



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

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

Dydd Iau, 25 Hydref 2012
Thursday, 25 October 2012

Cynnwys **Contents**

Cyflwyniad, Ymddiheuriadau a Dirprwyon
Introduction, Apologies and Substitutions

Craffu ar Adroddiad Blynyddol Comisiynydd Pobl Hŷn Cymru
Scrutiny of the Annual Report of the Commissioner for Older People in Wales

Papurau i'w Nodi
Papers to Note

Cynnig dan Reol Sefydlog Rhif 17.42(vi) i Benderfynu Atal y Cyhoedd o'r Cyfarfod
Motion under Standing Order No. 17.42(vi) to Resolve to Exclude the Public from the Meeting

Bil Trawsblannu Dynol (Cymru) Drafft—Sesiwn Friffio Ffeithiol gan Swyddogion
Llywodraeth Cymru~
Draft Human Transplantation (Wales) Bill—Factual Briefing from Welsh Government
Officials

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

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

Aelodau'r pwyllgor yn bresennol
Committee members in attendance

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

Eraill yn bresennol
Others in attendance

Sarah Rochira	Comisiynydd Pobl Hŷn Cymru Older People's Commissioner for Wales
Sarah Wakeling	Gwasanaethau Cyfreithiol, Llywodraeth Cymru Legal Services, Welsh Government
Dr Grant Duncan	Dirprwy Gyfarwyddwr y Gyfarwyddiaeth Feddygol, Llywodraeth Cymru Deputy Director, Medical Directorate, Welsh Government
Dr Chris Jones	Cyfarwyddwr Meddygol GIG Cymru a Dirprwy 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
Catherine Hunt	Dirprwy Glerc Deputy Clerk
Sarah Sargent	Dirprwy Glerc Deputy Clerk
Joanest Jackson	Uwch-gynghorydd Cyfreithiol Senior Legal Adviser
Stephen Boyce	Y Gwasanaeth Ymchwil Research Service

Dechreuodd y cyfarfod am 9.30 a.m.

The meeting began at 9.30 a.m.

Cyflwyniad, Ymddiheuriadau a Dirprwyon Introduction, Apologies and Substitutions

- [1] **Mark Drakeford:** Bore da a chroeso i chi i gyd i'r Pwyllgor Iechyd a Gofal Cymdeithasol. Yr ydym wedi derbyn ymddiheuriadau gan Kirsty Williams; nid yw Kirsty yn gallu bod gyda ni o gwbl heddiw. Rydym hefyd wedi derbyn ymddiheuriadau gan Darren Millar. Credaf fod Elin a Lynne ar eu ffordd.
- Mark Drakeford:** Good morning to you all and welcome to the Health and Social Care Committee. We have received apologies from Kirsty Williams; Kirsty cannot be with us at all today. We have also received apologies from Darren Millar. I believe that Elin and Lynne are on their way.

Craffu ar Adroddiad Blynyddol Comisiynydd Pobl Hŷn Cymru Scrutiny of the Annual Report of the Commissioner for Older People in Wales

- [2] **Mark Drakeford:** Croeso i Sarah Rochira i'r Pwyllgor Iechyd a Gofal Cymdeithasol am y tro cyntaf. Fel yr ydym yn ei wneud bob tro, byddaf yn gofyn a oes gennych chi unrhyw sylwadau agoriadol byr ar eich adroddiad blynyddol yr hoffech chi eu gwneud. Ar ôl hynny, byddaf yn troi at aelodau'r pwyllgor i ofyn cwestiynau.
- Mark Drakeford:** I welcome Sarah Rochira to the Health and Social Care Committee for the first time. As we do each time, I will ask you whether you wish to make any brief opening remarks on your annual report. I will then turn to members of the committee who will ask questions.

- [3] So, are there any brief opening remarks that you would like to offer us, and then I know that Members will have questions?

- [4] **Ms Rochira:** Bore da. I took up the post as the new Commissioner for Older People in Wales on 6 June this year. On day one, I promised to be a strong champion and an independent voice for older people. I promised to stand up and speak out clearly on their behalf; to fight discrimination and stand up for their rights; and to make sure that they get the support and the care they need to stay safe and independent and to live a life that has value to them. However, above all, I promised to do my best to give them back a voice of their own. As the commissioner, I said early on that I wanted to be known for making a difference to the lives of older people, and that is what I hope my annual report does. It shows what we, as a commission, have been doing to make a difference to the lives of older people across Wales.

- [5] I would like to point out that the photographs in the annual report are photographs of real older people—although I do not know whether there is such a thing as an unreal older person. They are real Welsh people who the commission and I have met since I took up post in June as part of our new engagement roadshow. These are the real faces of real people, who have real hopes and desires and real fears, and there is real change that I, as a commissioner, am focused on.

- [6] I would like, very quickly, to pay tribute to my predecessor, Ruth Marks, who established what was, at the time, the first older people's commission in the world. This was no easy thing to do. I would also like to pay tribute to my dedicated and committed team. I think that our work is a cause; it is not a job that we have. We are very clear—and this is why I deliberately titled my annual report as I did—about what we want to do, namely to make Wales a good place to grow older not just for some, but for everybody.

[7] My report is also an opportunity to look ahead, because people's lives do not end at the end of the financial year, as our reporting systems do; they go on. I wanted to lay out very clearly my early priorities. I had three as the commissioner. The first was our new engagement roadshow for my team and me to engage, listen to and meet more older people across Wales than ever before. Secondly, I wanted to develop and publish a very clear and transparent work programme, which I have already done. There are 11 headline areas for 50 specific areas that I will focus on. It is based on what older people have told me since June that they want us to focus on. Thirdly, I wanted to make it very clear across Wales that, as the new commissioner, I am very serious in my intention to bring about change for older people.

[8] There is much that we can and should celebrate about growing older in Wales. The first thing we should celebrate is that we are a nation of older people. I always feel that I should cheer slightly at this stage, because all too often we see it as a negative thing. It is a good thing that we are a nation of older people. How could I say otherwise, as the older people's commissioner? However, we cannot be complacent. Over 110,000 older people live in poverty, two thirds have a chronic health condition, half have a disability, too many people do not get the basic support they need to stay safe, too many older people tell me directly that they do not have the basic information they need, and loneliness and isolation are huge issues that older people face. Often, the language used about older people is patronising, derogatory and pejorative. We hear about the burden of older people and there are questions such as 'How will we cope with paying for the burden of the silver tsunami, the demographic time bomb?' Only yesterday, we had a senior member of the House of Lords talking in what I thought were highly patronising and derogatory terms in the public domain about older people. That is, quite simply, wrong. Older people add huge economic value to the Welsh economy; WRVS puts the figure at £1 billion a year. They are one of our greatest assets, and are anything but a burden, but we must be careful not to commodify them, and remember above all who older people are, because they are not a group apart—they are the backbone of our communities and our families. They are us. We often forget that most of us in Wales in public service are also older people.

[9] So, by way of closing remarks, older people are not a group apart, they are one of our greatest assets in Wales. They are real people with real faces—hence my photographs—with real hopes and real desires and real challenges for all of us in public service and real challenges for me. We need to bring about real change, because, if we get it right for older people, we will get it right, one day, for all of us, and that includes our children, who we hope will one day grow older too.

[10] **Mark Drakeford:** I am going to start with Lindsay.

[11] **Lindsay Whittle:** Thank you, Chair, and good morning, commissioner. Do you not just love it when you obtain a title and you lose your name? Everybody now refers to you as 'commissioner', but I think that it is a good thing. I was present, by the way, at the launch of your report over at the Wales Millennium Centre. It was a wonderful day, with a good choir as well, and you are right—the people in your report are real people, because one of them is a friend of mine. That is really super—I will not say who, for her sake really.

[12] I was just concerned that there has been a lot of publicity recently about one senior politician in London who is suggesting that pensioners should now earn their pension. I will not name the person, because I do not want to give him any more publicity than he already has had. That is really quite offensive. What is your opinion on that? It cannot be right, can it?

[13] **Ms Rochira:** Absolutely not. Sometimes statements are made for which, if you substituted the words 'older person' with words denoting someone of a different gender, for example, I think we would really struggle to think the statement was acceptable in any shape or form. I have put out into the public domain a response to those statements. I know exactly

what you are talking about. I thought they were outrageous, really outrageous, but, all too often, that is what older people tell me: they feel discriminated against, that they are not valued, and the language we use across society often reinforces that. I fight back really hard every single time I hear that language used. It is the little things we let go by every day that drive some of the problems that older people are facing. I am publishing a report later this year talking about the experiences of older people in relation to discrimination and I think that sometimes language is at the bottom of that. We have to, and I do, fight back strongly. Very early on, when I took up this post, there was an article in the *Western Mail* that talked about paying for the burden of social care, and it had been lifted from a feed elsewhere. I went back and made it publish a two-page article on why older people are many things, but one thing they are not is a burden, in any shape or form. We need to be careful not to commodify older people and not just focus on economic value. It is the wealth of knowledge and experience that older people bring to society that we have to value, and we have to value them for who they are and what they bring as well as the commodified aspect. I think my headline response yesterday was:

[14] ‘Older people should not have to re-earn their pension a second time’.

