



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

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

Dydd Iau, 8 Rhagfyr 2011
Thursday, 8 December 2011

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Motion under Standing Order No. 17.42(vi) to Resolve to Exclude the Public from the
Meeting for Items 7 and 8

Cofnodir y trafodion hyn yn yr iaith y llefarwyd hwy ynndi yn y pwyllgor. Yn ogystal,
cynhwysir cyfieithiad Saesneg o gyfraniadau yn y Gymraeg. Mae hon yn fersiwn ddrafft o'r
cofnod. Cyhoeddir fersiwn derfynol ymhen pum diwrnod gwaith.

These proceedings are reported in the language in which they were spoken in the committee.
In addition, an English translation of Welsh speeches is included. This is a draft version of the
record. The final version will be published within five working days.

Aelodau'r pwyllgor yn bresennol
Committee members in attendance

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

Eraill yn bresennol
Others in attendance

Dr Grant Duncan	Dirprwy Gyfarwyddwr y Gyfarwyddiaeth Feddygol, Llywodraeth Cymru Deputy Director Medical Directorate, Welsh Government
Dr Chris Jones	Cyfarwyddwr Meddygol GIG Cymru a'r Dirprwy Brif Swyddog Meddygol Medical Director NHS Wales and Deputy Chief Medical Officer

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

Sarah Beasley	Clerc Clerk
Llinos Dafydd	Clerc Clerk
Gregg Jones	Y Gwasanaeth Ymchwil Research Service
Catherine Hunt	Dirprwy Glerc Deputy Clerk

Dechreuodd y cyfarfod am 9.31 a.m.
The meeting began at 9.31 a.m.

Cyflwyniad, Ymddiheuriadau a Dirprwyon
Introductions, Apologies and Substitutions

[1] **Mark Drakeford:** Bore da, a **Mark Drakeford:** Good morning, welcome chroeso i gyfarfod olaf y Pwyllgor Iechyd a to the final meeting of the Health and Social Gofal Cymdeithasol cyn y Nadolig. Care Committee before Christmas. Apologies Ymddiheuriadau am fod dwy funud yn hwyr for being two minutes late in starting. We yn dechrau. Yr ydym wedi cael have received apologies from Darren Millar ymddiheuriadau gan Darren Millar a Kirsty and Kirsty Williams.

Williams.

9.32 a.m.

**Y Wybodaeth Ddiweddaraf am Faterion Polisi yr Undeb Ewropeaidd sy'n
Berthnasol i'r Pwyllgor Iechyd a Gofal Cymdeithasol
Update on EU Policy Issues Relevant to the Health and Social Care
Committee**

[2] **Mark Drakeford:** Diben yr eitem hon yw rhoi cyfle inni feddwl am yr hyn yr ydym fel pwyllgor yn dymuno gwneud yn y cyd-destun Ewropeaidd. Nid oes pwyllgor ar faterion Ewropeaidd yn y Cynulliad bellach, felly mae'r cyfrifoldeb i feddwl am y materion hyn yn syrthio ar y pwyllgorau eraill, fel y pwyllgor hwn.

Mark Drakeford: The purpose of this item is to give us an opportunity to think of what we, as a committee, wish to do in the European context. The Assembly no longer has a committee on European affairs; therefore, the responsibility to think about these matters falls to the other committees, such as this one.

[3] We have a quarter of an hour in which to hear from Gregg; first, we will have a five-minute introduction from him to outline some of the key issues in the field of health and social care that have a resonance at the European level. You will see in the paper that there are a number of suggestions as to how we, as a committee, might want to do some work in this area after Christmas. I do not think that we need to make a decision on that today; it is more a matter of tuning up our thinking. The item is only a quarter of an hour in length; we will come back to this issue after Christmas and decide how best to discharge the responsibilities that now fall to us regarding the European dimension of our subject area. Bore da, Gregg; we turn to you for an introduction to the item.

[4] **Mr Jones:** Good morning to you, Chair, and to the other members of the committee. It is a pleasure to be with you today via video-conference from Brussels. Before referring to the paper, I will briefly introduce myself and the role of the office, because not all Members will have met me, nor will they necessarily be familiar with my role. I am based in Brussels and work exclusively for the National Assembly for Wales. I am based in Wales House with colleagues from the Welsh Government, Welsh local government and universities. I have been described as the eyes and ears of the Assembly in Brussels and as a link between the work of the Assembly and that of the European Union—a two-way channel, if you like—so that we can feed in the work that we are doing and I can feed back the work that is going on in Brussels. The role includes visits, dealing with individual inquiries as part of the Research Service and providing advice and support on EU issues in general. As you mentioned, under this Assembly EU issues have been mainstreamed, which means that there is more of a co-ordinating role for the office, working with colleagues in Cardiff, to ensure that there is a joined-up approach. However, it is ultimately down to the Chairs and the committee members to decide on the priorities and areas that they wish to work on. So, it really is just advice from my point of view. I am hoping that this will be the first of regular sessions during the fourth Assembly, and I am obviously very interested to see that European issues are considered by the committee.

[5] Turning to the paper, with that in mind, what I have tried to do is use this as an introductory paper to explain how the EU policy-making process works and is relevant to the work of the Health and Social Care Committee. That includes a run-through of the competencies and the powers that the EU has in terms of influencing what goes on within member states, and also within Wales as part of a member state. I have then tried to run through the main EU institutions—the European Commission, Council of Ministers and Parliament—and I have mentioned some other bodies, such as the Committee of the Regions

and various EU networks. Section 3 then runs through some of the potential priority areas that are on the agenda at the moment that look particularly relevant to Wales and, as you have already mentioned, section 4 presents some suggested areas that the committee may want to consider working on. We will come back to that early next year.

[6] I was looking at the WalesOnline website earlier today and there was an article about differences in terms of how long people are living, relating back to where they lived in Wales. That was an interesting point, as that is one of the issues that is partly addressed in the paper on health inequalities. Last week, the Council of Ministers adopted some conclusions on health inequalities and there is a piece of work that the UK, as well as the Scottish Government, is heavily involved in, looking at a joint action plan on addressing health inequalities. That was one that jumped out at me, but I will hand over to Members, in terms of questions or issues that you want to raise on the paper.

[7] **Mark Drakeford:** I do not think that we will aim to make a decision today about work that we will want to do in this area, but it is a chance for us to ask Gregg any questions to help us to think that through. Personally, I was struck, in looking at the paper, by the number of issues in which we could, potentially, take an interest, where the European dimension has a direct impact on health and social care services here in Wales. I do not think that we are short of options or choices. Does anyone have anything that they would like to ask Gregg arising from the paper?

[8] **William Graham:** Good morning, Gregg. Thank you for your paper. We are looking forward to being with you in Brussels in 10 days' time. I will ask one quick question and then one longer one, if I may. You say a little about the revision of the working time directive. Are there any updates on that? Turning to the more substantive question, one suggestion as to something that we might look at is how organisations in Wales engage more broadly with EU funding opportunities. Could you give us some specific advice on that?

[9] **Mr Jones:** Good morning, William. The working time directive has been quite a controversial dossier here in Brussels. The European Commission tried to revise that a couple of years ago, and it was one of the first dossiers to fail at Third Reading, which is the conciliation phase. The European Parliament and the Council of Ministers could not agree on the final text. There was a blocking minority within the Council of Ministers, and the UK Government was part of that blocking minority. The Commission has been working on the proposals. In 2010, there were a couple of consultations and, in the 2010 work programme, it anticipated that new proposals would come forward in 2011. That has not happened, and for the work programme for 2012, it is not explicitly mentioned, so they are still working on it and trying to find a proposal that it thinks will overcome the problems that it had the first time around.

