



Cynulliad
Cenedlaethol
Cymru

National
Assembly for
Wales

Cofnod y Trafodion The Record of Proceedings

[Y Pwyllgor Iechyd, Gofal Cymdeithasol a
Chwaraeon](#)

[The Health, Social Care and Sport Committee](#)

25/01/2017

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Cofnodir y trafodion yn yr iaith y llefarwyd hwy ynnddi yn y pwyllgor. Yn ogystal, cynhwysir trawsgrifiad o'r cyfieithu ar y pryd. Lle y mae cyfranwyr wedi darparu cywiriadau i'w tystiolaeth, nodir y rheini yn y trawsgrifiad.

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. Where contributors have supplied corrections to their evidence, these are noted in the transcript.

Aelodau'r pwyllgor yn bresennol
Committee members in attendance

Rhun ap Iorwerth Bywgraffiad Biography	Plaid Cymru The Party of Wales
Dawn Bowden Bywgraffiad Biography	Llafur Labour
Jayne Bryant Bywgraffiad Biography	Llafur Labour
Angela Burns Bywgraffiad Biography	Ceidwadwyr Cymreig Welsh Conservatives
Caroline Jones Bywgraffiad Biography	UKIP Cymru UKIP Wales
Dai Lloyd Bywgraffiad Biography	Plaid Cymru (Cadeirydd y Pwyllgor) The Party of Wales (Committee Chair)
Julie Morgan Bywgraffiad Biography	Llafur Labour
Lynne Neagle Bywgraffiad Biography	Llafur Labour

Eraill yn bresennol
Others in attendance

Dr Victor Aziz	Cadeirydd Cyfadran yr Henoed yng Ngholeg Brenhinol y Seiciatryddion yng Nghymru, a Seiciatrydd Ymgynghorol yr Henoed ym Mwrdd Iechyd Lleol Cwm Taf Chair of the Old Age Faculty of the Royal College of Psychiatrists in Wales and Old Age Consultant Psychiatrist in Cwm Taf Local Health Board
Dr Ed Bridges	Rheolwr Materion Allanol y Gymdeithas Alzheimer's yng Nghymru External Affairs Manager for Alzheimer's Society in Wales
Dr Jane Fenton-May	Coleg Brenhinol yr Ymarferwyr Cyffredinol Royal College of General Practitioners
Rachel Lewis	Rheolwr Polisi, Age Cymru Policy Manager, Age Cymru
Sue Phelps	Cyfarwyddwr y Gymdeithas Alzheimer's yng Nghymru Director of Alzheimer's Society in Wales

Kieron Rees Rheolwr Materion Allanol, Cynghrair Cynhalwyr
Cymru
External Affairs Manager, Wales Carers Alliance

Dr Les Rudd Arweinydd Gwella Gwasanaeth Iechyd Meddwl,
Iechyd Cyhoeddus Cymru
Mental Health Service Improvement Lead, Public
Health Wales

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

Stephen Boyce Gwasanaeth Ymchwil
Research Service

Zoe Kelland Dirprwy Clerc
Deputy Clerk

Sian Thomas Clerc
Clerk

Dechreuodd y cyfarfod am 09:02.
The meeting began at 09:02.

Cyflwyniad, Ymddiheuriadau, Dirprwyon a Datgan Buddiannau
Introductions, Apologies, Substitutions and Declarations of Interest

[1] **Dai Lloyd:** Bore da i bawb a chroeso i gyfarfod diweddaraf y Pwyllgor Iechyd, Gofal Cymdeithasol a Chwaraeon yma yn y Cynulliad. A gaf i estyn croeso i'n tystion yn y lle cyntaf? Mwy amdanyn nhw yn y man. A hefyd hoffwn estyn croeso i'm cyd-Aelodau. Gallaf egluro ymhellach fod y cyfarfod yma yn ddwyieithog. Gellir defnyddio clustffonau i glywed cyfieithu ar y pryd o'r Gymraeg i'r Saesneg ar sianel 1 neu i glywed cyfraniadau yn yr iaith wreiddiol yn well ar sianel 2. A allaf atgoffa pawb i ddiffodd eu ffonau symudol ac unrhyw offer electronig arall, achos mae'n gallu ymyrryd efo'r offer darlledu, y darlledu byd-eang? Gallaf

Dai Lloyd: Good morning, everyone and welcome to this latest meeting of the Health, Social Care and Sport Committee here in the Assembly. May I extend a welcome to our witnesses, first of all? We'll say a little more about them a little later on. I would also like to extend a welcome to my fellow Members. I can further explain that this meeting is bilingual. Headphones can be used for interpretation from Welsh to English on channel 1 or for amplification of the verbatim contributions on channel 2. May I also remind everyone to turn off their mobile phones and any other electronic equipment, because it can interfere

yhellach hysbysu pobl nad ydym yn disgwyl tân o unrhyw fath y bore yma, felly os bydd y larwm yn seinio, dylid dilyn cyfarwyddiadau'r tywyswyr a gadael y lle yn ddiogel os bydd angen.

with the broadcasting equipment? That's international, of course. I also inform people that we don't expect to hear a fire alarm this morning. So, if it does sound, you should follow the instructions of the ushers and leave this place safely should that be necessary.

09:03

**Ymchwiliad i Strategaeth Genedlaethol Ddrafft Llywodraeth Cymru ar Dementia—Sesiwn Dystiolaeth 1—Y Gymdeithas Alzheimer's
Inquiry into the Welsh Government's Draft National Dementia
Strategy—Evidence Session 1—The Alzheimer's Society**

[2] **Dai Lloyd:** Symudwn ymlaen i eitem 2 ac ymchwiliad y pwyllgor yma i strategaeth ddrafft genedlaethol Llywodraeth Cymru ar ddementia. Hon ydy'r sesiwn gyntaf o dystiolaeth a'r tystion cyntaf yw'r Gymdeithas Alzheimer's. Felly, mae'n bleser i mi groesawu Sue Phelps, cyfarwyddwr y Gymdeithas Alzheimer's yng Nghymru a hefyd Dr Ed Bridges, rheolwr materion allanol y Gymdeithas Alzheimer's yma yng Nghymru. Diolch yn fawr i chi am eich presenoldeb a hefyd diolch yn fawr i chi am eich tystiolaeth ysgrifenedig. Mae Aelodau, yn naturiol, wedi darllen honno i gyd mewn manylder ac wedyn, fel sydd yn arfer i ni, fe awn ni'n syth i'r cwestiynau sydd wedi eu clustnodi eisoes. Mae'r cwestiynau cyntaf o dan law Julie Morgan.

Dai Lloyd: Moving on to item 2 and this committee's inquiry into the Welsh Government's draft national dementia strategy. This is the first evidence session and the first witnesses are from the Alzheimer's Society. So, it is my pleasure to welcome Sue Phelps, the director of the Alzheimer's Society in Wales and also Dr Ed Bridges, the external affairs manager for the Alzheimer's Society in Wales. Thank you very much for attending and thank you for your written evidence. Members, naturally, will have read all of that in detail and then, as is our usual practice, we'll move to our questions, which have been already allocated. The first questions are from Julie Morgan.

[3] **Julie Morgan:** Bore da. I think everybody who's given evidence says

how important it is to involve dementia sufferers, their carers and families in the design of the services and how the services develop. Could you comment on how you see that in the draft strategy?

[4] **Ms Phelps:** It is, absolutely. For us, it's fundamental that, throughout the consultation, we listen to the people affected by dementia living in Wales. And actually, when the idea of there being a national dementia strategy for Wales was first mooted—which we obviously were campaigning for and lobbying for and it's fantastic news as far as we're concerned as an organisation—but one of the things that we said was vital was that, from the beginning, leading up to the consultation and then throughout the consultation and ongoing afterwards, we try and capture the views of those living with dementia in Wales. So, Alzheimer's Society along with another organisation, DEEP, have been leading those consultation meetings funded by Welsh Government. So, we're really grateful for that funding to be able to do that thorough consultation, trying to reach people across Wales. So, we've had focus groups meeting prior to the draft coming out for consultation. Those focus groups are meeting again now, as we speak. There have already been—I think three have happened to date and there are some more this week, and they will continue to meet until the end of the consultation period. But then what we're hoping is that those people who have been involved in the consultation groups will continue to engage with us as the implementation rolls out. Something that Ed and I were talking about as something to suggest going forward is that the people that we've connected with through the groups, those people who are willing to do so, could possibly link with local health boards and strategic planning boards going forward, where the delivery will fit, so that they can see that their input is fed through and continues to influence delivery. Because that, for me, is the crucial thing now: once we've got the strategy agreed, the implementation is going to be key.

[5] **Julie Morgan:** And have you found that people are willing to engage? Have you had a good involvement?

[6] **Ms Phelps:** We have had some excellent response, and actually, what's gratifying for us as an organisation is that they're people that we don't necessarily know. So, we're reaching people who are not known to the Alzheimer's Society, which is good for us, and people who are living—some in very rural Wales, some in more urban environments. So, we're capturing a really good spread. Actually, there are people who've been diagnosed across the age spectrum as well—so, younger people with early-onset dementia to

the older person—but their carers and families and professionals who are supporting them as well. They're giving us feedback as to what they feel is needed.

[7] **Julie Morgan:** So, you feel you've got a representative group who are—

[8] **Ms Phelps:** Yes.

[9] **Dr Bridges:** And if I can just add, it's not just about the consultation events. I mean, those have been fantastic and a really good in-depth opportunity to explore some of the issues, but we've also done various online consultations. After the draft strategy was published, we developed a very short online survey to elicit people's views. I think within the first week of that we'd already had coming up to 300 responses. So, there has been a lot of engagement, not just from people with dementia but also families and carers as well. I think their voices have been reflected quite well in the draft document that we have today and during the current phase of consultation, I think there will be some additional comments and I hope and expect that those will be reflected in the final document as well.

[10] **Julie Morgan:** And have you been able to ensure—and how do you think the strategy will ensure—that people from particular groups, ethnic minority groups, LGBT groups—how do you think the strategy will cope in reaching those people?

[11] **Ms Phelps:** That obviously is a challenge. What we're hoping—. Obviously, the invitation to the focus groups is extended to everybody and it's those people—. So, they've been widely promoted and we are reaching people, but more focused activity could happen. We've got a group of people that we met with before Christmas from the BME community in Butetown, so we can go back to that group of people again to capture their views. I think we have to be a bit more selective and be more proactive in going out, rather than expecting them to come to the focus groups. So, yes, that is definitely on our agenda.

[12] **Dr Bridges:** I think, just to reiterate what Sue said earlier, once we get past the final draft of the strategy and into the implementation, there's something that health boards need to be doing as well about trying to make sure they're reflecting the widest possible spectrum.

[13] **Julie Morgan:** Do you think the draft strategy has got enough in it to

reach out to those groups?

[14] **Dr Bridges:** I think there's always more that can be done and I think that probably is an area where we would like to see a bit more meat on the bone within the draft strategy. There has been a lot of input and a very wide range of input into the consultation events, but I think, hand on heart, we would probably say that, when it comes to, particularly, minority perspectives, it would be good to see more being reflected, not just in the consultation events but in the document itself.

[15] **Julie Morgan:** Thank you. Then, the final question, really, is: what do you think about the actions in the strategy about services for people whose first language is Welsh?

[16] **Dr Bridges:** I think it's fair to say we were very pleasantly surprised by just how far the draft strategy went in relation to the Welsh language. It is something that is particularly important for people living with dementia, obviously. First-language Welsh speakers may lose their second language, English, and so it isn't just about patient choice; it's actually about clinical need. And I think seeing that reflected in the strategy was something that we took a great deal of heart from. It's something that we felt was really important, to reflect that clinical need. I think that is probably an area where we need to do a lot more work in the years ahead, and I think, over the lifetime of the strategy, that is going to be a really key element of this to see can we do more for first-language Welsh speakers when it comes to diagnosis, first of all, but then the support that comes afterwards. I don't think at the moment there is enough capacity in the system to diagnose and support people whose first language is Welsh. I'm sure that's something that in your later sessions you can explore with the psychiatrists. But I think the direction of travel here is really good, to see there is an understanding of the problem. There is more that needs to happen from health boards to make sure that the support is there for diagnosis, and there's more that service providers like us need to do when it comes to actually supporting people whose first language is Welsh. But understanding the problem is a vital first part, and I think, up until now, we haven't done that. We haven't reflected the fact that, for people with dementia whose first language is Welsh, having that support in their first language is a clinical need. So, seeing those words in here was something that we very strongly welcome.

[17] **Ms Phelps:** I think on that, as well, we have got—. One of the things that Alzheimer's Society has pledged to do is to try and identify some

notable practice to insert in the final strategy, and there is—the one that comes to mind is some work that's happening in Cwm Taf, one of the hospitals in Pontypridd—I think it's Pontypridd—where a ward is Welsh language speaking as well as being dementia friendly. So, I think if we can capture what's happening in that particular hospital and replicate that would be a really good addition.

[18] **Dai Lloyd:** Jayne, you had a question on this point.

[19] **Jayne Bryant:** Yes, just a quick question. Good morning. I was just wondering: as well as being sensitive to those people whose first language is Welsh, do you think enough is being done for those people whose first language is neither Welsh nor English?

[20] **Ms Phelps:** I'm not aware that it is, no. I think it's an area that we need to explore, yes. Because there are significant populations now across Wales, aren't there, with Eastern European languages and others. Alzheimer's Society produces information and resource in other languages, but, in terms of delivering diagnosis and responding to clinical need, it's probably something we need to explore more.

[21] **Dr Bridges:** As well as there being a role for the health service and health boards and social care, one of the things that has consistently come up in the consultation events has been about the importance for people affected by dementia of peer support, and, actually, I think when it comes to minority languages, for example, there's a really big role there for looking at how we can strengthen peer support within those communities. As well as making sure that there's state provision, actually, there is also more that we can do to make sure that there is really strong peer support, so that people within their own communities can talk to other people who've gone through similar challenges and problems.

[22] **Dai Lloyd:** Okay. Julie, question 4.

[23] **Julie Morgan:** Yes, the final question, really. You did refer to the fact that, in your groups, you have people from rural areas, but you do comment on the lack of specifics about how you reach out to people in rural areas in the draft strategy. Could you expand on that?

[24] **Dr Bridges:** So, last year, we brought out a very short report looking at dementia in rural settings, and, of the 45,000 people in Wales living with

dementia, we estimated that at least 17,000 of those are in rural parts of Wales. I actually think probably the figure is higher than that. At the moment we simply don't know enough about the problem to be able to do a great deal more in this strategy than what it is there. A lot more is needed in terms of data collection so we can see where the particular hotspots are within rural areas of dementia and what the likely demographic changes are going to be that will have an effect on that. What we wanted to see in the strategy was an acknowledgement that there is a significant problem around rural dementia in Wales, and that people affected by dementia in rural areas face serious and very specific problems. I know this committee's going to be doing a piece of work shortly on loneliness and isolation. There's clearly a big overlap there, not just for the people themselves but also for families and carers and how to support them.

09:15

[25] So, we have seen in the draft strategy an acknowledgement and an understanding of the fact that rural dementia is an issue. I think there is a big role for Welsh Government in terms of making sure that we generate more data so that we can better understand that problem, and there's a role for us and others to look at how we can improve services and support—you can make better use of technology, which the document also talks about. I think, at this stage, it's unrealistic to expect great swathes of policy until we can properly understand the problem. But the fact that it is in there, that there's that acknowledgement, I think is significant. I think, over the first three years of the strategy, I'd really like to see more being done so that we can better understand where in rural areas the problems are, what those problems consist of, and how, on a partnership level, some of those challenges can be addressed.

[26] **Ms Phelps:** I think, as well, linked to that is the work that's happening around, essentially, the overarching intent for Wales to become a dementia-friendly nation and the work happening at a grass-roots level in the community—so, creating dementia-friendly communities and raising that public awareness and understanding. That will help us capture that information, because, hopefully, people living with dementia will be involved in that social movement, if you like, to create dementia-friendly communities. So, we can then gather from those people living in rural communities what it means to them—what does a dementia-friendly or dementia-supportive community mean to them, what would make a difference. We can start gathering that information through that strand of

work, which, obviously, is referenced in the strategy.

[27] **Dai Lloyd:** Gan droi yn awr i gysidro rhannau o'r strategaeth sy'n ymwneud â diagnosis, gofal a chefnogaeth, mae gan Rhun gwestiwn.
Dai Lloyd: We'll move on now to consider the parts of the strategy relating to diagnosis, care and support, and Rhun has a question on this.

[28] **Rhun ap Iorwerth:** Rwy'n meddwl bod yna gytundeb bod sicrhau llwybrau gofal clir yn rhywbeth pwysig yn y maes yma. Beth ydych chi'n meddwl ydy'r prif rwystrau i'r gwaith o integreiddio nid yn unig iechyd a gofal cymdeithasol y wladwriaeth, ond y trydydd sector, y sector breifat ac ati?
Rhun ap Iorwerth: I think that there is an agreement that ensuring clear care pathways is very important in this particular area. What do you think the main barriers might be to the work of integrating not only health and social care, but the third sector, the independent sector and private sectors?

[29] **Ms Phelps:** Right—barriers. I'm coming at this because it's fresh in my mind, and a particular piece of work that we're involved in at the moment; I think commissioning plays a big role—commissioning of third sector, so, commissioning specialist organisations that understand dementia. There needs to be better collaboration, I think, between health, social care, and then the third sector to understand what is needed and then to commission services that are joined up. We've got instances where that's not necessarily happening.