[15] **Lindsay Whittle:** I think this is a really positive message to come from Wales, Chair: that older people are not a burden, and people who have a pension have earned it—they paid into it and they are entitled to it. Even with the state pension, they are entitled to it, and I think the message should go out loud and clear from all politicians in Cardiff—I am sure there will be no-one who will disagree—that we do not expect Welsh pensioners to earn their pension; they have already done so. I speak as an Assembly Member who employs someone who is in his 70s, and that is a positive message too, although he will not thank me for saying that.

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

[17] **Vaughan Gething:** Yes. On the section in your report about money, where you mention pensions and pension reform, I note what you say about the change in the age for women and women’s pensions, and I am interested in the feedback that you have had about the change to the age entitlement. People are going to get older, and I suppose it depends how you define ‘older’, but I am interested in the feedback that you have had on the change in pension ages, and also I am interested in the line that you have about the Dilnot commission and its recommendations on paying for care, in particular. I am interested in what sort of feedback you want to have about Dilnot, and in particular whether you think there are grounds for optimism or not—whether all the major parties on a UK level are actually going to talk about this in a sensible way to try to provide some sort of consensus this side of a general election.

[18] **Ms Rochira:** I will take the last point first, if I may. I wish that I knew the answer to that. I think we all felt that we were making progress around Dilnot. We had something that there was cross-party support for that we were starting to move forward on. I am concerned that that might be shifting back. I am meeting the new Secretary of State for Wales on Monday and one of the things that I want to talk to him about is whether we are moving towards resolution around this. The reason I want to know is because older people desperately need to know about that. One of the things that I have been quite taken with, as I have been out and about across Wales, just talking to older people in their homes and communities, is how spontaneously they have raised concerns about paying for care. It comes up all the time. Older people are now really concerned about whether they are going to be able to afford the care that they feel they are going to need as they grow older. It is really positive that we have the cap on social care charging; that makes a huge difference to many older people, but they get that we need to make decisions about these bigger issues.

[19] I do not know the answer as to whether it is going to be delivered. I am pushing for

resolution on that. Older people desperately need that. What older people say to me is, 'Look, somehow this compact seems to have changed; we have paid in all our lives on the assumption, because it was what we were told, that when we needed that care and support the state would provide it. The rules seem to have changed now and we are being told that we are going to have to contribute more towards that, but we do not know how much and we are in our later years and it is too late for us to re-plan financially. We do not have the time to retrain, to save more or to make different decisions. We need to know now.' Therefore, I am going to push hard for that.

[20] The issue around pension reform is also interesting. Older people know that we are living in changing times, and they know that those changes are going to impact upon them. However, what older people say to me is that they do not think they are ever going to be able to afford to retire anymore; they will just have to continue working in some shape or form. That is why it is so important to bat back the comments that were made yesterday, because many older people are quite simply not going to be able to continue to work. They need certainty so that they can forward plan financially and can plan the rest of their lives. It is a highly complex issue, and in the middle of it are older people trying to work out what is going on.

[21] **Vaughan Gething:** Going back to Dilnot, I am interested in the sorts of concerns you have expressed to you about paying for care. Is it about being able to afford the level of care, whether people have the means and the income to do it at all, or is it more along the lines of where the share falls, in the sense of how much an individual is expected to pay and how much the state is expected to contribute, especially for those on relatively modest means who own their own homes and whether they should be expected to cash in that capital asset and sell it to pay for their care? I am interested in the range of views you do and do not hear because I would have thought there would be more than one view from older people who come to you.

[22] **Ms Rochira:** I visited an extra care facility in north Wales and there was a very strong view that came up spontaneously from there, and I have seen this reflected wherever I have been; it is about the fairness of it. This is an issue that comes up very frequently. What older people will say is, 'Look, we did what we were told to do and were one of the generations that did save; people told us to save for the future and we did that, we worked hard, saved and paid our contributions, but now it feels that we are being penalised for doing so, because we are being told that we may have to sell our assets to pay for care, yet people who did not save do not have to'. So, there is a huge issue of social fairness and justice that runs through the narrative from older people. However, it is not self-serving; it is about concern for their families, and about 'I did this because I want to pass it on to my family and to help my children go to university and get the education they might need'. That is what older people do with their assets. They use it to grow their families' ability to achieve their aspirations, so that comes up. Coupled with that, there are concerns and real fear around whether they are going to be able to afford the care that they need and are they going to get the care that they need.

[23] One thing that worries me very much as commissioner is this culture of fear among older people and of, 'What is going to happen to us? Are we going to get the support that we need? Are we going to be able to pay for it? If not, what is going to happen?' This huge cloud of uncertainty is creating a climate of fear and doubt in people's minds. So, I think that it is the two issues, but in people's lives they wrap up together.

[24] **Vaughan Gething:** Finally, on this point about fairness, I am interested in the debate you have with older people about how the issue of fairness is seen. I can understand people who have an asset wanting to pass it on, but where in the debate that you have with older people is the point about fairness for poorer pensioners, who do not have assets to pass on? If

there is this idea that, ‘Those people have not saved and are getting everything, so, why, if I have an asset, should I have to use that for my care?’, I am interested how you assess that point about fairness because sometimes, there are contradictory messages about what is fair.

9.45 a.m.

[25] **Ms Rochira:** I have never heard an older person say that those who would struggle to afford care or do not have assets should not be able to receive it. I have never heard them say that. What I have heard them talk about is just this concept of, ‘We did what we were asked to do and now at this late stage, it seems the rules have changed and that does not seem fair to us’. All older people want to know is that they will get the care that they need when they grow older to stay safe and independent—not just for them, but for the people whom they care about. Many older people, for example, are caring for older older people. Many people in their sixties might be caring for relatives in their eighties and nineties. All older people are looking for is some degree of certainty about how the rules have changed and how they will impact on their lives. They accept that they will have to pay more of a contribution than they did in the past, but they need to know what that contribution will look like so that they can pay for that and make the best plans that they can. If you are 80, it is hard to be told that the rules have changed and we are not quite sure what they are going to be, because we have real challenges around them—you will be paying more, but we cannot work out exactly how much yet.

[26] **Mark Drakeford:** We will go to Mick next, but I have one follow-up question on that: 40% of Welsh pensioner households have no savings at all; what help is Dilnot to them?

[27] **Ms Rochira:** They would not be paying anyway, would they?

[28] **Mark Drakeford:** No, so it is no help to them.

[29] **Ms Rochira:** No.

[30] **Mick Antoniw:** I welcome your report and much of it covers the period before you took up your post. I also note that you are developing a strategic plan from 2013 onwards. As a commissioner and with your team, you receive around £1.8 million in public funding with a team of 25-plus people. To what extent are those resources being most effectively used at the moment? Do you have any particular views on how they could be more effectively used than perhaps they have been until now?

[31] **Ms Rochira:** That is an important question and is one thing that I am focused on. I have a narrative running through my head, which is the fact that I have £1.8 million of public money and I need to deliver value back to the lives of older people to the tune of £1.8 million in order to justify the money coming in to pay for what we do. You are right that I only came into post in June, but I am accountable for what we did last year. I think that we do add value to the lives of older people and I have tried to show that through the report.

[32] We provide support to older people that has direct impact on their lives, but much of the support that we provide to individual older people also resonates with and impacts on other older people. I will give you a couple of examples. One lady contacted us through our contact line. She was paying inappropriately for a personal security system. We provided her with support so that she was rebated and refunded that money. However, as a result of engaging with the local authority, we also changed its policy and refunded other older people to the tune of £90,000. That had a huge impact for them.

[33] A lot of our work is about trying to change the experiences of older people across Wales. So, I am confident that, as a result of our ‘Dignified Care?’ report, there are now more

dementia nurses in Wales and matrons back on the ward. Dignity in care is, for the first time in a long time, being taken seriously. That is beginning to improve the experiences of older people. We are not there yet, and I made that clear in my annual progress report on that, but I am clear that we are beginning to bring about that change for older people.

[34] We are also intervening in areas such as the current configuration of healthcare services, social care changes and domiciliary care changes to ensure that older people's needs continue to be met and are not disproportionately impacted on by the changes that are taking place. We operate at a number of different levels. Providing support to over 700 people every year is quite an impactful thing to do. This year, that number will rise to almost 1,000. However, it is also about how we take that learning and roll it out to other older people across Wales. Some of the issues that we pick up, such as the community transport subsidy, for example. Keeping that going has huge relevance and importance to older people across Wales. One thing that we can strengthen is our impact-and-reach reporting. So, I have already given a commitment that, next June, I will publish an impact-and-reach report—'reach' being the number of lives that we touch, and 'impact' being the difference that we make to those people's lives. People will then be able to judge for themselves whether we are worth £1.8 million. I think that we are; I think that we are making that difference. We also need to put it in context. It is a lot of public money, but there are 710,000 older people across Wales. We spend £8 billion or £9 billion on health and social care, so it is right and proper that we invest in a post that focuses independently on the needs of older people.

[35] **Mick Antoniw:** I will follow that through, because I very much value a lot of the work that is being done. I am concerned that, in the Assembly, we seem to put a lot of public money into organisations that produce lots of glossy reports and so on—this is a very glossy report—but it does not seem to be as focused as it could be, in terms of what really is being achieved, or on where the real challenges are.