[10] In terms of funding programmes, you will see in the paper that there is mention of the Health for Growth programme, which is the Commission's proposal for the 2014-20 period, building on an existing programme within this area. That is very much related to work that I have referred to in the paper about inter-governmental co-operation. Health is a national competence, primarily. Where the EU can get involved is in trying to address pan-European issues, and helping to strengthen co-ordination across areas of health policy. I mentioned health inequalities in my introduction, and that is one area where there is a lot of work going on. The UK Government is actively involved in a joint action plan with partners from across Europe. That looks to address health inequalities and get behind the problem to see if there are any ways in which best practice can be shared between member states. Health issues can be addressed in other ways through funding programmes outside of that. The EU structural funds, which are primarily to do with economic regeneration and investment, also include potential for addressing health issues. How do you get involved? Organisations from Wales are eligible to participate in those programmes. It is a question of having an awareness of

them, identifying issues within Wales, and taking a joined-up approach. Most of those initiatives will include working with partners from other parts of the EU to try to identify opportunities and those to work with. There is a whole host of agencies that can give support with that.

[11] **Elin Jones:** Good morning, Gregg. In your introduction, you mentioned the joint action plan on health inequalities and said that the Scottish Government and the UK Government have had an involvement in that. That is an area of importance in Wales. Could this committee or the Welsh Government be more actively involved in any work coming out of that joint action plan? What are the opportunities related to that?

[12] **Mr Jones:** I plan to send you an update note, because there were no details in the paper that you have. I can do that after the meeting. I have it in front of me—the EuroHealthNet website, which is referred to in the paper, contains some details on this. It identifies the partners involved and the types of activities that it is planning on undertaking. I did not see the Welsh Government listed there, which is why I have not mentioned it. I will check with colleagues if it is indirectly involved. It is possible that it is, because the Department of Health and the Scottish Government is involved. On the issues that EuroHealthNet is looking to address, the general objectives are: developing a knowledge for action on health inequalities; supporting engagement of member states, regions and other stakeholders in action to tackle socioeconomic health inequalities; sharing learning between member states and other actors; and supporting the development of effective action to tackle socioeconomic health inequalities at a European policy level.

[13] They all sound like issues that would be relevant to Wales, and to the work of this committee. Within the actions that I have suggested in section 4, one of them is to look at how we could get involved in EU initiatives, and how the Welsh Government actively participates in them. A lot of that, as I mentioned, is inter-governmental. It would be at member state level, and it should also involve sub-state governments. There could be a question to the Welsh Government on whether it is involved, and on how it would participate explicitly in this joint action as well as other actions. An innovation platform has been mentioned, as well as active and healthy ageing, which would be other examples of this in practice.

[14] **Mick Antoniw:** I am interested in three areas. The first is the procurement directive. A task and finish group has been set up, so perhaps it would not particularly concern us. However, there could be health aspects related to procurement, because it impacts on the largest budget of the Welsh Government. The second area that I am interested in is drugs—not with regard to procurement, but with regard to the approval of drugs throughout the European Union, as opposed to individual state systems, such as the National Institute for Health and Clinical Excellence.

9.45 a.m.

[15] The third area that I am interested in is on systems or models of ownership with regard to the care of the elderly—not so much in terms of policy, although please tell us if there is anything. Is there a way for us to get a clear picture from you, at some stage, of the different systems of ownership of care provision that exist throughout the EU?

[16] **Mr Jones:** On the first issue, which was procurement, the proposals for the revision of the current EU directives are due to come out on 13 December. There has been a big consultation exercise this year that Welsh stakeholders fed into; I also know that the NHS fed into that.

[17] To return to one of my earlier points about co-ordination and how committees work

together, the Enterprise and Business Committee is going to carry out an inquiry on this. It has set up a task and finish group, which Julie James will be chairing; it is due to start on this in January and the idea is to try to turn around a piece of work in that term. However, if there are any specific issues or concerns relating to health, the committee, in the appropriate ways in which this can happen, may wish to feed those views or suggestions through with regard to ensuring that concerns relevant to the health service are taken on board. We will produce an EU policy update on it to explain the proposed changes and how they relate to Wales. So, that will be aimed at all Members of the Assembly, as is the case with all EU policy updates. That will, hopefully, give people a general idea of what is included.

[18] I will have to come back to you on the drugs approval process, because that is quite a technical question. However, I will be able to give you a sense of the process involved in that. Similarly, the question of different care systems for the elderly is something that we can look at to see what the different models are. That is the type of thing that member states will be looking at with regard to the exchange of best practice as part of the structured working that I have talked about already.

[19] **Lindsay Whittle:** I will return to the issue of health inequalities, given that it is quite a burning issue—indeed, it is the main news in Wales today. In 2005, in my previous role as the leader of Caerphilly County Borough Council, I attended a World Health Organization conference in Verona in Italy, which is a very nice place to visit. It was a three-day conference, with three 10-hour sessions, so it was not the jolly that I had imagined.

[20] **Mick Antoniw:** Or that you had expected, perhaps.

[21] **Lindsay Whittle:** Yes. *[Laughter.]* At that conference, we looked at comparative good practice on a more local basis to address health inequalities. Is there any future legislation coming out of Europe that we could use, not just on a local basis, but on a national basis in Wales? That could contribute to some of our good practices and also allow us to learn from other countries.

[22] **Mr Jones:** That is a good question. I am not sure whether there will be any legislation, so I will have to check that. However, I suspect not, because health is a national competence, so it is more about how Governments can work together to address some of the problems that I have outlined already, such as joint action, which relates back to the EU Commission communication on solidarity in health and reducing health inequalities, which came out in 2009. There was also a communication in 2005, which would have been related to the conference that you attended.

[23] So, I do not think that there will be specific legislation, but I will check that in case there is anything. However, it is really about looking at how Governments can work together and how regional organisations and local authorities can work together, because these issues are not just about healthcare provision, but about the social context—the sort of environments in which people live and some of the social challenges that they face. So, all of that is wrapped up more obviously in the broader issues around people's way of living, equity issues and so forth. So, I would like to come back to you on that, if that is okay, Chair.

[24] **Mark Drakeford:** Thank you, Gregg, for all of that. I am sorry that it has been such a short slot with you this morning, but, in many ways, today has been a taster session, in which we have begun to think about the work that we might like to do in the European area. The extra information that you will provide will be helpful to us for that. As a committee, we will look at our future work programme in the round soon after Christmas, and this will definitely form part of that discussion. I will ask Members in advance of that to have another look through the paper, to think about the extra information that we will have from you and to come to that next discussion with some specific proposals as to any work that we would like

to concentrate on with a European dimension.

[25] Felly, diolch yn fawr iawn; mae wedi So, thank you very much; it has been useful
bod yn ddefnyddiol clywed gennych chi y to hear from you this morning.
bore yma.

[26] **Mr Jones:** Diolch. I will speak to you soon.

9.50 a.m.

Ymchwiliad i Ofal Preswyl i Bobl Hŷn—Cynllun Gwaith y Pwyllgor Inquiry into Residential Care for Older People—Committee Work Plan

[27] **Mark Drakeford:** This is a paper that helps us to plan in more detail for the major piece of work that we will do after Christmas on residential care for older people. The paper asks us to make four specific decisions, and I will take them one at a time. I will put the proposition to you to see whether anyone wants to say anything about it, dissent from it or whatever, and, hopefully, we will make the necessary decisions to allow the preparation to go ahead.

