



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

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

**Dydd Iau, 26 Mehefin 2014  
Thursday, 26 June 2014**

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of the Meeting

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

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

**Aelodau'r pwyllgor yn bresennol  
Committee members in attendance**

Leighton Andrews	Llafur Labour
Rebecca Evans	Llafur Labour

Janet Finch-Saunders	Ceidwadwyr Cymreig Welsh Conservatives
Elin Jones	Plaid Cymru The Party of Wales
Darren Millar	Ceidwadwyr Cymreig Welsh Conservatives
Lynne Neagle	Llafur Labour
Gwyn R. Price	Llafur Labour
David Rees	Llafur (Cadeirydd y Pwyllgor) Labour (Committee Chair)
Lindsay Whittle	Plaid Cymru The Party of Wales
Kirsty Williams	Democratiaid Rhyddfrydol Cymru Welsh Liberal Democrats

**Eraill yn bresennol**  
**Others in attendance**

Mark Drakeford	Y Gweinidog Iechyd a Gwasanaethau Cymdeithasol The Minister for Health and Social Services
Grant Duncan	Dirprwy Gyfarwyddwr yr Is-Adran Polisi Gofal Iechyd Deputy Director Healthcare Policy Division
Dr Chris Jones	Y Dirprwy Brif Swyddog Meddygol Deputy Chief Medical Officer
Carys Thomas	Sefydliad Cenedlaethol ar gyfer Ymchwil Gofal Cymdeithasol ac Iechyd National Institute for Social Care and Health Research

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

Helen Finlayson	Ail Glerc Second Clerk
Llinos Madeley	Clerc Clerk
Victoria Paris	Y Gwasanaeth Ymchwil Research Service
Sarah Sargent	Dirprwy Glerc Deputy Clerk
Philippa Watkins	Y Gwasanaeth Ymchwil Research Service

*Dechreuodd y cyfarfod am 09:15.*  
*The meeting began at 09:15.*

**Cyflwyniad, Ymddiheuriadau a Dirprwyon**  
**Introductions, Apologies and Substitutions**

[1] **David Rees:** Good morning. I welcome Members to this morning's session of the Health and Social Care Committee, in which we will be undertaking our final evidence session on the inquiry into the cancer delivery plan. The meeting is bilingual, and for those Members who wish to have simultaneous translation from Welsh to English, it is on channel

1, and for those wishing to have amplification, it is on channel 0. I remind people to please turn off their mobile phones, and to switch off any equipment that may interfere with the broadcasting. There is no fire alarm scheduled for this morning, so, in the event of a fire alarm sounding, please follow the direction of the ushers. We have not received any apologies this morning.

**Ymchwiliad i'r Cynnydd a Wnaed hyd yma i Weithredu Cynllun Cyflenwi ar gyfer Canser Llywodraeth Cymru: Sesiwn Dystiolaeth 7**  
**Inquiry into Progress Made to date on Implementing the Welsh Government's Cancer Delivery Plan: Evidence Session 7**

[2] **David Rees:** I welcome the Minister for Health and Social Services, Mark Drakeford. Minister, would you like to introduce your team?

[3] **Y Gweinidog Iechyd a The Minister for Health and Social Gwasanaethau Cymdeithasol (Mark Drakeford):** Diolch yn fawr, Gadeirydd. Mark Drakeford ydw i, ac rwy'n mynd i ofyn i'r swyddogion sydd gyda fi gyflwyno eu hunain. Gallwn ddechrau gyda Carys. **Services (Mark Drakeford):** Thank you very much, Chair. I am Mark Drakeford, and I am going to ask the officials who are with me to introduce themselves. We can start with Carys.

[4] **Ms Thomas:** Helo. Fy enw i yw Carys Thomas ac rwy'n gweithio i'r Sefydliad Cenedlaethol ar gyfer Ymchwil Gofal Cymdeithasol ac Iechyd, Llywodraeth Cymru. **Ms Thomas:** Hello. I am Carys Thomas and I work for the National Institute for Social Care and Health Research, Welsh Government.

