, and that there are two witnesses’? The last thing you want when you are in that situation is uncertainty as to whose job it is to sign the form and say, ‘Yes, we can go ahead’.

1.30 p.m.

[344] **Lesley Griffiths:** There is provision to appoint a representative under this piece of legislation. When the person who is appointed by an individual registers, the appointed representative’s name will be placed on the register. So, it will be very clear who the appointed representative is, and they will then be able to say what the person wanted and be able to prove that they are the appointed representative, as that will be on the register.

[345] **Mick Antoniw:** If there is an oral appointment, however, where you are asking for corroboration, there will not be anything like that, of course. How will you know?

[346] **Lesley Griffiths:** Do you mean if somebody says that they are the appointed representative?

[347] **Mick Antoniw:** Yes.

[348] **Lesley Griffiths:** Well, that would not be the case; they would have to be on the register as the appointed representative.

[349] **Mick Antoniw:** So, where it says that:

[350] ‘An appointment may be made orally or in writing’—

[351] I hope that my understanding of how this operates is right—an individual could be in hospital, having been severely injured et cetera, and two people can come up to the administrators to say, ‘We have been appointed by so-and-so, and these are the witnesses’, and so on. In terms of verifying all of that, will each hospital have a designated person as the only person who can do it, with substitutes et cetera?

[352] **Ms Vernon:** This will form part of the process of leading up to whether or not you seek consent, or seek to determine whether or not deemed consent would be applied. It is almost part of the conversation that you would have. I would add that the section on nominated representatives in the Bill more or less replicates what goes on now under the existing arrangements.

[353] When it comes to checking whether a person really is the nominated representative of the deceased individual, the Human Tissue Authority code of practice covers that already, to an extent. However, I think that it would be looking for reasonable evidence that you would probably expect someone who is an appointed representative to already have and to be able to produce. In terms of responsibility for it, there is a team of trained specialist nurses whose job it is to conduct these assessments, and so it would be part and parcel of that role to establish these sorts of facts before proceeding any further.

[354] **Mick Antoniw:** In any situation, whether someone has opted in or there is deemed consent, if there is any dispute from family members then, in practice, the donation will not proceed. Is that a correct understanding of the situation?

[355] **Lesley Griffiths:** Yes, that is as it is now. If the family objects strongly, the donation would not go ahead, because the clinicians have a duty of care to the family as well.

[356] **Mick Antoniw:** So, even if one member of the family is keen for the donation to take place, if another member of the family says ‘no’, or any member of the family disputes it, donation will not proceed.

[357] **Lesley Griffiths:** Yes. Disagreements do take place now, but there is the Human Tissue Authority code of practice. Obviously, the matter would have to be dealt with very sensitively, and we are working now on a new code of practice, ready for the legislation, with the Human Tissue Authority.

[358] **Mick Antoniw:** I do not know whether this is an issue or whether I am stretching this too far in terms of possibilities, but where you may have, for example, the immediate spouse or children saying ‘yes’, but somebody further down the family chain objecting, how would those situations be dealt with? Would it still be taken as a reasonable objection? When does an objection cease to be a reasonable objection?

[359] **Ms Vernon:** In reality, what needs to take centre stage is the wishes of the deceased,

and what the current guidance in the code of practice tends to focus on is keeping that at the centre of discussions. So, even though there could be family disagreements, regarding what the family wants, at the end of the day, it has to be about what the deceased would have wanted. Under a deemed consent system, if the person lived in Wales and knew that we had the deemed consent system in Wales and had not opted out, that forms part of what they would have known about, if I can put it like that.

[360] **Mick Antoniw:** I understand that and that answers the points that have concerned me about the legislation, because it seems that, in reality, it is not actually changing things, but is an aspiration seeking to change the culture to set a social standard. However, the concerns that exist—I think that everyone will have had representations on this—seem to focus on the uncertainty or confusion around the guarantee that, irrespective of the individual's wishes, or if a spouse or a member of the family is dead against it, in those circumstances it will not take place. Why is it not appropriate to incorporate that in some way into the legislation itself? That is an area where there is a bit of confusion. The Bill as drafted states one thing, but then we are being told, 'Oh yes, but that is all right, because in reality this is what will happen'. People then say, 'Well, it is all very well saying that now, but'—

[361] **Lesley Griffiths:** Basically, what you are asking is why there is no veto. Is that what you are asking?

[362] **Mick Antoniw:** I think so.

[363] **Lesley Griffiths:** Okay. I suppose that it is because the law is about the deceased person's wishes and not those of the family. So, it is important that the law maintains that the choice to consent to the donation lies with the individual when they are alive. That includes the choice to have their consent deemed. Does that answer your question?

[364] **Mick Antoniw:** I will not explore it further. I understand what you are saying and I understand the point you are making. It is an area that I think still causes concern, even though I understand and I think I agree with what you are saying.

[365] **Dr Duncan:** I would like to add to that, briefly. The situation that exists today is that, in Wales, some 32% of people are on the organ donation register. That means that about 68% of transplants involve families who do not know the wishes of their loved one. The evidence demonstrates that, where the families know the wishes of the deceased clearly, they take more comfort in that and tend to want to uphold them. So, it is cases where you have uncertainty as to the wishes that can lead to greater disputes.

[366] In addition, in the last survey that we did of the Welsh population, some 73% of people said that they wanted their wishes to be upheld. That strongly reinforces our belief that we should be looking through the lens of the individual's wishes and making sure that we go to all lengths to explore how they can be clarified with the family and how the family can be brought to understand their wishes.

[367] **Lesley Griffiths:** I would reiterate that this happens now. I think that about 13% of people who have registered as organ donors do not have their organs donated after their death because their family objects.

[368] **Mick Antoniw:** So, what we are doing is maintaining, although not on the face of the Bill itself, a right to override this for humanitarian and social purposes, really.

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

[370] **Mark Drakeford:** Elin has a question on this, briefly.

[371] **Elin Jones:** You are almost seeking to change an unknown unknown into a known unknown. However, I will leave that to one side.

[372] You have referred to the fact that you are redrafting the code of practice in light of this legislation. It may be useful for us and for the public to see a draft of that code of practice well in advance of our final deliberations on this Bill.

[373] **Lesley Griffiths:** Yes, absolutely. That is a very important point and the code will be laid before the Assembly for scrutiny in due course.

[374] **Mark Drakeford:** Vaughan, did you have a question on this?

[375] **Vaughan Gething:** Yes. My question relates to the issue of consent. Having heard a lot of what has gone back and forth on this, I am interested in the point about who the Bill would apply to and, in particular, the point about residency and whether someone is ordinarily resident in Wales or not, and how that applies to excepted adults who die in Wales, but who are not ordinarily resident. I have read what the explanatory memorandum says, but I wish to clarify whether, if you are working in Wales for a contracted period, after which you would expect to leave Wales but you die during that period, you would be classed as ordinarily resident. If you were here on a 12-month contract and you died during the ninth month, are you caught as having been deemed to consent, having been within the country for that period? If you are an undergraduate student, does it make a difference if you die in the summer term of year 1, 2 or 3 of your course? Most students would expect to return home at the end of their first undergraduate year, but plenty of students stay, whether they are from Wales or not. We know of many higher education institutions—I am thinking of Aberystwyth—where the majority of students come from England. Are they considered to be ordinarily resident after having attended two and a bit terms of university? How does this apply to them? This is a fairly large category of individuals, and students are notorious for not paying much attention to what goes on around them, so despite the communication campaign, they may pay no attention to it at all.

[376] **Lesley Griffiths:** It will apply to them—it applies to people who have lived in Wales for six months, and that does include students, so it is very important that our campaign reaches them. We need to look at freshers fairs as one way to reach students. You mentioned someone working here for 12 months; if they have lived here for six months, the law will apply to them.

[377] We consulted very specifically on the length of time in the White Paper. We also asked that very specific question in the consultation on the draft Bill, and no compelling arguments were put forward against that specific amount of time.

[378] **Mark Drakeford:** Would that apply to prisoners as well as students?

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

[380] **Ms Vernon:** In answer to some of the questions that have been posed as to whether it would apply to a certain group or not, the Bill does not exclude anyone specifically, but the concept of ‘ordinarily resident’ comes into play. Although you would have had to reside in Wales for six months not to be excluded straight off, there are people who might have lived here for six months or more but do not necessarily consider themselves to be ordinarily resident in Wales. As the Minister said, it could potentially cover all of those groups, but, in reality, it is necessary to have a conversation with the family to determine whether or not the person’s residence in Wales had that quality of being ordinarily resident. If they have an address here, that is the first place to start, but there are issues about whether or not they are

going to be living here permanently for a settled purpose, and so forth. All of those questions need to be explored as well.

[381] **Lesley Griffiths:** The safeguard is the family, because the family would be asked.

[382] **Rebecca Evans:** On capacity, concerns have been raised with us that the proposals for identifying people who lack mental capacity do not seem to be very robust in the Bill. I notice in the explanatory memorandum that you acknowledge that mental capacity might fluctuate over the course of time, which could even be over the course of the day, let alone over weeks and months. How will the Bill ensure that people's mental capacity is judged correctly?

[383] **Lesley Griffiths:** It will be the same as it is now. It is a very complex issue to establish whether a person has the necessary mental capacity to understand that their consent could be deemed; it is a very sensitive part of the process, and it will be woven into conversations with families at the time, when looking at other relevant medical information. If there is any doubt—if a family has any doubt that that person did not have the mental capacity—the donation would not go ahead.

[384] **Rebecca Evans:** In the Welsh Government's wider focus on mental ill health, you acknowledge that many people with mental illness keep that from their families and do not seek medical help. So, there could be people who lack capacity whose mental illness is not known to their families or to medical professionals. How can you protect them within the scope of this Bill?

[385] **Lesley Griffiths:** So, you are saying that the family would not know that that person lacked mental capacity. I do not know whether the lawyer could respond. Sarah, is there anything that you can add?

1.45 p.m.

[386] **Ms Wakeling:** It is more of a practical problem, and it must exist now. I acknowledge what you are saying: it is absolutely logical. They might not tell people. One would hope that if they have not told the family, it would be on the medical records. This would have to be explored with family members through discussion. It is obviously a case-by-case issue; I cannot set a hard and fast rule for this. Each case would need to be sensitively handled to ensure that those lacking capacity are protected.