[28] The first thing that we are asked to decide on is to be found between paragraphs 5 and 12 in paper 2, which set out a way of organising the oral evidence that we will take. I have been keen, in discussing matters with the clerk, for us to have a coherent and organised pattern of taking evidence. Given the scale of this inquiry, I do not want us to be in a position in which we have people turning up simply because their diary happens to be free on a day that we are sitting. That would mean that we have a scatter-gun approach towards evidence in which we are never quite sure which bit of the inquiry we are concentrating on at any one time. So, the paper suggests trying to organise witnesses into particular perspectives. For example, we will try to get all the organisations that have a remit for representing the voice and the experience of older people to come in together. We will try to ensure that all the regulators come in together and that all the organisations that represent workers who provide services to older people directly at the face-to-face level come in together. So, we will have a more coherent chance to try to capture the different voices and interests that we will want to consider in our inquiry. That is only one way of trying to get some coherence to it; there could have been others, but that is the one that the paper proposes to you. Are you happy with that way of organising it? I see that you are; excellent. Thank you.

[29] **Rebecca Evans:** On point 7, should we include some evidence from academics or people who do research in that field, particularly if they know of models that are working elsewhere in Europe, just to give us that perspective as well?

[30] **Mark Drakeford:** That is helpful; we should do that.

[31] The second thing that we are asked to consider is our working arrangements for the inquiry. Between paragraphs 6 and 8, you will see the suggestion of inviting Members to identify a particular strand in the inquiry in which they will take a particular interest. There are two reasons for that. Obviously, we will all take an interest in all the strands, but given that it is a complicated inquiry with lots of different aspects to it, if Members are prepared to sign up to taking a particular interest in a particular strand, that will guarantee that, around the table, everything that we are trying to cover will have someone who sees it as their job to speak up for that particular aspect.

[32] However, there is also a second reason for that, which is that I am keen that, within the allocated time that the committee has, we free up some time for us to get out of this

building and go out and meet individuals, organisations, projects, and so on—people who can tell us about the experience of residential care for older people. We cannot all go everywhere; if we tried to do that, we would end up with big logistical problems. However, if we have Members who are interested in a particular strand, then we could make sure that there is committee time to go out and do that sort of work, and then feed that back into the discussions that we will have when we have witnesses before us in more formal sessions. It is also a way of giving us a chance to do something more imaginative than just expecting everybody always to come to us. Does that make sense?

[33] **Mick Antoniwi:** That is interesting. At some stage, it would be quite interesting to talk to families, somehow or other. There is a danger of creating a public meeting approach, but meeting with the families of people who are taking the decisions regarding their parents going into care homes, and so on, would be useful. I do not know how we might do it, but we could also speak to some of the residents themselves.

[34] **Mark Drakeford:** We will have help in all of this, both from the committee secretariat, and from the Assembly's engagement team. If a member of the committee has a particular interest in the experience of residents, we could try to talk to residents themselves and their families. It would not be a matter of Members having to do it for themselves. We are not saying that they would have to make all the arrangements. There would be backup and help, because we would be doing it formally, on behalf of the committee, in committee time. If someone were to say, 'I would like to spend an afternoon talking to families and finding out about their experiences', then there would be help through the clerk's office to set that up, organise it, and allow people to go and do that work on the committee's behalf.

[35] **Vaughan Gething:** There is a bit in the paper about public engagement, and I think that it would be quite interesting to try to look at that, whether it was through a reference group, which is one of the options, or by going directly to listen to people. However, we would always get people's subjective view, and there is a danger in how representative that is of the whole public, and the whole experience. However, I do think that we should try to get some direct feedback from families, service users, clients—whatever term is used by the care-providing body for the people who they look after.

[36] **Lindsay Whittle:** I agree with Vaughan. The third bullet point says that we will look at the quality of residential care and talk to service users and their families. In a previous life, when I had a proper job, I was a housing manager with the Hafod housing association, which became the Hendre housing association, which took over residential homes in Cardiff, the Vale of Glamorgan and Torfaen. I managed two sheltered units and worked closely with the United Welsh housing association, so if I can help—if any Member has any questions—then my door is always open, and I can hopefully put you in touch with the right people. I like all of these options, actually; I want to take them all on.

[37] **Mark Drakeford:** That is very useful.

[38] **Elin Jones:** If a Member or a couple of Members decide to undertake some work or some visits, then I accept the fact that the clerk and officers would help with the arrangements for that, but I think it would be useful, and more structured, if the clerk would accompany them and help write a report on the meeting. Otherwise, it becomes a very subjective report on the part of the individual Member. It should be led by the committee members, but there might be some kind of variance as to how different Members do that work, so the support should be available throughout the process, if this is done officially in the name of the committee.

[39] **Mark Drakeford:** That is an important point.

[40] **Elin Jones:** I know that there are capacity issues.

[41] **Mark Drakeford:** There is a question about reliability, and the weight that can be attached to some of this stuff if it is just an individual's impression, or the particular views that the individual you happen to come across might convey. Inevitably, there is a bit of experimentation in all of this and it will be a matter of trying to do it a little differently in some ways. It then relies on individual Members looking through the strands of the inquiry that are in the terms of reference. I will ask Llinos to contact you and we will see what the pattern begins to look like.

10.00 a.m.

[42] The third thing that you will see is a suggestion that, given the complexity of this inquiry, it may be one for which we ought to try to appoint a special adviser who, in addition to what we would get from the research service, would bring with them particular expertise in the field. Are you happy for us to explore that? We will then come back to you with the names of the individuals who we might want to consider appointing.

[43] **Mick Antoniw:** It might be a bit early to raise this point, but within the scoping of this inquiry, there is a policy direction that relates to whether people have to go into care homes in the first place. Does that shift into community care, and so on, broaden this out too much?

[44] **Mark Drakeford:** We just have to be careful that we are clear that we are not interested in community services per se, but we are interested in the way in which the availability, or lack of availability, of community services had an impact on the decision of the individual to seek residential care.

[45] **Mick Antoniw:** I think that that summarises it well.

[46] **Mark Drakeford:** We always have to bring it back to the residential care issue, otherwise the danger is that there will be another inquiry there into domiciliary care services.

[47] **Mick Antoniw:** That was my concern.

[48] **Mark Drakeford:** We are interested in asking people how they came to make the decision to enter residential care and whether the availability of an alternative had an impact on that decision.

[49] **Mick Antoniw:** That is the point, really.

[50] **Mark Drakeford:** In terms of preparing for this work, you will see in paragraphs 17 to 20 a suggestion that, in terms of public engagement, as well as the visits that we have just talked about, we might try to establish a reference group. The idea of a reference group would be to have a group of people who would follow the inquiry as we are conducting it. One of the problems with some public engagement work that we do is that it is of the temperature-taking variety. You stick a thermometer into public opinion at any one point and see what people say to you. What we do not do very often is to try to take people on the journey that we will be going on and see how the views and evidence that we will collect might shape their views too. So, this is not just a matter of asking people for their views at any one point in time; it is about trying to get together a group of people who would take a continuing interest in our work, who would have access to the public evidence that we take, and, from time to time, we might see whether the sort of conclusions that we are coming to are the sort of conclusions that they are coming to, or whether they end up with rather different views about the issues that we will be exploring. So, it is a different sort of public engagement. It is there

to try to ensure that our views are at least tested against a group of people from outside the Assembly who are involved in this area on a daily basis.

[51] **Mick Antoniw:** I suggested to Lesley Griffiths when she set up her work that she have a people's panel. I wish that I had now used the term 'reference group'. There is merit in it if we can get it to work and if you can get the right group of people to sit down and work through the information in a fairly impartial way.