[30] I think the Act—obviously, we've got the Act now—would lend itself to that sort of activity, but there does seem to be a disconnect, and there are examples across Wales where health and social care are still not quite joining up, and then people with dementia are falling through the hoops.

[31] Through the consultation events, one of the key themes coming from people, as you rightly say, is that people with dementia are telling us that there isn't the pathway there, that they're having to repeat their story on a number of occasions to their social worker and then to their community psychiatric nurse, and then if a third-sector organisation goes in. So, I think we all have a responsibility—all of those agencies—to come together and make it better. It can happen—it just needs better communication and better collaboration.

[32] **Rhun ap Iorwerth:** There are very good examples, of course, in parts of Wales where the collaboration is already happening and to great effect. There's a new development in Anglesey that I'm really looking forward to seeing how that works now. Can we rely on rolling out that kind of good practice, or does there need to be a more formal, structural reconfiguration, if you like, of the systems as they currently are in order to make sure that we have this happening on a Wales-wide basis?

[33] **Ms Phelps:** I think it can happen if we share good practice. I think one of our biggest issues is that we don't actually share where it is done well. So, let's say we do that better—I think that will improve things. I know there is a lot of talk around potentially pooling resources, whether that be pooling budgets or pooling understanding. The whole lot, I think, needs to come together, because there is still this protection of social care funding, of NHS funding, of third sector funding. We need to break down those barriers and all come together. I personally feel—and I've mentioned this before—that, if we had an opportunity to review, across all the agencies in Wales, the current spend on dementia—. So, we know, from a report last year, that £1.4 billion is being spent on dementia. How is it being spent? Do we know how it is being spent and where, and is it being used to best effect? I would suggest that, maybe, there's an opportunity there to use resourcing in a much better way. So, I think that something that we could do, through the strategy, is push for—

[34] **Rhun ap Iorwerth:** So, the strategy needs to be, if not totally prescriptive in how you secure that pathway, but it's got to identify where good practice is.

[35] **Ms Phelps:** And monitor in a much more stringent manner, I think.

[36] **Dr Bridges:** Just to add to that, if you talk to people who are living with dementia, or are supporting people with dementia, the frustration that they will have about things getting lost between health and social care, or even within health and social care, is what Sue said: having to repeat your story seven or eight times to different people within the health system, within the social care system. I'm sure it's something that you all hear in your surgeries from constituents. The answer to that should not be a complex one. It should just be about making sure that information, particularly about people who are living with dementia, who are the people least able to want to have to repeat their story time and time again—you know, making sure that that information is shared properly and that practitioners are aware of people's

history, background and case notes before they go into that conversation. That is not something that should be a difficult or technologically-challenging thing to do. But getting that right will give people with dementia and their families a lot more confidence in the system that their situation is going to be understood and that they will therefore receive the care that they need.

[37] **Rhun ap Iorwerth:** Okay, thank you.

[38] **Dai Lloyd:** Time is marching on, and there are several questions, okay. Lynne has got the next one.

[39] **Lynne Neagle:** Thank you. Good morning, both. My questions are on diagnosis rates. You've been very clear that you don't think the target that the Minister has set is ambitious enough. Can you just expand on that and say where you think we should be in terms of targets? Because the Minister has said in response to me that we need to be realistic, but I would like to see us having an ambitious target. So, how do you marry up the need to be realistic with something that really does take us forward?

[40] **Dr Bridges:** So, diagnosis is absolutely fundamental. It is only through getting a proper diagnosis that you can unlock the support and services that are available to you. At the moment, we are diagnosing 51 per cent of people with dementia. Now, we wouldn't accept a diagnosis rate of 50 per cent for cancer or other major areas of disease, and we should not accept it for dementia, because that means that half of the people living with dementia in Wales are not getting the support and the services that they need. Wales lags behind other parts of the UK. There are various reasons for that, but I think we have consistently pointed to Northern Ireland and said, 'Well, they are diagnosing 64 per cent of people with dementia'. If you look at demographics, if you look at geography—we've talked about rurality already this morning—they are in a comparable situation to us. So, what is it that Northern Ireland is doing that Wales is not doing that is therefore allowing them to hit a 15 per cent, or thereabouts, higher diagnosis rate than us? I absolutely take on board that we have to set realistic targets and we don't want to set ourselves up to fail, but, under the 3 per cent per year improvement that the strategy sets out, by the end of the lifetime of the dementia strategy, we would just about be where Northern Ireland are now, and I don't think that that is sufficiently challenging and sufficiently ambitious for us. So, if we were to be closer to a 4 per cent target per year, I think that's something that we would feel more comfortable with, and that is,

hopefully, still realistic. Of course, some of that stuff costs money, and also—and we heard this in the consultation events—you have to make sure that the services and the support are there. There's no point diagnosing people and not giving them support. But, again, I would come back to the comparison with cancer. You wouldn't say to someone, 'Well, because we think that the health system is under stress, we won't bother to diagnose your cancer'. We would not accept that. We should not accept that for dementia either.

[41] **Lynne Neagle:** Can I just ask one other question? Your written evidence highlights a problem with the way that the Welsh Government is counting people with early onset dementia. Can you just expand on that?

[42] **Ms Phelps:** Go on; you're better at that.

[43] **Dr Bridges:** So, there's been a slight change in the system of measurement that Welsh Government have used. They've moved from a system called Delphi to a system called the Cognitive Function and Ageing Study method to measure diagnosis rates. There's good reason for moving to CFAS, and it does allow for slightly more meaningful comparisons with what happens in England. The difficulty with it is that CFAS, because it is based around older people, does not measure the number of people with younger onset dementia—so, under 65—which potentially means that the figures are 2,000–3,000 out. But also—and I think this is the really significant thing—it's harder then to keep track of younger people with dementia who have very specific and different needs. Clearly, if you are in your 50s or 60s and you are diagnosed with dementia, then that is going to have much more of an impact in terms of your ability to work, your ability to care for a family, to pay a mortgage, all the rest of it. So, we don't want to see those people ignored by the way we measure statistics and left behind by the services that are provided. So, there is understandable reason for the shift to the different system of measurement, but that has to also come with a commitment that we will continue to track the people with younger onset dementia and make sure that they are provided for, because there are really significant implications to not doing that.

[44] **Ms Phelps:** Added to that, with younger people, around the diagnosis for somebody who does get to a GP practice or to a memory assessment, is that often it's misdiagnosed. So, dementia is missed. There is still the lack of understanding that dementia can affect somebody in their 30s, 40s, 50s. So, we've got lots of people out there who don't get the diagnosis because, as I

say, they're diagnosed with something very different. So, that's an added issue.

[45] **Dai Lloyd:** Océ. Cwestiwn **Dai Lloyd:** Okay. Next question, nesaf, Rhun. Rhun.

[46] **Rhun ap Iorwerth:** Just a quick word on your thoughts about making more primary care settings dementia friendly, because that's quite an important part of that early diagnosis process.

[47] **Ms Phelps:** Again, in terms of notable practice, there is an example I know—just one that comes to mind because it's recent—in Cowbridge, where they're looking to make their primary care practice dementia friendly. So, at the moment, we've got the GP Wales Mental Health in Primary Care Network training that can be rolled out, and I think, at the moment, there's around a 50 per cent take-up around GP surgeries. So, we would be actively encouraging GP surgeries for there to be 100 per cent at some point, because that is a programme for the whole of the GP practice to become dementia friendly—that's from the receptionist right through to the district nurses and the GPs themselves. That can be delivered in two hours within protected learning time, so that there is a resource that we should be pushing forward. So, it's about the wider understanding of not penalising people for not turning up to appointments, for example. Somebody with dementia could forget their appointment, so it's being aware that perhaps a phone call might help there. Where you haven't got a voice saying, 'Can you come through to the doctor, Mrs Jones', but you have to rely on a screen, that is not dementia friendly. So, it's lots of practical things that can be done relatively easily to make the practice dementia friendly. So, I think that can be something that can be achieved.

[48] **Dr Bridges:** Because, although it may not be the dementia that has brought someone to the GP surgery or the hospital, it may well be the dementia that stops them getting the care and the support that they need. So, trying to reduce the likelihood of that happening has to be critical if we're to give the person effective care, and also make sure that it works from a GP point of view as well and that they are able to provide that.

[49] **Ms Phelps:** And I think, for me, one of the things that's missing in the consultation—it sort of links with this but it goes all the way through all of the issues—is that we've got a group of people—. So, a third of people living with dementia in Wales—well a third of people living with dementia per se—

live on their own. This is pertinent to GPs—somebody who hasn't got a carer to prompt them and support them to go to the GP practice may not get there, and they'll be excluded from the diagnosis and everything that's available because they're not getting that support. There isn't enough reference to people living on their own. Lots of reference to carers, and that's obviously crucial, but we do need to recognise those people who are living on their own, and what we can do to make the strategy live and breathe for those people.

[50] **Dai Lloyd:** Fine. A couple of quick points from Lynne.

[51] **Lynne Neagle:** The pledge to give everybody a support worker when they're newly diagnosed is very welcome, but currently that is 32 for the whole of Wales. You've expressed concerns that that's not enough. How many do you think we need? And also, do you think there's a gap then, because it's newly diagnosed, for people who are living with dementia, which could be for many years, as you know?

09:30

[52] **Dr Bridges:** I had a feeling you might ask a question about support workers. I know it's something that you've raised consistently, and, absolutely, we know that access to a support worker as that first line of contact, that first person who can signpost and direct people towards services, is absolutely critical. It's come up in the consultation as something that people strongly value. As you say, at the moment, there's one dementia support worker for every two GP clusters in Wales, so that's 32 DSWs to support 20,000 people with a diagnosis of dementia, which is clearly insufficient. I think if we are serious not just about providing access to a DSW to every person with dementia, but also increasing diagnosis rates, we probably need to be looking at certainly five times that number, and probably coming on for more like 10 times that number. But we really need to look at the workload of DSWs and the number of people we're diagnosing.

[53] But I cannot stress strongly enough just how important the support worker role is, not just to the person with dementia, but, actually, if you look at what they're able to do in terms of signposting and support and reassurance, they prevent people with dementia from potentially going into more costly parts of the system—going to their GP surgeries or ending up in A&E. So, it is a shrewd investment to have support workers.

[54] The other thing that I think is just worth stressing is, at the moment, support workers are delivered via health boards, so that means that you have seven different job descriptions for DSWs, which, in some ways, is fine, because there are going to be different challenges in different areas, but if you want to deliver that role consistently, I think there is something about looking at the existing models, seeing what works well and perhaps coming up with a good practice template for what the job description of a DSW looks like.

[55] **Ms Phelps:** I think, linked to that, for me, what is crucial is looking at the current Welsh Government spend that's gone to local health boards to deliver the key support worker role. Some of the local health boards have kept that money in-house, which is their prerogative, while others have come out to commission other organisations. So, I think that current spend does need to be explored. Is it being used for the purpose for which it was given? I would argue, working on the ground, our services are seeing that it's not, so I think we need to look at that. And, if there is any additional funding coming from Welsh Government to prop up and increase the key support worker role, we need to make sure that it's delivered in the way that it's intended, to have that effect.

[56] **Lynne Neagle:** Thanks. Just quickly on respite, do you support the proposal that a national model for respite should be looked at by the Welsh Government?

[57] **Ms Phelps:** Respite has come up consistently in our groups. People with dementia and their carers and families are saying—. It's not just respite in the traditional sense, it's looking at different ways of providing that respite. So, somebody doesn't necessarily have to go into a residential care home; we could look at delivering respite in that individual's home to avoid disruption and disorientation, et cetera. So, exploring better ways. And age-appropriate respite as well—those younger people with dementia are telling us that that needs to be taken into consideration.

[58] **Dr Bridges:** But, yes, we'd absolutely—

[59] **Ms Phelps:** Absolutely, yes, respite is a big issue.

[60] **Dai Lloyd:** Okay. Short questions, short answers now, really, not that I'm aiming at anybody in particular, Angela [*Laughter.*]

[61] **Ms Phelps:** No pressure.

[62] **Dai Lloyd:** Well, you could slide in a short one, as it were [*Laughter.*]

[63] **Angela Burns:** Thank you for your paper. I'm very concerned about what happens to people with dementia when they are admitted to hospital, because evidence, as you all know, shows that that can actually upset somebody and set them on a path of advancing their dementia more quickly. What do you think we could do to try to ensure that, if somebody's in hospital, that stay does not adversely affect that particular condition?

[64] **Dr Bridges:** Twenty five per cent to 40 per cent of hospital patients are people with dementia. And, as I said earlier, it may not be the dementia that has brought them there, but it could well be the dementia that stops them being treated quickly. It comes back to what is in here about making sure that hospitals, as well as primary care settings and care homes, are dementia-friendly environments.

[65] **Angela Burns:** But how do you make a hospital dementia friendly?

[66] **Dr Bridges:** There are infrastructure things that you can do about making sure that there is good signage, that there is the support around the infrastructure and people can see where they need to go and it's well laid out for people who may have dementia. But also staff training and making sure that you have clinical staff who understand the needs of people with dementia. Again, one of the targets in here is around 75 per cent of NHS staff having dementia training, which we strongly welcome. So, there's a twin track there.

[67] **Ms Phelps:** For me as well, I think it's important, where there are carers, for carers to be able to—for the flexibility around visiting, so that somebody with dementia can be supported by their carer or by somebody they're familiar with at the times of eating, dressing and washing, et cetera. And maybe a better use of volunteers, so using third sector organisations to recruit, train and support volunteers to deliver that one-to-one pastoral care on the ward so that somebody's not presented with a plate of food and then they're left and it remains uneaten—all of the stuff that we know happens—

[68] **Angela Burns:** But surely it has to be a bit more than that, because one of the things that concerns me is a lot of them will be elderly people. Are there any projects that you know about—I'll try and talk really quickly, so,

sorry about this. Are there any projects that you know about there where people try to replicate a home environment around that hospital bed in order to try to ensure that the person feels more relaxed and, therefore, that prevents that additional onset?

[69] **Ms Phelps:** The short answer to that is 'no'. I do know of examples where they have tried very hard. So, for example, around eating, there's some work going on in Hywel Dda, where the cutlery and crockery that are used are a colour that can be—so, food is served on blue, I think it's blue or red plates. I can't remember now—red, is it? That came back as feedback from people with dementia; it makes it easier for them to be able to identify that there is food there for them to eat. So, those are the types of notable practice that we want to start seeking and start introducing into the strategy.

[70] **Angela Burns:** The other question I wanted to very quickly ask you was—and I've seen this gap in all the evidence that we've had—about patients who have mental health issues, because having a mental health issue is not the same as having dementia. You identify protected groups, and so on and so forth, who need extra help or consideration, but there's no mention of people who might be psychotic or have any other mental health issue who then start getting dementia. Could you just make a comment on that?

[71] **Ms Phelps:** That's a good point.

[72] **Dr Bridges:** I think it is. I think that might be something where we may send in an additional briefing note. We can perhaps tease some of that out in a bit more detail.

[73] **Angela Burns:** I'd be very grateful, because I think it's a glaring absence in all the—

[74] **Dr Bridges:** Very happy to.

[75] **Ms Phelps:** You're right, it is. Also, there's passing reference to people with learning disabilities, for example. We know that 50 per cent of people with Down's syndrome will develop Alzheimer's disease, so something in there around that group of people—

[76] **Angela Burns:** I think that'd be really useful. Thank you.

[77] **Dai Lloyd:** Great, but not taking away from your excellent written evidence.

[78] **Angela Burns:** It's good evidence.

[79] **Dai Lloyd:** Right, Jayne, antipsychotic medicines.

[80] **Jayne Bryant:** Thank you, Chair.

[81] **Dai Lloyd:** Briefly, now.

[82] **Jayne Bryant:** I'll be very brief. So, what evidence is there that there may be inappropriate prescribing of antipsychotic drugs to people with dementia?

[83] **Dr Bridges:** This was something that the older people's commissioner covered in a previous report in great detail, and it's been talked about by the Royal College of Psychiatrists and the Royal Pharmaceutical Society. This is something that we know happens and is a problem. People talk about the chemical cosh being used as a way to pacify people with dementia. It's good to see that it's reflected in the document. It's absolutely something where we need further work and making sure that antipsychotics are only used where absolutely necessary and that only the lowest doses are given. So, there is more that we need to do on it, but it is good that it is reflected in here, because we know it is something that is of great concern to people with dementia and families.

[84] **Ms Phelps:** In terms of training and upskilling of health and social care staff, that person-centred intervention can help to reduce—. So, it's linked to the training—that if you take the time to understand the individual and provide a person-centred support plan, and identify what's causing, maybe, some agitated behaviour, then rather than using an antipsychotic, having that more person-centred intervention can help.

[85] **Jayne Bryant:** Do you think that enough is being done to ensure that there are regular reviews of the medication to make sure that there's not that overuse and also so that carers, perhaps, and individuals—as you've mentioned, there's that hole for people who live on their own, but do you think enough is being done to explain the medication implications and making sure that we're not overprescribing?

[86] **Ms Phelps:** No, I don't think there is, and I think there's the issue of overprescribing, but there's also the issue, particularly, of people living on their own—where they are prescribed with medication, they're not taking it, because they haven't got the support there to remind them to do so. So, yes, that needs to be addressed in the strategy as well.

[87] **Jayne Bryant:** And just briefly, on the range of alternative treatments available, you mentioned, as well, loneliness and isolation that do hit people with dementia particularly hard, and I know in my own constituency, in Newport, we've got the music and memories group, which is great, not just for people with dementia but also their carers. I was just wondering, because I think the stimulation of people with dementia is crucial, could you say a little bit more about that and alternative therapies?