[387] **Ms Vernon:** Some of the guidance that is already in existence, in terms of the Mental Capacity Act 2005 and so forth, talks about whether families have a reasonable belief as to whether their relative could understand something or make a decision about it. We would be looking at that kind of situation as well, as to what they would reasonably believe to be the case in relation to their relative.

[388] **Rebecca Evans:** How would people who are homeless and are of no fixed abode come into this legislation, in terms of the aspects relating to residency? I refer to people who are normally resident in Wales but who do not have a home address that can be verified.

[389] **Dr Duncan:** If someone has no fixed address, you cannot deem their consent. We have been talking with some of the stakeholder groups that work with homeless people and the like. They say that the sad fact is that these people are unlikely to die in circumstances where their organs would be available for transplantation, and that they probably suffer quite a lot of ill health. If people are homeless, you may not be able to reach their families. This goes back to the role of families as important safeguards.

[390] **Lesley Griffiths:** Following on from what Grant said, that is something that has to be remembered. You have to die in very specific circumstances to be a donor. According to the last figure that I looked at, about 220 people a year die in those situations in Wales.

[391] **Rebecca Evans:** It is also worth remembering that homeless people tend to die younger than the general population, so they could potentially have healthy organs. It is very complicated.

[392] **Lesley Griffiths:** Yes. You could not have deemed consent for homeless people.

[393] **Mark Drakeford:** I know that the Welsh Government will have published answers to some of the questions that I am about to put to you. Quite a large proportion of those individuals who have written to the committee with their concerns may not have fully understood the current set of circumstances. Perhaps I could put a quick set of questions to you, for the record. Looking back over the last few years, on average, how many people are organ donors in Wales now?

[394] **Lesley Griffiths:** Do you mean how many are on the register?

[395] **Mark Drakeford:** No. How many people provide—

[396] **Lesley Griffiths:** Are you asking how many donors we have per year?

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

[398] **Dr Duncan:** Last year, I think it was 67.

[399] **Mark Drakeford:** Of that 67, what proportion would have been people who had actually opted in and whose views were known in the current system?

[400] **Dr Duncan:** About 30%.

[401] **Mark Drakeford:** Okay, so 70% of the 67 are people who are not on the organ donor register, and the decisions relating to them were made as a result of discussions with families.

[402] **Dr Duncan:** Yes.

[403] **Mark Drakeford:** Regarding the people who were on the organ donor register, I believe that you provided a figure for the proportion of people who did not go on to be donors because their families had objected.

[404] **Dr Duncan:** Yes. That figure is between 10% and 15%.

[405] **Mark Drakeford:** So, 10% to 15% of people who had said that they would opt in and could be donors were not donors because the families intervened and expressed their views.

[406] **Dr Duncan:** Yes.

[407] **Mark Drakeford:** Could you describe to us simply the restricted circumstances in which it is possible to be a donor? The Minister has said that donation takes place in very narrow circumstances. Would it be possible to give us a description of those circumstances? Where do people have to be, and in what circumstances do they have to die to be a donor?

[408] **Lesley Griffiths:** They have to be in intensive care. This is why the decision does not

have to be taken just like that. Sensitive conversations with the family will probably start with a specialist donation nurse. If someone is brought in from a road traffic accident, for instance, and they are on life support, those conversations will start early—'early' sounds awful, but you know what I am trying to say. If a situation is becoming apparent, that conversation will start.

[409] **Dr Duncan:** The important point that I have taken from this is the role of the clinicians. This is a clinically-driven process. The clinicians will, at an early stage, start to make an assessment of an individual and whether he or she could be a donor. Essentially, it then comes down to being in intensive care and the person's health and general background making them suitable to be a donor.

[410] **Mark Drakeford:** So, to be a donor, you have to die in a hospital setting—

[411] **Dr Duncan:** Yes.

[412] **Mark Drakeford:** And you have to satisfy a series of criteria in relation to your more general state of health to enable you to be a donor.

[413] **Lesley Griffiths:** Yes. That is why the conversation will start earlier with the family.

[414] **Mark Drakeford:** And this Bill does not seek to extend that set of circumstances.

[415] **Lesley Griffiths:** No. This Bill is purely about consent.

[416] **Mark Drakeford:** I have letters from people who are genuinely concerned, as do other committee Members, I am sure. Part of their concern is that they believe that a far larger number of people are already organ donors. They think that the circumstances in which you can be a donor are much wider than the circumstances that you have just described—

[417] **Lesley Griffiths:** I think that that is completely correct.

[418] **Mark Drakeford:** They are fearful that if someone dies at home, for example, it would be deemed that they have given their consent, but that is not the case.

[419] **Lesley Griffiths:** That is not the case, no. You have to die in very specific circumstances.

[420] **Mark Drakeford:** Thank you. I wanted to get that on the record.

[421] **Mick Antoniw:** So, for clarification and certainty, even if someone has opted in, has expressed their wish to be a donor and dies in those very narrow circumstances, which allows them to be a donor, if the nearest family members are two daughters, for example, and one of them objects, donation will not take place?

[422] **Lesley Griffiths:** That is correct.

[423] **Vaughan Gething:** I have a question on this point about different circumstances around consent. If someone has expressed in writing that they want to opt in—they say 'I want to be a donor'—and they die within the circumstances and are an appropriate donor within the areas they said they were happy to donate, what happens if there is a dispute within the family? I understand what happens if they have the same relationship, but if a spouse is happy for the donation to go ahead but another family member, say a brother of the deceased, does not want the donation to go ahead, would it still be the case that the donation does not proceed?

[424] **Lesley Griffiths:** Yes, because the code of practice would be the same as now.

[425] **Ms Vernon:** I think that you would have to look at it on a case-by-case basis, because there is no real rule or cut-off or anything like that. It is a question of exploring with them why they feel that they do not wish to proceed with the wishes of the deceased. Often, it is because they have concerns about the process and are worried about what is going to happen to their deceased relative. If those sorts of things can be worked through, the specialist nurse can very often effect a different outcome and people can agree on a way forward. If you have far-reaching objections from a family member, then it is unlikely to go ahead.

[426] **Lesley Griffiths:** I think that the point that you are trying to make, unless I am mistaken, is that no-one has priority in the list of family members. Are you asking whether the spouse should have priority over the brother, for instance?

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

[428] **Lesley Griffiths:** The list is as it is. There is no prioritisation of that list. Does that answer your question?

[429] **Vaughan Gething:** Yes, that is what I wanted to be clear about. Thank you.

[430] **Mick Antoniw:** Just to clarify, it is not the case that a donation is unlikely, but the fact of the matter is that it will not go ahead. If you have someone who is on the list saying that they object, I am still a bit concerned about using the term ‘unlikely’. In fact, it is very clear that it will not take place.

[431] **Lesley Griffiths:** The practicalities mean that it will not.

[432] **Rebecca Evans:** You mentioned the important role that clinicians play in those discussions. Can you give us an idea of what the current training is for clinicians in terms of organ transplantation and having those discussions? Do you have any plans to extend that training, if this Bill was to become law?

[433] **Dr Duncan:** I know that someone from NHS Blood and Transplant is coming in, and they will be able to give you the definitive chapter and verse relating to the training that is provided. It provides training to specialist nurses and the clinical leads for organ donation. We are working with it on this particular work to define and agree on what training and awareness may be needed. That is, in terms of how the registration will work and conversations with family. So, we are already having those conversations with it now. In the overall cost provision, we have made available funding for training.

[434] **Mark Drakeford:** I would like to put a number of points to you that have been raised with us by faith groups in particular, but not exclusively. There is a strand of thought that says that deemed consent is a contradiction in terms, that there is no such thing and that consent is an active matter, in the sense that you have to give it; it cannot be assumed that you have given it. Therefore, it is argued that the Bill is fundamentally flawed because it tries to make operational a concept that does not stand up to scrutiny.

[435] **Dr Duncan:** I would counter that by saying that opt-out systems exist in many countries across the world. Some of those countries have a greater religious background than we currently have, and they make their systems work perfectly well within their countries and within their legal frameworks. I disagree that deemed consent is a myth, because we will be communicating with people in order to help them to clarify their wishes, giving them an ability that they do not easily have today to opt out, if that is their wish. They will then know

how the system will work and that if they do nothing their organs will be available. So, we will have told people how the system works in order to clarify it.

[436] **Mark Drakeford:** Some faith groups would not agree; we are rehearsing these different points of view. They go on to say that by presuming consent in circumstances where they do not think that consent can be presumed, the Bill will produce a situation in which a lack of respect will be shown to the human body after death, and that that would be a violation of fundamental rights to privacy and respect.

[437] **Dr Duncan:** This takes us into some of the areas of myth: myths that risk frightening people. The deceased will be treated as they are now, with all due respect by professionals—clinicians and nurses. Nothing could be further from the truth.

[438] **Mark Drakeford:** Minister, in thinking about the practical operation of the Bill, has any thought been given to the particular sensitivities of faith groups that have particular religious rituals and requirements at the point of death, which they are anxious that this Bill will interfere with in some way, making it more difficult for them to carry them out and so on?

[439] **Lesley Griffiths:** Yes; it will be as it is now. Having spoken to specialist nurses in organ donation and the organ donation teams that are in each health board, I know that those considerations apply now and will continue to apply. Going back to what Grant was saying about myths, we have a leaflet on this. I do not know whether it is specifically for faith groups, but we are looking at doing leaflets for each individual faith group in order to do some myth-busting work, because that is very important. As Grant said, they are myths and they can scare people. It is important that we get those leaflets out and develop our publicity campaign to ensure that they address those specific issues.

2.00 p.m.

[440] **Mark Drakeford:** As there is no-one who wants to ask a question immediately, I want to move to a different sort of question. A different line that we have heard from people who have some anxieties about the Bill is that, if the Bill succeeds, the NHS infrastructure will not be sufficiently equipped and robust to deal with the consequences. We have received evidence from people who have written to us in those terms, and will be taking evidence from such people. I am sure that you are familiar with them. Would you like to say something about that?

[441] **Lesley Griffiths:** Critics have said that we have insufficient critical care capacity in Wales to cope with an increased number of organ donors. That is not true and it is important that we get that into perspective. We have mentioned that we expect the soft opt-out system to increase donors by around 25%, which would equate to about 15 donors per year. To break that down, on average, that is one per six months for each health board in Wales. There are issues around where the critical care beds are now, on which we are having a piece of work done and I am expecting the report on that. I accept that we need to do more work around critical care, but I do not think that it is right to focus solely on just one aspect of critical care bed use. This is just one element, and there are lots of other issues around that.