[52] **Vaughan Gething:** It has to be representative; a range of people will need to be a part of it. We have six fairly subjective people and you would need to think about how broad it would be. However, in principle, I think that it is a good idea to at least try to see what value it adds to what we are doing.

[53] **Mark Drakeford:** In a way, today is about seeing whether you are prepared for us to try it out to see. We would have to come back to you with the names of the people and what expectations we might have of them and with some ideas at what points in the process we will keep in touch with them to hear from them and to test our views with them. When we look at all of that, we can then decide whether or not we want to go ahead with it.

[54] **Elin Jones:** I do not know whether this would be either a good idea or practicable, but I will say it anyway, but would it possible for this group to choose one care home, so that we choose a care home in Wales and all the associated people around that care home—residents, staff, and the local authority—although we may run into issues regarding whether it is a local authority or a third sector home. That could be way of engaging in a completely different way, because I always think with reference groups that it is difficult to avoid the usual suspects coming through on that level. I am just putting that out there, without having really thought whether it is a good idea or not.

[55] **Mark Drakeford:** It is a very interesting idea; let us think it through. It might be a really good way to try to do it.

[56] **Lindsay Whittle:** There are registered social landlords working in partnership with local authorities as well. I am not so sure about the involvement of the private sector. It would be even better if we could find a care home with a tripartite agreement, but I do not think that there is one.

[57] **Mark Drakeford:** We will do some work on it. My basic motivation is that I want to think a bit more—

[58] **Lindsay Whittle:** Could I ask a question about the adviser, whoever he or she may be? I sometimes have issues with advisers. With the greatest respect to age and experience, I do not particularly want to see someone who was an expert in her or his field 25 years ago. I would like to see someone who is a bit more modern, dynamic, upbeat and who is looking to the future, not the past.

[59] **Mick Antoniw:** Someone a bit like you.

[60] **Lindsay Whittle:** No. Maybe for a small fee. [*Laughter.*]

[61] **Mark Drakeford:** We will see who is out there that is a plausible person to do this. The committee will be given a number of names and we will decide on that. So, it will be the committee's decision as to who we appoint, if we appoint anyone.

[62] Last of all on this, we have had a letter from the Deputy Minister for Social Services, Gwenda Thomas, saying that she has decided to postpone the group that she was intending to

establish on residential care issues, because she thinks that the committee's inquiry might largely do the job for her. That was an interesting decision on her part, and it adds to the weight and importance of the committee's work in this field, in that the Government will take a direct interest in it and has decided to hold back on a piece of work it was going to do itself.

[63] **Diolch yn fawr. Mae hynny'n** Thank you. That is very useful as we go
ddefnyddiol iawn i ni wrth inni geisio paratoi about our attempts to prepare things.
pethau.

10.08 a.m.

**Papur Gwyn ar Roi Organau—Sesiwn Friffio ar y Materion Technegol Gan
Swyddogion Llywodraeth Cymru
Organ Donation White Paper—Technical Briefing from Welsh Government
Officials**

[64] **Mark Drakeford:** Croeso a bore da unwaith eto i Chris Jones sydd wedi bod yma o'r blaen. Ef yw cyfarwyddwr meddygol GIG Cymru a'r dirprwy brif swyddog meddygol. Bore da am y tro cyntaf i Grant Duncan, dirprwy gyfarwyddwr Cyfarwyddiaeth Feddygol Llywodraeth Cymru.

Mark Drakeford: Welcome and good morning again to Chris Jones who has been here before. He is the medical director of NHS Wales and the deputy chief medical officer. Good morning for the first time to Grant Duncan, deputy director of the Welsh Government's Medical Directorate.

[65] I remind Members that this is not a session about the policy. We will have plenty of other chances to discuss the policy. This is more of a technical briefing for us from officials on the process. When we come to play our part in scrutinising the Bill, we need to have a properly informed understanding of the process that the White Paper is going through to inform the work that we will do.

[66] For the benefit of witnesses, I am going to take this issue in three or four segments. So, I am going to ask you for a few moments about a particular part of the process. I will then ask any Member who has a question on that to contribute and we will move on to the next part of the process. I would be grateful if you could give us a few moments on the background to the White Paper, how it came to be formed, what the Government is hoping to achieve and what evidence was drawn on in forming the White Paper, particularly the extent to which it drew on the extensive work done in the third Assembly in this area. So, it is the background part first.

[67] **Dr Jones:** Perhaps I could kick off and start to respond. If I may, I will just offer a couple of sentences by way of clinical context, although I realise that it is not about policy. This is about supporting the process of organ transplantation, which is a highly cost-effective treatment for a lot of end-organ-failure conditions. These are conditions such as heart failure and kidney failure—conditions that are associated with very poor quality of life and very high risk. Transplantation surgery brings a huge increase in quality of life and prolongs survival significantly. Unfortunately, transplantation is limited by the lack of organs available. Therefore, there are a lot of people waiting for transplants at any one period of time, with long waiting times for transplants. Unfortunately, a lot of people never get their transplant and die while waiting. Over 1,000 people die waiting for an organ transplant each year in the UK; about 50 die every year in Wales. So, that is really what this is about. It is a plan that forms part of a range of different measures designed to increase the availability of organs for transplantation.

[68] It is true to say that we stand today at a point in a journey. We have already had about

three years of that journey. In 2008, the previous Minister for health initiated an informal period of public engagement, with public meetings and telephone consultation. Out of that came a clearly expressed view that the public of Wales would welcome a change in the current system. We currently operate an opt-in system, supporting an organ donor register. That was followed by further preparatory work, which led to a formal period of three months public consultation, which kicked off in May 2009. That had over 500 formal responses, and, of those responses, 81 per cent favoured a soft opt-out system. That is a system that reflects the repeated survey evidence that people in Wales support transplantation, organ donation and would wish to receive an organ if in that situation. Yet, only a minority opt in. The current situation is that most of the organs that are available come from people who are not on the organ donor register. So, the current system does not seem to be reflecting the mood of the people. An opt-out system, whereby you have an opportunity to say you do not want to be a donor, would appear to reflect the mood of the people of Wales.

[69] So, following that period of public consultation, further work was done to prepare a legislative competence Order, reflecting the previous legislative arrangements. That was laid before the National Assembly for Wales in January 2010. It was then withdrawn following the vote for a change in the legislative arrangements in the referendum last March. That was the process. Since then, we have engaged in an extensive period of engagement with a number of different groups. We have run stakeholder groups for professional bodies, the third sector and the NHS. We have also brought together an expert advisory group, comprising people with a recognised track record throughout the UK, to advise us about the production of a White Paper. That has been running over the summer. Grant and I have chaired several meetings and we have taken advice from these various bodies and experts and that has all gone into the White Paper.

[70] The White Paper was launched for public consultation five weeks ago. It is a relatively high-level description of a soft opt-out system to increase the rate of organ donation. A lot of the policy details have yet to be resolved. They will be resolved following the information that we receive through the public consultation process.

10.15 a.m.

[71] **Mark Drakeford:** Thank you. That is a helpful description of the background. Is there anything that anybody wants to ask about the way that the White Paper has been brought about?

[72] **Rebecca Evans:** I have a question on engagement. How have you engaged and sought the views of hard-to-reach groups, who are, by definition, difficult to engage with?

[73] **Dr Jones:** The stakeholder groups leading up to production of the White Paper, particularly the group reflecting the voluntary sector, brought to the table a lot of groups representing those with special concerns. It is fair to say that we have not—I do not think that it would have been appropriate—engaged the whole Welsh public in the production of the White Paper. That engagement now happens through this consultation period.

[74] **Rebecca Evans:** Is it possible to have a list of the organisations in the third sector that you have already engaged with? Do they include homelessness groups, mental health charities and so on?