[88] **Ms Phelps:** I think alternative therapies absolutely have their place, and there is research out there to indicate that. I think the other thing as well around music and memories and those sorts of therapeutic activities is—that, again, is where dementia-friendly communities can lend themselves and services like befriending that can provide that one-to-one support for people to be able to continue with the hobbies that they've been used to, or even learn something new. There is a myth that somebody with dementia can't learn—they can with the right support. And I think that can go a long way to improve a person's physical and mental well-being, if they are supported to through meaningful activity, absolutely. So, I think peer support there—.

[89] I think we've made reference to training for health and social care professionals, but, actually, training, for want of a better word, or information and education, for people who are diagnosed and for carers—targeted carers information programmes that can explore the use of alternative therapies and meaningful activities et cetera would really, really help, and would be relatively cheap to provide, if you like, or easy to provide.

[90] **Dai Lloyd:** Shall we move on to Rhun?

[91] Cwestiwn 15.

Question 15.

[92] **Rhun ap Iorwerth:** Mae hwn yn benodol ynglŷn ag edrych ar ôl y rheini sy'n edrych ar ôl y bobl sydd â dementia, sy'n gwbl hanfodol. Rydym wedi cyfeirio at *respite* a ballu yn

Rhun ap Iorwerth: This is specifically in relation to looking after the carers of those with dementia, which is essential. We've referred to respite and so on already, but it's about

barod, ac mae yna lawer mwy na much more than that. How do you hynny. Sut ydych chi yn meddwl y think that the strategy as it stands gallai'r strategaeth fel y mae hi gael could be strengthened in order to ei chryfhau er mwyn sicrhau bod y ensure that the carers receive the gofalwyr eu hunain yn cael y gofal a'r care and support that they need? gefnogaeth y maen nhw eu hangen?

[93] **Ms Phelps:** Okay. Yes, I mean, it goes without saying that carers have a crucial part to play. I think there has to be a respect of their knowledge and understanding, so I think anybody who is delivering a service, whether it be a GP or a consultant psychiatrist or a nurse on a hospital ward, has to take the time to sit down and listen to what the carer is saying to them. They know the person well. So, documents like 'This is me', which has come up in the consultation events—. That 'This is me' is completed before a person goes into hospital, goes into residential care, so there is that person-centred approach that's taken, and the carer obviously is involved in that—.

[94] What else have carers said to us? I think the respect, going back to the hospital ward, involving the carer on the ward and giving them the opportunity to stay with the person—. The other thing for me is around—it's a tenuous link, I guess, but it's around eligibility criteria. So, if we're truly talking about supporting people in their own communities for as long as is possible for them to be independent—at the moment, the eligibility criteria to support services are getting higher and higher. That is going to have an impact on carers. So, we are only being able to refer people in at almost a crisis situation, where there is a breakdown of care. That, to me, does not make sense in a world where we should be trying to be talking about prevention.

[95] So, I think, through the strategy, we do need to be looking at eligibility criteria so that the impact on carers—. And carers assessment as well—we need to be pushing that they have their carers assessment. Also direct payments—can we look at the better use of direct payments so that carers of people with dementia can make choices about the type of support that they need and when they need it? That isn't used to best effect for people with dementia.

[96] **Rhun ap Iorwerth:** Are those kinds of elements reflected strongly enough in the strategy as it is, or is this an area where there does need to be—?

[97] **Ms Phelps:** I think, for me, the eligibility criteria are not reflected enough at all.

[98] **Dai Lloyd:** Fine. Two questions, three minutes. Okay? So, Caroline first and Dawn, you can roll your two into one.

[99] **Caroline Jones:** May I ask your views on whether implementing the strategy will require additional and separate funding, and if so, where could this most effectively be used?

[100] **Dr Bridges:** Yes. A nice brief enough answer for you there.

[101] **Dai Lloyd:** Excellent—[*Inaudible.*] [*Laughter.*]

09:45

[102] **Dr Bridges:** It absolutely does have to be done with—. You do need to have some dedicated money for it, and I think as I explained earlier, there are significant parts of this where, if you fund it properly and in the right way, it will actually save money elsewhere in the system. So, support workers, I think, are a perfect example of that, where you are ultimately investing to save, and I think that's a really important area. So, there are areas like that where you will save money elsewhere in the system. Diagnosis is probably the one where you will invest but it will cost you: the more people you diagnose, you are going to have to pay for the support. But I think it's the right thing to do. So, those are the two areas where I think I would most like see funding allocated.

[103] **Ms Phelps:** But I think commissioning plays a role there as well—so, better commissioning and understanding what third sector organisations can provide. Often the third sector can provide services more cheaply. So, it's looking at that as well.

[104] **Dai Lloyd:** Point taken.

[105] **Caroline Jones:** Thank you.

[106] **Dai Lloyd:** Dawn.

[107] **Dawn Bowden:** Very quickly, Chair, yes. Two very quick questions; one on the dementia strategic action plans oversight. I know you've commented

on who might be involved in that, particularly referencing younger people with dementia. Do you just want to say a little bit more about—maybe not concerns, maybe that’s too strong a word, but a little bit more about what you think that should do? And secondly, around measurements and, again, you have commented on that, about how the strategy should be measured, but what do you think should be the main priorities and how should those be measured? So, those two questions, really.

[108] **Dr Bridges:** Shall I pick up on the governance?

[109] **Ms Phelps:** Yes, fine.

[110] **Dr Bridges:** So, in terms of governance and oversight, I think, in some ways, the Welsh Government might end up being a victim of its own success—that, because there’s been this really strong involvement of people affected by dementia during the consultation phases and people and groups have had a really strong voice in the process so far, I think there’s now a really important need to make sure that those people, or those groups, have a voice as the strategy is then taken forward and delivered and that it isn’t something that is purely governed and run within Welsh Government. So, there needs to be a mechanism to ensure that there is ongoing feedback and ongoing dialogue with people affected by dementia and families and carers so that their voice is heard throughout the process. I think it’s been really helpful to the development of the strategy to have that voice, and I think if we’re to make sure that it is properly delivered, that needs to be something that is factored in so that it isn’t just done by civil servants within Cathays Park; it needs to be something that the widest possible cross-section of people affected by dementia feel ownership of.

[111] **Ms Phelps:** And I think added to that is the overarching group, the older people’s mental health group, which I believe is going to be the body that’s going to monitor its implementation, and to make sure that the people around that table reflect all agencies, so that it’s not very—. My experience of that group to date, with the vision, has been that it’s quite health-focused. I think there needs to be representation from social care, there needs absolutely to be the voice of people living with dementia, but housing needs to be around the table, and the third sector et cetera. So, a better cross-section who can really feed into it, monitor and scrutinise. Picking up on monitoring, for me, that is key, and I was really pleased to see that three-year break, if you like, to check in and see how we’re doing against all the key elements; it’s a real positive, and we need to make that dynamic and

meaningful at that point.

[112] **Dawn Bowden:** Thank you for that. I'm conscious of time, so the second part of my question: just very briefly, what would you see being the key priorities? We've got to measure these: what do you see as being the outcomes, how they should be measured, and what should be the key priorities that we're looking to measure, really?

[113] **Dr Bridges:** Diagnosis, diagnosis, diagnosis is absolutely vital. So, I think that's the first thing that I would want to see as a key priority. The second is around support workers and seeing how we're doing with that aspiration of making sure every newly diagnosed person has access to a support worker. And then I think the third is around training, and that aspiration of 75 per cent of NHS staff to be dementia trained; that's a good target, but where will we be in three years' time? How will we be performing against that? So, those are the three that I think are the most important, but the diagnosis one, I think, will be a really strong indication of not just how the strategy is going in terms of its oversight, but actually if the funding there to support it as well.

[114] **Ms Phelps:** Can I just add to that? On top of that, because the overarching title of the strategy is about creating a dementia-friendly Wales, for me, it's asking people with dementia, 'Are you experiencing dementia-friendliness in the community that you live in?' So, it's overarching public awareness and understanding. I think we're at a position with dementia now where it's bigger than any one agency—I say that all the time—and we need to ensure that there is a societal responsibility now for dementia to really make a difference to the lives of those people living with it. So, I would want to be checking in and saying to people, 'Does your community feel dementia-friendly now, and if not, why not? What can we do to improve?'

[115] **Dai Lloyd:** Grêt. Diolch yn fawr. **Dai Lloyd:** Great. Thank you very much. Wonderful evidence this morning, I have to say.

[116] **Ms Phelps:** Diolch yn fawr. **Ms Phelps:** Thank you.

[117] **Dai Lloyd:** Mae'r dystiolaeth ysgrifenedig yn fendigedig, ac mae'r cwestiynau a'r atebion y bore yma, **Dai Lloyd:** The written evidence was excellent, and the questions and responses have also been wonderful o'ch rhan chi, wedi bod yn this morning. Thank you very much.

fendigedig. Diolch yn fawr iawn i chi. Mi gewch chi drawsgrifiad o'r cyfarfod yn fan hyn i'w wirio i wneud yn siŵr eich bod chi'n hapus efo'r ffeithiau ac ati. Ond diolch yn fawr i chi unwaith eto am eich cyfraniad. Diolch yn fawr.

You will receive a transcript of this morning's proceedings so that you can check it for accuracy. But thank you once again for your contribution. Thank you.

09:50

Ymchwiliad i Strategaeth Genedlaethol Ddrafft Llywodraeth Cymru ar Ddementia: Sesiwn Dystiolaeth 2—Age Cymru a Chynghrair Cynhalwyr Cymru

Inquiry into the Welsh Government's Draft National Dementia Strategy: Evidence Session 2—Age Cymru and Wales Carers Alliance

[118] **Dai Lloyd:** Rydym ni'n symud yn syth i'r eitem nesaf: eitem 3, fel y mae Aelodau yn gwybod eisoes, achos dyna beth yr ydym ni wedi bod yn gwneud trwy'r bore, yw'r ymchwiliad i strategaeth ddrafft genedlaethol Llywodraeth Cymru ar ddementia. Hwn ydy'r ail sesiwn dystiolaeth. Mae Age Cymru a Chynghrair Cynhalwyr Cymru o'n blaenau ni rŵan am y tri chwarter awr nesaf. A gaf i felly groesau Rachel Lewis, rheolwr polisi Age Cymru—bore da i chi—a hefyd Kieron Rees, uwch-reolwr materion allanol Cynghrair Cynhalwyr Cymru?

Dai Lloyd: We'll move immediately to our next item, which is item 2. Again, as Members are aware, because this is what we've been undertaking all morning, this is the inquiry into the Welsh Government's draft national dementia strategy. This is the second evidence session, and we're joined by Age Cymru and the Wales Carers Alliance for the next three quarters of an hour. So, may I welcome Rachel Lewis, policy manager, Age Cymru—a very good morning to you—and Kieron Rees, senior external affairs manager for the Wales Carers Alliance?

[119] Yn naturiol, rydym ni wedi derbyn, fel Aelodau, yr holl dystiolaeth ysgrifenedig, ac felly yn ôl ein traddodiad, fe awn ni'n syth i mewn i gwestiynau ar y strategaeth ddrafft yma. Mae'r cwestiynau cyntaf o dan law Julie Morgan.

Naturally, we, as Members, have received all the written evidence that you provided, so according to tradition, we will move immediately to questions on this draft strategy. The first questions are from Julie Morgan.

[120] **Julie Morgan:** Thank you, Chair, and good morning. I think all the agencies that have contacted us have stressed how important it is to involve people who are suffering with dementia and their carers and families in the design and in the development of services. How do you think the draft Bill matches up to that?

[121] **Ms Lewis:** I think I would have expected to see a little firmer guidelines on involving people and their carers in the strategy. We would expect to see—. It's really, really important that people designing services—not only people designing services, but people commissioning services, really understand and talk to and engage with people living with dementia, their carers and families, and also the third sector organisations that have expertise. I don't think it's strong enough—I didn't see enough reference to involvement throughout the strategy. It is there, but I do believe it could be strengthened. We believe that all people delivering services—public sector—should have really strong and robust mechanisms in place for gaining the views of people with their carers, and I think there's a lot of work to be done in that area. So, perhaps a performance measure based around getting those mechanisms in place would ensure that real involvement does happen at every stage.

[122] **Julie Morgan:** What sort of mechanism?

[123] **Ms Lewis:** Well, mechanisms to talk to people. If a commissioner is commissioning a service for people with dementia, they should have to as part of their training have talked to people within the community, and have talked to third sector organisations, perhaps, about what the particular needs are. So, I would expect every commissioner to have to have that training, and that awareness and that understanding. I should think there would be ways of people working with people with dementia having those conversations, making sure that those 'what matters' conversations really, really tease out the things that matter to that person. I think there are ways that those can be strengthened to ensure that they are taking place.

[124] **Mr Rees:** I think, for us, one of the big issues in involvement in the design and delivery of services, particularly in health, is about a continuing lack of awareness of the role of the carers of people with dementia in supporting and working with the person with dementia. So, we're still here, and the Carers Trust did a piece of research three years ago called 'A Road Less Rocky' that very much found that carers didn't feel they were involved

or talked to throughout the healthcare process. Some of the findings of that were that it was down to a lack of understanding among professionals, and that's why we worked with the Royal College of Nursing to develop a triangle-of-care model for dementia, which was all about making sure the carer is also involved, and that everyone understood their role in relation to each other. So, something that would improve the way the strategy approaches involvement of carers would be about making sure that there's a real awareness of the role of carers of people with dementia.

[125] **Julie Morgan:** Thank you very much. Moving on, I think Age Cymru have stressed how important it is to have independent advocacy, and that is mentioned in the draft Bill. Do you think this Bill will improve access to independent advocacy?

[126] **Ms Lewis:** I hope so. It's in the Bill and it's in the strategy as one of the actions, isn't it, that people should have access to an independent advocate. So, we would hope that, yes, it does. I think we mentioned in our written evidence that we would like to see it reflected in the performance measures as well, that there should be a measure of how many people are accessing independent advocates. Age Cymru is running a project where they're going out and talking to health providers and local authorities about the role of the independent advocate and how important it is to commission these services. So, we're hoping that that will raise awareness of the importance of the role of advocacy, with the draft strategy again saying that this is needed. We hope that that will happen, but without the proper performance measure, we're not going to know. So that would be a concern, that it's something that perhaps could easily be dropped off.

[127] **Julie Morgan:** Right. So, you'd like something put in that would ensure that happens.

[128] **Ms Lewis:** Yes. And to chart the number of people that are actually getting that advocacy service, and advocacy in care homes, independent advocacy in care homes, which is a very important area as well.

[129] **Julie Morgan:** Thank you. Anything to add to that?

[130] **Mr Rees:** No. We agree with Age Cymru's comments.

[131] **Julie Morgan:** That's fine. The other issue I think you mention in your evidence is about access for different ethnic groups to services and the fact

that there's a higher rate of dementia in some ethnic groups. Do you think this strategy is going to make it easier to reach out to some of those people at an earlier stage? Because I believe that they turn up much later in the process.

[132] **Ms Lewis:** Yes. There is strong evidence, actually, that shows that awareness is lower among BME communities. Simple things: in many languages there's no definition of the word 'dementia', so, therefore, diagnosis, awareness, and public health campaigns have to reach out hard and really make that effort to make sure that they're going into those communities and raising awareness. I'm hopeful that there's an action that—. All local authorities have to develop actions that will reach out to BME communities, and we're hopeful that we can see what these will be. There are examples of very good practice. In London at the moment, they did have a Faith in Health project, where they have trained imams to actually go into the community and talk to people and raise awareness among those families of people living with dementia. It's always an issue that people from BME communities access services later. They have less awareness of what their rights are to those services, particularly people that may not have grown up in Wales. So, I think by working with community groups, perhaps making sure that health boards have a diverse staff membership as well, there are ways to reach out. But, given the evidence around higher rates in BME populations, I think that getting rid of that stigma, raising awareness and making sure that people access services at the right time is really, really important. We are looking to see what sort of actions local authorities develop.

[133] **Mr Rees:** And on that point, something we do know is that carers in many BME communities can be particularly difficult to reach, and often need very targeted services. And our experience of support in Wales at the minute is that those targeted services, on the whole, aren't there in the areas they need to be.

[134] **Julie Morgan:** Thank you. It's very interesting, I think you mentioned that in some languages the word 'dementia' isn't there. I was going to ask you about services in the Welsh language. I don't know if I can defer to the Chair about whether there is a word for 'dementia', or whether you know, in the Welsh language. Is there?

[135] **Ms Lewis:** I don't know, but I was thinking exactly the same thing, actually. I'm not sure.

[136] **Dai Lloyd:** Well, a word in English would be a good start, because 'dementia' is another language as well, but never mind.

[137] **Julie Morgan:** Indeed. That's a very important point. So, what do you think about the services in the Welsh language and do you think that this draft Bill will improve them?

10:00

[138] **Ms Lewis:** I think there's evidence that shows that people do revert to their first language when they're living with dementia, so it's really important that those services are there. I think we would of course be looking to ensure that, where people want to access a service in Welsh, they should be able to do so. So, I think there's room for improvement there and I think that the actions in the strategy could go some way to raising awareness of that need to ensure that people can speak Welsh when they need to.

[139] **Mr Rees:** On that issue, I think that something that the strategy doesn't deal with is that providing, particularly in rural areas, a Welsh language 'breaks and befriending' service, for example, requires more resource than the very pressured social care sector currently has. I don't think that the strategy really does get to grips with some of the commissioning issues around replacement care.

[140] **Julie Morgan:** And going on to the rural areas, you feel there's not enough in the strategy in order to address issues in the rural areas.