[442] **Mark Drakeford:** Part of the evidence given by the people who make these points is that although only 15 extra donors are expected as a result of the Bill, those 15 donors account for around 22% of potential additional donors. To get 15, you have to have four times that number, because of the points that were being made earlier about the different tests that need to be applied to see whether a person can be a successful donor. Therefore, 15 is an underestimated figure of the real cost that the NHS will have to face because it will have to deal with up to 100 extra people to get the final 15.

[443] **Dr Duncan:** That goes back to the previous point regarding how to make the best use of managing the existing critical care capacity. That is a signal that there is general work to be done. We are not going to provide extra critical care beds just for organ donation. If there is a need to improve, then there is a need to improve generally. Clinicians are involved in making these decisions today about the relative prioritisation of the use of that infrastructure.

[444] **Mark Drakeford:** I have a final question on the cost issue, then I will see whether Members have further questions. After that, Minister, if you feel that there are points that have not emerged clearly enough or that you want to ensure that you leave with us, there will be a chance to do that.

[445] Once the system is up and running, the Bill suggests that it is cost neutral and that there is no more money for the NHS in Wales to be able to respond to a new set of circumstances. Is that realistic given the circumstances faced by the NHS?

[446] **Lesley Griffiths:** Yes. It is up to health boards to sort out their budgets. We give them large budgets. I mentioned dialysis and how much it costs each health board, where you have patients on dialysis three times a week for life. So, I accept that where they spend money in some areas, they will save money in other areas. Therefore, it is up to health boards to balance that out. That could be reviewed in the future.

[447] **Mark Drakeford:** Did you suggest quite near the beginning that one extra donor of this sort has a big impact on the costs that would be saved from the treatment that is currently being provided to people who need other forms of treatment like dialysis?

[448] **Lesley Griffiths:** Our own economist in the Welsh Government has undertaken a lot of assessment in relation to financial implications. We have looked at evidence from other countries. Do you want to say more about financial evaluation?

[449] **Dr Duncan:** As is laid out in the regulatory impact assessment and in terms of the economic analysis, although what that does show is that—although there are different factors of course—broadly, one extra donor pays for the overall investments over the eight to 10 years that the economic model has been run for.

[450] **Elin Jones:** If I read this in detail, I am sure it would give me the answer, but what assessment in that regulatory impact assessment have you made of the percentage of organs that will be retained in Wales and the potential cost savings to the Welsh NHS and Welsh budget as compared with Scotland or England?

[451] **Dr Duncan:** It did analysis of both and it included the analysis that said that if you allowed for, broadly, a 30% retention of organs in Wales, which reflects the last four years, then essentially, it is the same argument that one extra donation would pay for the system.

[452] **Rebecca Evans:** I would like to return to the role of the families, because this is a particular issue that has been raised. The explanatory memorandum suggests that in cases where donation transplantation did not go ahead against the expressed wishes of the deceased person because of the feelings of the family, the family or the next of kin would be asked to sign a form to the effect that organ donation did not go ahead against the expressed wishes of the deceased. What purpose would that serve, other than to add more distress at an already distressing time?

[453] **Dr Duncan:** Again, it is about looking at this as trying to uphold the wishes of the deceased. It is about trying to clearly point out to the family that they are wishing to overturn the expressed wish of their loved one. So, it helps to reinforce the point.

[454] **Rebecca Evans:** So, the form would be a tool to encourage the family to take a certain view, as opposed to a legal or administrative requirement.

[455] **Lesley Griffiths:** I do not think it is a certainty. It is the view of the deceased person and their wish, and it is important that the family realises that it is going against the wishes of the deceased.

[456] **Rebecca Evans:** The form is a tool, not an administrative requirement.

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

[458] **Ms Vernon:** It might also be worth mentioning that that is what happens in Scotland at the moment under its system of authorisation. So, if the person had authorised or given their consent to organ donation when they were alive, then the family is asked to sign a form if it is not going to go ahead because it does not want it to happen.

[459] **Mark Drakeford:** Are there any further questions from Members at this point? I see that there are not. Minister, if there are final thoughts you want to make sure you leave us with, we have a couple of minutes for you to do that.

[460] **Lesley Griffiths:** I reiterate the point I made at the beginning about the benefits. We are doing this for the benefit of the people of Wales. I want to mention the register, which has not come up, and what we want to see there. What we want is one register for the whole of the UK that will meet the requirements of each of the four UK countries, because we have identified that that would be less risky. It would not cost much more to redevelop a register for the whole of the UK. This has been accepted in principle by NHS Blood and Transplant, and I have written to my counterparts in Scotland, Northern Ireland and England. We have also said that we would take the brunt of the cost, although we have asked for contributions. I have had a response from the Minister in Scotland, who is very happy and positive in support of that. We are viewing all options with counterparts at the moment because I would like to get that up and running certainly by next month.

[461] **Mark Drakeford:** Excellent. Thank you very much indeed.

[462] Diolch yn fawr iawn am ein helpu ni y prynhawn yma.

Thank you very much for helping us this afternoon.

[463] Thank you very much indeed to all of you for helping us with this first session of our consideration at Stage 1.

2.10 p.m.

Bil Trawsblannu Dynol (Cymru): Cyfnod 1—Sesiwn Dystiolaeth 2
Human Transplantation (Wales) Bill: Stage 1—Evidence Session 2

[464] **Mark Drakeford:** Fel y gallwch chi weld, mae Mr Roy Thomas, cadeirydd gweithredol Sefydliad Aren Cymru wedi cyrraedd yr ystafell, felly gallwn symud ymlaen at eitem 8 ar ein hagenda a pharhau â'n trafodaeth ar y Bil Trawsblannu Dynol (Cymru).

Mark Drakeford: As you can see, Mr Roy Thomas, executive chairman of Kidney Wales Foundation is now with us, therefore we can move on to item 8 on our agenda and continue with our discussion on the Human Transplantation (Wales) Bill.

[465] Gofynnaf yn gyntaf a oes gennych

I will first ask you if you have any comments

unrhyw sylwadau i'w gwneud ar y dechrau ac, ar ôl hynny, trof at aelodau'r pwyllgor i ofyn eu cwestiynau.	to make at the outset and, after that, I will turn to committee members to ask their questions.
[466] **Mr Thomas:** Prynhawn da, Gadeirydd ac Aelodau. Rwy'n hapus i fod yma a diolch am y gwahoddiad. Siaradaf ar ran Sefydliad Aren Cymru, ac ar ran ein cefnogwyr i gyd sydd wedi bod gyda ni drwy gydol y broses hon.	**Mr Thomas:** Good afternoon, Chair and Members. It is good to be here and thank you for the invitation. I will speak on behalf of Kidney Wales Foundation, and on behalf of all of our supporters who have been with us throughout this process.

[467] Thank you, Chair and committee members, for inviting me today to discuss this very important project and campaign that we have been running for some years at Kidney Wales Foundation. We believe that the change in the law is vital and that Wales will lead the way. As you heard from the Minister, this is something that the UK as a whole should consider seriously, given that the more progressive European countries and western civilised countries have adopted deemed consent, as it is now known in a different guise. It is also known as 'presumed consent', 'opt-out' and various other expressions. The Government is right to introduce a new phrase in 'deemed consent', because it brings a little more clarity, and that expression is favoured by us. We believe that the deemed consent system would achieve greater certainty, as shown in other countries. We therefore believe that it is morally unjustified to perpetrate a system that falls short of increasing the availability of organs for people who might benefit from transplantation.

[468] **Mark Drakeford:** Thank you. I will go to Vaughan first and then to Rebecca.

[469] **Vaughan Gething:** Good afternoon, Mr Thomas; it is good to see you and thank you for your paper, which we have had a chance to look at. I am interested in particular in the contribution that you generally think the Bill, if enacted, would make. Could we not substantially increase the rate and number of donors with a wider-spread education and information campaign? I can think of two examples, namely Belgium and Spain, and I note that you refer to the Belgian experience in your paper. So, I am interested in whether you think we could see a substantial improvement in donors, which we would all wish to see, without this Bill or whether you think we will not see an increase unless legislation is passed in addition to providing the communication and education campaign that the Minister outlined—which has taken place in the past—which would accompany the Bill.

[470] **Mr Thomas:** I believe that the do-nothing scenario is not an option. In fact, we have been at this for many years. Wales led the way in terms of lobbying the UK Government in the 1980s to ensure that driving licences included a reference to donor consent. We then started the register on computers in Wales. So, we have a long track record of pushing the boundaries on this. This is the next stage. In the UK, we know where we stand. In Norway, after relatives have been informed of the intention to remove organs, irrespective of their consent, it happens. In Italy, if relatives do not object, it happens. In Belgium, where a dead person has not expressed an objection, this is confirmed by the relatives and consent is then presumed. Irrespective of the relatives' views, it happens in Austria. So, all of those countries that I have quoted cannot be wrong. However, I accept your points on education—we have to bring the goodwill of the people of Wales along with us. We have had a great deal of success and I notice that the explanatory memorandum that the Government has provided does not mention the third sector.

2.15 p.m.

[471] I pay tribute to the charities in that sector: Diabetes UK, the British Heart Foundation, the British Lung Foundation and the Welsh Kidney Patients Association, which have been

instrumental in bringing this to the attention of the Welsh public through the Tell a Loved One campaign. That seems to have been erased from the explanatory memorandum for some reason. However, that raised the organ donation rate and, as part of that communication campaign, we used the charities and the great networks that they have to increase the educational perspective.

[472] We feel that NHS Blood and Transplant has been pretty below average in what it has been doing; certainly in England it is below where we are in Wales. Issuing a press release and having a Minister stand on Queen Street on a summer afternoon with a patient is not what it is about. I also do not think that communication by tv or pamphlets is the case. In our written evidence, we suggested some novel forms of communication. Again, putting transporter lorries outside supermarkets is deemed to be consultation and is not something that we would support. We believe that we should be communicating; we are a small nation and we should be communicating with the people of Wales with proper dialogue.