[75] **Dr Duncan:** We will get you the list. I do not think that it included homelessness groups specifically, but it did include mental incapacity groups. If anyone has any suggestions of groups with whom we should engage that you see are missing, we will happily and actively take that forward. I have a meeting following this one with the voluntary sector. This is all part of the ongoing discussions that we want to have with it on how we can make this as

accessible to as many people as we can.

[76] **William Graham:** I will say something fairly broad, if I may. During the last inquiry, we had much public comment. The majority of the representations that I received were very much in favour, which supports what you have said. However, those who were not in favour were very concerned that they did not want the state deciding exactly what happens to them. They feared, quite irrationally, that, if they were killed in a motor accident, that the medical profession would swoop on their bodies and take the best bits. How do we get over that in the simplest way?

[77] **Dr Jones:** I absolutely take that point. There is a huge amount of misunderstanding out there. People have brought those fears to the public meetings that we have been running as part of the consultation process. We realise that they misunderstand the legislation. First, this affects very few people. Last year, there were around 70 organ donors in Wales, out of around 30,000 deaths. Individuals have to be in a specific situation, in a critical care unit, with a recognition that continuing care is not in the interest of the individual. So, it is a planned and managed environment for a minority. It is not something that is going to happen to everybody who dies peacefully at home, or in an accident, or whatever. Also, what is not appreciated is that all the clinical processes, which are tightly regulated by the provisions of the Human Tissue Authority, are unaffected by the legislation. All of the clinical decisions that are taken in the interests of the individual who, unfortunately, is dying, will remain unchanged. The separation between the clinical team and the organ donation team and the code of conduct for the organ donation team will remain unchanged, and the conversations with the family will be largely unchanged. It is a clinical process now, and it will be the same clinic process in the future. The state has no role in it. That is a misunderstanding that has, unfortunately, got out to a minority of people, which we need to address by better education about what the genuine process is and the implication of the change.

[78] **Elin Jones:** I have two issues. One is on engagement, either with organisations or individuals who have expressed opposition to legislation in this context. I think that it is important—and, I hope that you do too—that there is dialogue with those organisations, just as with the number of the organisations that you are already dealing with. So, I would like to have confirmation that that is happening.

[79] Secondly, you mentioned that 81 per cent had been supportive of the previous consultation on a soft opt-out scheme. This is a high-profile piece of legislation. It will be high profile in Wales and further afield. How do you intend to digest the views of organisations or organised campaigns from outside of Wales, and possibly outside of the UK, who may have strong views on issues regarding the principle involved? How do you then work out what the people of Wales think as well as other people who may send in all kind of e-mails without address or who may send in a large lobbying campaign from the USA, for example? How have you thought about the process of dealing with a high-profile piece of legislation like this?

[80] **Dr Jones:** Perhaps I could take the first part of your question and then pass on to Grant about the consultation process. In the lead up to the White Paper, we engaged with everyone who we felt we should engage with, irrespective of what we thought their view was likely to be. We did not just want friends in the tent, but we wanted everyone. Some of the conversations were challenging. For instance, the expert advisory group in Wales included Baroness Finlay of Llandaff, who has taken a Bill to the House of Lords previously, which I do not think became law—but we were not sure what her position would be—and Professor Sir Mansel Aylward. Outside Wales, we consulted with the chair of the Royal College of Physicians' ethics committee, John Saunders, who is a physician practising in Wales; and with Sir Peter Simpson, the chair of the UK organ donation ethics committee. We did not necessarily know what these people's views would be. Some of the conversations were

challenging, but they were constructive. The same applies to all the stakeholder meetings. We engaged with all groups that we felt had a legitimate interest and expressed an interest to participate, irrespective of their position. Throughout the whole process, we have entirely respected everyone's view, and we have tried to learn from what people have been saying to us.

[81] **Dr Duncan:** We are also going back to the same groups to show them the White Paper and discuss it with them further, irrespective of their views. We will seek to analyse the consultation responses according to whether they are responses from individuals or organisations, and whether they are from UK-based organisation. Many of the professional bodies are operating on a UK basis. So, from the analysis of who has responded and where, we will be able to get that understanding. We will have to try to separate out a number of different groups and their wishes, and ensure that we can reflect those of individuals. There will be richness in the consultation responses to the questions that we are really keen to get answers on—the questions about how this should work. That is perhaps more important from the individual's point of view than that of an organisation. We will get a range of views and the analysis will try to take that into account.

[82] **Elin Jones:** There is always a danger if you entertain in a consultation a numbers game; you used the figure of 81 per cent in favour. As you said in your response, a lot of it has to be about the content of the consultation, not just about being an event like *The X Factor*.

[83] **Dr Jones:** I want to emphasise the fact that this consultation is about how to do it, not whether we should do it. There is a commitment in the manifesto to do this. Our further commitment is to do it in the best possible way. The consultation is to inform that process.

[84] **Mark Drakeford:** That is an interesting point. Just to reiterate, I think that Elin was suggesting to you that when it comes to an analytical strategy for making sense of the replies, this may be one of the interesting areas where we are legislating only for Wales but where you may get a whole host of views from people beyond Wales who have an interest in this because of the nature of the principle at stake. I do not think that Elin was necessarily expecting an answer today, but she was alerting you to the fact that you will have to think about how you attach differential weight to these sorts of views, given that the legislation itself is Welsh specific. So, we might want to come back and ask you that again after the consultation closes and we know the range of responses you have had.

[85] **Mick Antoniw:** Following on from that to the 100 or so objections or negative responses you had in consultation, those are relevant because one of the things you will be looking at is the extent to which what is being proposed does not conflict with initial assumptions relating to what this is about. Is it possible to give a very brief summary as to what the grounds for the main objections were and whether there were any main trends in terms of who was objecting?

[86] **Dr Jones:** I am not sure either of us can answer that question because that consultation was before both of our times in the Department for Health, Social Services and Children. However, I can reflect a little on some of the opposition that people bring to the public meetings. I think that a lot of it is a misunderstanding about how the legislation or the change might interfere with the clinical processes. Actually, the more one thinks about it, and the more I have to answer questions on it, and the more I am in discussion about it, it is clearer all the time to me that it does not interfere at all. So, that is a message that has to get out there, as it were. Also, there is, to some extent, a fear of change. Change always brings a degree of uncertainty and, possibly, a degree of risk of unintended consequence, and there is a fear that if people believe that the state is interfering and overriding the rights and views of individuals, it will put people off being organ donors. Again, that is an unintended

consequence that is based on a misunderstanding, but, on the other hand, it is something that we have to be aware of. When there is a genuine honesty about what the change is, which is simply a change in the arrangements and which seems to reflect the views of the people of Wales, people are reassured. I do not think most people realise that two thirds of the organs that are made available for transplantation now come from people who are not on the organ donor register, but their families have made a decision on behalf of their deceased loved one that that is what they feel they would like to happen. So, it is quite powerful evidence to note that even where people have not registered to participate, the majority of families want their loved ones to be a donor.

[87] **Mick Antoniw:** I have a question that comes under the objective, which we will move on to later.

[88] **Mark Drakeford:** Thank you. That is probably enough on the background to it all. Would you like to say something to us about the specific questions that are included in the White Paper, the process by which those questions were identified as the key ones, and the basis on which they were included?

[89] **Dr Duncan:** In terms of how the questions were arrived at, it was, as Chris has outlined, through the process of discussion with both the stakeholders and the expert group around what we saw as some of the key issues that could help make this a success. There are questions around residency. We say that this is the opt-out system that will apply to Welsh residents, but there is a question around how long you need to have lived in Wales and a test for that. There were a range of views on that point. There were discussions around age for example, and we are sticking to the Human Tissues Act 2004, which applies to those aged 18 plus, but people may wish to express a view different to that. So, that is a question.