[36] I would like to hear your views on two areas that seem to me to be massively important at the moment. One is the issue of the advocacy role itself—how people are represented and how that is driven forward. How do you see that role developing? The second role is concerned with the challenges and the impact of welfare reforms. I am increasingly contacted by elderly people who are terrified about their future housing prospects. They are told that, because they have a spare room in their family home that their family might come back to use now and then, suddenly their benefits will be reduced, or that they should move. There is a high degree of fear about what is happening, and it does not seem to me that there has been a sufficient focus on that particular challenge, from you as commissioner and your team. So, I am putting that to you in a constructive sense, because these are two areas that seem to be really driving forward at the moment.

[37] **Ms Rochira:** I tried really hard not to write a glossy report, actually. I designed it deliberately, because I wanted people's faces to be the real thing that we saw. The words are lower down the page, because it is about remembering what we do, and who we do it for, in public service. So, I feel that I have failed slightly there, because I did not want a glossy report; I wanted one that focused on people, because that is what I think it is about.

[38] On day one, I said that I would be a strong voice for older people, and that means standing up and speaking out, and sometimes saying things that people do not want to hear. I think that I have done that consistently. We have had very extensive press coverage, since I started, around the issues facing older people. There are not many weeks when I am not on the radio or television in some shape or form, and for the first time ever we have been on national television as well, pushing the need for us to do more for older people. So, I think that I am standing up strongly and speaking out on their behalf.

[39] At the end of my first 100 days, I published a very clear public statement about

needing to do more for older people, recognising what was good, but highlighting where we were failing older people too. I have already started to use my legal powers to stand up for older people. We have had our first tribunal case, in which we advocated for an individual, and we won. That case has not been published yet, because I am waiting for the appeal process to come through. I have used my section 12 guidance to lay out the standards that I expect to be used. So, I am starting to push it out there, in terms of saying ‘Look, I have got to speak out for older people’, and that means, sometimes, pushing the issues as well.

[40] Advocacy is incredibly important. Many older people do not have a voice. It is my job to be their voice when they do not have one. I am also trying really hard to give older people their voice back, because that is what I really want to focus on. I have already published a review since June in relation to independent advocacy and its importance. I have made it quite clear that that will be underpinned by section 12 guidance, which places a duty on authorities and health boards to pay regard to that, in the way that they deliver services. So, I think that we are already starting to push that standing up, speaking out, and challenge back for older people.

[41] In relation to the welfare reforms that are going on, I have made it very clear that I will undertake a piece of scrutiny on the impact of those changes on the lives of older people. What the UK Government does might be outside my jurisdiction, but it is absolutely within my jurisdiction to hold it to account for the impact of those changes. I intend to do so through that review. I will be talking to the Secretary of State for Wales on Monday about that. The UK Government made promises to protect those who are poor and vulnerable—the most disadvantaged, if you like. I will be holding it to account for that; I have made that clear. I will publish that report, which will be very fair, but it will scrutinise the impact on older people. I agree with you. I meet too many older people who tell me about the impact of those changes on their lives. So, I will be a strong and independent champion for them. I have to stand up, speak out and tell it like it is about those issues.

[42] **Rebecca Evans:** I have a question on the funding for the commission. The budget was originally £1.8 million and it has reduced year-on-year since, only by incremental amounts. For 2013-14, it will be reduced to £1.715 million. Does this place any constraints on your work or on the staffing of your office?

[43] **Ms Rochira:** My first focus, as the new commissioner, has been on identifying those areas where I think that I can add the most impact to the lives of older people. One of the big challenges for me is what does and does not sit on my desk. That is why engaging with older people was my absolute first priority. I am really confident that my published work programme includes the issues that older people told me mattered to them. That was my first priority: what does my job look like in practice?

[44] My second priority is to get on and deliver some of that change, to make a difference to the lives of older people. Then, when I have published my impact-and-reach report next year, I will be in a really strong position to have the debate about whether that is a sufficient level of funding. I want to be able to evidence that I am wisely and effectively using every penny that I get from the public purse, to bring about that change. Will I then come back to ask for more money? I may do, but when I do, I will be able to say, ‘With every extra £1 that you give me, this is the difference that I will make to the lives of older people’. We can all look to make efficiencies, and I am certainly doing that in my organisation. I would never come back to say ‘I need more money, full stop’—we could all do that—but I may well come back to say ‘If you give me more money, this is how I will further improve the lives of older people across Wales’. We took a 1% cut, and we will manage within that for this year. However, if we really want to see older people as an asset to invest in, I am sure that, at some stage as commissioner, I will be making the case for why we should invest more in my office. When I do so, it will be based on robust evidence about the difference that we are making.

[45] **Elin Jones:** I want to ask you about consultation and service change. There is quite a lot of service change in the health service and financial cutbacks for local authorities. I have seen good practice in consultation—Hywel Dda Local Health Board holding meetings with 50-plus fora and consulting well with older people. I have also seen abysmal practice—Ceredigion County Council closing a day centre 18 months ago where the older people who used the centre were the last to know; there was no consultation.

[46] I want to understand from you whether you think there is a role for you in issuing guidance or best practice for public authorities in how they consult with older people. Perhaps you do this already—you can tell me about that. I want to ask about day-centre provision, in particular, because it is something that local authorities provide in several communities, although there is no statutory requirement for them to do so. It is a service that some local authorities might cut back due to financial priorities. I want to know whether there are ways that older people and, possibly, the third sector could work to take on or develop services for older people, which local authorities might be withdrawing.

[47] **Ms Rochira:** One of the first things that I did when I came into post—it sounds like I did many first things, but I did—was go back to our inquiry and case support line and say, ‘Tell me what older people are telling you’, because field intelligence is incredibly important to me. I need to know what is concerning older people out there. So, our inquiry line is one important source; it is only one source, and our direct engagement and engagement with other groups, such as carers groups, dementia groups and a wide range of others, is also important.

10.00 a.m.

[48] However, it was very interesting to look at what was coming through that route. A number of concerns were coming up around service reconfiguration, which seems to be the phrase that most people use. There were three that, thinking about it, I put straight onto my desk as the new commissioner—not just because these came up through the inquiry line but because I knew and was hearing from older people that these were concerns. The three big configuration changes are to do with healthcare, residential social care and day-centre-based social care. I took a decision very early on that they would sit on my desk. They were a huge concern to older people and, therefore, they were a concern to me. What I mean by something being a concern to me is that I am going to take it through into action. I have done a number of things since then and I have been very active on this.

[49] Taking health configuration first—although the theme is the same in each—I have written to health boards to say that I know that these changes are happening and that I understand the reasons behind them, but that I want to be very clear, as the commissioner, what my expectation is. I outline three very clear expectations. The first is that older people are effectively engaged in the debates going on; the second is that, where changes are taking place, they are to the betterment, not the detriment, of older people; and the third is that, where there is a strong financial element to the changes, there is no disproportionate impact on older people. I have set that guidance out very clearly to health boards. Where I have heard representations on individual issues—about hospitals closing, for example—I have also gone back to health boards and said to them that evidence must be provided to me that they are meeting those three criteria.

[50] However, I am taking that a step further. I am going to be calling in, from health boards, board papers that show the impact of their engagement with older people and I am going to be calling in some of the impact assessments as well. I want to see their evidence that older people have been engaged effectively. I want to see how they have changed their plans as a result of that engagement, and I want to see the evidence that services are going to be better for older people as a result of those changes. I have made it very clear that, where those

criteria are not met, I will push people back and make them start again at the beginning, because I do not think that due process is a lot to ask. However, I also understand the power of people's voices. Actually, older people are very good at telling us what they need to deliver the outcomes.

[51] I have done something similar in relation to the care-home closures that are going on across Wales. I am very actively engaged in that with a number of local authorities. Again, I am saying, 'I've had representations. Show me the evidence on that.' The same applies to day-centre closures. So, it is a case of both responding to individuals and going back corporately to those organisations and saying that I need to see the evidence on those three factors.

[52] We have also been working with the Welsh Government on guidance on care-home closures. One thing that I realised very early on was that the extant guidance, which is called 'Escalating Concerns With, and Closures of, Care Homes Providing Services for Adults', does not really fit the environment that we live in. It was really developed around the Southern-Cross-type experience, where a care home might close at very short notice. It is not sufficient at the moment, and I am really pleased that I was asked, just last month, by the Welsh Government, to lead a piece of work to develop more robust guidance that it can publish next year. I am trying to shore up that whole process, because I am getting increasing numbers of representations from older people who have concerns.

[53] I have also been going out to visit places such as care homes that are closing, to hear directly from residents. Again, I have made it very clear that, if I am not happy, I may use my legal powers to undertake a formal investigation. Therefore, I think that I have set out my stall really clearly on these matters. I have told people what good practice will look like. I have also offered to issue good practice guidance on those areas. However, I have made it clear that I am following this through and that I will use my scrutiny powers if I need to. It matters enormously to older people. Those three issues sit right at the centre of my desk at the moment. Ultimately, all that I am looking for is the evidence that older people have been effectively engaged in these debates and that we are using their knowledge about how to deliver good care. I do not think that that is a lot to ask, but I want to see the evidence. I want to see the evidence that the changes are to the betterment of older people, because I think that that is the whole point—that is why it is called 'reconfiguration' and not 'cuts'. I want to see the evidence that there is not a disproportionate impact.