[473] **Vaughan Gething:** In the paper that you provided, there is an annex about the Belgian experience, and you made a comparison with European countries that have some form of deemed consent. One of those was Austria. To clarify, you said that, in Austria, deemed consent can take place without consulting family. I would be troubled if there were no involvement with family in a deemed consent case. I want to be clear about whether the proposal, as it is before us—the mechanism in the Bill, plus wider education—is what you would prefer to see.

[474] In the rest of your paper, particularly in paragraphs 22 and 23, you talk about the rates and levels of intensive care beds. I am interested in what you say contributes to improving the rates of donation—how much is it a change in the law and how much is it a wider and better education campaign? There are cultural differences. In your paper, you flag up the cultural differences in Spain, which has a higher rate of church attendance and faith attendance than we do here, but still has a higher rate of donation. In those two paragraphs, you talk about intensive care beds. How far are we going to go? Your paper suggests that a big part of the difference is the differential rate in intensive care beds. So, are we not going to achieve everything that we could unless that changes? How far will the law take us, if there is a change, in improving the numbers and volumes of transplants, which, as we all know, will improve quality of life, if not save it?

[475] **Mr Thomas:** That is a very long question, Mr Gething.

[476] **Vaughan Gething:** It is indeed. I do that quite frequently.

[477] **Mr Thomas:** I will try to answer in four parts, because you raised the issues of relatives, communication, Belgium and intensive care beds.

[478] In terms of relatives, the system in Austria is deemed to be a harder way of consent, but I understand from that country, having done our own research, that they do talk to relatives. So, it is not as mandated as it would seem. Indeed, the system of mandated choice would be that if you signed a form when you were 18 and you were unfortunate enough to die later on, that would still be the case. It is important that the relatives are consulted and I note that the discussion has taken place about what happens if they disagree, but that happens now. Indeed, the process in the Bill of an appointed representative is a good one, and I think that is worth pursuing.

[479] The key issue is that the individual has the right and no relative has property claim over the body of the deceased. That is essential. So, really, we should look at whether there is evidence against. I know that the Minister was quizzed on this earlier, but we should be looking at evidence against. That is a key factor. So, for me, the right of the individual to

donate is paramount. Indeed, that is the case under the Human Rights Act 1998, which I am happy to talk about later.

[480] Communication and education are important. Those who are scared of change talk about education. We have been trying to educate the UK populace for many years and this does not increase the organ donation rate. So, the gap is widening while we go about trying to educate. Clearly, the education is not happening and therefore we need to do something about it, as other countries have done.

[481] It is interesting to look at other models. In Belgium, where the system was introduced in 1986, only 2% opted out, which is quite interesting. It did have divergence. For example, the teams in Antwerp were against the law and continued to go about it in the educational sense. However, the team in Leuven, where they were a bit more progressive, decided to go along with the system. You will note that the team in Antwerp had to change its practices because it became very evident that it just did not work. So, there have been changes in Belgium that are worth noting. I note from the Members of the committee that we are going into the unknown, but we are not. We do not need to reinvent the wheel. There are people who have been at this for some time—for some 20 or 30 years. I cannot remember your last point, Mr Gething, but I think that it was about intensive care beds.

[482] **Vaughan Gething:** Yes, it was on intensive care beds.

[483] **Mr Thomas:** It is a very important point; I should not have forgotten it. Being a former lawyer, or still a lawyer yourself, you will understand that the law is just an environmental issue along the tracks of how we behave. We cannot force people to do things. If they wish to commit anarchy, and it happens across the world, then they will. The law is the law. Enforcement of the law is terribly important. So, that is one reason, but what convinces me is that when there has been a change in the law in civilised countries, there has been an increase in donation rates. I agree that there has been a change of organ donation co-ordinators, for example, which is very clear and important. There has also been a change in the culture of the doctors: they feel empowered that they can ask the question and that they can have a conversation with the relatives during a very difficult time, because they can then refer to and fall back on the law. It is not to say that the law should then take precedence over the feelings of relatives.

[484] **Vaughan Gething:** I will pick up on one point in what you just said. You mentioned that the wishes of the deceased should be paramount and that no-one has property rights on the deceased, but is it not the practical reality that that is what happens? If family members object, even where there is an express written document opting in to donation, at present, effectively, they do have property rights and they can prevent a transplant taking place. The new Bill that we have before us will not change that.

[485] **Mr Thomas:** I agree and disagree on that proposition—

[486] **Vaughan Gething:** You should be a lawyer.

[487] **Mr Thomas:** I agree to the extent that the wishes of the relatives should be taken, but this law will deem consent. Therefore, the burden changes completely onto the relatives and onto the doctors to say, ‘Where was it that this person said that they would not donate?’. There is a clear change there and a clear axis of change that needs to be accepted. I am not sure whether that has been accepted yet.

[488] **Vaughan Gething:** Is that what the Minister told us? I do not think that it is. I think that the Minister told us that while consent can be deemed, there would have to be a discussion with the family and that, in reality, while it does not say it on the face of the Bill,

strong objections from a family, regardless of the wishes of the deceased, would mean that the donation would not go ahead. That is different from the way that you are putting it, where you are suggesting that consent is deemed unless—

[489] **Mr Thomas:** I am not the Minister.

[490] **Vaughan Gething:** No, but this is what the Minister was telling us is the intention of how the Bill will work. I think that there is a difference in what you are saying: that it should be the case that consent is deemed and someone has to disprove it, or effectively has to prove that they did not really want donation to go ahead—

[491] **Mr Thomas:** Why change the law, then, Mr Gething? We could be doing the same thing that we have done before. The emphasis must be on the relatives talking to each other, as the Minister said, but there is no power of veto—I think she said that as well.

[492] **Vaughan Gething:** There is no legal power of veto. I think that what she told us was that, in practice, for example, if I am the person who dies and I have expressed a wish for my organs that are fit and all the rest of it to be provided, and my wife and brothers object, then regardless of my expressed wish to make a donation, in practice, there will not be a donation. With deemed consent that would still be the same. If I pass away without having had a discussion with my wife or anybody else, and she says, ‘I do not really want this to happen’, and she is not able to prove that I was opposed to a transplant, then my understanding of what we have been told is that, in practice, clinicians would not go ahead with the transplant. That appears to be a different formulation—

[493] **Mr Thomas:** It is not different. They are trying to put some wedges in there when they say so. It is not that different because what you would need to do is speak to the relatives, as they do now, and the question would be, ‘Are you opposed to organ donation? Have you considered it? Had the deceased considered it?’, and when there is no expressed wish either on the register or through the appointed representative route, there would be a discussion. No doctor is going to go against the views of the close relatives, and that is what happens in Austria at the moment. In practice, as one of the officials rightly said, this is done on a case-by-case basis; people react totally differently and, therefore, you will have consent after some period of time. Indeed, you have to look at the conditions. Many of these people are in intensive care, so the doctors have known these families for some time. This does not happen as quickly as people think: they know the thoughts of the family, they know the circumstances of the death, and therefore they will take all these considerations into account. The doctors that I have met are very sensitive to all of that. Indeed, evidence showed that those families who have refused organ donation have then felt really badly about it afterwards, because they have felt that they have gone against the wishes of the deceased. That happens now, but that case in point happens because of the emotional state of the family, and the difficult circumstances that they are under. It is huge pressure from all sides. The good thing about Wales is that we are talking about this now. Nobody likes to talk about death. It is one of the things that we talk about least. Not many people make wills, for example, as we know. So, it is important that we have this discussion, and the great things about the Tell a Loved One campaign that you ran was that people were having these discussions—young people were doing so more than the older generation. Indeed, we made a huge impact in higher education and the universities were superb, where most people signed up to the organ donation register.

[494] **Mark Drakeford:** I will move on to other Members on these points, but just to put one more point to you, Mr Thomas, when the Minister described the role of the family, she said that the views of families would be respected because the NHS has a duty of care to the wider family as well. From the point of view of Kidney Wales and the other supporters that you have, would it be fair to say as well that the reason the wishes of the family are unlikely

to be overridden is you have a concern for the public reputation of the donation system, and that it would be damaging to the whole business of donation if there were to be headlines in newspapers about families saying that their views had been overridden in that way? There is that dimension to it as well.

[495] **Mr Thomas:** Let us put this on the record very clearly: the views of the family, we have always said, are essential, and key to all of this. There is no way that we would override their wishes, or want to see them overridden. Indeed, Wales laid the first donor stone, which sits in Cathays park to respect the wishes of donor families. We were the first part of the UK to do that. We had 300 donor families come along to that celebration of their lives. So, we are very familiar with that. There is a difference between a donor family and a recipient family, and we are in contact with several donor families. We have experienced what it is like with them and how they have gone about things, which is never easy, and we have witnessed the coming together of donor families and recipient families.

2.30 p.m.

[496] **Mark Drakeford:** I will go to Elin next, then to Rebecca and then to Mick.

[497] **Elin Jones:** Er mwyn i mi fod yn glir ynglŷn â'r hyn rydych wedi ei ddweud, rydych wedi dweud bod rôl a barn y teulu yn bwysicach na barn yr unigolyn, hyd yn oed os yw'r unigolyn sydd yn rhoi'r organau wedi dweud eu bod eisiau eu rhoi ac wedi cofrestru hynny. Aeth y Gweinidog yn bell iawn yn ei thystiolaeth yn gynharach, os deallais hi'n iawn, a dweud, hyd yn oed os yw rhywun ar y gofrestr rhoddwyr organau, os oes unrhyw un o restr weddol hir o deulu yn dweud eu bod yn erbyn hynny, ni fydd yr organau yn cael eu rhoi. Mae gennyf un cwestiwn yn ychwanegol at hynny. Mae pob un sydd ar y rhestr honno o'r teulu yn gyfartal ac nid yw barn un yn bwysicach na'r llall, ond mae teuluoedd yn gallu anghytuno ar faterion fel hyn, ac mae gan rai pobl wrthwynebiad moesol neu wrthwynebiadau gwahanol. A ydych yn credu, ynghylch y rhestr hir honno o deulu, y dylid rhoi rhyw fath o flaenoriaeth i farn gŵr neu wraig dros farn ffrind hirdymor, er enghraifft?	**Elin Jones:** So that I can be clear about what you said, you have said that the role and the opinion of the family are more important than the opinion of the individual, even if the individual who is donating the organs has said that they want to donate them and has registered. The Minister went very far in her evidence earlier, if I understood her correctly, and said that, even if someone is on the organ donation register, if anybody from a quite a long list of family members says that they are against that, the organs will not be donated. I have one additional question on top of that. Everyone on that list of family members is equal and the opinion of one does not carry more weight than another, but families can disagree on matters such as this, and some people have an ethical objection or different objections. Do you believe, with regard to that long list of family members, some kind of priority should be given to the opinion of the husband or wife over that of a long-term friend, for example?
[498] **Mr Thomas:** Diolch am y cwestiwn. Mae barn deuluol yn bwysig. O ran y rhestr, gall fod yn hir iawn, felly rwy'n credu bod barn gŵr, gwraig, mab neu ferch yn bwysig yn hyn o beth, a bod teulu agos yn siarad am bethau yn y cartref yn bwysig. Fodd bynnag, ambell waith, nid yw teuluoedd gyda'i gilydd, ac mae'n rhaid gweld hynny hefyd a pheidio â'i anwybyddu. Ambell waith, mae'n emosiynol ac rwy'n credu bod y bobl sydd gennym mewn ysbytai yn gallu delio â'r pethau hyn yn dda iawn. Maent yn gwneud	**Mr Thomas:** Thank you for the question. Family opinion is important. In terms of the list, it can be very long, so I think that the opinion of the husband, wife, son or daughter is important in this, and that it is important for immediate family to talk about things at home. However, sometimes, families are not together, and we have to look at that too and not ignore it. Sometimes, it is emotional and I believe that the people that we have in hospitals can deal with these things very well. They do that now and they can see people's