[90] One of the very sensitive areas discussed is mental capacity and fluctuating mental capacity. So, there were some questions around that and the role of the family in acting as a safeguard. The other area is generally on the role of family members and how they can be involved in decision making. I am not going into specific questions one at a time, Chair, but just giving you a broad overview of their flavour. The other thing is how the actual registration system should work, and there are a number of options available. One of the key messages in all the discussions that we have had is the use of language and making sure that systems are simple, understandable and reliable, and that the language used for communication can be understood by the majority of people. That is what we want to test for the registration system as we design it. So, that gives you a broad overview of the thrust behind the questions.

10.30 a.m.

[91] **Mark Drakeford:** Are there any issues or questions on the way that the questions are framed in the White Paper, or how they came to be there?

[92] **Lindsay Whittle:** Would there be an age limit in terms of an organ being useful or not?

[93] **Dr Duncan:** That question of whether there is an upper age limit came up in all the public consultation events so far. There are guidelines around that, but the general answer is 'no'. The oldest eye donor that I know of was 104. There have been kidney donors in their 70s and early 80s. However, it is condition specific and it is about the state of the organs.

[94] **Dr Jones:** It is based on clinical criteria and the viability of transplanted organs.

[95] **Mick Antoniw:** I have a question on the objectives and purpose of the White Paper

and the legislation. It seems to be a strange piece of legislation, because it is not about changing the law in a practical sense. It is more about a message and a cultural change that it wants to achieve. If the soft-option approach were adopted, then most of the same processes would still apply, more or less. The family would be respected if they objected. It is about the message relating to changing the burden of proof. It is about shifting the assumption without creating any specific legal change. How will the legislation deliver its objectives? What needs to go with it to achieve those? If you legislated to ban smoking, for example, you could tell people that smoking is now illegal. However, we are not doing that sort of thing; it is about changing the culture. The legislation itself is important, as is what might go with it, in terms of the quality of the way in which people and families in that situation are dealt with, and how the presumption is educated and explained. It is more to do with the importance of the things that are not part of the legislation, which could be more important than the legislation itself. They have to go hand in hand. How do you envisage that? Sorry; that was a bit long winded.

[96] **Dr Jones:** I am afraid that I am not able to answer questions on the legislation, Grant may be better placed to do that—although neither of us are lawyers. This proposal is likely to bring around a societal change. It changes the position, but the decision that individuals face is the same as now. You can either express a wish to be an organ donor in the event of your death, or object if you do not want to be. That is the same decision as now. It would be recorded in a different way, in that the expectation is that we would record the objections. The default position in Welsh society would be that you make yourself available to be an organ donor, subject to the consent of your family, in the real world. More people would therefore make a commitment to be an organ donor. At the same time, the evidence from worldwide comparisons is that the family refusal rate in that situation goes down. So, although I mentioned two thirds of families agree to organ donation and a third disagree, in countries that have an opt-out system, where that is the societal norm and expectation, it is more around 5 per cent to 10 per cent. The worldwide evidence from a number of countries that operate an opt-out system, as opposed to those that operate an opt-in system, is that the opt-out arrangements generally provide about 25 per cent more donors.

[97] With regard to the other work that has to be done around the legislation, I agree that it is about public awareness and public education. First, there has to be a long lead-in period before this change can happen. So, the expectation is that, if the Bill passes satisfactorily through the Assembly, the implementation date will be 2015. That puts in place a two-year period during which there must be quite an extensive campaign or programme of media activity in lots of different ways to help people in Wales understand the situation, the choice that they have and how to exercise that choice. That campaign will have to be ongoing as well, so that that opportunity to exercise a choice is always apparent in people's minds, and that when people come to Wales from England or elsewhere, they will understand what the situation is in Wales. So, this will bring about a debate, which is healthy, and, in its own right, an increase in public awareness. However, we will need to actively support that as well, and if, as a result of that, more people have conversations with their family about what they would like to happen in the event of their death, that can only be a good thing.

[98] **Mark Drakeford:** Is it the intention of the consultation to capture evidence of that sort, which will allow the Government to better shape the two-year period? I am sure that Mick is right that this is about a cultural shift as much as it is about a piece of legislation. Is the process of consultation on the White Paper helping the Government to think about ways in which that cultural shift can be best brought about?

[99] **Dr Jones:** I think that it is, because it is making us very aware of misunderstandings that exist, partly about the process of organ donation, the diagnosis of brain death and all of these clinical processes, but also about the impact of the legislation. So, it is showing us that, even before the two-year period, we need to be helping people to better understand these processes.

[100] **Dr Duncan:** What has come forward critically is that it should not just be a one-off communication campaign; the educating and engagement must go on continually, so that, when people turn 18, they will have an awareness of the system. There are implications for linking with education to address the need for people to have those conversations, which people avoid. So, it is an ongoing critical issue.

[101] **Mark Drakeford:** As a point of detail, and to check my memory, is it the Government's proposal to continue the opt-in register, at the same time as having a soft opt-out system? So, if you are a 16-year-old wishing to opt in, would there still be a way of doing that?

[102] **Dr Duncan:** Yes, that is correct.

[103] **Dr Jones:** That will also enable that wish to be exercised in England.

[104] **Mark Drakeford:** Of course. We now move on to the third strand. You have mentioned quite a bit already about the process of consultation and how it has been conducted. Could you summarise a little about what is being done to ensure that as many people as possible are able to contribute their views?

[105] **Dr Jones:** There are a variety of means that enable people to respond to the consultation. The consultation paper is, clearly, on the Welsh Government website, and there are other web addresses, and there is also an opportunity to post a consultation response. We are running a series of public meetings—10 have been planned since the beginning of the consultation period before Christmas. I am attending all of those meetings, which are all over Wales, and Grant has attended the vast majority as well. This week, for instance, I have been to Haverfordwest and Aberystwyth, and I will be in Bangor this afternoon. Sorry, I was in Haverfordwest last week; I am getting a little confused about where I have been. We are all over Wales; it is a bit of a whirl at the moment. It is sometimes difficult to remember where you have been the day before.

[106] We are very much on a tour of Wales, engaging in lots of public meetings. The quality of the conversations in these meetings has been very rich and helpful. As with all of these kinds of meetings, you attract people who have strong and often carefully-thought-through views, often based on their own personal experience. Quite a few of these meetings attract people who have had transplants, so their testimony is powerful and grounding. There is a richness coming through the public meetings, although they have not been packed to the rafters. There is now a commitment and a realisation that we need to continue to do this after Christmas—there will be more meetings.

[107] **Dr Duncan:** If I may add to that, picking up on accessibility, we will publish an easy-read version, today or tomorrow, which we have worked up with Learning Disability Wales. It adds a different flavour to some of these questions that we are looking at.

[108] **Lynne Neagle:** You have started holding public meetings, but it might be useful if we could have a list of the ones that are still to come; I say that because constituents have raised this with me, and I would like to pass the details on to them. How are you advertising those public meetings in communities?

[109] **Dr Duncan:** We organised them through the community health council structure. In general, we hope that they have been advertised in the local press, through leafleting and advertisements on local radio, but we have also had feedback that some people have not known about them, so we want to redouble our efforts at publicity and we will take you up on your offer of spreading details of future events. We will run more in January as well.

[110] **Lindsay Whittle:** I have seen the list of meetings. As I recall, I do not think that there was one in south-east Wales.