[54] On your point about whether the third sector could take on more, some of you will know that I came from the third sector, so I know what the third sector can deliver. The third sector is very good at making a pound go a long way. It is very good at providing person-centred care. The short answer is 'yes', we could ask the third sector to do more, but we must recognise that the third sector needs funding as well, and that it is not a zero-cost option. What older people need is a wide range of options to choose from. One size does not fit all, and what fits in an urban environment does not fit in a rural environment. We have to tailor those services to older people. If you look at what we spend on health and social care across Wales—£8 billion to £9 billion—and then at what we spend on the third sector, you see that it is a drop in the ocean. That was a slightly long answer, sorry, but I hope that it answers your question.

[55] **Elin Jones:** I just want to follow up on one detail. You said that you had written to the health boards with three expectations of the service reconfiguration. So, your expectation is that they will respond to you, on the basis of their consultation, on how they have met your three criteria.

[56] **Ms Rochira:** Yes. I have asked them to send me their reconfiguration plans, because I am taking an early interest in this, but I am also digging in early to any specific concerns

raised with me, and then I will call in the evidence behind those. I put all these letters on my website, because I like openness and transparency. I am trying really hard to show people what we are doing as a commission, because we need to get better at doing that. It is a challenge for us all, actually, to show how we are trying to push through that difference. I am tenacious on this issue, because it matters enormously to older people.

[57] **Lynne Neagle:** Good morning, Sarah. I want to ask three questions, if that is okay. The first is on ‘Dignified Care?’, which particularly impressed me as a piece of work. I was also impressed by the rigour with which it was followed through. You have provided an update in your report and stated that there will be a conference this autumn. You have also indicated some of the areas where you feel that significant improvement has been made. Could you provide the committee with some feedback this morning on where you feel some considerable work still needs to be done?

[58] You also referred to the work that you have done on the closure of care homes. One of the issues on which I have had dealings with your office this year is the closure of sheltered housing in my constituency, which has caused a great deal of stress and distress to residents. Do you have any plans to look at the procedures around that, given that it is something that we are likely to see more of as the pattern of how people live in the community changes?

[59] Finally, I know that there is good engagement with older persons’ fora and those kinds of organised groups, but what are you doing to reach pensioners who are harder to reach, such as those who do not go out very much and who probably need a voice more than anyone else?

[60] **Ms Rochira:** On dignity in care, one of my early questions was ‘What next?’ after that really hard-hitting report. I wanted to know how we were going to drive that report to what it needed to lead to, which was a change in the patient experience at the ward level. That is ultimately what it was all about. We had our conference on 1 October and, shortly after that, I published what I call my ‘interim progress report’, one year on, of what the NHS has been doing to meet the recommendations that I laid out in the ‘Dignified Care?’ review. I met the chief executive of the NHS in Wales regarding that, and I was clear about what my focus was going to be. I told him that I was going to focus on three things, rather like in a report. The first was whether the NHS was going to take this issue seriously, really seriously. I worked for 23 years in the statutory sector, so I know what taking an issue seriously looks like. I told him that he needed to assure me and convince me of that, and I outlined in my one-year progress report that I believe that he has. Dignity in care is now a tier 1 priority for the NHS in Wales. It is now being accorded the place that it should have been accorded all along. I am satisfied on that.

[61] Secondly, I asked for evidence of whether there were things going on now that had not taken place before. I did not want what was going on before to be reshuffled into an action plan or strategy. I wanted to see that the things that the report demonstrated were not happening were now happening, and I am satisfied that they are. I have seen much of it for myself as I have gone out and about across Wales. So, there is work now taking place in relation to those action plans that was not happening before. That is improving people’s experience, which is good and is as a direct result of that report.

[62] The third and most important point was to ask for evidence of the change in the patient experience. What is really changing day in, day out, at ward level? Do we now have appropriate staffing levels? Do we have staff who are trained and who understand the needs of people who have dementia? Do we have patients whose continence is being managed properly? It is about those really hard issues, and my assessment one year on was very clear: I do not have the evidence for that yet. I am holding back any judgment in relation to that. I made it very clear to the NHS. I said, ‘You have 18 months to evidence that back to me’. I

have asked for a further progress report in March, with Welsh Government, and it has agreed to provide me with that, and I have said that I want to see that starting to focus on the patient experience.

[63] What I have now done is shift my focus from the action plans—and they were a good start, but plans are plans—to more of an assurance framework. So, I said that I would be happy as commissioner when patients tell me, and when you publish patient satisfaction data that tell me, that dignity in care is being addressed properly. I will be satisfied when front-line staff tell me that they have the staffing levels and the experience and skills they need to deliver good care. I will be satisfied when the chairs and chief execs of health boards give me assurances that they are getting it right more often than they are getting it wrong. So, I have set out my stall clearly for what they need to do to satisfy me, as commissioner. I will keep that pressure on and will work with them very closely, particularly with regard to collecting patient data, because, ultimately, all I want is to meet patients who say, ‘Do you know what? I got really good care’. I do not want to meet patients who say to me, ‘The clinical care was great, but the experience left me feeling awful’. It is really easy, actually, to satisfy that criterion if we focus on what the patients want. So, I have set out the whole stall for the NHS in Wales. I have said what it needs to do to satisfy me and what a good job well done looks like. I have told them to stop focusing so much on the action plans and start focusing on changing the patient experience at the ward level, and then show me the evidence back.

[64] In 18 months’ time, I will pass what I have called a ‘public verdict’: the NHS will pass or fail on that. There is no halfway. Either they do it and get it right or they do not. They will have had up to two and a half years, so I have given them time to do it and I have shown them what a good job looks like. They are working on it. There is a lot of effort going into that. It is now a priority, and the focus is on the final attainment and delivery for the patient. I think that that is right, because it is partly about my advocacy role of standing up, speaking out and telling it like it is, regardless of whether people want to hear it.

[65] Turning to engagement, thank you for asking that question, because engagement matters enormously to me. Actually, it is a statutory duty, and what I do is driven by what older people tell me matters the most to them. We did a good job last year of going out to meet older people. I think that we can do more, and we have already started to do more. If you will excuse me, I will just refer to some numbers that I have jotted down here. I thought that I would be nervous and would not remember them. Just by way of comparison and to show how we are building on what we did last year, we did a total of 30 visits out to older people’s groups last year, and we went to nine of the 22 local authorities. Many of those were professional older people’s groups, which have huge value. This year, since June alone, we have done a total of 65. I have personally done a total of 33, and we have been to 17 of the 22 local authorities. I continue to meet with the professional older people’s groups, because they are wonderful. They are a huge asset to our country, they really are. Most of the time, however, I go out and I meet ordinary older people. I have been to dementia cafes, carers’ groups, intergenerational lunches, care homes and singing groups. I have met with black and minority ethnic groups and the Dyfed Diners in west Wales. I go out and meet ordinary people in the ordinary places in Wales where we all live. They do not have to come to me; I am their commissioner and I go to them. So, I am very significantly building on what we started over the past four years. You are absolutely right. I want to hear from the people who do not otherwise have a voice, because they are the people I have to stand up and speak out for. I am confident that we are getting much better at doing that.

[66] Alongside that, we have also started to commission a series of research pieces on what I have called the ‘voices of older people’, to give a voice directly back to them. With our research into domiciliary home care, for example, I think I knew, actually, what that was going to find, but I wanted to give older people the respect of getting their voices back, so that they could tell us what they thought about it. I am going to continue to commission that

research, so that when I speak and challenge, I am absolutely confident that I speak with the voices of ordinary older people—actually, there is no such thing as ‘ordinary older people’, just older people—across Wales.

[67] Oh, sorry, there was a third point.

[68] **Mark Drakeford:** Sheltered housing.

[69] **Ms Rochira:** Yes. I had not forgotten, but talking about engagement with older people fires me up.

10.15 a.m.

[70] You raised a really good point, and it is not one that I have thought about before. I have visited a lot of extra-care sheltered housing and I have seen for myself how brilliant they can be and how they give back a lease of life to older people. It is not something I had thought about, but I am keen to and perhaps we could pick that up by way of a conversation outside the meeting.

[71] One thing I have done is write to all Assembly Members, saying, ‘Look, you have constituents, many of whom are older people, and I am really keen to hear from you, too, what you think the issues are’. Gathering field intelligence is important to me. It is not about what I think the issues are, but about what older people tell me they are. So, the more information I have coming in, the stronger my work programmes will be. Ultimately, I want older people to read my work programmes and to think ‘That’s exactly what we’ve been telling people about for years, and at last somebody’s put it into their work programme’. That is why I have such an eclectic range of things. There are some big, complex issues such as pensions—and I am not totally sure that I did justice to your question earlier—and paying for social care, and toilets, because they matter enormously to older people. In older people’s lives and in all our lives, there is an eclectic range of issues, and so there is, too, in my work programme.