hynny yn awr ac maent yn gallu gweld sefyllfa emosiynol pobl. Ni fydd y doctoriaid am weld diflastod mewn teulu, felly gallaf weld sefyllfa lle mae doctoriaid yn osgoi gofyn am y peth yn ormodol. Fodd bynnag, yn Sbaen, maent yn gofyn rhyw chwe neu saith gwaith ac yn mynd ymlaen amdano. Mae diwylliant gwahanol mewn gwledydd fel Sbaen a Gwlad Belg.

emotional situation. Doctors will not want to make things unpleasant for a family, so I can see a situation in which the doctors shy away from asking about it too much. However, in Spain, they ask about six or seven times and go on about it. The culture is very different in countries such as Spain and Belgium.

[499] **Mark Drakeford:** Diolch. Rwy’n mynd i droi at Rebecca nesaf, ac wedyn Mick.

Mark Drakeford: Thank you. I will turn to Rebecca next, and then Mick.

[500] **Rebecca Evans:** Stepping back to look at the overall aim of the Bill, which is to increase the number of organs and tissues available for transplant, if you had the £8 million that the Minister has allocated to this over the next 10 years and a blank sheet of paper, what would you do to increase the organs and tissues available as much as possible?

[501] **Mr Thomas:** That is a very good question, because £8 million is a big amount. I am not sure how many years that is over—

[502] **Rebecca Evans:** It is over 10 years.

[503] **Mr Thomas:** The amount of money that is spent needs to be spent efficiently these days, and I would go through some of the charities a bit more. I do not think that the Government on its own can communicate with the people. That is borne out on several fronts. With regard to the use of other organisations, we should certainly look into the use of voluntary sector. We have done that in the past, and I think that the charity sector in Wales is very efficient, and it has some very good people in it. From a communication perspective, savings could be made. Clearly, the register is going to be a big cost. There is no requirement for it to go out to tender in this case, but NHSBT has its sights on it, I am sure. Then again, the cost of running the register needs to be looked at, and whether those costs could be contained in Wales, rather than elsewhere is something, again, I am sure the Minister will be looking at. So, we should look at the costs.

[504] I think that it does offer value for money. Saving lives is a very difficult thing to put a value on. I thought that the explanatory memorandum from the chief economist was very clear, particularly the appendices presented on cost and the quality-adjusted life years. Also, the cost of dialysis is huge, as is the social cost. When people are on dialysis in the case of kidney failure, they are not working. Indeed, when you have a child or anybody in the family on dialysis, it really disrupts the family’s productivity, not to mention their emotional and psychological wellbeing. So, there is a wider cost to having dialysis and not having a transplant.

[505] I noted the figures in there, which are in pretty raw terms, for the cost of a transplant and the cost of furthering dialysis. However, if you are doing home dialysis, the cost was outlined, but it could be much more, because you could be dialysing six or seven times a week, rather than three times, particularly if you are in a job that will not allow six or seven hours of sitting attached to a machine, which is pretty horrible. The same goes for children, as there is a disruption in education—a huge amount of disruption takes place when people are ill, and that goes for people who need other organs as well.

[506] **Rebecca Evans:** I visited a dialysis unit in my region, and I was surprised to hear there about the surprisingly large number of people who are eligible for an organ transplant

but who decide not to have one. In your experience, why would somebody make that choice?

[507] **Mr Thomas:** They are scared. It is as simple as that. It depends on age. Also, there is a certain life to an organ that one needs to look at. It depends on how desperate and how ill they are. The drug regime these days is pretty good, but, if they are desperate, then, clearly, they will be in need of an organ. So, it depends on all sorts of factors.

[508] Young people suffering from kidney disease will, of course, want not to be tied to a machine, so they are pretty keen to have a transplant and, these days, with the drugs that we have on offer, the success rate is excellent. We see this all the time in Wales, where our young people are transplanted in Bristol, and there are a great many success stories that I could quote to you.

[509] There are also people who do not want to dialyse. We have had instances of people who were scared of dialysis, because they had seen their parents or other loved ones dialyse, and they know that that is a problem. The big important factor there is that, if you have a transplant before dialysis, the time you have with your new organ will be far longer than if you had had dialysis. That is a hidden number, because it does not feature on the NHSBT weighting list.

[510] **Mick Antoniw:** I just have a short point. You have addressed most of the issues that I wanted to raise, but the legislation itself to some extent changes the nature of donation, in that it puts it in a far more formal framework. Obviously, communication with families and so on at the time you want to discuss donation is a very sensitive area. The legislation also creates more burdens and responsibilities. Are we sufficiently geared up to deal with and communicate with families? How much more do we need to do, and do you have any specific views with regard to what we need to do to make the legislation effective and ensure that all of those communication and consent factors are handled properly? It seems to me that there is potential for a lot of people around at the time to be involved, and there does not seem to be any intention to have a designated person as such. Do you have any views on that?

[511] **Mr Thomas:** Mr Antoniw, what happens at the moment is that there usually is a designated person. There is an organ donation co-ordinator, who tends to get very close to the family, and not only during that difficult time, they will have a relationship—which I have seen because we have some excellent ones in Wales—and I have seen that relationship develop even some years after the family has lost a loved one. However, you make an important point, because there are some intensivists that are unsure. I raised the example of Antwerp and Leuven in Belgium, and that happens here. I have listened to lead intensivists in Swansea, for example, who were unsure about this law. I have great sympathy for that, because that person has to sign a certificate of death. I believe that the law should also be changed on that, by the way. I think that two doctors should sign that certificate; the burden should not fall only on one. They are concerned about that, because they have a duty of care to the person who is dying and to the family.

[512] Different intensivists and different doctors have a different view, but, to talk about your point, there will be a bit more of a burden, as you mentioned, on the shoulders of others, and the doctors, in particular, need to be a little bit more educated in these ways and means. Again, I think that they can learn from countries such as Belgium, where doctors face this on a regular basis, and swap some experiences. I hope that happens, because it is not easy and, again, for a doctor faced with that objection and, indeed, an emotional family, it will not be easy. Indeed, the family may not want to hear about the law at that time, and some of us can well understand that.

[513] **Mark Drakeford:** I would like to put three points to you. I think that you have covered at least two of them already, so please feel free briefly to summarise your position.

The first is a point that Rebecca has already raised with you. Some people have written to us to say that, if the Welsh Government put the amount of money and energy that it is putting into this Bill into other ways of raising the level of organ donation, it could get to its target for the increase in the number of donors that it thinks this will achieve without all of the upset and anxiety that the deemed consent principle gives rise to. Do you think that there is something to be said for that point of view?

[514] **Mr Thomas:** First, you have to accept that it will cause upset and anxiety as a premise, but I do not think this Bill will. I think that this is a Bill that, if implemented properly, will see some clear outputs. Indeed, it is very important on the education side to show the outputs and the fact that people's lives have been saved and improved as a result of organ donation. There are lot of people going around, I am sure, saying that that is not the case, but they also say that there is no evidence to prove that this system of legislation will increase the organ donation rates. That is simply not true. The Government has cited Abadie and Gay, and we have been doing that for four or five years. In all of the analysis that has been looked at, with the exception of Brazil and Israel—those countries are cited by those who oppose the scheme, but the communication strategy in Brazil was very poor and Israel has a different complexity, which all of us in this room know about—the evidence is very clear that if implemented properly, this is a good thing that will change and save many people's lives.

2.45 p.m.

[515] **Mark Drakeford:** The second question is from the perspective of those people who write to us with anxieties about the Bill. Some people claim that it will damage the reputation of transplantation to a point that it will do more harm than good. Is there a risk to the reputation of transplantation as a whole?

[516] **Mr Thomas:** The notion of the damage to the reputation of organ donation emanated from the King's Fund in the 1990s, and it has progressed, unfortunately. It depends on how you look at things. A number of Christian groups say that this is about the body effectively belonging to the state at death, the potential loss of choice and that the state will intervene as it does in taxation, for example. A number of patient groups, particularly Patient Concern, which I think you are taking evidence from, have said that a number of individuals are willing to donate their organs because of the feel-good factor.

[517] We have taken all those issues into account, and we feel, based on the evidence, that we can rebut all of that. From a moral standpoint, the social context in which any law is to operate and any medical action that arises is important. In Wales, I think that we will find it morally acceptable, with the medical profession being alongside and the support of the wider community. We are a small nation, and I can give you evidence of smaller parts of Belgium and Austria where this has been effective through communication. I think that we will lead the way, and I hope that the UK will see what we are doing in Wales, because we will be providing organs outside of Wales, in the same way that we receive organs now from as far away as Spain. Helen Jones, who was a nurse, from my beloved village of Glynneath had her organ from Spain when she was very desperate and we were very close to losing her.

[518] In humane terms, it is important that we look at the bigger picture and see that this is an important law.