[111] **Dr Duncan:** There are two next week.

[112] **Lindsay Whittle:** Are there? I must have seen the wrong list.

[113] **Dr Jones:** They are in Cardiff and Barry. We realise that we need to go to Newport as well. We have been to Cwmbran, and Haverfordwest was this week.

[114] **Lindsay Whittle:** You will have to shift to get to Bangor today.

[115] **Mark Drakeford:** Yes, if you get to Bangor today, you will do very well. Is there anything else on the consultation strategy? I see that there is not. I will ask you two specific questions. First, are you making any particular efforts in relation to black and minority ethnic communities, given that there is a specific issue in the field of organ donation in relation to such communities? Secondly, are you doing anything to capture the experience of those people who have already been directly involved in those difficult decisions that families have to make in these circumstances? There are people who are based in hospitals who do this work already. As part of the consultation, is that particular experience being captured?

[116] **Dr Jones:** We have not, so far, undertaken any specific activity in relation to black and minority ethnic populations, but we recognise that we need to take stock of the consultation process over the next few days—next week is a little quieter than this week—and that will be one of the considerations. As you indicated, there is an issue, because there is a greater likelihood of requiring an organ transplant if you are black or Asian in particular, and a relatively low number of those people are currently on the organ donor register. The viability of the transplant is often much better if it is matched within the ethnic group. Relatively few organs are available, so they are waiting a lot longer—approximately twice as long as other people on the transplant list.

[117] With regard to capturing the experience, over the last five public meetings, we have been joined by a specialist nurse in organ donation. These are all employed by NHS Blood and Transplant. They are not there to support the policy, necessarily, but they have been helpful in giving a proper, honest explanation of what the real conversations and processes are around that period. That has enriched the public consultation meetings. There is also a need for us to do some work, through storytelling, to ground some of the issues for the public. To some extent, the debate has been a little esoteric, whereas we are trying to deal with a more practical set of issues. There is some work to be done on framing the stories about real-life experiences for people.

[118] **Dr Duncan:** The conversations very often focus on donation and donors, but where recipients have turned up to the consultation events, their stories have been really powerful and they have shifted the feeling of the meetings, because they ground them in reality, and we are capturing that.

[119] **Elin Jones:** On the issue and question around 18 plus, do you have any intention of consulting with people who are aged under 18, because this question would be of specific interest to them. Schools or colleges are an obvious place to do this, and through school councils, because there is a specific area of interest there, and an audience that is very gettable in terms of consultation.

10.45 a.m.

[120] **Dr Jones:** They are obviously able to respond to the consultation, as is everyone else. The point about accessing schools and raising awareness in schools has been raised at public meetings on a number of occasions. A lady at one of the recent meetings who had personal experience of transplantation told me that her teenage son wanted to come to one of the meetings, but she was not sure if it was a good idea—I think because of the risk of opposition being expressed at these meetings—so he did not come. However, it is a point for reflection about whether we could do more during the second half of this consultation period to address that. There is a stocktake coming up for us to consider what we need to do now over the next six weeks before the end of January.

[121] **Mark Drakeford:** We are on the last lap now. I wonder if you would give us a few minutes on your thoughts so far on how you will go about analysing the results of the consultation, what sort of strategy you plan to use to make sense of the information that you will have collected, and whether you have any timescales in mind that you might be able to share with the committee.

[122] **Dr Duncan:** Perhaps I should work backwards on that, in terms of timescales. Our hope and intention is to introduce a Bill to the Assembly in 2012-13, so a draft Bill would be considered over the next year, with further consultation to help shape that. The consultation responses will be analysed as outlined earlier, both in terms of specific questions about some of the important technicalities around how systems will work, the framing of questions, technical aspects, and different roles, responsibilities and age limits. We will have to aggregate that, separating it out by organisation and by individuals, and make sure that we can use it to inform our thinking as we develop the legislation.

[123] **Mick Antoniw:** How extensive will the consultation on the draft Bill be? Obviously, you will not go through the same process as before, as it is for a very different purpose—the draft Bill. Will you be going through a much narrower group of consultees? What are your intentions?

[124] **Dr Duncan:** It is too early to say at this stage. We will have to reflect on that based on existing consultation experience.

[125] **Rebecca Evans:** In the paper there are examples of schemes that operate in Spain and in other countries. In the analysis that you have been doing, have you taken into account the difference in our societies? For example, there are a lot of organs available in Spain because they have a high rate of road deaths, and so on. Do you take all that into account in your modelling?

[126] **Dr Duncan:** Broadly, yes. One of the research papers added an analysis of different countries and made allowances for infrastructure, culture, wealth and things like road traffic accidents. Broadly, you can expect an increase by moving towards an opt-out system. The evidence is—this is consistent with what we looked at in the third Assembly—that this is not the simple answer to everything. It has to be part of an overall package, continuing the existing work on organ donation that the clinicians and nurses are doing, with education and communication, so that it is part of a number of activities, not just one single thing.

[127] **Elin Jones:** Is it your intention to publish all consultation responses?

[128] **Dr Duncan:** Our intention is to follow the Assembly's best practice, which includes publishing where people have said that they are willing for that to be done.

[129] **Rebecca Evans:** They have to opt out or opt in to publication. [*Laughter.*]

[130] **Lindsay Whittle:** I am glad that Rebecca brought up the issue of Spain, because I

read in one of the many papers that we have had to go through over the last couple of days that it took 10 years for their system to become really successful, and that was done by having what seems to me to be a champion of this cause. I do not want people who are waiting for transplants to think that, after 2015, everything in the garden will be rosy; it will take a long time. There is going to be a huge cultural change in the NHS to ensure that it can cope with the number of transplants, and that the after-care and the specialists who are needed are in place to look after what we hope will be a great increase in the number of donations. I assume that there will also be a shift in spending patterns. Will the NHS in Wales be able to cope with that?

[131] I also want to ask about students while I am here. What about students who are living in Wales but are from another country?

[132] **Dr Jones:** I will try to respond to that—I think that there were three points there.

[133] Spain is a very high-performing country in terms of organ donation—it is the highest, generally. Still, it is used as an example of why this legislative change should not be done, and that is an interesting story. Spain changed to an opt-out system in the 1980s without engaging any of the other infrastructure changes, and I think that they saw very little difference. Since then, however, they have seen a huge improvement from having engaged in these other processes, to which Grant has alluded. These are processes that we have been putting in place in Wales over the last couple of years, and we have started to see significant increases. There are organ donation committees in all of the health boards, there are board-level champions, there are clinical leads for organ donation, every hospital has a specialist nurse for organ donation, and the family of each deceased individual is approached to ascertain that person's views, even if they were not on the register. These are all important elements, but we are still not at the same level as Spain. We are committed to putting all the required elements in place to get the maximum benefit. In a sense, I still feel that we need to aspire to what Spain has achieved.

[134] With regard to the second point, the issue of the resource to support this system in a new world comes up at public meetings, and a lot of people challenge me on that. One has to realise that, in real terms, it is quite a small change, unfortunately—we only had 70 or so donors last year, and a 25 per cent increase would mean another 15 to 20 donors. Admittedly, each donor provides an average of three organs, which would mean another 40 to 50 organs, but they will be allocated across England and Wales, as at present. So, it is not a massive change, unfortunately, in the number of transplant operations. Having said that, transplantation is a highly cost-effective treatment, and it avoids some of the huge costs associated with maintaining people who have end-organ failure, such as those on dialysis, which costs £30,000 a year. The cost benefit analysis has not been completed yet, but it is reasonably favourable—I would think that we would always want to support transplantation.