[72] **Rebecca Evans:** I am particularly interested in carers, and I was pleased to hear you mention older carers earlier. Can you update us on how you are working to secure improvements for older carers and also on what older carers are saying to you about their ability to access respite care? Do you think that there is a problem for older carers in accessing the carer’s allowance or carers’ assessments?

[73] **Ms Rochira:** You are absolutely right. I have signalled clearly in my work programme that improving support for carers has to be a priority for me, as commissioner. That was partly driven by meetings that I have had with carers out and about across Wales. I was taken by a conversation that I had with a group of carers in north Wales who shared their experiences with me. For those of you who like these sorts of things, I have to confess that I tweet extensively, and I blog as well. I blogged about meeting these carers, and it was one of the most moving and salutary meetings I have ever had, because they shared with me the sheer desperation that so many of them faced. They desperately wanted to do a good job and to care for the people they loved, but so many of them felt that they did not get the support that they needed and were struggling to cope. It was one of the most poignant meetings and conversations I have ever had.

[74] I then went to speak with the carers’ associations and groups as well and said, ‘Look, this is a big issue, so do you need me to stand up and speak out for you, too?’ and they just said, ‘Yes, we do’. So, I am standing up and speaking out for them. It is early days for me in shaping my work on that, but I went back to the carers’ groups and asked them if there were three things that I could do, what would they be, and that was how I have shaped my work

programme. There are a couple of things that I am focused on. One is the impact of the Carers Strategies (Wales) Measure 2010. It is hugely important that we have a carers Measure, but we need to see, carers need to see, and I want to see and track the evidence of the impact of that. However, in the short term, I am interested in the training provided to carers, particularly on some of the complex needs that they have to deal with in the home, because that is a practical thing that we could get better at. Carers talk to me a lot about the importance of respite care. I remember talking to one carer who said, 'My mother had to go into residential care, because we just needed a bit of respite care in the afternoons and we couldn't get it. She didn't want to go there, and we desperately didn't want her to go there, but we just couldn't get that little bit of help that we needed'. I think that that is desperately sad, because all that they were asking was for a little bit of help. That is a theme that comes up from older people all the time. They just need that little bit of help sometimes to stay safe and independent.

[75] I am clearly signalling that I will be a champion for carers. We are talking about older carers now, but if you are 25 years old and you are caring for someone who is in their 60s or 70s, I am your champion, too. I have said that clearly to carers. Some of this is difficult stuff, and I will fight their corner for them, because all too often they do not have someone to do that.

[76] On the carer's allowance, it is quite simply wrong that that stops at the age of 60. I have added my weight behind the Age UK campaign on that, because it is discriminatory and counter-productive. We recognise now in Wales that we need to do more. We have the carers Measure. I am going to keep up the pressure to do more, and I am going to give a direct voice to carers to try to make sure that we move to a position where we can see the evidence that the situation is getting better for them.

[77] **Rebecca Evans:** The health boards are all submitting their carers' plans to the Minister for health by the end of this month. Will you also seek to have copies to ensure that you are satisfied that they meet the needs of older carers?

[78] **Ms Rochira:** I am absolutely going to call those in. I am also calling in a whole range of other documents in my, if you like, informal scrutiny role. I will be calling in equality strategies from across local government and the Welsh Government. I will be calling in some of the key plans and policies that we have, and I want to see older people running right through those, so that there is a real understanding of their issues and a real focus in terms of delivering change, which we can measure in some shape or form. I have already started to engage with a wide range of Ministers across the Welsh Government in terms of some of the strategies, plans and policies that we have at the moment. I want to see the evidence for myself. I just want to be reassured that it is leading to difference for older people. We might not get it right for everybody, but we have to start getting it right for more people than we have before. The joy of giving voice directly to older people is that they are so very clear about what a good job well done looks like. Very often what they focus on are the low-cost, high-impact things. Older people tell me all the time, 'We haven't got the basic information and advice that we need. We just need a little bit of timely help to stay safe and independent'. In the grand scheme of things, these are the lowest-cost things for us to get right, yet they seem to be the things that we are struggling most with. I think it is right and proper that I call in plans and scrutinise them and give commentary, sometimes publicly, on those.

[79] **Mark Drakeford:** I want to make sure that William has a chance to ask a question, if he has any. It may have been covered already.

[80] **William Graham:** I can just about speak now, Chair, but I do not have a question.

[81] **Mark Drakeford:** Then I have two questions to explore with you, commissioner. One is that you will know that we have been conducting our inquiry into residential care

services for older people, and we are on the final straight with that, but the very first witness that we heard evidence from was the office of the commissioner, so as we come to the very end, I just want to give you an opportunity to offer us any thoughts that you may have on that, from the work that you have been doing since June.

[82] To lead into that, I think Mick asked you a question about advocacy that you did not have a chance to pick up directly at that point. I just want to put this to you to see what you think. Some of the evidence that we had in the inquiry in relation to advocacy did not share the perspective that I think you have, which is that there needs to be a separate advocacy service for older people in residential care. They argued that the system is already full of people who ought to be speaking up for the needs of older people, but that the system itself does not allow that to happen easily, so that the voices of family are not powerfully felt in the system. Social workers surely have an obligation to advocate on behalf of their users, and care workers in the system have responsibilities here. Their argument was that, rather than setting up a whole new cadre of yet more professional workers in an already crowded field, what we ought to be doing is working on the system we already have to make sure that those people who are already there are able to advocate more effectively on behalf of older people. I wonder what your reaction to that proposition was, but also just to see whether there are any broader points that you think we ought to be taking into account as we complete our report.

[83] **Ms Rochira:** There is a wide range of issues relating to social care that are rapidly coming into the centre of my desk. Some of them are outside the scope of your inquiry, but will feature very strongly in my new four-year strategy. Perhaps one area to focus on for me is about how people go into residential social care. What I hear from older people and groups that represent them as well, and many others, is that all too often older people do not have the information, knowledge or time that they need to make this big decision about where they are going to live for the rest of their lives. It is a huge decision for any of us to make, and for too many older people it is almost the equivalent of going home after work on a Monday and your partner saying, 'By the way, we're moving next week', and when you ask where, you are told, 'We're not sure, but we're definitely moving'. Too many older people just do not have the time to make these important decisions.

[84] I have focused in my own work on a couple of issues, and this is where I think advocacy comes in. We published advocacy guidance earlier this year, which we are currently consulting on, and it says that if you are in hospital, for example, and you are considering going home, and independent advocacy would play an important part in helping you make the right decision, it should be made available to you. I do not have a particular view on where that should come from, but I do think it is important that it is strong, independent advocacy, that people have a right to have, that it is offered to them, that they know how to get it, and there is some standardisation of quality underpinning that. I do not take a particular view on whether we need a specific service for older people or whether we have a generic advocacy service. We just have to match the advocacy service to the older person and make sure that they get the information, knowledge and advice that they need. Too many older people are going into residential care after a period in hospital, when they could, and perhaps should, be going home. That is why I published guidance in relation to that, and I have made it very clear that I am going to issue section 12 guidance underpinning that. That, in relation to advocacy, is the strongest use that I can make of my powers. What I am signalling very clearly is: let us just match it up; let us get that independent advocacy to the people when they need it, to help them to make those decisions. I will also publish more general guidance after Christmas in relation to the same topic, but for people who might be at home and considering going into residential care—again, so that they have the knowledge, information and advice they need to make that really important decision.

[85] I would hope, and I suspect that that is something that the residential inquiry will have already picked up. Again, it is this theme, which, in the scheme of things, is not a lot to

ask: a little bit of time, information and support that people need to make really big decisions. For most people who go into residential care, they stay in the setting they go into. It is a hugely complex decision to make; there are many different types of homes and it is about finding the right type of home that is going to meet people's needs. We forget sometimes what the words 'care home' mean—'care' and 'home' are really special words; it is much more than the bricks and mortar that we live within. So, for me, that has been, and will continue to be, a really strong focus.

[86] There is a lot of good, independent advocacy out there, but I do not think there is enough of it. We are not nearly good enough at getting it to the people who need it, when they need it, to make sure that they can make the right and appropriate decisions. So, that will continue to be a theme for me as commissioner—just giving people a bit of voice, choice and control and some self-determination over their lives. It is what we would all want, and I struggle to see that it is too much to ask for older people.

[87] **Mark Drakeford:** Thank you very much indeed. Diolch yn fawr. We are just about on time, so we will draw it to a close. Thank you very much indeed for coming and helping us to work through your report and to hear about your plans for the year ahead. We look forward to a year's time when we will be able to ask you about the work that you have been engaged in and hear how some of these plans have worked their way through. Diolch yn fawr iawn.

[88] **Ms Rochira:** As do I; diolch yn fawr. Thank you.

10.27 a.m.

Papurau i'w Nodi Papers to Note

[89] **Mark Drakeford:** Eitem 3 yw i dderbyn cofnodion y cyfarfodydd ar y 3 a'r 11 o Hydref. Ydy pawb yn fodlon? Gwelaf eich bod.