[519] **Mark Drakeford:** A third and final point to you is that other people who have provided written submissions to us say that the Bill will fail because the infrastructure in Wales does not exist in a state that can deal with its consequences—that there are insufficient intensive care beds and capacity in operating theatres, and so on—and that the Bill will not achieve its objectives for that reason. Is there anything that you would like to say to us on

that?

[520] **Mr Thomas:** In sharing experiences with other countries, we have seen that there is a knock-on effect. You create a law and the environment will apply pressure to have those beds available. At the moment, there is no pressure—we are just allowing people to die, which is incredible in a civilised country where we can do something about it. We are allowing people to just wait on what they would call ‘death row’—a lot of these people will not talk openly about where they are at. They also feel very bad about taking a deceased person’s organs, and this is why charities such as ours bring this issue to the surface. They feel very bad about it because someone has had to die for them to live. It is a psychological issue that they face and have to deal with. However, knowing that people want to give and seeing how good we are in Wales at dealing with this very important subject—which we have been doing over the years; we have a great history in relation to all of this—I think that Wales can lead the way.

[521] **Mark Drakeford:** Diolch yn fawr. Gwelaf nad oes cwestiynau eraill gan aelodau’r pwyllgor. Os oes unrhyw bwyntiau sydd heb eu codi eto y prynhawn yma neu unrhyw bwyntiau yr hoffech eu pwysleisio unwaith eto cyn y diwedd, mae munud neu ddau ar ôl cyn diwedd y sesiwn i wneud hynny.

Mark Drakeford: Thank you. I can see that committee members have no further questions. If there are any points that have not yet arisen this afternoon or any points that you would like to re-emphasise before we close, a few minutes remain before the end of the session to do that.

[522] **Mr Thomas:** Diolch, Gadeirydd.

Mr Thomas: Thank you, Chair.

[523] I would like to pay tribute to the civil service and to all the people in the Assembly who have brought this Bill about. We are here because of many people. We, on the outside, often knock the civil service, but the lawyers and others have done an excellent job in bringing the Bill to this stage and in terms of drafting and preparing the explanatory memorandum. There is a long way to go and some of the polling is worrying in that we have had polls of over 70%, so the understanding of what we are about has gone down a little. That may be because people want to derail the Bill. We are conscious of that derailment and we will do everything within our powers to put up a reasonable argument against that derailment, whether that is from the church or from any other quarter. We see what they say, but the committee should also look at other places where this has worked; I emphasise that point. It is important that we do not reinvent the wheel and that we share other world-wide experiences.

[524] **Mark Drakeford:** Diolch am ddod i’n helpu’r prynhawn yma. Dyna ddiwedd ein sesiwn gyda Mr Thomas. Cawn egwyl fach am bum munud. Mae’r bobl yn yr ystafell hon bron wedi rhewi, felly bydd cyfle i gael paned o de. Nid oes angen i bobl adael yr oriel gyhoeddus, ond atgoffaf Aelodau bod y meicroffonau ymlaen, felly bydd pobl yn yr oriel yn gallu eich clywed yn ystod yr egwyl.

Mark Drakeford: Thank you for coming to assist us this afternoon. That is the end of our session with Mr Thomas. We will now have a brief break for five minutes. The people in this room are almost frozen, so there will be an opportunity to have a cup of tea. There is no need for people to leave the public gallery, but I remind Members that the microphones are on, so people in the gallery will be able to hear you during the break.

Gohiriwyd y cyfarfod rhwng 2.51 p.m. a 2.59 p.m.
The meeting adjourned between 2.51 p.m. and 2.59 p.m.

Bil Trawsblannu Dynol (Cymru): Cyfnod 1—Sesiwn Dystiolaeth 3
Human Transplantation (Wales) Bill: Stage 1—Evidence Session 3

[525] **Mark Drakeford:** Gyda ni ar gyfer ein heitem nesaf mae Sally Johnson, cyfarwyddwr rhoi organau a thrawsblannu, Gwaed a Thrawsblaniadau'r GIG. Diolch yn fawr am ddod i'n helpu'r prynhawn yma. Fel arfer, gofynnaf i chi a oes gennych unrhyw sylwadau agoriadol cryno i'w gwneud. Wedi clywed yr hyn sydd gennych i'w ddweud, byddaf yn troi at aelodau'r pwyllgor, a fydd yn holi cwestiynau.

Mark Drakeford: With us for our next item is Sally Johnson, director of organ donation and transplantation, NHS Blood and Transplant. Thank you very much for coming to help us this afternoon. As usual, I would like to ask you whether you have any opening remarks to make. After hearing what you have to say, I will turn to committee members, who will ask some questions.

[526] So, Ms Johnson, please make any opening remarks that you would like to put on the record for us, and then we will go into questions after that.

[527] **Ms Johnson:** Okay, I will be brief. As you have heard, I represent NHS Blood and Transplant. We are the procurement organisation for organ donation in the UK and, as such, we employ the specialist nurses who work with families to seek their support for organ donation.

3.00 p.m.

[528] We work with the clinical leads donation committees to make sure that they have the skills and the education they need to do their job. We are responsible for the organ donor register. We also commission the retrieval services, which is an important issue that has not been covered today, and we are also responsible for the matching and allocation of organs across the UK. We are unusual in that, as far as I know, we are the only NHS body that covers the whole of the UK, so it is a unique position.

[529] I want to say something about the circumstances in which people can donate their organs. I have been listening to some of the evidence and I suppose that I am particularly close to this, so I probably have a little bit more knowledge than some. We have heard a lot about donation from intensive care and, even in intensive care, it is not everybody there who can be an organ donor; you need to be ventilated and intubated mostly. Increasingly, we are also facilitating organ donation from emergency care departments, where people come in with unsurvivable brain injuries, and particularly for those who have already expressed a wish to donate, we want to make that wish come true, and so we will do all that we can to facilitate donation from emergency departments. Sometimes, those people will go from the emergency department to intensive care before they donate, but that is not always the case. So, sometimes, it is quite a short time process in which to engage with the family and that is an important point.

[530] Also, in Scotland, there is a new pilot beginning, which is looking at enabling donation for those people who maybe have a heart attack in the community and go into hospital and resuscitation fails. Where they wanted to be donors, then we want to try to fulfil that wish for them. It is important that when you are considering this law, it needs to be considered on the basis of the fact that the boundaries for organ donation are continually moving and that we are always trying to find more ways to enable people to donate. We think that donation is not only something that the donor proud to sign up to do in advance, but that their families will be proud of them doing afterwards.

[531] **Rebecca Evans:** With regard to your staff on the front line in these circumstances, have you canvassed the views of your staff in terms of whether they are supportive of what is

in the Bill, or whether they have particular concerns? I am sure that they would have a particularly interesting perspective.

[532] **Ms Johnson:** We have not officially canvassed them. It is not a huge team—there are 15 of them—and I am aware that they have a range of views. Ultimately, the important thing is that when and if this law is passed, then NHSBT staff will do everything they can to facilitate donation within the law of the country. That is our job.

[533] **Rebecca Evans:** That was it for now; I might have some more questions later.

[534] **Elin Jones:** I want to ask you about something in your paper, which is on exempting certain products from transplantation under section 16. You have mentioned blood and blood products as organs or tissues in section 16 that should be specifically exempted on the face of the Bill. You have linked it to the issue of criminal offence of commercial dealings. Can you explain to me as somebody who is not an expert in this area exactly the issue that you are trying to get at?

[535] **Ms Johnson:** I never quite understood why blood was included in a Bill about organ and tissue donation; it is not particularly relevant. What we did not want within the Bill is something that would confuse people. That was the basic thing; I think it is just a distraction.

[536] **Elin Jones:** So, it is nothing to do with commercial dealings around blood in particular. Have I misunderstood that part of your evidence?

[537] **Ms Johnson:** I think so, yes.

[538] **Elin Jones:** I raised with the Minister—I do not know whether you were here to listen to her evidence earlier—the transplantation of faces, hands and all kinds of other new areas of transplantation work. I asked her specifically why those areas, such as my face and other tissues, would not be exempted under section 16. You could argue that this Bill, on the whole, has been about the life-saving potential of the legislation, and you could argue that a face or hand transplant would not be seen by some as life-saving. Do you have any views on that and on whether it should be specifically excluded in the Bill, just as you have mentioned in relation to blood and blood products?

[539] **Ms Johnson:** At present, when people sign up for organ donation and express consent, we do not take it to include any form of novel transplant, because a novel transplant comes along every two or three years, and we need to futureproof whatever we do. So, we would suggest excluding novel forms of transplant. I also think that it is quite difficult for people to discuss that in advance. It is hard enough to discuss the things that are inside you, never mind the stuff that is on the outside. Furthermore, it is quite a misleading area, given that there is such a small number. At the moment, the only teams that we train, in terms of seeking consent for face or hand transplants, are those that are very close to the transplanting centres, which are London and Leeds. Therefore, it would not apply in this Bill.

[540] **Elin Jones:** Currently.

[541] **Ms Johnson:** Yes.

[542] **Elin Jones:** However, in terms of futureproofing the legislation, it may be something that this committee could consider, because, as you said, this is changing all the time, and those centres exist now, but, in five years' time, there could be new centres of expertise if more work is done on this.

[543] **Ms Johnson:** There might be. The experience is that these things tend to happen very

rarely, and you do not want lots of centres. You want a small number of centres that do them exceptionally well. I also have a view that we need to get people to sign up to organ donation to save and transform people's lives. There is no doubt that face and hand transplantations transform people's lives, but I think that it is, perhaps, going a step further than people would feel comfortable with.

[544] **Mark Drakeford:** I will follow that up for one moment with one other point that you make in relation to living donation in your evidence. You say that you think that references to living donation should be removed from the Bill.

[545] **Ms Johnson:** It would concern me if people became confused and thought that deemed consent might apply to living donation. Clearly, it cannot; you have to actively consent to living donation. However, my experience is that myths develop quickly in this field, and if there is anything that people might misunderstand, that opportunity could quite easily be taken. So, we would like to make sure that, if this Bill is passed, it is effective and does what we all hope it will do, which is to get us some more organ donors, and not confuse people.

[546] **Mark Drakeford:** So, living donation is a situation in which I agree to donate a kidney to somebody else while I am alive. You think that that should not be part of this Bill because it is peripheral to it, and that it confuses people by being included.

[547] **Ms Johnson:** I do not think that there is any intention that deemed consent would apply in the case of living donation.