[141] **Mr Rees:** It's things like—often local authorities commission replacement care, including replacement care for people with dementia, on an hourly rate that's flat across the local authority, for example, and it doesn't take into account where there are long travel times between calls, so that money doesn't get you as much in return.

[142] **Dai Lloyd:** Symudwn ymlaen at **Dai Lloyd:** Moving on to diagnosis ddiagnosis ac arallgyfeirio, ac mae and signposting, Angela has a gan Angela gwestiwn. question.

[143] **Angela Burns:** I just wanted to ask you about increasing the number of primary care settings that are dementia-friendly. For us lay people, could you just give us a quick overview of what you think dementia sufferers and their

carers would like to see, rather than us imposing it on them? What would they like to see?

[144] **Mr Rees:** From the carer's perspective, there are a number of actions that have cropped up in a couple of pieces of research as well as in a campaign called John's Campaign, which is, for example, around making hospitals more welcoming to carers and people with dementia. We've heard some very troubling stories about carers being kept away from their friend or family member, who they are looking after. So, we've called consistently for out-of-hours access to wards.

[145] In GP surgeries, often we—. Information is so important to the carer, but also, particularly when it's a carer of someone with dementia, it's not just one particular point they need information on—it's a journey from diagnosis to when a caring role becomes more active, to when the person loses their mobility, to when the carer's health may deteriorate. They need information at all of these points. There are things that you can do in GP surgeries like awareness raising and having the receptionist, the nurse or doctor ask the person, 'Are you a carer, do you need support?' to help signpost them to the support they need. Four out of five carers in Wales first encounter a statutory service in a community-health-based setting. So, we think it's just about that visibility and that awareness.

[146] Similarly, one of the reasons we developed the triangle-of-care model that I mentioned was because we've heard some very—. When we carried out the 'A Road Less Rocky' research, we heard some very troubling stories about carers who weren't being given information on medication changes for the person who they were caring for and on GPs refusing to share information with the carer for confidentiality reasons. So, I think that increasing the awareness of the role that that carer plays would help make that setting more carer-friendly.

[147] **Angela Burns:** Is there anything in terms of physical alterations that we should be making—more colours or pathways or anything like that?

[148] **Ms Lewis:** I think it has been raised about having colours—a yellow door to show the toilet, and I know that Sue mentioned the plates and having different coloured plates. So, I think there are guidelines that have been drawn up in collaboration with people living with dementia on what would make their lives easier. So, there are things around the built environment that can certainly, and should, be implemented. But again, it's about being

able to talk to the person. People in hospitals do have strict visiting times and we agree also that, where it's appropriate, and where people want to be with their loved one, they should be able to, particularly if that loved one has had a diagnosis of dementia, where things can perhaps become more confusing. So, we would support John's Campaign. Engage with the person, find out what the carer wants and what's appropriate for them.

[149] **Angela Burns:** Thank you.

[150] **Dai Lloyd:** Okay. Lynne, you've got the next three questions.

[151] **Lynne Neagle:** Thank you. Can I just ask for your views on whether the strategy is adequate in the number of dementia support workers it's looking to provide?

[152] **Ms Lewis:** I think there's 32 dementia support workers—and we would always call for that, as it's such an important role. I think the performance measures, just to increase the number—. So, with that set number to aim for, that's going to be hard to be achievable. It could just mean two or three and then you've achieved your target. I think there should be firm targets around how many dementia support workers there are. Don't underestimate the importance of having that single point of contact, that one person to talk you through the interface of all the different caring organisations that you might come across—with the professionals, with health and social care and the GP. People can get many calls on a daily basis and someone to help them deal with that and manage that is invaluable. So, we would like to see firmer targets around the number and an increase in dementia support workers.

[153] **Mr Rees:** I'd agree. Given the scope of the population in Wales with dementia, I'd echo the Alzheimer's Society's comments about it needing to be five to 10 times that.

[154] **Lynne Neagle:** Okay, thank you. Your written evidence says that you think a national strategic approach should be taken to funding dementia services. How do you see that looking?

[155] **Ms Lewis:** One of the problems for people with dementia is access to services and the fact that there's a postcode lottery. When Age Cymru did the work commissioned by the older people's commissioner, they talked to 60 people across Wales living with dementia, and their carers. It was quite striking and worrying, the difference and variation in what services were

available and how people talked about what they could access. So, for us, a national approach would encompass not just third sector but public sector services and some commitment and some joint working, perhaps via regional partnership boards, that they're going to look towards making sure that they iron out this postcode lottery and that there are services there that people can access. Because of course, without the services to access, the strategy is going to be meaningless. It's got to have—. Without the money behind it, that joint working between health boards, local authorities and third sector, sharing expertise, engaging with people—. There's got to be some sort of a strategic approach to try and make sure that that will happen, perhaps via the regional partnership boards looking at population needs assessments, what's there, and developing actions in response to that.

[156] **Lynne Neagle:** So, you're talking about ring-fencing as well, or is it just better regional working?

[157] **Ms Lewis:** Better regional working, I think—pooled budgets, looking at how systems can develop new services in response to demand.

[158] **Mr Rees:** I think we'd agree with that, but one thing we have been consistently talking about is that we do think there needs to be national investment in breaks and respite and replacement care to support the health and well-being of carers.

[159] **Lynne Neagle:** Okay, thank you. And just finally, the document says that health boards and local authorities will work with local communities and third sector organisations to encourage them to open up their services so that people with dementia and their families and carers can participate. You've asked for clarity on that. It does seem a bit of a strange thing to say. Can you just expand on that?

[160] **Ms Lewis:** Yes, sure. I think there were two points around that. It was evident that people had been turned away from more generic services at the moment—I imagine that that evidence is there. So, moving on from that, in principle, I think, yes, that's a good idea, to make sure that people with dementia aren't turned away from generic services and befriending services. Anything that's going to encourage an all-inclusive approach is to be welcomed. Our concerns as well would be where these services are being withdrawn. I think we mentioned in the evidence that, in Swansea, the befriending service that has been running for 10 years is due to end now, in 2017. Our concerns would be, as the services are diminishing: how will

opening up these services benefit people living with dementia? It's a real, real concern for us that these community services aren't really there.

[161] **Mr Rees:** I was just going to say that I agree. And actually, with our network partners—our local services operators—they're all under tremendous financial pressure at the minute. That has included, in the past few years, a couple of services having to close and the language about 'opening up' services to groups suggests that there's unused capacity in the third sector and I'm not sure that that's the case.

[162] **Lynne Neagle:** No, okay, thank you.

[163] **Dai Lloyd:** Rydym ni nawr yn **Dai Lloyd:** We will move on to the troi at yr adran yn y strategaeth section of the draft strategy relating ddrafft sy'n ymwneud efo gofal to care in hospitals. Angela. mewn ysbytai. Angela.

[164] **Angela Burns:** Thank you. Could you tell me what you think we should mean by 'dementia training for hospital staff'? What should that achieve?

[165] **Mr Rees:** From our perspective, we think the training for hospital staff should include a self-assessment of what policies are in place to support carers of people with dementia, as well as include training on what the needs of carers are and how hospital staff can support and involve carers meaningfully, to avoid circumstances where carers are shut out and are not getting the information they need. For example, if hospital staff were able to signpost a carer to information and advice when they needed it, that would be tremendously beneficial. The evidence is really clear that if you support the carer it means the person with the care needs stays at home for longer and stays healthier and more well as well.

[166] **Ms Lewis:** I think the strategy mentions the good work framework and I think within that there are clear guidelines. I think it's quite a robust learning and development framework. So, I think we would welcome staff being trained using that resource.

[167] **Angela Burns:** I think what I'm trying to drive at is that we use the words 'strategy' and 'policies' and 'guidance', et cetera, and they're valuable and really easy. But I had cause to spend a substantial amount of time on various wards not so long ago and I was horrified—absolutely horrified—by the numbers of people with dementia and by the absorption and difficulty of

managing them. I saw very, very frightened people; I saw very, very aggressive people; I saw members of staff really struggling to cope; I saw members of staff actually having to do nothing but look after people with dementia to the detriment of others; and I also saw some acts of absolute pure compassion that were uplifting. I'm trying to figure out what it is we physically actually need to do in a hospital to make a hospital setting a safer, kinder and less chaotic place for somebody with dementia, especially when you read the research that says if somebody has dementia at this sort of level and they're committed to hospital for a while, their dementia will substantially increase. What we obviously want to do is to be able to try to minimise that increase, so that they can come back out to their homes and carry on for as long possible. So, I'm just looking for something that's a little bit more tangible.

[168] **Ms Lewis:** I take all your points on that and it is a daily reality that on wards in Wales today there will be people with dementia. That's something that the NHS has to develop its response to and how it's going to ensure these people get the care that they need. There are very good volunteer schemes where people can go and train volunteers.

[169] **Angela Burns:** Could you name one because we're looking for tangible evidence?

[170] **Ms Lewis:** Age Cymru Gwent do a Robins scheme. I can send you information on that.

[171] **Jayne Bryant:** I could wax lyrical about the Robins scheme.

[172] **Angela Burns.** Brilliant. [*Laughter.*]

[173] **Ms Lewis:** Yes, you visited it, didn't you?

[174] **Dai Lloyd:** But not now, Jayne. [*Laughter.*]

[175] **Ms Lewis:** So, that's one. I know that the Royal Voluntary Service have hospital volunteers in hospitals. So, that's something that can be looked at, and the guidelines around care and the carers being involved in the care as well. For some people, they might welcome that respite when a loved one is in hospital, but for others they want to be there, they want to be able to help, so it seems very odd. Actually, my dad had dementia for three years and I spent a whole day with him in A&E, looking after him when he was unwell,

but as soon as he went on to the ward I was told to leave. That was scary for him as well. It's that cut-off: 'Sorry, he's been admitted. I'll see you later.' I think there needs to be some real rethinking, bearing in mind the numbers of people with dementia on the wards, how this is going to be—. I accept all your comments. It needs to have a real rethink.

[176] **Angela Burns:** Yes, thank you.

10:15

[177] **Mr Rees:** On that point about the carer and the access, we know that social continuity helps to maintain the dementia at that level, as you said, rather than letting it escalate. So, by allowing the carer access to provide that social continuity, it can reduce the anxiety and help maintain the wellness of the person. But also, I think, something that we have found—there was a piece of research that found that where there is a carer, when there's a delayed transfer of care, in 63 per cent of cases, it's problems with the carer that cause the delay in the transfer of care. So, by making sure that the community social care support's in place, it means that that person can leave the ward earlier and then is less likely to experience the detrimental effects that staying in hospital with dementia can have.

[178] **Angela Burns:** And a real quick follow-up: do you have the same issues with carers having access to people in care home settings or are they a bit more flexible?

[179] **Mr Rees:** That's not something that's come up in our work.

[180] **Ms Lewis:** I think it is a little bit more flexible; it depends on the care home, but there certainly are care homes that still do have the two to four hours. My belief is that it's going towards a much more flexible approach and you can go in. Good practice would mean you could go and help with the meals and sit and help your loved ones eat and change perhaps or what's appropriate, you know.

[181] **Angela Burns:** So, do you think the draft strategy actually will give carers access to their loved ones in hospitals?

[182] **Mr Rees:** I don't think so. When you look at the key proposed actions in the document, there's very little around access to hospitals or supporting carer-friendly policies.

[183] **Angela Burns:** Thank you.

[184] **Dai Lloyd:** Symud ymlaen i ofal lliniarol a diwedd oes, mae cwestiwn gan Rhun.

Dai Lloyd: We'll move on to look at palliative and end-of-life care and Rhun has questions.

[185] **Rhun ap Iorwerth:** Jest i'r ddau ohonoch chi. Rwy'n gwybod bod Age Cymru wedi dweud yn y dystiolaeth ysgrifenedig eich bod chi'n credu y dylai pobl allu marw lle y maen nhw'n byw. Mae'r Alzheimer's Society hefyd wedi dweud rhywbeth tebyg. A oes gennych chi ragor i'w ddweud wrthym ni ynglŷn â beth yn union y dylem ni ei glywed yn y strategaeth derfynol ynglŷn â'r pwnc yma?

Rhun ap Iorwerth: For both of you. I do know that Age Cymru has said in its written evidence that you believe that people should be able to die in their place of residence. The Alzheimer's Society has also said something similar. Could you tell us a little more about what you'd like to see in the final strategy in relation to this?

[186] **Ms Lewis:** I think there is very good wording in the strategy around end-of-life care and the need to ensure that professionals, healthcare workers are trained to make sure they have those difficult conversations with people and with carers about their end-of-life care. Never underestimate the value of that. I think the point that we've picked up on particularly was around end-of-life care for people living in care homes. A lot of people with dementia will end their life in care homes, and it's ensuring that they are also well prepared to allow people to end their life within that care setting, instead of what I think happens in reality is that when someone gets ill or looks like they're getting very unwell, an ambulance is called. I think there's got to be a rethink in care homes around, you know, 'Let's really work together to make sure that we become a place where people can end their lives as well', instead of the default option being to ring that ambulance. Really, it's passing the buck, isn't it? We welcome a lot of the content of the strategy around end-of-life care—there was a really strong report about dementia care by Marie Curie—but for me, that little bit is missing. *[Inaudible.]*

[187] **Mr Rees:** Just to add to that, until recently there was a very good piece of work in Swansea called SPice—the Swansea palliative intermediate care team—which was the local authority, third sector and health working together to make sure people could die in their place of choice—of their own

choosing.

[188] **Rhun ap Iorwerth:** What was it called again, just to make sure we've got it?

[189] **Mr Rees:** It was called SPice, which I can send a note to the committee on.

[190] **Rhun ap Iorwerth:** And that's something that offers up an example of good practice that could be rolled out in other parts of Wales, with the guidance of the strategy, you think.

[191] **Mr Rees:** Yes, absolutely. I think it had some very strong evaluations. But also it was a good piece of work in terms of local authorities and health working together to provide people with the situation they wanted.

[192] **Rhun ap Iorwerth:** What was the key thing that that strategy got right?

[193] **Mr Rees:** I think it was having open lines of communication, and it involved a replacement care provider, so that the local authority would make sure that there was the homecare to support the person as well, once they'd come out of hospital.

[194] **Dai Lloyd:** Ocê. Jayne efo'r **Dai Lloyd:** Jayne has the next two
ddau gwestiwn nesaf. questions.

[195] **Jayne Bryant:** Kieron, you mentioned earlier that for people with dementia and for carers it's actually a journey. Can you just expand a bit on that, and do you think that the draft strategy will contribute to the provision of better support for carers for people with dementia?

[196] **Mr Rees:** We were really pleased to see how many mentions of carers there are throughout the strategy, but then that seemed slightly at odds with the commitments that were made in the actions and the performance measures, of which, I think, only one relates directly to carers. We also felt that the strategy didn't reflect that journey, and actually doesn't engage with the 10 or so points, where some of the circumstances changed throughout caring for someone with dementia. So, I think what we'd like to see in the strategy would be recognition about the provision of information, and that's kind of tied up with awareness among healthcare professionals of the role of carers and how they can be signposted. And I think, in terms of that support

the carers need, we'd also like to see more around replacement care respite breaks, because the only real commitment there is to investigate a national respite scheme, which we very much welcome and we called for it—we've been calling for a carer well-being fund over the past 18 months—but that can only be a piece of the puzzle really.

[197] **Jayne Bryant:** Definitely, and as you said, people with dementia—the carers can start off in one position but it's that support throughout the disease, that I think they need as it gets further on—

[198] **Mr Rees:** And especially with the fact that their own health or circumstances may change.

[199] **Jayne Bryant:** That's the crucial point, isn't it? Because a lot of people are caring for loved ones with dementia, and if their health deteriorates, then that puts those people—perhaps it ends up in people going to hospital. And you feel there's not enough in here about that.

[200] **Mr Rees:** And we've heard examples in Cardiff of where the carer has become unwell, and then both have to go into hospital. Obviously, as well as the health and well-being implications of that, there are the financial implications as well.

[201] **Dai Lloyd:** Lynne's got a supplementary just on this point.

[202] **Lynne Neagle:** I just wanted ask Kieron: have you got any evidence that the raising of eligibility criteria is meaning less access to respite care for families?

[203] **Mr Rees:** So it's still very much early days in terms of the impact that the eligibility criteria are having. We did a series of workshops with social workers in September and October, so about six months into the Act. And I think we talked to around 100 social workers, and what was coming through was just how mixed it is at the minute. So some social workers were telling us there's been a real increase in people requesting assessments because it's filtered through that they have the right to an assessment. But then we also heard, for example, that one local authority and the social workers were under the impression that if there's something in the community, then the local authority can't offer any assistance, which is actually quite a misinterpretation of what the regulations say. So we're interested to see, perhaps one year in, where things stand.

[204] **Dai Lloyd:** Jayne.

[205] **Jayne Bryant:** Just to follow up on that. Age Cymru stated in the evidence—Rachel stated that—with no mechanism to monitor the impact and delivery of the carer support plan, an increase in the number of plans is meaningless. Perhaps you could expand a bit on that, and also talk about the effectiveness of the performance measure.

[206] **Ms Lewis:** I think that's an issue for us across the performance measures—increase the number. Well, increasing the number doesn't tell us how that's impacting on the older person. Our concern is how this is going to improve lives for older people. Increasing the number of carer's assessments could be meaningless if it's just someone going in, having a five-minute chat and writing, 'I've done that'. And that does happen; we've heard of that happening. So, for us, we'd want more monitoring and evaluation and going back to that person, saying, 'Okay, so what's happened, what's changed for you? How has this improved your daily life, your ability to be with that person and care for that person?' So, just increasing them is not going to have that really quantifiable impact that we would like to see.