Mark Drakeford: Item 3 is to accept the minutes of the meetings on 3 and 11 October. Is everyone content? I see that you are

Cynnig dan Reol Sefydlog Rhif 17.42(vi) i Benderfynu Atal y Cyhoedd o'r Cyfarfod Motion under Standing Order No. 17.42(vi) to Resolve to Exclude the Public from the Meeting

[90] **Mark Drakeford:** Cynigiaf

Mark Drakeford: I move that

yn unol â Rheol Sefydlog Rhif 17.42(vi) fod y pwyllgor yn penderfynu cwrdd yn breifat ar gyfer eitem 5.

the committee resolves to meet in private for item 5 in accordance with Standing Order No. 17.42(vi).

[91] A yw'r Aelodau i gyd yn fodlon? Gwelaf eich bod.

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

*Derbyniwyd y cynnig.
Motion agreed.*

*Daeth rhan gyhoeddus y cyfarfod i ben am 10.28 a.m.
The public part of the meeting ended at 10.28 p.m.*

Ailymgynullodd y pwyllgor yn gyhoeddus am 1.15 p.m.

The committee reconvened in public at 1.15 p.m.

**Bil Trawsblannu Dynol (Cymru) Drafft—Sesiwn Frifffio Ffeithiol gan
Swyddogion Llywodraeth Cymru
Draft Human Transplantation (Wales) Bill—Factual Briefing from Welsh
Government Officials**

[92] **Mark Drakeford:** Prynhawn da a chroeso i chi gyd i sesiwn prynhawn y Pwyllgor Iechyd a Gofal Cymdeithasol. Rydym wedi cyrraedd eitem 6 ar ein hagenda, sef trafod y Bil Trawsblannu Dynol (Cymru) drafft. Rydym eisoes wedi cwrdd â Dr Chris Jones a Grant Duncan, ond heddiw, am y tro cyntaf, rydym yn cwrdd â Sarah Wakeling, sy'n gweithio i wasanaeth cyfreithiol y Llywodraeth. Croeso i chi.

Mark Drakeford: Good afternoon and welcome to you all to the afternoon session of the Health and Social Care Committee. We have reached item 6 on our agenda, namely our discussion of the draft Human Transplantation (Wales) Bill. We have already met Dr Chris Jones and Grant Duncan, but today we meet for the first time, Sarah Wakeling, who works for the Government's legal service. Welcome to you.

[93] Dyma'r trydydd tro i ni gael cyfle i siarad am y pwnc. Fel rydym ni wedi'i wneud e o'r blaen, rwy'n mynd i ofyn i Chris i agor y drafodaeth ac, ar ôl hynny, byddwn yn clywed am yr hyn sydd wedi digwydd o dan y Bil drafft ac yna cawn feddwl am y camau nesaf o ran amserlen.

This is the third time that we have had the opportunity to discuss this subject. In the same way that we have done it before, I will ask Chris to open the discussion and, after that, we will hear about what has been happening under the draft Bill and then we will consider the next steps in terms of the timetable.

[94] Thank you to all of you for joining us again this afternoon. The human transplantation Bill is heading fairly rapidly towards the committee and this will be the last time that we will have the chance to ensure that we are as well informed as we can be about the work that has already gone on. So, I am looking forward to hearing from you. I know that you will start by giving us an overview of the draft Bill and how the responses to the White Paper influence its content.

[95] **Dr Jones:** Chair, I hope that it would be acceptable if I deferred to Grant, as the senior responsible officer for this work.

[96] **Mark Drakeford:** Of course; you orchestrate things as you need to.

[97] **Mr Duncan:** Thank you for the opportunity to come back and discuss this with you. I will remind you that we introduced a draft Bill in June this year, which was preceded by consultation on a White Paper. We consulted over the June to September period on the draft Bill and we published the consultation report last Friday. We had some 2,900 responses to the consultation, of which 2,600 were in the form of a standard letter, organised through one particular group.

[98] The other point that the committee may be interested in is that we also published last week an independent survey on attitudes to organ donation across Wales. It has been asked in this committee before how we know that we are making progress. That has been part of measuring a baseline, which showed that around 49% of the Welsh population favoured a change, but also asked questions, which gave us information about how we could go forward.

[99] I will give you an overview of the Bill and its related concepts. The Bill covers organs and tissues. It proposes duties on Ministers to promote transplantation and

communication thereof, and it then goes into detail about consent systems, the flipside of which is offences. On consent, it introduces two concepts: express consent and deemed consent. The deemed consent is stated to be the default position. So, unless an individual has expressed a wish to either opt in or opt out, which is a new provision, it will be deemed that they wish to donate in the event of their death. The proposal covers those aged 18 and over, which offers standardisation. It is applicable to those who live and die in Wales, and outlines things like residency; the proposal is for a six-month residency period. All of these have checks and balances associated with them.

[100] Of course, the proposal lays out exceptions and control mechanisms. The exceptions are for children and those lacking capacity, and the proposal brings in the role of the family as well as offering important safeguards, checks and balances. We also talk about the register of people's wishes; that is brought out in the explanatory memorandum that accompanies the draft Bill. We have been consulting on a proposal for a single register for Wales that captures everyone's individual wishes. Going back to the consultation, there are some things that do not change, and it is important that people understand that as well. I will pause there, Mark.

[101] **Mark Drakeford:** Thank you, Grant; that was a useful introduction. We will now turn to Members for their questions.

[102] **Rebecca Evans:** On the weighting of responses, you mentioned that a large number of responses had been organised, as you say, and that was certainly a highlight in the Minister's statement earlier this week. Last time you came to committee, you told me that all responses would be weighted equally, so is that still the case?

[103] **Dr Duncan:** The consultation is not a popular vote or a case of asking, 'Do we want this or do we not?', but it gives us information about the concepts. As regards individual weighting, the consultation gives us important information relating to what refinements may or may not be needed. We will take a considered view to advise the Minister about the changes needed based on the evidence brought forward. We will use that to influence the final Bill.

[104] **Dr Jones:** Perhaps I could tell you a little more about the nature of the standard letter. Essentially, it raised a number of points, which I think can be broadly drawn into three different categories. The first category, in a way, covers points that related to aspects of the draft Bill. Those will be seriously considered along with all of the others; they will not be considered 2,600 times, as it were, but they will be seriously considered and may lead to change. The other area of concern was expressed around issues such as the diagnosis of brain death. Although one respects those concerns, they are outwith the range of this legislative proposal.

[105] The third area of concern, which I think is regrettable, is that there was a suggestion that this would amount to some sort of forcible removal of organs against people's wishes. I thought that that was really regrettable because certain communities were clearly targeted with this letter. The vast majority of these responses came from Muslim communities in south Wales. A lesser number came from churches—one church in Edinburgh obviously got involved in this. The assumption made would be completely wrong, and it is regrettable that anxiety and fear have been found in those groups.

[106] **Mark Drakeford:** Just for the record, Dr Jones, could you set out for the committee one more time why the diagnosis-of-death issue is not a relevant consideration for this legislation?

[107] **Dr Jones:** The whole process of care is not affected substantially by this legislative proposal. This is a proposal that changes consent arrangements around decision making in

relation to donation. It does not change any of the clinical decision making of an attending team. It does not change the nature of the diagnosis of brain death. Clearly, a lot of work has gone on worldwide among the medical community with wide engagement about that and about opportunities for donation to occur after cardiac death in a smaller number of individuals. Those considerations are unaffected by the consent arrangements, which are central to this proposal.

[108] **Mick Antoniw:** That is not the concern on that point. I understand exactly what you are saying: that this legislation would only kick in at the stage where organ donation would be considered in any event. Of course, the concern that is raised is that there may be a deemed consent, or what may be a more supported consent arrangement for organ transplantation that will impinge on the way in which those mechanisms, up to that point, are interpreted. That is where the area of concern is, is it not? It is all very well saying that we are fine up to this point and that nothing has actually changed, but if it is perceived that the process will be easier for organ transplantation to occur, people could think that that will somehow change the robustness of the procedures before that.

[109] **Dr Jones:** I think colleagues would like to come in on this point, but I think that is the concern. However, I think that it is an unfounded concern. We have moved on, in any case, in Britain, beyond the simple use of the organ donor register, because we are implementing the recommendations of the organ donation taskforce, which now means that we approach all families of potentially suitable donors, whether they are on the register or not. I do not see that as being a very different scenario from approaching all families of a potentially suitable donor in Wales, other than you have the added safeguard in the future of knowing that they have not opted out and to not approach them, if you see what I mean.

[110] **Mick Antoniw:** It is a matter of how those assurances are given, though, is it not? A lot of things with law and changes are about perception. It is about how those perceptions are alleviated or accommodated, is it not?

[111] **Dr Duncan:** May I come back on that? This is why the independent survey that we have been doing is so important, because I have discovered, over the period of this consultation, that people who have strong views express those views strongly for or against. I think that we must be concerned about the silent majority that does not necessarily engage in some of these things, which is why the survey—I went for about 1,000 people in a representative sample that tests their views—is important. As I said, the survey said that 58% of people were aware of changes. So, we need to do more, but that is still quite a high awareness rate. In addition, 49% thought that opt-out was, in my words, a good thing. That is a two to one majority. The other thing is that introducing opt-out gives people the ability to do just that if they wish. Today, only 31% of people are on the register, so that means that the majority of conversations around donation are with families who potentially do not know individuals' wishes. So, an opt-out system in this method helps to clarify people's wishes. I agree with your point about communication, which is why it is proposed to have a two-year introductory phase for wide-ranging communication and engagement on the specifics. We do not underestimate the effort that is needed and the sophistication that that will be done with.