[5] **Dr Jones:** I am Chris Jones, deputy chief medical officer.

[6] **Mr Duncan:** I am Grant Duncan of the healthcare policy division.

[7] **David Rees:** Thank you very much. May I thank you very much, Minister, for your written evidence that was supplied to the committee? We have had evidence from a number of witnesses and they have raised some issues on which we wish seek your clarification. So, we will go straight into questions and Gwyn Price will ask the first one.

[8] **Gwyn R. Price:** Thank you, Chair, and good morning, everyone. What is your response to witnesses who say that a more integrated all-Wales approach is needed to ensure the delivery of the plan and that an overarching strategy planning, delivery and performance monitoring body, which is clinically-led and brings all local health boards together with authority, should be established? Do you agree, Minister, with witnesses who say that the all-Wales cancer care plan group is unable to effectively bridge the gap between national policy and local implementation, and, if so, what resources would be required to ensure that the group could monitor and implement the plan at a local level?

[9] **Mark Drakeford:** Thank you, Gwyn, for that question. I have read some of the evidence that the committee has received from other bodies, including those that have made this argument. I think that my answer to it is twofold, in a way. One is that I think that some of the criticism undervalues the achievements of the structure that we have at the moment, including the cancer implementation group. I think that one of the strengths of the cancer delivery plan is that it has drawn out of the service strong clinical leadership in the cancer field, and that you can see the results of that strong leadership in the achievements that there have been against the delivery plan over the two years. So, I think that more has been achieved within the structure that we have already than some of the evidence that you have

received would suggest. By and large, the evidence that you have had from people who make this argument is made by people who are really committed to the cancer agenda and want to push it even further than we have managed so far. So, it is generally a critique from friends of the way that things have happened in Wales wanting to improve it even further.

[10] The second thing that I would say, however, is that, in some ways, I think, in Wales we occasionally have to persuade ourselves to be just that little bit more patient with things and to give structures and ways of doing things time to mature and to deliver. Here is a delivery plan that is only two years old, where the structures that we have had are still maturing. I do not think that it is necessarily helpful to want to reinvent things quite as quickly as is maybe suggested. I think that there is some merit in us allowing the system that we have to continue to show that it is able to deliver, and it has certainly shown that in the last two years. However, the cancer implementation group, the national body, is meeting next week. It is looking at its priorities for the next 12 months; it has four suggested priorities in its papers, one of which is to get the most out of the cancer structures that we currently have. So, it is not an argument for saying that everything should stay just as it is, but there is more to be extracted from the structures that we have, and I think that that is my approach for the next 12 months: not trying to reinvent structures and change structures, but allowing what we have there to mature while working hard to get the most out of it.

[11] **David Rees:** As part of that process—because we were informed that the cancer implementation group actually met four times a year for around two hours—do you believe that there is a need perhaps for more frequent meetings of that group to allow that greater discussion to lead to development?

[12] **Mark Drakeford:** A great deal of what the group does happens all of the time and outside those formal meetings. The meetings, in a way, are a summation of all the work that goes on in between. The work of the group does not depend upon those two hours. Those two hours, really, are spent drawing together the threads of everything that will have gone on in the three months between meetings. I have no difficulty with that group meeting more frequently or in a different way if it thought that that would be more effective.

[13] **David Rees:** Janet is next.

[14] **Janet Finch-Saunders:** Good morning, Minister.

[15] **Mark Drakeford:** Good morning.