[207] **Mr Rees:** And on the carer's assessments measure, it's not even increasing the number of carer's assessments carried out, it's increasing the number of carer's assessments offered, which means you don't know if those carer's assessments are then being carried out, and once they're carried out whether the actions contained in them are actually happening. So we'd agree that we'd rather focus on what's the impact of this on the carers themselves, particularly as, given there's a statutory duty on local authorities to offer a carer's assessment to a carer, I'm not sure that measuring the increase in that happening means that much, because this should be increasing anyway.

[208] **Dai Lloyd:** Caroline Jones sydd **Dai Lloyd:** Caroline Jones has the
â'r cwestiwn nesaf. next question.

[209] **Caroline Jones:** Diolch, Chair. When caring for people suffering from dementia, staff need to be confident that they've had sufficient training in order to deal with any eventuality, really. What are your views on the draft strategy for improving the training of people working in dementia services?

[210] **Mr Rees:** We welcome that the strategy talks about increasing the

training, and the section on public awareness as well, but I think what is absent is, again, that point on the role of the carer and how to involve the carer meaningfully. We know that half of all carers of people with dementia struggle to get their friend and family member a diagnosis. These are the people who know the person best and know when something perhaps isn't quite as it used to be. I remember reading about one person who said that the GP had asked the person with dementia a question about, 'When did your symptoms start?', and they responded, 'Seven months ago', whereas, if they'd spoken to the carer, it was that morning that the symptoms had started. That's where involving the carer can really help get clarity and get that diagnosis quicker.

[211] **Ms Lewis:** We would say that dementia training is crucial to understand how you can work with the particular the needs of the person with dementia—it's understanding that no two people are going to be the same. You need to engage and find out a bit about the person, their history and particular needs. People making appointments in doctors' surgeries all need to understand the challenges that can face someone living with dementia on a daily basis so that they can react appropriately when, perhaps, an appointment is missed, or someone turns up too early or someone turns up too late—for us, that's all crucial. But, looking again at the commissioning of services, are those people who are delivering and commissioning services, are they trained? Are they really able to deliver that domiciliary care, perhaps going into the home of someone with dementia with no knowledge of the illness? That, for us, would raise a red flag, so we think training is really crucial, but it's got to be very widespread.

[212] **Caroline Jones:** Yes, I agree. Thank you very much.

[213] **Dai Lloyd:** Y cwestiwn olaf i **Dai Lloyd:** The final question comes from Dawn.

[214] **Dawn Bowden:** Thank you, Chair. Just two short questions to finish: I don't think either of you specifically referred to this in your evidence, so I'd just be interested to know whether you think that oversight of the delivery of the strategy by the delivery assurance group is the most appropriate way to deliver this, and, if so, if there's anything else that you'd like to see in that.

[215] **Ms Lewis:** I think that's okay, but I think we would ask again that it involves people with dementia within that group and that third sector expertise is called upon—so, perhaps that group but broader. We'd be

looking at what that group comprised—who was on it—and we would expect to see a really representative group there.

[216] **Mr Rees:** I'd agree and, again, I think what it comes down to for us is to make sure that the performance measures and the actions in the strategy are right to begin with so that you're scrutinising the right things.

[217] **Dawn Bowden:** Okay, that's fine. Can I just pick up on something I think you said earlier, Kieron? You talked about a reference to unused capacity—in your experience, it just isn't there. What do you think, then, is the likelihood of there being capacity both in the NHS and the social care sector for the delivery of the strategy?

[218] **Mr Rees:** I think, in terms of social care and replacement care, it'd be a real struggle, particularly when you look at that the things that someone with dementia needs from social care are often more expensive per se than otherwise. So, you want to try to make sure that they're having the same person going into the home—providing that continuity and providing the extra training to make sure that they're aware of how best to interact with and support someone with dementia. Unfortunately, we're seeing a situation where the costs of delivering social care are increasing—the statutory costs—so, pension auto-enrolment, the scrutiny of travel times as well as inflation, but what's not increasing, and is actually decreasing in almost every local authority, is the per hour amount that local authorities are funding providers of social care. For us, until those sorts of issues in commissioning are tackled, we're not going to see social care meeting the needs of people and carers generally, but including the carers of people with dementia.

10:30

[219] **Dawn Bowden:** So, it's the gap in social care that's the big concern, really, for delivering it.

[220] **Mr Rees:** For us, yes, and I think that, when you look at the role social care plays in keeping carers well and healthy, and keeping people out of hospital, it's one of the fundamental things in keeping people at home and well for longer that the strategy talks about.

[221] **Dawn Bowden:** Sure. Okay.

[222] **Ms Lewis:** I would agree with Keiron's concerns. The one thing I will

hope, or one thing I sense, is that there is a real will to change now. There is real will among healthcare professionals to make these improvements. So, I hope the draft strategy will drive that change. Obviously, without the funding allocated to it, it's going to be increasingly very difficult to achieve, with the problems with social care, but we hope that where there's a will, there's a way, and having a draft strategy there and some sort of vision that people will be able to see, and make the changes that they are able to—. But without the funding behind it, we have got real concerns.

[223] **Dawn Bowden:** Okay. Thank you, Chair.

[224] **Dai Lloyd:** Diolch yn fawr. **Dai Lloyd:** Thank you very much. That Dyna ddiwedd y cwestiynu. Felly, brings us to the end of our dyna ddiwedd y sesiwn dystiolaeth questioning, and so to the end of this yma. A gaf i ddiolch yn fawr iawn i evidence session. May I thank you chi'ch dau am eich tystiolaeth both very much for your evidence, ysgrifenedig a hefyd ar lafar y bore both written and orally this morning? yma? A gallaf i bellach gyhoeddi y May I therefore tell you that you will byddech chi'n derbyn trawsgrifiad o receive a transcript of this part of the ran yma'r cyfarfod er mwyn i chi meeting so that you can confirm that gadarnhau ei bod yn ffeithiol gywir? it is factually accurate? So, thank you Felly, diolch yn fawr iawn i chi, ac a very much, and may I tell Members gaf i gyhoeddi i fy nghyd–Aelodau y now that we'll have a short break till cawn ni egwyl fer nawr tan 10:40, 10:40 when we will return to confirm pan ddeuwn ni nôl i gadarnhau'r the questioning for the next two sessions? So, that's 10:40. Thank you Felly, 10:40. Diolch yn fawr. very much.

*Gohiriwyd y cyfarfod rhwng 10:32 a 10:48.
The meeting adjourned between 10:32 and 10:48.*

Ymchwiliad i Strategaeth Genedlaethol Ddrafft Llywodraeth Cymru ar Ddementia—Sesiwn Dystiolaeth 3—Coleg Brenhinol y Seiciatryddion a Choleg Brenhinol yr Ymarferwyr Cyffredinol
Inquiry into the Welsh Government's Draft National Dementia Strategy—Evidence Session 3—Royal College of Psychiatrists and Royal College of General Practitioners

[225] **Dai Lloyd:** Bore da. Croeso i'r **Dai Lloyd:** Good morning. Welcome drydedd sesiwn dystiolaeth am y to this third evidence session this

bore. Fel y bydd gwrandawyr cyson yn ymwybodol, hwn ydy ymchwiliad y Pwyllgor Iechyd, Gofal Cymdeithasol a Chwaraeon i strategaeth ddrafft cenedlaethol Llywodraeth Cymru ar ddementia. Fel rydw i wedi crybwyll eisoes, hwn ydy trydedd sesiwn dystiolaeth y bore. O'n blaenau ni rwan mae Coleg Brenhinol y Seiciatryddion a hefyd coleg brenhinol y meddygon teulu. Felly, croeso.

[226] Rydym ni wedi derbyn gwybodaeth, tystiolaeth ysgrifenedig, gennych chi, felly diolch yn fawr iawn am hynny. A gaf i groesawu Dr Victor Aziz, cadeirydd cyfadran yr henoed yng Ngholeg Brenhinol y Seiciatryddion yma yng Nghymru, a seiciatrydd ymgynghorol yr henoed ym Mwrdd Iechyd Lleol Cwm Taf? Bore da ichi. A hefyd, a allaf groesawu hen ffrind, Dr Jane Fenton-May, o goleg brenhinol y meddygon teulu? Bore da, Jane. Rydym ni wedi darllen y papurau gerbron. Awn ni'n syth i mewn i gwestiynu, gan gofio nad oes gennym drwy'r dydd, yn anffodus. Mae amser ychydig bach yn dynn ac, felly, i'r perwyl hwnnw, fe wnaif i ofyn i Julie Morgan agor y cwestiynau.

[227] **Julie Morgan:** Thank you. Good morning.

[228] **Dr Aziz:** Good morning.

[229] **Dr Fenton-May:** Good morning.

[230] **Julie Morgan:** The first question I wanted to ask was: how do you feel

morning. As our regular viewers will be aware, this is the Health, Social Care and Sport Committee's inquiry into the Welsh Government's draft national strategy on dementia. As I've already mentioned, this is the third evidence session this morning and, before us, we have the Royal College of Psychiatrists and also the Royal College of General Practitioners. So, welcome to you.

We have received your written evidence, and thank you very much for that. So, may I welcome Dr Victor Aziz, the chair of the old age faculty of the Royal College of Psychiatrists in Wales and a consultant psychiatrist in Cwm Taf Local Health Board? May I also welcome my old friend Dr Jane Fenton-May, from the Royal College of General Practitioners? Good morning, Jane. Now we have read the papers that you've sent us, so we'll move straight into questions, bearing in mind that we don't have the whole day, unfortunately. Time is a little tight and, therefore, I will ask Julie Morgan to begin the questioning.

that the provisions in the Bill will be equitable in order to deal with people from different groups, such as issues to do with sexuality, disability and ethnicity? Do you think the provisions in the Bill are sufficient to ensure those groups are reached?

[231] **Dr Aziz:** For me?

[232] **Dr Fenton-May:** Do you want to start?

[233] **Julie Morgan:** Either.

[234] **Dr Aziz:** Anyone?

[235] **Julie Morgan:** I don't mind.

[236] **Dr Fenton-May:** Please help yourself.

[237] **Dr Aziz:** Okay. Thank you for inviting us. I think the principles generally are welcomed. However, in our submission we did say that it doesn't really meet everyone's needs. We did say that there needs to be an emphasis on different groups, in our submission, that, actually, you feel it's like I'm mentioning it without meaning it. So, we want it to be meaningful to those minorities and in groups like the prison service—lots of groups were mentioned. Actually, they are not really properly mentioned in the document. But, if I may, I think it's very nice to have a strategy. It's very nice to have an overarching document, but, at the end of the day, we are dealing with individual patients. I believe that the needs of that individual patient need to be the most important in this document regardless of where they are. I think that that's a bit missing. So, individual needs are different from one patient to the other. Individual needs are different—as we were talking earlier—from one valley to the other. The population needs are different in different areas. That's really the most of what we deal with. It's about patients and carers. There is emphasis, for example, on ethnic groups and carers, but, actually, there's not that much emphasis on them. How are we going to support them? How are we going to become meaningful to provide and meet their needs? That's a very important thing that, actually, we need to emphasise more in the document.

[238] **Julie Morgan:** Thank you.

[239] **Dr Fenton-May:** I would agree with that. I did put an example in there

about—. I used to work in Butetown—I retired a couple of years ago—as a GP. We used to have link workers in the Butetown health centre who, if you could get hold of them, were really good at translating, particularly for our elderly Somali population. But actually getting them to come on home visits was difficult, and the service was cut. They were mostly going into secondary care and supporting patients going to appointments.

[240] Now, with anybody who has dementia, things that are learnt more recently are forgotten. So, even if these people have learnt English or Welsh, they're more likely to forget that, and so caring for them is very difficult and they need the one-to-one support and care in the languages that they understand. We've got other populations. We've got an increasing, large Polish-speaking population. We've got lots of other Asian populations that speak different languages in Wales, as well as the issue about the Welsh speakers that need support in Welsh because that is their first language. So, they're not necessarily looked after.

[241] It's not just the medical bit; it's much, much more important to get that social care input. Because, if you're put into a care home and you don't understand anybody that's talking to you, that is difficult. Actually, for our English-speaking population, and for some of the care homes, it's very difficult because the population of carers are not necessarily very good at speaking English. So, we need to address some of those issues around language. I haven't got any summations, but I'm just highlighting that it is difficult, and it is particular for the demented group of patients because they lose the tolerance to cope with the difficult-to-understand person that's trying to support them, because they haven't got very much tolerance sometimes anyway. That escalates then into behaviour problems, and then we're into the realms of thinking, 'Oh, what are we going to give these patients?', and somebody comes up with a wonderful idea of giving them antipsychotics, which basically is a medical clubber, so—

[242] **Dai Lloyd:** Don't worry; we've got questions on that later on. [*Laughter.*]

[243] **Dr Fenton-May:** I'm sure you have, but I brought them up there.

[244] **Dr Aziz:** Can I add something relevant there as well? It's not just about the language; it's the culture. And, again, I'm not talking about just us or healthcare or social care, or even in schooling, because if you don't understand the culture from, really, education upwards, work and all sorts of

things, you're actually going to misinterpret a lot of the problems. I think our medical schools—for example, our training—doesn't really—. We used to, at some point, emphasise the doctor–patient relationship and would say it's triangular, because of the family and that cultural background. If you don't understand, you are going to misperceive a lot of things. That's also a bit missing there.

[245] **Julie Morgan:** I think you've both made the point very strongly that you feel there should be more emphasis in the strategy on these issues.

[246] **Dr Fenton–May:** Can I just come back to some of the other issues? We've talked about ethnic people. I think some people who have physical and mental health problems get a rough deal, so that's really—. That was your question, sorry. Because they neither fit easily into the physical problems or the mental health problems, and people push the wrong—. You know, they fall in-between, and I think there's a big issue about people who have got different—. The trans population and things like that, because they find it much more difficult sometimes, or the carers find it much more difficult, to interact with them, and they then perhaps have difficulty receiving the support that they feel is—.

[247] **Angela Burns:** Sorry to cut across there; I know we're tight on time, just to extrapolate that slightly more, do you think that, in this draft strategy, there's enough mention made of people with learning disabilities and mental and physical health disabilities? Julie's really identified one particular group of people who need protection and help. Do you think that there might be a sense that dementia is seen as a mental health issue, which is why it's not being pulled out separately?

[248] **Dr Aziz:** I think we need to be a bit careful there because dementia, for example—I'm talking as a psychiatrist—is about 50, 60 per cent of the work of old-age psychiatry. And again, in our training, we put a lot of emphasis on the integration between physical and mental health. And one way forward—. I had the luxury of rewriting the curriculum of old-age psychiatry that is going to be submitted to the GMC in March and, actually, we put black and white targets in the curriculum to meet physical health needs, chronic conditions, end-of-life care, palliative care, because we are saying that the way forward is about proper integrated care. There is mention of integrated care, but, in Wales—I looked at the UK and Welsh Governments; all sorts of things, actually—there is a lot about integration, but it hasn't happened. So, in health boards, there is still a bit of disparity between

primary and secondary care. There is a bit of a problem between secondary and secondary care—‘That’s your patient; that’s my patient’, although they are in the same hospital.

[249] So, I think there is a lot of work to be done about integration, and, if we’re really talking about proper integration, it means we are all one team. And, sorry to say, it needs to come from the top down. So, we haven’t integrated, not just in health—we haven’t integrated properly between social and health. So, we are still talking about these things, but we actually haven’t implemented it properly. So, there are issues, and the solution is there; it’s just how people can link together, how people can work together. It’s not a competition. Coming back to my point about the patient being at the centre, we are missing that, while putting in lots of boundaries. Even by funding things, we’re creating boundaries. It needs to be meaningful.

[250] **Dai Lloyd:** Okay. Julie, your second question.

[251] **Julie Morgan:** Yes, I was going to ask you about rurality and how you think—. I mean, do you think the provisions for coping with people in rural areas are adequate in this strategy?

[252] **Dr Aziz:** I think there are two issues. One, we are missing the workforce intelligence. There has been a lot of work done in Wales about workforce intelligence by the Royal College of Psychiatrists. And, again, rural areas are being affected because we are not really thinking about them. ‘What is the incentive for me?’ I don’t mean any negative thing, but we are actually advertising for new GP trainees to come, we pay them more, and we say, ‘You’re not going to do on-calls’ and these things. So, actually, there is an incentive to come, but we’re not giving the same incentive to nurses, to social workers, to medics, to anyone, to cover rural areas.

11:00

[253] And, again, the second point in helping the situation is how we can encourage local people locally to stay local, because, again, we want to increase the retention that is not happening now. So, it’s not just about recruitment; we’re not retaining the staff in the rural areas, which is another problem adding to the workforce problem.

[254] Culture—we are very often now in the blame culture. I was talking to one of the senior nurses yesterday as a matter of fact, and I said that every

little thing now is registered as a complaint when it's not a complaint, so the staff feel really very defensive. Rather than say that, we need to change to, 'How can we support you?', 'How can we develop you?', 'How can we make you perform better in a supportive way?', 'Don't worry about that mistake, we all make mistakes.' And when people feel that, maybe the issue about rural areas is going to be recovered by encouraging those people that, actually, they are valued.

[255] **Dai Lloyd:** Ocê. Mi wnawn ni symud ymlaen achos mae yna nifer o'r rheini yn dilyn mewn cwestiynau sydd i ddod. Mae Rhun yn mynd i ofyn y cwestiynau nesaf. Mae'r rheini'n rhannol wedi cael eu hateb hefyd.