[548] **Mark Drakeford:** No.

[549] **Vaughan Gething:** I guess that the alternative view, and I am interested in your view on this, is that if you are dealing with other forms of transplantation, why not have them all in the same Bill, rather than have living elements in the 2004 Act and other elements here? Would it not make sense to have them all in the same Bill, especially as, for the purposes of living donation, there is no change to the law? You still have to provide direct, expressed consent.

[550] **Ms Johnson:** My only concern would be that, in translating the Bill into the education and communication programmes, people will get confused. At the end of the day, that is all that matters to me: how we operationalise this. What the law says is clearly incredibly important, but that is for you to decide, not me.

[551] **William Graham:** Could you just amplify why you think the word 'deceased' should be removed?

[552] **Ms Johnson:** Do you mean in relation to donation after circulatory death?

[553] **William Graham:** Yes, you refer to it in relation to section 12.

[554] **Ms Johnson:** This is a complex area. Perhaps I had better say a bit about donation following circulatory death. There are two types of donation. The first is donation after brain death and death being confirmed by neurological criteria—which is the kind of donation with which many people are familiar, where the person is on a ventilator and looks alive but they are not, they are dead. The ventilator is turned off and the organs are retrieved. The second type is donation after circulatory death, which is a more complex process in that when we first start discussing donation with the family, the patient is still alive, but the clinicians believe that any further treatment is futile and will not be of benefit to the patient. If the family agrees to organ donation, or supports the express wish for organ donation, treatment will be

withdrawn and the organs will be retrieved quite rapidly thereafter. One of the things that people are exploring is how we can ensure the organs are in a better condition in those cases. That means being able to give treatment to the patient that will preserve the organs. If you specifically put ‘deceased’ in and state that deemed consent applies only once they are deceased, nothing can be done before they are deceased to preserve their organs, at which point you will not get the benefits of that intervention.

[555] It is quite complex and we are pursuing this cautiously, but what they can and cannot do is a matter of concern for intensivists; that is, what is truly in the best interests of the person who is dead or dying to make their wish to be a donor a reality and to ensure that if they are going to be a donor, that they donate as much they would have wanted. It is a sensitive matter, which may lead to some concerns and practical issues for our intensive care colleagues.

[556] **Mark Drakeford:** I will put that to you from the opposite point of view. Quite a lot of people who have written to us with concerns about the Bill are concerned that the point of death may become a bit of a movable matter in order to be able to harvest organs—as they sometimes put it—more easily. Is it not the case that including the word ‘deceased’ in the Bill helps to answer some of their anxieties, in that somebody really has to be deceased before organs are removed from them?

[557] **Ms Johnson:** It may well calm those anxieties. I can assure you that they are definitely deceased and we have extremely clear guidance in this country about how to confirm death. For donation after neurological death, two doctors have to confirm death when doing the brainstem death testing. After the withdrawal of treatment, there has to be a standard down period—a gap—before organs can be retrieved, even though that might have an impact on the quality of the organs, so that there can be absolute certainty.

[558] **Rebecca Evans:** In your response to the Government’s consultation, you say that you do not agree that the equality impact assessment properly sets out how the legislation will affect different sections of society, including children and people who lack capacity. Can you expand on those concerns and any suggestions that you might have for amendments to the Bill?

[559] **Ms Johnson:** We had some concerns about the fact that the initial draft, with regard to children, focused on those who were over the age of 18, because we know that many children make a decision to be an organ donor when they are younger than that. We provide training packs for use in schools—they are not used in every school, but where they are used they have a big impact on children. Children can understand the implications of those decisions at quite a young age. To say that it applies to those who are 18 and above means that some people who would want to donate might be denied that opportunity. That was initially, when we were having a lot of discussion about whether expressed consent would sit alongside opt-out. I think that being able to continue to express consent is very important, so I have fewer concerns about that.

3.15 p.m.

[560] In terms of mental capacity, it is not so much a question of the Bill being difficult in terms of whether people have mental capacity and how they make a decision about organ donation; it is more about the challenge for our specialist nurses, about how they know what people’s views are under deemed consent, and whether they genuinely have the capacity to decide whether to opt out, to opt in or just really have not understood and therefore have fallen in the centre. Nothing has changed in the Bill from the Human Tissue Act, but the defining difference it that opting out is very different from opting in or seeking to ask the family. Therefore, it is very important that people genuinely have the opportunity and the

understanding to opt out. After much discussion with our colleagues and the officials in the Welsh Government, I think that we are accepting of the fact that we would take the family's word for the understanding of their relative.

[561] **Rebecca Evans:** Could you envisage a case where it would be impossible for one of your specialist nurses to determine a person's mental capacity, given the fact that some people with mental ill health often keep that condition from their families and do not seek medical help? They are essentially living with a potentially serious mental health condition, but have not actually told anybody about it. There is no way that I can see that the specialist nurse or anyone else can take that into consideration.

[562] **Ms Johnson:** I suppose that depends on whether you believe that having a serious mental health condition means that you do not have the capacity automatically to make a decision about organ donation. I do not think that that is necessarily the case. I would accept that if the family do not know, there is no way that the specialist nurse can know.

[563] **Rebecca Evans:** You would accept, though, that if you had a serious mental health condition, you might just be focused on getting through the day, rather than the wider framework of life. People talking about presumed consent, opting in and opting out might be completely outside the experience and the thought process of a person with a serious mental illness.

[564] **Ms Johnson:** It might be outside the thought process of those without a mental illness, to be honest. One of the things that is key at this point is the fact that lots of people do not think about organ donation, which is why it comes as such a surprise to their families when they are in a situation that means that they are one of that tiny group who can donate. It comes as a huge surprise to their families because nobody has thought about it.

[565] **Vaughan Gething:** I want to go back to clarify in my own mind the points that Elin raised about section 16(2). In the draft Bill, you wanted to add blood, blood products, blood components and stem cells to the list of exceptions in section 16(2). You also point out that section 17(6), as it now is, states that,

[566] 'references to transplantation are to transplantation to a human body and include transfusion.'

[567] For my own mind, so that I am reading this the same way that you are, is the reference to transfusion in 17(6) incidental to transplantation, rather than any form of blood transfusion?

[568] **Ms Johnson:** Yes.

[569] **Vaughan Gething:** Is that why you want to see blood, blood products, blood components and stem cells added to the list of exceptions of relevant material that are not caught by the provisions of this Bill?

[570] **Ms Johnson:** Yes.

[571] **Vaughan Gething:** Fine, I just wanted to understand that.

[572] **Elin Jones:** I have a question on the new UK-wide register. The Minister told us that she had written to her equivalent Ministers in the other countries seeking their views, agreement and possible funding for the new UK-wide register. In your evidence, you say that you have had a verbal commitment from the Welsh Government regarding funding. Could you tell us something about the estimated cost of a new register, and what was the nature of

the Welsh Government’s verbal commitment? Also, how do you think that this will work in practice? What will be the development costs and the timeline for the development of the new register?

[573] **Ms Johnson:** The costs that are in the Bill are those that we have been discussing with the Welsh Government. So, we have worked together and engaged some external people who have experience in developing such registers to tell us what they think that it would cost. We have had that quality-assured by a separate company. I am not an expert in register development, although, of course, we have people who work with us who are experts at running registers. The costs are estimated to the best of all the experts’ abilities, but it will have to go out to tender. At the end of the day, we will have to see what the tenders come back at. That is a standard NHS procurement process. So, the Bill sets out the costs that we have been discussing and I hope that they will come in at that level or below it.

[574] **Elin Jones:** In terms of the timeline expected in the enactment of this Bill and the Welsh Government’s expectation, do you think that that is all practical?

[575] **Ms Johnson:** I think that it is practical and achievable, provided that getting a decision from all four Governments about buying into a single new register, which is the only safe way of doing it, does not eat up all the contingency in our plans. So, we need to know soon; I would say that we need to know definitely by the end of February if we are to meet the expected timetable.

[576] **Mark Drakeford:** I have a few questions. Do you believe that the term ‘ordinarily resident’ is sufficiently clear as it is set out in the Bill?

[577] **Ms Johnson:** I think that it is possible to work with the families to determine whether they believe that they are ordinarily resident in terms of the way in which it is set out, yes. It is not something that I think our specialist nurses would make a definite determination on; they would be guided by the families. I would not want to put them in a position where they had to say that someone is ordinarily resident, if the family said that they were not.

[578] **Mark Drakeford:** Right. You would expect them to be guided by family members, which is also what the Minister said to us in her evidence. Thank you.

[579] A slightly more complicated issue, or so it seems to me anyway, is the business of an appointed representative. The Bill provides for an appointed representative to be brought into being and suggests that if they are not contactable, no further attempt will be made to gain consent from any other person in a qualifying relationship. You say in your written evidence that you prefer the system of the 2004 Act, where, if the appointed representative cannot be found, then you go down a descending list of other people who could be contacted. Could you tell us a bit more about that?

[580] **Ms Johnson:** Yes. Operationally, if the appointed representative is the next of kin, it is not a problem; we will be able to find them. However, I have some concerns if, say, somebody appointed their lawyer, for example, how would we know who the appointed representative was and how would we know how to get in touch with them—often at a very inconvenient time—when the person who has appointed them as their representative is likely to be unconscious? So, from a practical point of view, we need to make sure that whatever is put in the Bill is practically implementable in the really quite challenging world of organ donation.

[581] **Mark Drakeford:** The Bill resolves that, practically, by saying that if the person cannot be contacted, that is the end of that and we do not go any further. However, you prefer a different practical system in which you would go on to contact other people. Why do you

think that that is preferable?

[582] **Ms Johnson:** If the person had wanted to be an organ donor, but, for example, did not trust Government databases and did not want to put their name on one, but had wanted to tell somebody, would it not be a shame if, because that person happened to be out of the country or was not contactable, that individual’s wishes were not fulfilled? That is why.

[583] **Mark Drakeford:** Thank you. If your idea of devolving that decision down the list of qualifying relationships were to be followed, do you think that it would be important to rank qualifying relationships in any way? The Bill does not do so; the Bill lists qualifying relationships and just says, ‘There they are’. We have had a series of questions this afternoon about whether some relationships are more significant than others and whether they should be ranked. Should there be a ranking would it help in the circumstances that we have just described?