[112] **Mick Antoniw:** Rebecca, did you get to the end of your question?

[113] **Rebecca Evans:** I did, but I just wanted to pick up on something that has just been said. I was just trying to formulate it in my mind, so it might come out sloppily. You just mentioned that only a certain number of people who hold these views strongly actually contributed to the consultation, but then, at the same time, you have the silent majority that does not express a view. Is it not the silent majority that this law is going to affect?

[114] **Dr Duncan:** Even with the first consultation, we had 1,234 responses, which was a

record for the Welsh Government. This time we had 2,900, but, against a total based on the population of Wales, the point is that it is still a quite a small number. So, it is those who engage in consultation processes that actually contribute to it. There are other large parts of society who do not necessarily pick up on this, which is why a survey looking at a wide range of views helps to gauge how effective communication campaigns will be.

1.30 p.m.

[115] **William Graham:** I will ask a question, which is just an aside, on the awareness aspect. Looking at the figures, it is lowest in Cardiff and the south-east. I am a little surprised about that. Do you have any thoughts on that?

[116] **Dr Jones:** Whether that is because there is a younger population in that area, I do not know. The level of awareness, I think, was higher in the areas that have slightly older populations. It was highest in north Wales, regionally. Whether that is because there was a slightly older population there and a younger one in south-east Wales, where the level of awareness was lower, I do not know.

[117] **William Graham:** My real question is about costs and benefits. At another meeting, we talked about these quality-of-life assessments. By their nature they are very arbitrary, in my opinion. In terms of that, how has that influenced some of your questioning, when you know that there is a demonstrable benefit?

[118] **Dr Duncan:** We have never gone into this from the point of view of cost benefits. The cost benefit, coming out as it did, helped to give further evidence, but we were not relying on that in the first instance; we were going down that route for the overall benefit of saving more lives.

[119] **Dr Jones:** On the road, during these periods of public consultation, we were challenged several times by people who asked, ‘Is it right to spend money on this change?’, ‘Wouldn’t you be better off investing more money and trying harder to get people on the organ donor register?’. It was quite important for us to see what an economic analysis of this policy could bring us. The economic analysis was very powerfully in favour of the change in policy. Given the very high clinical benefit of transplantation surgery, and that each individual donor can contribute three or four organs and enable three or four procedures, and given that those benefits are sustained over years, the benefits to society, financially, add up very quickly. It showed that we only had to identify one extra donor out of this change in policy for the cost of the introduction of the policy to be overcome—for it to be a cost-effective change in policy. That was very powerful. We were surprised at the time, but it does make sense when one thinks about how these figures are arrived at.

[120] **William Graham:** My final question, picking up on some of the comments in the press, as this is the forum to address them, is on the issue of capacity. There were tremendous comments in the press that even if huge numbers of people were donors, you would not have the capacity to deal with them anyway. That is not true, is it?

[121] **Dr Jones:** No. Another thing that will not be affected by this is the fact that only a tiny number of people, compared with the total number of people dying in Wales, will be donors. Of more than 30,000 deaths each year, I think that, last year, there were 220 potential donors, of which, 67 were donors. A 25% increase, which is what we would hope for and what the international evidence would seem to point to, would be a small absolute number of extra donors spread over Wales during the year. So, I do not think that it has significant capacity implications. Having said that, I think it is true to say that those countries that have higher critical-care bed capacity can generate more organ donors. Grant was showing me, before we came in, a plot of countries’ donation rates, showing that the highest donation rates

are generally in countries with an opt-out system, other than the USA, which demonstrates quite a high donor rate per million, but I would assume that that is because it has privately funded critical-care capacity that is huge. So, I think that critical-care capacity can be a determinant of donation rates. However, I do not think that the change in policy in itself will have a significant impact.

[122] **Vaughan Gething:** I was interested to see, when looking through the baseline survey of public attitudes to organ donation, and how that feeds into your communication strategy, that there appears to be a number of contrary messages from the public: 63% of people saying that they would not opt out if such a system was introduced; 68% agreed with the statement that the proposed opt-out system would save lives in Wales; and, when asked whether they were in favour of, or against, changing to an opt-out system, or whether they needed more information to decide, only about half said that they are definitely in favour. We then see that while 67%, which is two thirds, agree that the system would maintain freedom of choice because people can opt out, more than 40% of people say that the system gives the Government too much control. The people who answer, ‘Yes, freedom of choice is maintained’ would not then say that it gives the Government too much control. So, in terms of what appear to be contradictory messages, I am interested in how the communication strategy is aimed at trying to resolve some of those conflicts in attitude that the public appears to have.

[123] **Dr Jones:** It is difficult to respond to the detail of your question, but we have very much known, for a long time, that communication is essentially right at the heart of this policy and we have to get communication right. So, we have quite a substantial communications element to our team developing policy here. As Grant said, we have the two-year plan and colleagues with expertise are thinking very carefully about what this survey tells us about how to communicate effectively—what barriers and opportunities there are, how to reach different groups, and all the different challenges.

[124] We have commissioned a public relations company to help us with the communications strategy—Cambrensis Communications Ltd has been commissioned to help us on that front. We have also commissioned a company called Cognition Communications Ltd, which is a diversity company, to help us listen to minority and vulnerable groups and different racial and ethnic groups. So, I am sure that there are lessons for my communications colleagues in the survey, but we are reflecting on it at present.

[125] **Vaughan Gething:** I am also interested, from a communications point of view, in how you expect to deal with the significant regional variation—I was genuinely surprised at quite how wide the variance was. I am interested in whether you think that gives a representative sample from within that region; 1,000 people in the whole country might be represented, in terms of weighting, but is it representative when broken down by region? Is there a deficit of information and awareness in certain regions? If you are against the proposal, you might say that those who are against it are better informed. It depends on your point of view, I suppose.

[126] **Dr Duncan:** I, too, was surprised, looking at the survey, by some of the information underneath it. We have more work to do underneath it, but that gives us something to focus on. For example, I live in the Swansea area and I was immediately drawn to the statistics for the Swansea area, which were generally less in favour than other parts of Wales. I do not know why that is. So, we need to do more to understand why there is a regional variation. There could be multiple reasons for that—I am expressing an opinion here rather than fact. Chris mentioned age, or it could be the way communities work and engage with each other, but it emphasises that, quite rightly, in terms of communication, we cannot have one size fits all. We need to go for tailored communications for different communities and have different ways of getting messages across. That communication is about listening, as well as saying what is happening.

[127] So, we have more work to do on that to understand some of the subtleties. There have been contradictions there, underpinning some of the reasons for going for this. In a previous survey, about 90% of people said that they were in favour of organ donation and that they would be willing to be recipients, but only 31% went on to sign the register. So there is a mismatch in terms of what people want and what they actually do. Introducing an opt-out system helps to clarify people's wishes, at its simplest.

[128] **Mick Antoniw:** There seems to be an awful lot of confusion among people about opting in or opting out and what it all means. I wonder whether it is because people's perception of a piece of legislation is that it compels something to happen. However, this is a strange piece of legislation, because it is symbolic rather than binding. In effect, it does not really change anything, but it symbolically emphasises a value. That confusion is there and it seems to permeate the consultation process. What are your thoughts about that, because people do not seem to be clear on what it is really about?

[129] **Dr Jones:** I see it—this is a personal view—as a societal view; it is changing the default position for Welsh society, from being one in which you are not a donor, to being one in which you are. That requires a system to enable those who do not want to be a donor to express that view. What we hope is that the increase in the number of donors will come from families having more assurance about the wishes of their loved one, either because they will have had those conversations, after dinner for example, before the person's death, which will mean that they know the wishes of their loved one who has died, or because they will know that they had an opportunity to opt out and did not. That will give them reassurance. In the end, families approached will feel very comfortable with the idea of supporting the process of donation in a very considerable percentage of cases.

[130] At present, in the case of those who are not on the organ donor register, where you have not necessarily had all those conversations and where you do not have the opportunity to opt out, so you cannot quite know whether someone would have opted out, 60% of families say 'yes' and 40% say 'no'. We hope that, in future, when the default position is that you will have discussed it and that, yes, you are a donor, the refusal rate will go down significantly, which will give rise to the extra number of donors.

[131] **Dr Duncan:** If I may add to that, we have found in the public consultation events that one of the facts that people find surprising is what Chris said earlier, which is that organ donation is a relatively rare event. There is the spectre of compulsion or a Burke and Hare-type scenario, which is not true. When you tell people that it is a rare event because there are 30,000 deaths with only 67 donations in specific circumstances and that we are looking for a significant improvement on that but that it will still be a small number, people say, 'Oh, right' and it changes their perception. It comes back to how we can find even better ways to get across that it is not about compelling people and that, in fact, an opt-out system makes things more democratic in some ways by giving people the ability to say that they wish to opt out.