Dai Lloyd: We'll move on because a number of those issues are covered by subsequent questions. Rhun is going to ask the next questions, which have partially been answered.

[256] **Rhun ap Iorwerth:** Ydy, wel, yn sicr gennych chi. Tybed a fydden ni'n gallu cael sylwadau y coleg meddygon teulu ynglŷn â'r agenda integreiddio rydym ni wedi bod yn ei drafod yn y fan honno, a'r pwysigrwydd o sicrhau integreiddio rhwng gofal iechyd a gofal cymdeithasol, er mwyn rhoi i ni'r llwybr gofal cyflawn yna y mae cleifion ei angen.

Rhun ap Iorwerth: Yes, certainly by you. I wonder if we could have some comments from the Royal College of General Practitioners on the integration agenda that we've been discussing there, and the importance of ensuring integration between healthcare and social care, in order to provide us with that full care pathway that patients need.

[257] **Dr Fenton-May:** I think it's really important that we do get some sort of integration, but, at the moment, I think the biggest problem is the different silos that the funding is in. So, currently, if somebody's regarded as needing care as opposed to healthcare, there's a big fight that goes on over the patient, about, 'I don't want to pay this; I haven't got enough budget to cover this patient'. So, we need to integrate it, we need to smooth it out. And, in some areas, there has been drawing together of people. I think in the Gower they've got a unit that has got social care and nursing care going to visit people to try and keep them out of hospital, and I think that's working quite well, and they've pooled their budget and things. But it needs to be done on a localised basis, and it needs to cover the whole of social care.

[258] In general practice, for example, we see people from small children to

old people, and, if you pick up the phone because there's an issue about social care, can you get the right social worker, because there's a psychiatric one, and there's an old people one? And if they're two weeks off their birthday, they fall into a different bucket. It's really difficult, and nobody will see them until they do that. So, we need to take away those barriers to care, and, as I say, that helps with people who've got physical and mental problems as well.

[259] **Rhun ap Iorwerth:** What can this strategy do though, because I think we're all probably frustrated here about the lack of integration between health and social care? Sadly, I doubt that this dementia strategy is going to be the answer to the whole integration agenda, because it's not just about dementia; it's about the whole health and care system. What can this strategy do, either to propose specific reconfiguration or to direct the implementation of best practice? What might that be in this specific strategy?

[260] **Dr Fenton-May:** I suppose if you did get the budgets coming together for these workers, some of them could be—. You know, we have healthcare assistants. They could equally be working for social care as opposed to qualified nurses. Yes, you need the qualified nurses, but we need that broader base of workers that support the professionals, both social workers and health workers. And the budgets need to be combined and unified somewhere—and there isn't any mention of that, because the trouble is that the councils are having their budgets squeezed and so they want to draw in and reduce the amount of provision of social support for patients.

[261] **Rhun ap Iorwerth:** And this pooling of budgets is something that's coming through in other pieces of evidence. Do you have anything additional to add on that?

[262] **Dr Aziz:** That's absolutely essential to remove this competition, but there is something else very important. Again, there are so many competing—something we're talking about as well—targets in Wales and very often, there are so many competing policies. We just mentioned that recently I made some comments about the primary care inquiry, but hang on, there is primary care there and dealing with dementia is still part of that. Why is there no link? Why is there no link with the social care Bill? Why are we having so many competing targets that are actually taking me away from looking after the patient, taking the nurses away from looking after the patient, and becoming a tick-box exercise? We all measure how many care treatment plans we complete, but we are not really looking at the quality of what we

provide. So, all of these targets are taking us away from patient care. So, we need longer-standing policies that become sustainable rather than keep changing every two years—move the target and move something else. We need to have the same focus, I think.

[263] **Rhun ap Iorwerth:** Okay. A quick response each perhaps on another target, which is important. We have picked up as a committee, I think, a frustration about the target in terms of increasing diagnosis rates in Wales. We're low now. The draft strategy talks about increasing at a rate of 3 per cent annually. We're hearing lots of people saying that we should be aiming higher. What are your thoughts?

[264] **Dr Fenton-May:** My concern is that some patients who have obviously early dementia do not want to be labelled with that because of the implications for all sorts of reasons. What is the point of giving them a label if we can't give them any care and support, because, you know, you give them a label and they say, 'What are you're going to give me, doc, to help me?', and you say, 'Well, you can go to the clinic and they might give you a diagnosis'? And there'll be very limited care, particularly in those early stages. At the moment, we haven't got magic wands for improving people's memory loss. We've got various things that we can do to help support them, but they don't necessarily need the diagnosis of dementia.

[265] **Rhun ap Iorwerth:** So, diagnosis isn't that important to you in terms of something that we should be—

[266] **Dr Fenton-May:** It is important in some ways because at some stage they do need that label so that they can get the support, but for some people in the early stages, it may be that they're just really anxious and they've got a bit more memory loss and there's that blurring of dementia with other anxiety memory loss things. We all forget things more as we get older, but we're not demented so that it's difficult. Once somebody's got proper dementia, then they need that diagnosis and they need the package of care, but a lot of people in the early stages say, 'Well, I'm just a bit forgetful', and they don't want a label. And you can't force them to have a label.

[267] **Dr Aziz:** I'll be very brief. I think the term 'diagnosis' is important. Timely and appropriate and accurate diagnosis is really, really important. It's very important for that diagnosis to be done by a specialist who is able to make that diagnosis. One of the sayings in the dementia strategy is that a dementia assessment must be completed by a suitably competent

professional. Who's that? Who can make that diagnosis appropriately? Are we talking about an appropriately trained specialist like a psychiatrist or are we talking about an assistant healthcare professional? So, that's really very important. On the other hand, the strategy is actually about specialities or specific speciality services.

[268] **Rhun ap Iorwerth:** Are you as sanguine as the general practitioners about the need, as we hear from other witnesses, to push up diagnosis rates?

[269] **Dr Aziz:** It can be done, but it's about how we're going to do it and who has got the confidence to do it. For example, one of the ways, in my heart, I wanted to do it is—. For example, in Wales, there are clusters, and I said, personally, I would be more than happy to have a clinic in a cluster, so that, actually, we're all working together and we're all supporting each other. Geriatricians very often refer to us rather than just making the diagnosis. Neurologists very often refer to us. How can we encourage all these people, all those professionals who are specialists in their field, to make that diagnosis, to have that confidence? It's not about the 2 or 3 per cent, it's about having that confidence and those appropriate skills in making that diagnosis. If we do that, automatically the rate is going to go up, but if we just push it as a target, it may not work.

[270] **Rhun ap Iorwerth:** Okay, thank you.

[271] **Dai Lloyd:** Okay. Lynne, on this point.

[272] **Lynne Neagle:** Are you saying, Dr Aziz, that there's a risk then, with the strategy worded as it is, that we could get inappropriate people providing diagnosis.

[273] **Dr Aziz:** I have waited, for some patients—which is actually frustrating for them—two years to make a diagnosis. Why? Because they didn't fit in. In the last two years, I've had four patients who did not fit in any box—four younger onset dementia—and I had to diagnose unspecified dementia. All sources of investigation, including genetic testing, came back as negative. So, clearly, they are dementing, but actually—. Sometimes people want to say vascular or Alzheimer's, but that's not the most important thing. You still need to meet that individual—

[274] I've had neurologists quickly diagnosing Alzheimer's disease but, when the brain scan comes, it's very, very vascular, and I've had to go back

to the patient—it's actually a wrong diagnosis. Those are the appropriate skills that we are trained for for years. If you're making a quick, inappropriate diagnosis—. You're talking about people. I've had to, unfortunately—. If you see younger onset dementia, people have to leave work, stop driving—they have families—. Financial problems—some have lost their houses because they couldn't afford the mortgage. Transport, housing, all sort of things—. That's a complex thing to deal with. Unless you are a specialist or have those skills, it's going to be very inappropriate.

[275] **Dai Lloyd:** Okay. Time is marching on now, team, and there's several questions. Short questions, short answers—young Jayne.

[276] **Jayne Bryant:** Thank you, Chair. Dr Aziz, you've mentioned some of the issues for primary care in terms of identifying people who may have dementia. Perhaps you can talk a little bit more about managing that and providing treatment for them and the challenges they face. Also, in your evidence, there's a recommendation that all hospitals and primary care settings should achieve dementia-friendly status by 2021. Perhaps you could say a little bit more about that.

[277] **Dr Aziz:** Again, I think, very often, dementia now is everyone's business. It's not that—. I'll answer the last bit first. I had a conversation with a consultant—and this is a consultant psychiatrist—who was saying, 'Actually, I have no skills; I don't know how to deal with a patient with dementia.' So, imagine the wider picture within the health and social care setting—'I don't want to deal with anything to do with dementia.'

[278] Unless you raise that profile and unless you remove that stigma among us that, actually, this is not—. With cancer, we've done it. So, now we are dealing with cancer and we have no fear of cancer. Why are we having this fear of dealing with people's dementia? So, we really need to be behind that agenda, across all of us. We need to work together.

[279] Again, talking about primary care, there is something in my mind I'm actually planning to do in tackling this particular thing—we'll talk about it. I've spoken to Cardiff University and I'm having a serious conversation with the Royal College of Psychiatrists about doing a postgraduate certificate over a weekend for healthcare professionals—about dealing with an elderly person from all sorts of aspects, about increasing awareness, about increasing the training package, and not just focused on dementia or something. It's about everything. It's about primary care—in primary care,

what are the sorts of things they deal with? It's not only the comorbidities—actually, primary care is not only the GP. Primary care is all sorts of things. In the community—the community pharmacists, the non-pharmacological, the district nurses, the health visitor, and all those sorts of people. How can we skill them to deal with those issues? And again, the focus is support. If we don't work together, we're not actually going to achieve anything; we're still going to be talking. So, really high on my agenda is how we can work together and how we can we increase this training, without being fearful and without being intrusive, in a meaningful way.

11:15

[280] **Jayne Bryant:** Thank you. The proposed waiting time target of 28 days for a first assessment and 12 weeks for a working preliminary diagnosis—what are your views on that?

[281] **Dr Aziz:** I'll tell you something very quickly: I have no issue. But do you know how long a patient is waiting for a brain scan? A patient may be waiting, if you are looking for a CT scan, up to two months and the report can take one to two months to come back. If you are looking for an MRI scan—if you are GP referring it, it will take longer. If you're looking for an MRI scan, it will take longer. So, it's not about the duration, it's about what else—. We have nurses who can do the pre-screening. My personal waiting list is eight weeks, and I have—*[Inaudible.]*—19. I discharge a lot of patients because I say, 'If you want a diagnosis, I'm quite happy to give you all that information, on all the diagnoses, but what can I do? So, how can we support you? How can we support the GP? How can we provide the support that actually helps you cope?' Alzheimer's, for example—in the targets, every single one is going to have a support worker. Is that appropriate? Or a dementia adviser—whatever you want to call it—or, actually, is it about that patient's needs? They may need far, far more than just someone to give them any support, or they may need just a phone call—'How are you?' So, I think we need to think differently about that.

[282] **Jayne Bryant:** So, just on your point about the dementia support workers that you've just mentioned there, do you believe the current level of funding is sufficient to meet that? Do you think they're anywhere near the numbers that you think that—?

[283] **Dr Aziz:** It's very unrealistic. If you see the amount of patients we see. We were talking about the word 'well'. So, actually, if we are going to offer it

to every single person, we haven't got that workforce. It's very unrealistic. But also, there is another thing I'm actually going to mention specifically: advocacy. In the measure we spoke about how everyone should have an advocate—again, unrealistic. But where is the family? What is the role of the family as an advocate? What is the role of the family that we are missing in this document? Actually, they are doing everything. They have the burden. They carry the burden—they carry everything. Why are we waiting until they collapse and there is a crisis? Why? It's: 'You don't fit the criteria.' So, I think that rather than focusing on wording, it's mainly making it meaningful to that particular individual.

[284] **Jayne Bryant:** I think that's particularly powerful evidence when you're talking about the role of the family and carers. Just briefly, you've mentioned on a number of occasions in responses to others the importance of working collaboratively with others, but what do you think the value of case finding is to health boards and local authorities that they'll be expected to implement? Do you think there's any value in that?

[285] **Dr Aziz:** It's all of our job, but it's not just about dementia. As I said, a minimum of 40 per cent of our work is on depression, and, actually, diagnosing depression accurately to be able to do something about it. I have patients who are actually having a grief reaction being referred straight away. So, actually, that's normal, so, again, I think the focus of case finding is fine, but it's all our job. So, it's identifying the problem correctly and appropriately; that's the main focus.

[286] **Dai Lloyd:** Ocê. Mae'r ddau **Dai Lloyd:** Okay. The next two gwestiwn nesaf o dan law Caroline questions are from Caroline Jones. Jones.

[287] **Caroline Jones:** Diolch, Chair. Good morning. What do you think we need in hospital settings to better meet the needs of patients with dementia? And do you think that the draft strategy will address this?

[288] **Dr Aziz:** There is not much emphasis on physical health and comorbidities, and, again, one of the biggest problems in an elderly person is multiple comorbidities and the multiple medications. Who's going to be appropriately reviewing those medications? Who's going to be appropriately managing all of these conditions? Very often—. I'll give you a simple, practical example: one of my patients, who is actually currently an in-patient, has dementia—she has Alzheimer's disease—she's on medication. She had

urinary tract infections and a chest infection. She was admitted to a general hospital, and actually, in one incident there was a conflict with the nurses, and then, because of that conflict, she was detained under the Mental Health Act and she was transferred to a psychiatric ward. So, have we addressed her needs?

[289] **Caroline Jones:** No.

[290] **Dr Aziz:** No. So, just because you have dementia, doesn't mean you're not falling; doesn't mean you haven't had heart problems, chest problems or other needs that need to be addressed. So, again, there are two ways. Again, we are talking about integration, working together; it's not about shifting the patient. How many times do we shift patients from one ward to another, from a district hospital to a community hospital, to a psychiatric ward, to a nursing home, to another nursing home? Again, I think our focus is not just about targeting, it's about how we can improve that worker relationship. How can we have that patient focus?

[291] **Caroline Jones:** Yes. What about the communication between the departments?

[292] **Dr Aziz:** But, how often do we e-mail each other rather than picking up the phone? I actually spent three days fighting for a patient to be admitted with uraemia to the general site—three days. The patient stayed 36 hours in A&E—a patient who was nearly dying, just because he was labelled mentally ill, was 36 hours in A&E, with no bed, and I fought for three days. So, that's really the focus of the care. We need to really—.

[293] One of the ways forward is—. We did actually say it several times in different meetings. The Royal College of Psychiatrists' accreditation for in-patient mental health services programme actually provides a fantastic way forward, because it provides you with structure across district general hospitals, across memory clinics, across psychiatric wards. If you apply them—. We did it with electroconvulsive therapy across the whole of Wales. If we use one structure, standard, across the whole of Wales, we're going to have a better quality of care than just waiting for that person to do something different to the other person.

[294] **Caroline Jones:** Thank you for that.

[295] **Dai Lloyd:** Okay. Your second question, Caroline, because it applies to

GPs.

[296] **Caroline Jones:** Yes. On the views of the Royal College of General Practitioners on whether the implementation of the direct enhanced service is the best way to improve healthcare for care home residents. What are your views on this?

[297] **Dr Fenton-May:** I don't know what the details of the enhanced service are, so I can't make any comments about that. Ideally, we need to enable it to—. At the moment, you have to have a certain number of patients in a care home, as a GP practice, in order to qualify for it, and there are a couple of tick-box things that you have to do. But the workload involved in minding patients in care homes is great, and along with that is the education of the care home staff in how to manage the patients. So, it needs to be enhanced quite a lot, I think is the problem, in order to make it effective.

[298] There are a lot of issues about how you manage people with multiple comorbidities and review all their medication and make sure that they're actually not treating patients with inappropriate drugs for them in that setting; and preventative treatment when they're actually beyond the number of years that will make much difference to enhancing their lives.

[299] The other thing is we need to make sure that there are sensible care plans for these patients that are developed with the patients and their families—and not all patients will be demented, so they will have some input—so that we can advise how to manage those patients and potentially keep them out of hospital, which is one of the problems. Sometimes, these patients shouldn't be going to hospital in the first place and when they are in hospital, we need to be able to get them home as quickly as possible. They need to be assessed by somebody and have some sort of management plans. If they've got uraemia, maybe they don't need to go into hospital to start with; if they're end-of-life, there needs to be some plan about that. But if they do need assessment and treatment, to get that up and running and get them back to wherever they came from—a care home or their own home—because the chances of them getting much more confused, depressed and everything else will be reduced if you can get them back into the normal environment where they normally live, with the people who they know are supporting them.

[300] One of the problems is, sometimes, there are so many carers going to people and they're changing all the time. I went to one meeting and one

person had had 60 different carers in one month.

[301] **Dr Aziz:** And the companies change.

[302] **Dr Fenton-May:** So, there needs to be consistency of care with social care as well as the medical care. We have a big problem with communication—patients will be discharged from hospital and you quite often don't know what's happening, particularly if they go into a different place. So, they went from home to hospital to a care home, and their old GP will get the discharge summary, so it take a while to get the notes of that patient and to find out all of the previous history. So, we need to improve that communication across the board and keep them out of hospital, if we can, by improving the care they get in the community.

[303] **Dai Lloyd:** Okay, moving on to a big topic: antipsychotic medicine and allied things. Lynne.