[584] **Ms Johnson:** In practical terms at the moment it can be helpful if they are ranked, but in practically every circumstance the specialist nurses are seeking to achieve agreement from everyone around the bedside about the best outcome for their relative, friend or whatever relationship that they have. That is not always easy. I suppose that if you are in a situation with deemed consent and you have lots of people around the bedside all having a view—my nurses will tell me stories such as, ‘We had 14 people around the bedside, and we had some people on the phone from a different country’—it is quite difficult to get agreement in those circumstances. Sometimes, you want to be able to take the people closest to the individual and work with them, and then if they support organ donation, they can talk to the wider group. So, it can be helpful but, in a practical sense, you really want everyone to sign up for this. We are in new territory here with deemed consent. We are used to working in a situation where there is either expressed consent or it is a complete unknown. Where it is a complete unknown, you are seeking to ensure that everyone makes the decision that is right for them and what we hope will be a decision to say, ‘Yes, it is right for the potential donor’. When it is deemed consent, it becomes more important because you have a slightly different way in which you approach things. You are approaching the family with an expectation of donation, not seeking to explore their past views and whether they had any knowledge of donation et cetera. It is subtly different.

[585] **Mark Drakeford:** This is the last question from me, and then we will see whether there are any further questions from Members. If not, there will be a chance just for you to put on record any points that have not arisen in the discussion or anything that you think that we may not have emphasised enough perhaps. You referred in your opening statement to the fact that your organisation is responsible for organ retrieval and that we have not explored that aspect of the subject so far this afternoon. Would you like to tell us a little bit more about what you do, and how you think that this committee should be thinking about it in relation to this Bill?

[586] **Ms Johnson:** It is important to understand that the people who do the organ retrieval are usually from a completely different hospital. They come after consent has been given by the family and by the individual to retrieve the organs and, obviously, they check the forms to see that consent has been given et cetera. That is relatively straightforward in a situation where you have an opt-in. When you have an opt-out, they have to be absolutely certain that there is no evidence of the individual having opted out before they start to retrieve the organs, otherwise, they would be very concerned about whether they were committing a criminal act. I know that the law states that if they do it in good faith, on the basis of the best evidence available, they are not, but let us be honest and admit that they still have some nervousness about this. It is important that they understand, and that it is very clearly stated not only in law, but in the explanatory memorandum, that they will be acting in good faith and that they will not be at risk. We would not want to be in a situation where the retrieval surgeons felt

uncomfortable about actually making that gift of life happen at the very last minute.

[587] **Mark Drakeford:** We had some exploration of this in a slightly different way with the Minister earlier when we were asking her whether, in the information campaign that will follow the Bill, she would expect to give some sort of priority, in terms of visibility, to the opt-out system and making it absolutely clear to people that you could opt out, and the very simple way in which they could do that. Do you think that, if there is a proper system of that sort in place, it will help people at that point? You might assume that, if someone wanted to opt out, they would have known about it and would have been able to do so reasonably straightforwardly.

3.30 p.m.

[588] **Ms Johnson:** Yes, I hope that that will give the retrieval teams additional confidence. I know that they will want to see it very clearly expressed both in the law and in the accompanying documentation. Training retrieval teams to understand this is very important, as is training all doctors to understand the change in the law. If they are not fully on board with this, no matter how much willingness there is, it is going to be very difficult to get the gains that we are all seeking.

[589] **Mark Drakeford:** Are there any further questions that committee members want to ask at this point? I see that there are not. We have a couple of minutes left. As I said before, Ms Johnson, if there are any issues that have not emerged clearly enough in our discussion, or any points that you feel are important for the committee to be aware of as we continue our scrutiny of the Bill at Stage 1, we would be very grateful if you could convey them to us now.

[590] **Ms Johnson:** It is perhaps worth saying a couple of words about the role of the family, as that has been much discussed today. The way in which we approach families now is that, if someone has express consent, we will seek the family's support. We do not ask for their consent; we seek the family's support for that consent. You have heard that, in some cases, families still do not feel able to say 'yes'. We know that there is international evidence, particularly from America, that organ procurement organisations have been able to go ahead with organ donations even when families have felt uncomfortable with that, partly by using the law. That is something that we are exploring and it is important to put that into this domain at the present time.

[591] We are developing a new strategy for organ donation for the UK, which we hope will be published later this year. It will support many of the efforts that the Welsh Government is making, in terms of opt-out. That is an important thing to recognise. When we approach a family in a situation of deemed consent, I would expect that we would also be saying that the assumption is that the person wanted to be an organ donor and, therefore, we would be seeking the family's support, rather than approaching it in a more neutral way, as we currently do, and, where there is an opt-out, we will not be talking to them about it at all, as you can see from the explanatory memorandum. This is a matter that is very difficult to envisage if you have not watched one of those engagements with a family. It is a lengthy and very sensitive process, but how you begin and manage that process is important.

[592] The other thing that I think the committee should be aware of is that our specialist nurses are extremely well-trained and do this many times, but not every family is approached and supported by a specialist nurse for a whole range of reasons. In about a third of cases, it may be the intensive care doctor who has been looking after the family, or someone else, who will be asking them about organ donation. That means that there is a huge number of people who need to understand the implications of the Bill and how best to approach families if we are to make it successful. That is all that I wanted to add.

[593] **Mark Drakeford:** Thank you very much indeed. There may be a couple more questions arising from that. Indeed, I can see that there are. I thought that there might be. [*Laughter.*]

[594] **Elin Jones:** You referred to opted-out individuals, and that you may not have any conversation with their families. Does it strike you that there may be an imbalance resulting from this legislation, whereby the family of an opted-in individual can influence the final decision, whereas the family of an opted-out individual may not even have a conversation about potential organ donation?

[595] **Ms Johnson:** I would rather think that express consent and opt-out should have parity, in that the wishes of the individual should be respected and enacted one way or another, and that the business of the family is in those cases where there is deemed consent and no clear indication had been given.

[596] **Mark Drakeford:** The Minister told us earlier that in around 10 to 15% of opted-in cases in the current system the family's wishes overturn that expressed wish. You think that probably ought not to be part of this.

[597] **Ms Johnson:** What we do not know enough about is whether the family, at the time they said 'no' to the organ donation, knew of the expressed wish of the individual. It may be that the intensive care clinician who is caring for them approaches them about organ donation without calling the specialist nurse and checking the organ donor register. So, they might not know that they have overturned the wish, but, yes, some families will overturn wishes, and what we are seeking to do is get to a point where that does not happen. A lot of people ask, 'Why should I sign up if you are going to listen to my family and not what I wanted?'

[598] **Vaughan Gething:** That point has been put to me by a few people, as I am sure that it has to others. Are you suggesting, then, that you would like to see the Bill amended to reflect that so that express opting-in trumps a later family objection? What we are told very clearly at the moment is that that would move away from current practice, whereby family wishes can override express consent, and, in terms of the debate that we are having, if that were a possible outcome to this process, then we should be upfront about that sooner rather than later. I am not sure whether you are saying that you would like to see that at some point in the future or whether you are saying that you would like us to consider that now, as this Bill is before us.

[599] **Ms Johnson:** I think the reality is that this is about working with doctors and nurses about how they ensure that the family respects the wishes of their relative. You can put it in the law, and it might help, but actually at the moment it is the law that the individual's wishes have primacy, but it is very difficult to effect that in a highly charged, highly emotional clinical situation. We know that the Americans have been successful in doing that, and we are looking at how they have done that. If there is learning from America where they have found ways to use the law to back that up in a slightly different way, then that would be worth exploring. However, we are still at the very beginning of looking at this at present.

[600] **Rebecca Evans:** I read in the explanatory memorandum that, in situations such as those that we are discussing, a family member might have to sign a piece of paper to say that they are overriding the express consent of their loved one. Do you think, bearing in mind everything that you have told us about how delicate and sensitive and emotional these situations are, that that is helpful?

[601] **Ms Johnson:** Certainly the experience in Scotland would suggest that it can be in terms of them really realising what they are doing. After all, there are very few families that would override a will. A will to be an organ donor is broadly similar. Our colleagues in

Scotland have found that to be quite helpful. If that gives people more confidence that their wishes will be respected, and encourages more people to express consent for organ donation, thereby taking the difficult decision away from their family—even with deemed consent, the family will, I suspect, often think that it is its decision, even though the legal framework will say that, if you have not opted out, you have, effectively, opted in—then I think that it could be helpful, yes.

[602] **Mark Drakeford:** Thank you very much indeed, and thank you for those last points, which provoked a further round of interesting questions. We are grateful to you for coming to help us with our work this afternoon.

[603] Dyna diwedd ein sesiynau tystiolaeth am heddiw.

That is the end of our evidence sessions today.

3.40 p.m.

Papurau i'w Nodi
Papers to note

[604] **Mark Drakeford:** Mae rhai papurau i'w nodi. Mae llythyr gan y prif ystadegydd ynghylch cynnwys ac amseru ystadegau swyddogol ynghylch iechyd. Nid wyf yn siŵr a yw pobl wedi cael y cyfle i ddarllen y llythyr—nid yw ond yn ateb y pwyntiau yr oeddem wedi eu codi gydag ef o'r blaen.

Mark Drakeford: There are some papers to note. There is a letter from the chief statistician on the content and timing of official health statistics. I am not sure whether people had an opportunity to read the letter—it just answers the point that we raised with him previously.

[605] Hefyd, mae papur 6, sef llythyr gan y Gweinidog Iechyd a Gwasanaethau Cymdeithasol, yn ymwneud â chamau a gymerwyd yn sgîl y cyfarfod ar 5 Rhagfyr. Mae rhai pethau a godwyd gennym ar ôl y cyfarfod hwnnw y bydd y Gweinidog yn dod yn ôl atom ni amdanynt mewn llythyr arall.

Also, we have paper 6, which is a letter from the Minister for Health and Social Services, concerning action taken following our meeting on 5 December. There are some things that we raised after meeting that the Minister will come back to us on in another letter.

[606] A yw pob un yn hapus? Gwelaf eich bod. Dyna ni: diwedd y prynhawn. Diolch yn fawr iawn i bob un sydd wedi bod yma drwy'r dydd.

Is everyone content? I see that you are. That brings us to the end of this afternoon's business. I thank everyone who has been here throughout the day.

Daeth y cyfarfod i ben am 3.40 p.m.
The meeting ended at 3.40 p.m.