[132] **Lindsay Whittle:** I find this language very unfriendly. I am all in favour of organ transplant and the more we can achieve the better. However, friends of mine have said, 'Well, if I opt out, I am not giving you my organs, am I?' and that is in the cold light of day. When we are at the critical stage of saying this to relatives, it is going to be an extremely traumatic and sad time for them. They will be very distressed. Will they understand what 'opt-in' and 'opt-out' mean? I would much rather we went for a plain English expression. I do not have one, but we must find a better phrase than this. It is too confusing. 'Opt-out' sounds as though you are saying, 'I do not want you to have any part of me at all when I am dead' and that is quite the reverse of what we want.

[133] **Mark Drakeford:** Was that confusion reflected in the public consultation meetings

that you held?

[134] **Dr Jones:** Yes, I think that we have come across that sort of view. As we said before, the repeated message that we are receiving is that we have got to get the communications right, because this is a policy change that is good for people. It is good for people who need organs, it is good for Welsh society, potentially, and it is good for the democratic rights of individuals to express a view. It is not a threatening policy, but we need to get that language right in the communication campaign. That is part of the challenge. The way that this is communicated is absolutely crucial. In my opinion, the success of the policy depends almost entirely on it. Admittedly, it is difficult to compare things country by country, because they all have different background situations and they are deploying less energy or more energy at certain other parts of the process. It does not always improve things, so we have got to make sure that it does. Overall, the situation is better in the countries that have this type of system, but we need to make sure that we get the most benefit from it for the people of Wales—and England.

1.45 p.m.

[135] **Mick Antoniw:** Do you have any particular concerns that those anxieties, which have been expressed during the consultation, are not, perhaps, adequately reflected in the way that the draft of the Bill is coming? I have not looked at it in detail, but just on a cursory reading, it seems to me that there is an awful lot of scope for potential conflict as to who might be in a particular category and what might happen where you have family members expressing different views and so on. The one thing that you would want to avoid in that situation we almost seem to be exacerbating in the legislative process. Do you have a concern with that?

[136] **Dr Duncan:** One challenge for this consultation was that we were consulting on a draft Bill, written in legal terms, and a draft explanatory memorandum, which, albeit less legalistic, was still written in more formal language. Part of the ongoing communication is about translating it into plainer English. In the first consultation, we drew up a leaflet, which Learning Disability Wales helped us with. The work that Cambrensis is doing looks at how you tell stories around this and relate it to people's real lives. Cambrensis is bringing forward some case studies and case histories of people's experience of the system. We need to separate them out. They do overlap, but I think that we need to separate the discussion around some of the legalistic side of this from the communications challenges to the wider population in terms of how this will work and affect them directly.

[137] **Mick Antoniw:** So, this will possibly be quite substantially different.

[138] **Ms Wakeling:** This is recognised on the face of the Bill, because this is so important. You will see that there is a duty on Welsh Ministers to provide information about transplantation, and specifically about the circumstances in which deemed consent will be given in the absence of expressed consent. So, although that is on the face of the Bill, it is in legal language. That provision comes into force upon Royal Assent, and there will be the two-year lead-in period where communication will be crucial—to pick up on the points that you have already raised. That will have to be in user-friendly, clear language, because deemed consent can only be valid if, in taking no action, you have full knowledge of what is involved and know that your consent will be deemed to have been given. Underpinning that will be a separate code of practice, which will detail how exactly this will work.

[139] **Mark Drakeford:** Rebecca, do you wish to ask a question on this?

[140] **Rebecca Evans:** I know that there is a lot of public confusion about the role of the family. Looking at the responses to the consultation document, you can see that 94% of people did not answer the question directly when asked whether the role of the family was

clear. To me, that is quite telling. Looking at the consultation events that you held—the public stakeholder meetings—I see that, in respect of the role of the family, it states,

[141] ‘officials confirmed at most meetings that there would be no retrieval of organs under deemed consent if there were no qualifying relative present with whom to discuss the donation’.

[142] It was only at one meeting—the Cardiff meeting—that it was clarified that that is not the same as the family making the decision for them. There is still a lot of work to be done. Many people will assume that the family will have the final say, but it is not stated in the legislation.

[143] **Dr Jones:** Perhaps I can attempt to answer that. I think that the political intention has been for a soft opt-out system in which the family play a part. This process has uncovered something that people are generally unaware of with the current system. Legally, the wishes of the deceased are paramount, but in real life, day-by-day, clinical scenarios it is generally considered not a good thing to retrieve organs in the face of sustained family objection—it is not, generally, felt to serve the cause of donation and transplantation. So, generally there is a sort of sensitivity around that and people do not do it. That comes from the code of practice issued by the Human Tissue Authority. This is a very sensitive area for the specialist nurses and the clinical teams. However, there is a difference between the purely legalistic framework and how it happens in practice sometimes, and that will be the same in the future. I think that people have become aware of that and found it a difficult thing to understand.

[144] **Rebecca Evans:** I think that people are looking for reassurance and safeguards in the Bill, rather than in the established practice.

[145] **Dr Jones:** I do not think that one can give the family any form of veto over the individual’s wishes, for legal reasons. Indeed, through consultation, we have received the view from a lot of people that they would hate to think that that would be the case. If they had a view and had expressed a view, then they would want that view to be respected. On the other hand, all of these things have to be dealt with very sensitively.

[146] **Mick Antoniw:** Is it not the case that that is what a soft option does? Does it not, in effect, give the family, and the associated broader family, a veto? It does, because, otherwise, you have a position where the whole concept of the Bill, and what has been discussed about who can express a view or change a view, disappears.

[147] **Dr Duncan:** It is perhaps more subtle than that. The word ‘veto’ can be seen in a negative context. The independent survey showed that 73% of people were crystal clear that they wanted their wishes upheld—‘My wish is my wish’ type of thing. Having a soft opt-out system allows for the clarification of everyone’s wishes and there is a greater basis for families to enter into those conversations with specialist nurses and clinicians with a greater degree of awareness. You made the point earlier that the conversations often take place in traumatic circumstances, and therefore people’s previous understanding influences those conversations. It is about that process, which helps.

[148] **Mark Drakeford:** We have just over five minutes left, so I want to move on to the next stage in this. It would be useful for the committee to hear, given the work that we will be doing next, what sort of strategy the Welsh Government has for analysing the responses that it has received to the consultation. How do you see the relationship between those responses and the final Bill? What is the Welsh Government’s timetable as a result?

[149] **Dr Duncan:** I will take those questions in reverse order, if I may. The broad timetable remains as it was; the anticipation is that we will be laying a Bill before Christmas.

The processes are the same as before. Every response and general comment has been read, so we are now using those to refine the explanatory memorandum and any of the particular elements within the Bill on a broad range of subjects. There will be decisions for the Minister to make about the way in which she wishes to go in certain areas. So, we are following due process, Mark, in terms of the final Bill.

[150] **Mark Drakeford:** So, the responses are analysed, and the Minister gets advice on the basis of what you have heard. The Minister then makes a series of decisions on issues that fall to her, and the results of that will appear in the Bill, which we can expect before Christmas.

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

[152] **Mark Drakeford:** Does anyone have anything to add to that?

[153] **William Graham:** There were 1,234 responses to the first consultation—642 were in favour and 482 not so. We are told here that, of those 642 responses, 520 were virtually identical. Is that right? Did you discount those? How did you look at those, given that they probably came from the same source?

[154] **Dr Duncan:** That goes back to the question that Rebecca asked earlier. It is not about giving individual responses weighting; it is about picking up the messages that are behind them. So, those responses to the previous consultation generally came from the Kidney Wales Foundation, but even it had different views about the role of a register and that type of thing. So, it is about helping to influence where policy can be made to best effect.

[155] **William Graham:** So, you would still concur that the majority of responses were in favour?

[156] **Dr Duncan:** From the first consultation, yes.

[157] **Rebecca Evans:** My question is on a different issue, but it is an important one.

[158] **Mark Drakeford:** Go ahead; it will be the last question.

[159] **Rebecca Evans:** I am looking at the sections on people who lack capacity. In the explanatory memorandum, it is acknowledged that, for some people, mental capacity may fluctuate—from day to day, or over a period of weeks, months or years. How will you account for that in the Bill?

[160] **Ms Wakeling:** That is a big theme that has come out of the consultation responses. You have highlighted how difficult the issue is to pin down in legislation, because capacity fluctuates and it is a difficult concept. We have been in discussions with the Department of Health and the Wales Office on these issues. We are giving this more thought and the Bill will be refined to clarify how that will be assessed and how we will safeguard people with different levels of capacity. It is something that is being worked on at the moment.

[161] **Rebecca Evans:** Good. I am glad to hear that.

[162] **Mark Drakeford:** Thank you all very much indeed for coming to help us. It is really useful for us to be able to keep in touch with the way in which thinking about the Bill and the design of the Bill has been developing over the last 12 months or so, and I am sure that it will inform a great deal of the work that we will go on to do once the Bill is put before us. So, thank you very much for all of your help on that.

[163] That is the end of today's meeting. We will meet again on 7 November for Stage 2 of

the Food Hygiene Rating (Wales) Bill.

Daeth y cyfarfod i ben am 1.56 p.m.
The meeting ended at 1.56 p.m.