[135] The issue with regard to students is difficult, and we will have to reflect on it in detail as we develop policy. Generally speaking, we believe that, to be a part of this, you would have to be resident in Wales for a period of time, so that we would have some confidence that you understand the situation in Wales. It would seem to me that it would be difficult to include a first-term university student. On the other hand, a fourth-year medical student who has been in Wales for the majority of that time could be included. We would need to consider how that would happen, and there may be a role for the universities in that.

[136] **Elin Jones:** You said that the current system is an England and Wales system of organ donation, but the White Paper references it as a UK transplant system. Is there a difference?

[137] **Dr Jones:** It is England and Wales, is it not?

[138] **Mark Drakeford:** Is it not correct that Welsh donors' organs end up in Scotland and Northern Ireland, as well as in England?

[139] **Dr Duncan:** NHS Blood and Transplant manages requests from across the UK.

[140] **Elin Jones:** You can come back to us if you do not know the answer.

[141] **Dr Duncan:** I think that NHS Blood and Transplant is an England and Wales organisation.

[142] **Mark Drakeford:** Will you clarify that for us if necessary?

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

[144] **Lindsay Whittle:** I do not think that most people who have an organ transplant card, as I have, care where their organs go—they can go anywhere in the world, as far as I am concerned.

[145] **Elin Jones:** The point is that it is in here as 'UK', so what happens to Scotland? I just want to clarify that.

[146] **Rebecca Evans:** Some people feel differently about different types of organ and tissue donation. For example, while someone would not mind their lungs being transplanted, perhaps their eyes would be a different issue. With modern advances, we have seen face transplants and so on. Do you feel that the different types of organ and tissue transplants are sufficiently reflected in the consultation?

[147] **Dr Jones:** That point also comes up in the meetings. Paragraph 62 makes a commitment that there will be a means for people to register an objection for one or more organs to be transplanted. It is not necessarily all or nothing.

[148] **William Graham:** Going back to the point that was raised about Spain, my recollection of the discussions with Spanish authorities was that they were very insistent that their system had worked so well latterly, as you rightly point out, because it was based on a system of 20:20:40. It took 20 minutes to get the patient, as it were, to the centre, 20 minutes to have the organ properly examined and 40 minutes for the operation to take place, or at least for storage to be adequately arranged. What we do not have in Wales is the first 20 minutes.

[149] **Dr Jones:** It is a very different arrangement in Spain, and I do not think that we would want to create a new Spanish situation in Wales; we want to do this in a Welsh context. The context is that you have to be in a critical care unit to be a donor. At the moment, you cannot be a donor if you die outside of hospital or even outside of a critical care unit within a hospital. So, it is going to be a different situation. I do not know whether that will change in the future, but we envisage the broad circumstances of this being as they are in Wales, rather than as they are in Spain, where a wider group is treated almost with donation in mind.

[150] **William Graham:** Quite so, but the point is that, in order for the organ to be in prime condition, there are certain time limits. We would have great difficulty in meeting those time limits.

[151] **Dr Jones:** There are different issues between being a brain-dead donor or a diseased cardiac death donor. Most donors in Wales at the moment are brain-dead donors; they are maintained on a ventilator, so the timing is not quite so critical.

[152] **William Graham:** You still have to get them to the centre in that first 20 minutes.

[153] **Dr Jones:** No, they would be in the critical care unit. No aspect of their care is driven by the need or wish for them to be a donor. The current and future clinical care that they receive in Wales is the best possible care for them as individuals, to save their lives and to make them better. The question of donation only arises once it has become clear that that person is not going to survive, or their brain stem—

[154] **Elin Jones:** There will be Welsh people whose local hospital critical care unit will be in England, and who will die in England. Under this option, those people would not be covered by this legislation. In terms of consultation and awareness raising, those people living on the borders in some places in north, mid and south-east Wales may have an expectation that they will be covered by this legislation, as a result of the publicity that they have heard about this. Is there a role for you to specifically consult with those communities about the fact that they will not be covered by this legislation?

[155] **Dr Jones:** We clearly cannot legislate for England, but the point that you raise is a real one. There is some complexity around the border issues, which we need to address through the policy. Broadly speaking, the assurance for any individual is gained by discussing their wishes with their family. If they make it clear to their family that they would like to be an organ donor, their family will be able to represent their view wherever they are. That is their protection.

11.00 a.m.

[156] **Elin Jones:** I understand that point. However, because of the publicity surrounding this discussion, their expectation at this point may be that they do not need to have those conversations, given that they live in Wales and are covered by this legislation. So, from a consultation point of view, I am asking whether the views of people who may never be covered by this legislation are taken on board as part of the consultation.

[157] **Dr Jones:** We will need to reflect on that in our stocktake. People in Wales will be more likely to discuss these issues with their families in the future, as a result of the processes that we are going through. If someone wanted to opt out, they would clearly register that in Wales. They would need to explain the situation to their family, and their family could take that view, also in England.

[158] **Mark Drakeford:** Thank you, both. This has been a very useful session. I have learned things that I did not know beforehand. Thank you also for agreeing to provide us with some extra information and clarification. I hope that some issues arose in the discussion that will be helpful to you in the stocktake, and in thinking about what can be achieved in the second half of the consultation.

[159] **Lindsay Whittle:** This has been most informative, Chair. I could sit here and listen to the witnesses all day.

[160] **Elin Jones:** Why do you not go to Bangor with them? [*Laughter.*]

[161] **Mark Drakeford:** That would take all day.

[162] I will put a marker down here. From the committee's perspective, we want to keep in touch with the consultation in preparing ourselves for the job that we will do later in the process. It is, therefore, quite likely that we will ask the Minister to make the witnesses available to come back to give us a technical insight into how things have gone after the consultation has closed and the business of analysis is under way.

11.02 a.m.

**Papurau i'w Nodi
Papers to Note**

[163] **Mark Drakeford:** Mae rhai papurau i'w nodi. Yr ydym wedi cael cofnodion y cyfarfodydd a gynhaliwyd ar 16 Tachwedd a 24 Tachwedd i'w nodi. Hefyd, dylid nodi'r dystiolaeth ychwanegol a gyflwynwyd gan y tystion a roddodd dystiolaeth yn ein hymchwiliad blaenorol i fferyllfeydd cymunedol. Dylai pob un ohonoch fod wedi cael copi o'r papurau hynny. Hefyd, fel y nodais eisoes, yr ydym wedi cael llythyr gan y Dirprwy Weinidog Plant a Gwasanaethau Cymdeithasol mewn perthynas â'r ymchwiliad y byddwn yn ei gynnal i ofal preswyl yn y gwanwyn.

Mark Drakeford: There are some papers to note. We have had the minutes of the meetings held on 16 November and 24 November to note. We should also note the additional evidence that was submitted by witnesses who gave evidence to our previous inquiry into community pharmacies. All of you should have received copies of those papers. Also, as I have already noted, we have received a letter from the Deputy Minister for Children and Social Services in relation to our spring inquiry into residential care.

11.03 a.m.

**Cynnig o dan Reol Sefydlog Rhif 17.42(vi) i Benderfynu Gwahardd y
Cyhoedd o'r Cyfarfod ar Gyfer Eitemau 7 a 8
Motion under Standing Order No. 17.42(vi) to Resolve to Exclude the Public
from the Meeting for Items 7 and 8**

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

Mark Drakeford: I move that

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

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

[165] Gwelaf fod y pwyllgor yn gytûn.

I see that the committee is in agreement.

*Derbyniwyd y cynnig.
Motion agreed.*

*Daeth rhan gyhoeddus y cyfarfod i ben am 11.03 a.m.
The public part of the meeting ended at 11.03 a.m.*