[304] **Lynne Neagle:** Antipsychotics weren't developed for people with dementia and often aren't licensed for people with dementia and they also have very risky side effects for people with dementia. In view of that, why do you think we are still seeing antipsychotics being prescribed both in the community and in hospital settings, and do you think that this strategy will do anything to tackle that problem?

[305] **Dr Aziz:** No. The simple answer is 'no'. For the past three years, we've been working with the older persons' commissioner, with the Royal Pharmaceutical Society, with different groups, with different publications about antipsychotics. For the past three years, I have been requesting, myself, a national audit—the same as the memory clinics audit—of the use of antipsychotics, again covering care homes, primary care, secondary care and DGHs, but it hasn't happened and it was declined. So, in a way, if you don't know—

[306] **Lynne Neagle:** Who declined it? Was it the health board or—?

[307] **Dr Aziz:** In the discussion, generally, across different groups in Wales. So, we did raise the issue. Because, again, on one hand it's not about the use of antipsychotics; it's about the appropriate use of antipsychotics. Again, very often, they are used very appropriately, but you want to reduce that inappropriate use with the side effects. So, if I'm going to use an antipsychotic because I don't like the patient or the patient is a bit agitated,

that might be inappropriate. But, the patient is psychotic, the patient is extremely aggressive or something, so that's an appropriate use and there are guidelines about that, but we don't know the extent of the problem. We don't know even who's prescribing the antipsychotics. I've done, for three consecutive years in my area, an audit of antipsychotic use in care homes. I don't know who prescribed them. I didn't prescribe a lot of them. They may have come from the DGHs, but who prescribed them, no-one knows. There are different GPs and, again, we had different locums as well, so we don't know who started it. That record is not there and why it started, what is the target symptom is not there.

[308] So, I think we need to find out the extent of the problem and the pattern of that prescribing. There have been lots of publications, lots of guidelines, about their use, so we need, really, to think about that. And what is the alternative? Because, again, sometimes we all love to have behavioural, psychological, non-pharmacological interventions, right? Is it available? Is it available for care homes, is it available for everywhere? If you haven't got any alternatives to those antipsychotics, what are the guidelines, what are the bits and pieces you can use? So, it's bigger than just the simple use of antipsychotics. We need to really understand the process before we can tackle the outcome.

[309] **Dai Lloyd:** It's bigger than this morning's session as well because we're going to have a full review just on antipsychotic medication.

[310] **Dr Aziz:** Perfect. I'm more than happy to come and talk to you.

[311] **Dai Lloyd:** Well, I think you've probably talked yourself into a session. [*Laughter.*]

[312] **Dr Fenton-May:** If I could join in there, there is talk about providing occupational therapy for older people's wards. We need the same availability for people in their own homes, who are often sat there by themselves for long hours with intermittent visits, and people in nursing homes, who more and more seem to be left in rooms by themselves with little input from the staff, or put in front of the television that they can't follow the story of. The staff are watching the television, they're excited because they're watching whatever it is, the soap that they like, but the patients—

11:30

[313] **Dai Lloyd:** They could be watching this. [*Laughter.*]

[314] **Dr Aziz:** Yes.

[315] **Dr Fenton-May:** They could be watching it. [*Laughter.*] The patients have got memory loss, and they can't follow the story, I'm sorry—it's very difficult.

[316] **Dr Aziz:** Yes, true. Can I—very quickly?

[317] **Dai Lloyd:** Briefly, yes.

[318] **Dr Aziz:** Both of you mentioned something important—antipsychotics in care homes. There was documentation—. There was, I think, a consultation a few years back within the Welsh Government about care homes and removing the categories. I don't know what happened to that, because, again, the whole idea about funding—again, coming to funding, coming to antipsychotics in our care homes—if we have care homes full stop, and the focus is on the individualised care plan, the patient doesn't really need to move from that care home because there is no category. There is no elderly mentally infirm nursing, there is no residential, there is no such thing, it's about the patient. So, maybe, if we go back to this documentation and focus on that individualised care plan, it might be the solution.

[319] **Dai Lloyd:** That may well happen with this review. Angela, training questions.

[320] **Angela Burns:** Just a really quick question: given the scale of dementia and how it's now proving, I think I'm right to say, to be the biggest killer of people than anything else, do you think that we should do more to embed dementia training in the basic training for doctors, nurses, allied healthcare professionals, et cetera? What would you recommend?

[321] **Dr Fenton-May:** Yes.

[322] **Dr Aziz:** Yes.

[323] **Dai Lloyd:** Excellent—that's the sort of answer I like.

[324] **Dr Fenton-May:** Can I say that the Royal College of General Practitioners was funded by the Welsh Government to put together some very

excellent training for GP practices? That was aimed at ensuring that the whole practice—not just the doctors—got the training. When we ran that in our surgery, the most important people who were there were the receptionists. They came along during the training and said, ‘Well, we’ve got these patients who keep coming backwards and forwards, saying, “I don’t know if I’ve got my own medication”’, and we identified quite a number of people through that. So, you need the front-line people and you need the community, and it goes back to the dementia-friendly society.

[325] **Dr Aziz:** So, it’s there—implement it.

[326] **Dr Fenton-May:** Yes.

[327] **Angela Burns:** Thank you.

[328] **Dai Lloyd:** Mae’r cwestiynau **Dai Lloyd:** The final questions are olaf o dan law Dawn Bowden. from Dawn Bowden.

[329] **Dawn Bowden:** Diolch, Chair. You talked in your evidence earlier on about pooling resources between health and social care. As Rhun said, we’ve heard that evidence from several sources, but that’s not going to happen anytime soon—certainly not immediately and certainly not within the timescale in which we’re looking at implementing this strategy. So, accepting that and parking that for one moment, do you think that additional and separate funding is likely to be needed if this strategy is to be implemented effectively?

[330] **Dr Aziz:** It’s very difficult to answer, because we have different ways of funding that haven’t achieved their targets. With the focus on what was actually the outcome we wanted to achieve, do we just want numbers—that’s why we were talking earlier about numbers—or are we really looking at the quality of care? I think that if the funding is targeted into a definite outcome, you might achieve it, but if you just fund it full stop, you’re not going to get much.

[331] **Dawn Bowden:** So, you’re saying that the strategy should be clearer about the required outcomes.

[332] **Dr Aziz:** Yes, it’s not clear in the strategy—it’s very, very loose. If I am talking as a college, it’s very loose. If I am talking about myself being part of the health board, lots of targets have actually been passed to the health

board. Actually, can the health board do it? Have they got the workforce? Have they got the facilities?

[333] **Dawn Bowden:** Sorry. What would be the most effective sort of target or outcome that you'd be looking for, then?

[334] **Dr Aziz:** There are three outcomes that you can really think about. One, at the heart is the patient's satisfaction. Are we meeting that patient's needs or not? Two, you may think about, as a clinician, what we can do and what our targets should be as clinicians. But, at the same time, are we meeting the quality of care that we are providing to that patient? It's very, very difficult to measure quality of life. So, if we are really focusing on the individual patient, we need to focus on their quality of life more than anything else.

[335] **Dawn Bowden:** Okay. Do you think we've got the capacity to do that at the moment?

[336] **Dr Aziz:** No.

[337] **Dawn Bowden:** So, what did you mean in your evidence about having an overarching clinical strategy and management of dementia plan to complement this? What was the meaning behind that?

[338] **Dr Aziz:** Putting it in a very, very simple way, we have, for example, different health boards in Wales. Are we going to ask every single health board to do it their own way, or are we going to have one clinical pathway that is consistent across all of Wales, so it doesn't really matter where the patient is, they are going to have the same quality—?

[339] **Dawn Bowden:** You're looking at consistency—

[340] **Dr Aziz:** Consistency. So, for example, if I'm talking about antipsychotics, these are the guidelines about antipsychotics that everyone should do in principle, but, actually, you are a clinician, you have skills, it's an individual patient, and you may go a different way if you have evidence, not just evidence from the literature, but actually the patient need is different. But at least the starting point is the same across the whole of Wales. So, rather than—. You have to think about it. Do we need to all sing from the same hymn sheet or, if we leave it to everyone again, which we've done in the past, did it work or not?

[341] **Dawn Bowden:** Yes, I understand that. Finally, my final point, Chair, would be: given what you were just saying then about the outcomes, you would see, presumably, the strategy prioritising those areas, and the measures for those would be those particular outcomes, that they would have been achieved, yes?

[342] **Dr Aziz:** In the Royal College of Psychiatrists, we did a paper this year, or towards the end of last year, and a paper in 2012, about outcome measures in old-age psychiatry, and, again, we did respond to the dementia strategy in England, and we tried to just produce three simple outcomes that can be applicable to everyone, because you need it to be SMART, but also you need it to be easy. So, for example, if I say about the well-being tool, which is a very, very simple tool that can be used by anyone, and, again, it's about the well-being of the patient—. So, if I'm using a one-to-five satisfaction questionnaire on how happy you are—.

[343] In Wales, a while back—it's a shame that it disappeared—we had a very simple paper called, I think, 'Your say' or something like that—simple, simple. This is proper feedback, because if you put more and more and more for the patient, they are not going to put anything. 'Have your say'; it was 'Have your say.' It's a simple way of getting this feedback, a simple way—'Are we meeting your needs or not?' If I put a whole questionnaire and the whole outcome measures, who's going to do it? It would take me away from patient care. So, if we simplify things and if we know what we are measuring, it will be perfect.

[344] **Dai Lloyd:** Diolch yn fawr iawn ichi. Dyna ddiwedd y sesiwn. Diolch yn fawr iawn ichi am y papurau gerbron yn y lle cyntaf, y dystiolaeth ysgrifenedig, a hefyd am ateb y cwestiynau mewn ffordd mor aeddfed a chelfydd. Diolch yn fawr iawn ichi. A gaf i gyhoeddi y byddwch chi'n derbyn trawsgrifiad o'r cyfarfod yma i'w wirio fe i gadarnhau ei fod e'n ffeithiol gywir? Ond diolch am hynny. Gwnawn ni symud ymlaen i'r sesiwn nesaf. Mwy na thebyg y gwnawn ni eich gweld chi yn ein harolwg ar

Dai Lloyd: Thank you very much. That concludes the session. Thank you very much for your written evidence and also for answering our questions in such a skilled manner. May I just tell you that you will receive a transcript of this meeting so that you can check it for factual accuracy? But thank you very much for your evidence. We'll move immediately to our next session. I'm sure we will see you again in our inquiry into antipsychotic medicine. Goodbye for the time being.

feddyginiaeth gwrth-seicotig, felly.
Hwyl am y tro.

[345] **Dr Aziz:** Thank you.

[346] **Dr Fenton-May:** Thank you very much.

11:38

**Ymchwiliad i Strategaeth Genedlaethol Ddrafft Llywodraeth Cymru ar
Dementia—Sesiwn Dystiolaeth 4—Iechyd Cyhoeddus Cymru
Inquiry into the Welsh Government’s Draft National Dementia
Strategy—Evidence Session 4—Public Health Wales**

[347] **Dai Lloyd:** Good morning. Welcome aboard.

[348] Gwnawn ni symud yn syth ymlaen, felly, i eitem 5 ar agenda'r pwyllgor iechyd y bore yma a pharhau efo'n hymchwiliad i strategaeth ddrafft genedlaethol Llywodraeth Cymru ar ddementia. Dyma'r bedwaredd sesiwn dystiolaeth—pedwaredd sesiwn dystiolaeth y bore, a dweud y gwir. Yma o'n blaenau ni nawr mae Dr Les Rudd, arweinydd gwella'r gwasanaeth iechyd meddwl Iechyd Cyhoeddus Cymru. Diolch yn fawr am eich tystiolaeth ysgrifenedig gerbron ac wedyn, gyda'ch caniatâd ac fel sydd yn draddodiadol erbyn hyn rŵan, awn ni'n syth i mewn i gwestiynau llafur gan yr Aelodau. Mae'r ddau gwestiwn cyntaf gan Caroline Jones.

We'll move immediately, therefore, to item 5 on the health committee's agenda this morning, and we continue our inquiry into the Welsh Government's draft national dementia strategy. This is our fourth evidence session—our fourth evidence session of the morning, if truth be told. Joining us now is Dr Les Rudd, who is mental health service improvement lead, Public Health Wales. Thank you very much for your written evidence, and, with your permission, and as has become something of a tradition for our committee, we'll move immediately to oral questions from Members. The first two questions are from Caroline Jones.

[349] **Caroline Jones:** Thank you, Chair. Good morning, Dr Rudd.

[350] **Dr Rudd:** Good morning.

[351] **Caroline Jones:** I've amalgamated my questions. So, could I ask,

please, what you think is required in the draft strategy regarding public health interventions that may minimise risk factors, which may help to delay or even avoid the onset of dementia? Secondly, how can we ensure that such interventions reach the whole sections of Wales—the whole population—including Welsh speakers and those people with protected characteristics?

[352] **Dr Rudd:** Okay. I need to introduce myself properly, really, by saying that I work in Public Health Wales, for Public Health Wales, but my field is in service improvement. I work specifically on the dementia care improvement programme, which I lead, which has five key components: memory assessment services, district general hospitals, community services, including residential care and nursing homes, which goes particularly to issues around medications, carers, and psychiatric in-patient units. So, the expertise that I'm bringing to the table is more around those issues.

[353] My colleagues in Public Health Wales lead on the work around health, healthy lifestyles, nutrition, countering obesity, and those kinds of issues. We have increasing evidence that the things that we would ordinarily recommend for a healthy and long lifestyle actually are good preventive factors in dementia as well. So, I would commend the work that they do and emphasise that we should do that as well in the context of dementia care and, indeed, cognitive impairment more generally.

[354] **Caroline Jones:** Thank you.

[355] **Dai Lloyd:** Symud ymlaen. **Dai Lloyd:** We'll move on to Rhun. Rhun.

[356] **Rhun ap Iorwerth:** Bore da iawn i chi. Mae'r term 'dementia-friendly' yn rhywbeth yr ydym ni yn ei drafod mewn perthynas—ac mi wnawn ni yn nes ymlaen—ag ysbytai a gofal sylfaenol ac ati. Os caf i jest yn sydyn gofyn i chi am y syniad o ddatblygu cymunedau sydd yn ystyriol o ddementia, beth ydy pwysigrwydd hynny a beth ydy rôl y strategaeth mewn datblygu hynny?

Rhun ap Iorwerth: A very good morning to you. The term 'dementia-friendly' is something that we discuss—as we will do later—in relation to primary care and hospital settings, but if I may just ask you about this idea of developing communities that we would describe as dementia friendly, what is the importance of that and what is the role of the strategy in developing that?

[357] **Dr Rudd:** I think a large part of what we need to do with the strategy, in raising awareness, is to combat stigma. I think the emphasis on dementia-friendly communities is something that will help people remain at home, in the community, for longer. You will have a priority for countering isolation. That's a particular issue for a lot of the people that we will be talking about in terms of living at home alone. In that context, I think so much of what we need to do with this strategy needs to be focused on our ability to help people, support, with a good quality of life and to stay at home as long as possible. I think the more that we can do in promoting dementia-friendly communities—and I mean that in its broader sense, not just dementia-friendly general practice surgeries, where we might think about the physical environment, but the culture, the way we respond, the support that we can expect from our families, from our families' children, just general issues that go really into, I think, a misunderstanding and the stigma that's often associated with a diagnostic label.

[358] **Rhun ap Iorwerth:** Who drives change on that? Who drives that cultural change, and is that addressed enough in the strategy as it is, or does there need to be a little bit of change and improvement and strengthening there?

[359] **Dr Rudd:** I'm really focused on driving that cultural change within all of our services—health, social care, the voluntary sector services—and that drive must come from the top. The change that we would hope to expect within a broader culture, I think, goes to our education systems; it goes to our broad mainstream media relations and the ways that we can communicate about things. So, I think that's a very huge and a big agenda. I'm particularly interested in the issue of driving cultural change within our health and social care services.

[360] **Rhun ap Iorwerth:** And, again, does the strategy focus enough on that?

[361] **Dr Rudd:** No. No. The issue is, for me—and I'll probably say this a number of times—we're well behind the curve. In 1990, we were talking about the ageing demographic. We are behind the curve. We haven't caught up. We've got to go really fast now—really fast now. Does the strategy give us enough? It says the right things. It's given us some new money. You could argue there's always the need for more new money, but will it be one of the top three priorities for the chief executives of local authorities, going to education as well as social care and housing, and one of the top three priorities for the chief executives of our health boards? Unless it is—we've got too many priorities. I think it's really important if we're going to put

something behind this. Give this a No. 1 priority for the next five years.

[362] **Rhun ap Iorwerth:** One suggestion made in the draft strategy is that Welsh Government should consider, with Public Health Wales, supporting a dementia mapping project across Wales. Is that useful?

11:45

[363] **Dr Rudd:** It would be useful. They have it in England; it helps us identify more at a locality level. It's more focused around the primary care clusters than it is the local authority clusters, and I think here we would be more interested in looking at it at local authority and, indeed, at community levels. I think the single biggest issue, though, is that we only have 51 per cent, as you know, of people diagnosed. So, where are the other 49 per cent, and how quickly can we help identify them? And, if we can't identify them, how can we identify their needs? A lot of them will be in residential care and nursing homes without a diagnosis. How do we make sure that we can get to them quickly to actually make sure we can provide the bespoke support and care packages that are needed? Sorry, I've slightly missed your question there, I think.

[364] **Rhun ap Iorwerth:** No, you haven't. I perfectly understand that it's something you support, and we'll no doubt come on to diagnosis rates shortly. Thank you.

[365] **Dai Lloyd:** Angela has got the next three questions.

[366] **Angela Burns:** I just wanted to talk very quickly about training, diagnosis, care and support. You've covered some of it, but, in your evidence, you particularly talk about the need to train for distressed and challenging behaviour. Could you just expand on that a little bit?

[367] **Dr Rudd:** Yes, I would like to. Eighty-four per cent of admissions to medical and surgical wards are over 85—the median is 87—which means—

[368] **Angela Burns:** Sorry, could you just say that—84 per cent of admissions are people—

[369] **Dr Rudd:** To medical and surgical wards will be people over 85. They will have co-morbid conditions, so they may have been admitted for a hip or for a physical issue, but they will have co-morbid conditions. A third are

likely to have a cognitive impairment, possibly a dementia, another proportion will have a delirium that we can help to treat, and a higher proportion will also have depression. So, the core business of our district general hospitals is not just physical healthcare, it is co-morbid physical and mental health care, and we've got to move away from the silos.

[370] We have given a lot of priority to providing dementia-awareness training for our staff. We've helped to devise an e-learning module, which I'm not sure they made mandatory, but it was very basic and simple. I know that there's some excellent work being done around the knowledge and skills framework for dementia care. Part of the reason for giving you that evidence is that we see a lot of what we call—I hate the term—'challenging behaviour'; behaviours that challenge the staff in the provision of care. These behaviours, in my opinion, are a response to distress, are a response to not knowing the environment, to worry. Helping our hard-pressed staff to have the time and the skills to be able to communicate effectively, particularly in the provision of personal care—the highest incidence of violence and aggression patient to staff comes in the provision of personal care, good nursing care—. We know from services back in the 1990s when we were working with learning disability services, to use them as an example, that the provision of psychological approaches to the ways in which we communicate, to the provision of personal care, can help reduce these behaviours. We should be doing more of that. Part of the evidence that I submitted was to say this should be a priority.

[371] So, we have a lot of priorities given within the strategy for good education and good awareness and, as I say, we are behind the curve. Actually getting that into our wards is not easy. But this particular training requires some support, and I'm not sure that we have the staff to provide some of it. Occupational therapists, technical instructors, psychologists—we don't have them embedded in our psychiatric wards, let alone on our district general hospital wards. Who's going to be providing some of this training to support people on the wards? So, I kind of want to get into that space a bit more and say it should be much more of a priority.

[372] We have now—. Recently, Welsh Government have funded the expansion of liaison psychiatry services, and good. And about time. How are we going to support our busy general hospital staff in being able to themselves learn the skills to be able to do their job better with people with a challenging behaviour or a cognitive impairment? We need access to their support. So, this is partly my thing—and I'll come back to it—about being

behind the curve, and we really need to give it a priority.

[373] **Angela Burns:** Given the increase in dementia, because, thankfully, we are living longer and we should celebrate that, given the fact that it's now, I understand, the biggest killer of older people—in fact, I think it's across the whole population—do you think, having listened to what you've just said, that we need to review how we train our doctors, our nurses, our healthcare professionals and should we embed dementia training, actually, in the basic training, in the first sets of training, so that when they come out of their training and their degree courses and all the rest of it, they've already got some understanding of this?

[374] **Dr Rudd:** Absolutely. Fundamentally. In fact, we're doing it. But, when you're learning as a psychiatrist, it needs to be one of those that's mandatory, as opposed to one of those that's—or as a physician, one of those that's made a mandatory requirement, not one of those, 'Oh, that's mental health over there'. I think that's my point, really. How do we, though, get the training that we need to get people up to speed who are already in post? That's our challenge.

[375] **Angela Burns:** Could you just go on to talk to me about the increased vulnerability of certain groups to dementia? One of the concerns I've had over the evidence that we've received is—I worry that there's a slight conflation of dementia with mental health issues, because I don't see people with mental health issues and learning disabilities being seen as a protected group, at all.

[376] **Dr Rudd:** I'm exaggerating to say that co-morbid conditions are almost the norm, certainly in terms of what we see within our hospital settings—physical and mental health problems. But within the mental health context, we mustn't forget that people with an organic illness or cognitive impairment are probably likely to have a functional illness as well, often a depression. That would go to their skills, capabilities and, sometimes, their motivation for self-management of conditions. So, I think providing support generally within the district general hospital setting to identify people, particularly, who may be depressed or anxious, where we can provide support for their self-management of what is often a chronic condition—it could be any condition—that goes to a concept of a psychologically minded health and social care service where, as a norm, we are all trained to acquire to provide basic training and support for people in the cognitive skills. We use the term, sometimes, 'cognitive behavioural therapies,' but the skill set behind that is

something that is really there just to support people to be able to better manage their own conditions. That's just basic self-management, and I think we can do a lot more.

[377] **Angela Burns:** Just one really quick question. A lot of elderly people, for example, get admitted to hospital because they have orthopaedic issues, and there is a growing use now of orthogeriatricians, because they look at them in the round and not just go, 'Oh, it's a broken leg or a fractured hip,' but they look at the whole thing. Is there an equivalent person who would look at co-morbidity that comes with dementia? Or do we just have to try—we know how difficult this is—to pull together a load of strands of services?

[378] **Dr Rudd:** You will have seen Victor, who, as an old-age psychiatrist, will bring quite a lot to—

[379] **Angela Burns:** It was powerful.

[380] **Dr Rudd:** But I think how we bridge those gaps—and there are gaps—'This is a physical health problem, this person's now got a mental health problem, over to you.' No: 'How do we support that over here?'

[381] **Angela Burns:** We need generalists, don't we?

[382] **Dr Rudd:** It's a generalist—

[383] **Angela Burns:** A specialist generalist.

[384] **Dr Rudd:** I mentioned the liaison psychiatrists, whose role is not to come in to take over, but to support, empower and upskill the existing physicians, and I think that's something that we have begun to do. We were very late in doing it, but there's great evidence for its effectiveness. How do we do that? Joint care wards; physical and mental health care wards. We've got to bridge those gaps; we've got to integrate the service better.

[385] **Dai Lloyd:** Gan symud ymlaen, **Dai Lloyd:** We'll move on, and the mae'r ddau gwestiwn nesaf o dan law next two questions are from Lynne Neagle.
Lynne Neagle.

[386] **Lynne Neagle:** Thank you. Are you satisfied that the target to improve diagnosis rates by 3 per cent a year is ambitious enough?

[387] **Dr Rudd:** Welsh Government will have a target and not stretch the ambition of that target beyond a point that is not achievable. It doesn't want people to fail. So, from the perspective of my advice to Welsh Government, it would be: make sure you have a target that's deliverable. That's probably deliverable as we are right now in terms of something we can move towards. Is it enough? No. Fifty per cent; it doesn't say in that document that this is the lowest rate across the whole of the UK. Northern Ireland, which you will have heard about, is 61 per cent, and Scotland's up there. Why are we so low, and what are we doing about it as a priority? Now, if we want to make it a priority, it goes back to the fact it can't be one of a hundred priorities. It has to be a top-drawer priority. If we made it a top-drawer priority, we can change that—change it more effectively. I think in part of the written evidence a 75 per cent target was put there. My question back to them would be: how are you going to do it? Are we going to throw more money at it? Probably not likely. So, I think more GP-led clinics is a start. More outreach to in-patient nursing homes, community care homes—particularly by both the GPs and the memory assessment services that can outreach. Do they have the capacity to do so? That is a question.

[388] So, there are definitely resource issues, but I think there are definitely ways we can do it. Central to the question, for me, is: why do GPs perhaps become reluctant to use the diagnosis? I think a large part of that goes to: have we clearly demonstrated sufficiently for general practitioners that the diagnosis is worth giving? Access to post-diagnostic support services—is the evidence there for that? Now, we have to go and sell that. We have those services; cognitive stimulation therapy services, for example. We're increasing the ways in which we can do that within memory assessment services. But out there, getting access to the support in the community, making sure they're resourced—I think that's a significant issue. Some of the therapies—speech and language therapy: we have one speech and language therapist in the memory assessment service, based in Cardiff and the Vale. Why don't we have that as a post-diagnostic support service across the whole of Wales? To use that as an example.

[389] So, there's something here that goes to our teams, the multidisciplinary composition of our teams, with OT, with psychology, speech and language therapy. Our equity of provision for this is very limited at the present time. We've got to drive that further, and herein lies a tension—forgive me—we want to get better and drive a target to increase the numbers of people that we diagnose: 810 people, new people, last year, through memory assessment services. If we double it, we're going to spend

less time and have less resource available to do the post-diagnostic support services. So, there's a tension in here that needs to be drawn out within this strategy. What is our priority? If you want increased diagnosis, we're going to lose something in our post-diagnostic support services, and we're going to lose the very arguments that we want to make to general practitioners—that it's actually worthwhile. And families; a lot of GPs will not give a diagnosis because the family are worried about the diagnosis and they don't see the purpose and the benefit. So, there are some real issues there.

[390] **Lynne Neagle:** Okay. Can I just follow up on a couple of things you've said? In our previous evidence session, we heard a couple of reservations about diagnosis rates. Dr Aziz was concerned that, by having more general people doing diagnoses, that there was a risk of perhaps that being done wrongly. But you seem to be saying something different. Dr Fenton-May said that she had the worries that you've referred to—why diagnose people? Where's the support, really? Clearly, support is crucial if you're going to increase diagnosis rates. So, do you think it's possible? You've got to do the two; one without the other is a waste of time. And have you got any concerns that, if we had, say, GPs and nurses doing diagnoses, then we might have problems—maybe the wrong diagnosis, et cetera?

[391] **Dr Rudd:** Yes, I'd be concerned about misdiagnosis. I know Dr Aziz, and Dr Aziz is with the college, but I would trust our GPs. I would trust our GPs, and we should train them to be able to do much more, and they want to do much more. I don't see this—. Having access to brain scans, and some of the kit that goes with it, these things will take time. But if I was a person presenting, I would want to go to my GP. This is a normal, friendly environment for me. If I can get the service that I want there from my general practitioner, who knows me, that's where I'd want to be. I think: how can we better upskill and support, particularly our general practitioners? But there are other professionals that I think can get involved.

12:00

[392] Can I mention something about the language issues? I've a little bee in my bonnet about something. The Alzheimer's Society have produced a really good toolkit, a cognitive assessment toolkit. It's got six tools within it. I think if any GP looked at those tools—. They probably use them already, as there's a GP cog inside that: a cognitive assessment tool. We've translated them into Welsh. Great. And we're using them, and all the memory assessment services can provide bilingual services. But if there was a service where it was really

important to make sure that the different language issues were picked up, then this is that service, in terms of people in later stages wishing to use their first language. The bee in my bonnet is: we've got these tools, but we haven't had the research to validate them in their Welsh language versions. We don't know what the norms are. So, we can use a Welsh language translated tool, and we use English normative data to validate the tool. There's some good evidence that being bilingual or multilingual is a protective factor, so I think it's really important. So, research please; helpful research is a priority to validate some of the very good existing tools we've got.

[393] **Lynne Neagle:** Thank you.

[394] **Dai Lloyd:** Right, we're getting towards the end now. Jayne has got a question that's possibly partially been answered, but carry on.

[395] **Jayne Bryant:** I was going to say I think it has been covered in some of your answers. You've been very comprehensive in your answers. You've mentioned about the resource issue, and you said there are definitely resource issues; do you think implementing the strategy will require additional separate funding? And you've suggested some areas, such as more GP-led clinics and outreach, where you've given specific examples. Do you have any more examples that you'd like us to focus on?

[396] **Dr Rudd:** I could probably give you a list, but I'm coming from a pragmatic place. We have actually had Welsh Government support for some additional resources in mental health services, particularly around child and adolescent mental health services as well, and, for this strategy, the dementia support workers—some of the support to our in-patient services in the provision of technical instructors and OTs to provide some of this training. So we've had some, and we're really fortunate and lucky to have it in this resource-constrained environment. And it would be good to have more. But I think, back to my issue, if we're going to move the strategy forward, we are looking at the use of mainstream resources that are within health boards, which are out there in district nursing and in generic social services, and what we're looking to do is to make sure they're all dementia champions. That's our way forward. So, there's lots we can do to try to improve the little bits of the service we've got and the ways we can, maybe, provide better post-diagnostic support. And you could argue lots of different ones within that, but for me, the central priority is: make it a top priority, not one of the 100 priorities for the GP. And within that, look to the more

efficient use of resources.

[397] I haven't mentioned medications. We did some really good work in nursing homes, where we were working with them using a community pharmacist to work with the team to provide much more personalised, person-centred care for the residents of their home. And a large part of that involved the community pharmacist working with the general practitioner on a medications review, and we saw some significant reductions in the use of antipsychotics and the avoidance of substitute sedatives, which is often the case. There are cost efficiencies we can make here if we can support the use of those drugs. It's particularly often around the management of behaviours that the home finds difficult and, if we can support the home in being able to manage those behaviours that distress more positively—and I think we can, but it's quite intensive work. Time is the resource.

[398] **Dai Lloyd:** Okay. Julie.

[399] **Julie Morgan:** Thank you very much. Actually, I think, the capacity in the NHS and social services to deliver this strategy—I think we've discussed that. What about the oversight of the delivery of the strategy? Do you think that would be most appropriately undertaken by the older person's delivery assurance group?

[400] **Dr Rudd:** Well, I'm sure the group—good group, good function. We need an assurance function. We need to make sure we've got robust and reliable measures. It's often the case with strategies that we end up with 100 measures, and a lot of those measures are process and activity measures: 'How many widgets do you have?'—forgive me. I'm interested in the impact evaluation. Let's find ways in which we can get carers and people with dementia feeding back regularly on their experience: 'Is it getting better?' Let's get that—if there was one measure, that's the measure.

[401] So, I think it depends—. You know, I'm sure we've got measures we can use. I'm interested in the question: what one or two measures are going to tell us a lot about a whole range of different measures?

[402] **Dai Lloyd:** So are we, actually. Dawn, I think that's your—

[403] **Dawn Bowden:** That was actually my question but, if I could, what would you say would be the key priorities, then, in the strategy? You said that measuring outcomes is absolutely crucial. What would be the key

priority from a measurement point of view?

[404] **Dr Rudd:** I just think, across the whole of the service—. In mental health services generally, we're not very good at monitoring outcomes from the service because they're long term. And the way we've approached that is to seek better repeat test measures of change over time from the person using the service, and from their carers and family. So, I think something along those lines that goes specifically to the question, 'What is your goal? What is your most important goal?'; 'My most important goal is to remain at home with a good quality of life for as long as I have this diagnosis'. Whatever that goal is, how are you doing with that goal over time? Let's monitor and measure that goal and support people in doing that. It doesn't have to be the dementia service that does that; the district nurse, generic social services—I think there are ways we can get that experience fed back to us. I've got to say, whenever people do feed back, they tend to be so positive about the service in a situation where it says a lot that their expectations are so low. You know, there's a part of me that wants to drive the expectation to expect more of this.

[405] **Dawn Bowden:** Okay, that's fine.

[406] **Dai Lloyd:** Diolch yn fawr. **Dai Lloyd:** Thank you very much. That Dyna ddiwedd y sesiwn dystiolaeth— concludes our evidence session. We tystiolaeth pwerus iawn. Diolch yn had some very powerful evidence. fawr iawn i chi; perfformiad arbennig Thank you very much; an excellent y bore yma. Gallaf bellach gadarnhau performance this morning. I can y byddwch chi'n derbyn trawsgrifiad confirm that you will receive a o'r sesiwn yma i gadarnhau ei fod e'n transcript of this session to check for ffeithiol gywir. Gyda gymaint â hynny factual accuracy. With those few o eiriau, a allaf i ddiolch yn fawr iawn words, may I thank you once again i chi unwaith eto am eich for your attendance this morning? presenoldeb? Diolch yn fawr iawn i Thank you. chi.

[407] **Dr Rudd:** Thank you for inviting me.

12:07

Papurau i'w Nodi
Papers to Note

[408] **Dai Lloyd:** Symud ymlaen i eitem 6 nawr gogyfer fy nghyd– Aelodau, a phapurau i'w nodi. Fe fyddwch chi wedi darllen y llythyr gan Ysgrifennydd y Cabinet dros iechyd ynghylch adroddiad blynyddol Ombwdsmon Gwasanaethau Cyhoeddus Cymru. Unrhyw beth yn codi o hynny? Papur i'w nodi yw e. Pawb yn hapus.

Dai Lloyd: We'll move on to item 6, fellow Members, which is the papers to note. You will have read the letter from the Cabinet Secretary for health on the Public Services Ombudsman for Wales's annual report. Does anything arise from that? That's a paper to note. Everyone is content.

Cynnig o dan Reol Sefydlog 17.42 i Benderfynu Gwahardd y Cyhoedd o'r Cyfarfod

Motion under Standing Order 17.42 to Resolve to Exclude the Public from the Meeting

Cynnig:

Motion:

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

that the committee resolves to exclude the public from the remainder of the meeting in accordance with Standing Order 17.42(vi).

Cynigiwyd y cynnig.

Motion moved.

[409] **Dai Lloyd:** O dan eitem 7, a allaf i gynnig, o dan Reol Sefydlog 17.42, i benderfynu gwahardd y cyhoedd o weddill y cyfarfod i drafod manylion y bore yma? Pawb yn hapus? Diolch yn fawr.

Dai Lloyd: Under item 7, may I propose, under Standing Order 17.42, to exclude the public from the rest of the meeting so that we can discuss the details of this morning's evidence? Everyone content? Thank you very much.

*Derbyniwyd y cynnig.
Motion agreed.*

*Daeth rhan gyhoeddus y cyfarfod i ben am 12:07.
The public part of the meeting ended at 12:07.*