[16] **Janet Finch-Saunders:** Overwhelmingly, in a lot of the evidence that we have taken, the general theme seems to have been that, across Wales, adherence to the cancer plan is patchy and inconsistent. Indeed, Macmillan Cancer Support actually said that there was no compliance. It is fair to say that Macmillan is on the ground in all communities. You have just said the opposite, almost. How do you address concerns? We took an awful lot of evidence from people who are very committed to working to further support for cancer patients, treatment and diagnostics, but the overwhelming responses that we have had in taking evidence are that, across Wales, it is inconsistent, certainly in north Wales in particular. Quite often in the Chamber we hear about Velindre Cancer Centre, and it does amazing work, but we are talking about the actual plan and adherence to it and compliance with it. That is being described as inconsistent and patchy, and that there is a lack of adherence to it in certain quarters. How do you address those concerns?

[17] **Mark Drakeford:** The point that I think that I have read in the evidence is to do with inconsistent reporting of what health boards do against the national cancer delivery plan. We expect every local health board to produce its own local plan to reflect the work that goes on. A few months ago I met the all-Wales cancer network—I hope that I have that right. It is the

Wales Cancer Alliance: it is the 11 voluntary sector groups that come together in that alliance. I had a very good discussion with them there about the concerns that they had about variability between the plans. I asked them whether they would be willing to do a piece of work on our behalf, which is to go through all of the local plans and to provide me with an analysis of where they thought that plans were strong, and where they thought that there were gaps in them. I am very grateful because they have done that piece of work and they have sent me their views on it. One of the things that they suggest, which we will be working on—because we are almost in the third set of local delivery plans—is whether we can now draw together a stronger national template for those plans.

[18] **Janet Finch-Saunders:** And ensure adherence to it.

[19] **Mark Drakeford:** Yes, and make sure that we take the best from each one, because what they said in their note to me is that every local health board reports in the best way on some aspects of their work, but the health board next door would be reporting in a different way on something else. So, we can take the best of them all and create a national template, which we then expect local health boards to use in reporting. That will either demonstrate that it was reporting that that was the problem, or it will drive out the fact that some things are not happening everywhere as they should. I think that we will be able to make more use, and more powerful use, of those plans if we do them in that way.

[20] **David Rees:** Elin is next.

[21] **Elin Jones:** I may not be as convinced as you are that local health board plans are the way to do this, and I am still reasonably convinced that they do not actually marry up to the cancer networks and the cross-local health board border cancer reality pathways that happen, but you say that local health boards report on their cancer plans. Do you think that the structure in place in terms of reporting and accountability with regard to the delivery of the local cancer plans is clear enough for you as a Minister to know where it is happening, who is driving it and who is driving that consistency? I do not think that we have been convinced that the cancer implementation group knows that that is part of its job or whether it is part of its job. It is not clear enough where the drive for local health boards comes from to implement the all-Wales cancer plan.

[22] **Mark Drakeford:** I think that that is an important question. The answer may be a little more complicated than it might appear, and part of the complexity is why it is not always as clear as it might be, because my answer to that is that there is no one place where this responsibility is located. It is a shared and dispersed responsibility. The primary responsibility of local health boards for their services is to their own local population, and I do not want health boards always looking up to somebody apparently above them and reporting to them to find out whether they are doing the right thing. They also need to make sure that they are reporting to their local population, and by that I mean both their clinical population—. They need to make sure that their local cancer plan is one that their local clinician population takes responsibility for and that it has a role to play in taking up issues with the local health board if it feels that the plan is not working in the way it should. They have responsibilities to their local population, and there are ways in which the local population, I think, needs to be engaged in those plans, both through their community health councils and the local groups of the different components of the Wales Cancer Alliance.

[23] One of the reasons I think the cancer alliance was able to do a quick and, I think, effective job of reviewing all the local health board plans is that it has local groups in all the health board areas that it was able to mobilise to look at those plans. We need to have a better sense that health boards are responsible to those local populations and their plans are actively considered by those groups and that, if local populations do not think that health boards are supplying a service of the sort they would wish to see, they put pressure in the system locally.

However, then, there is a role both for the implementation group, as the overarching national group, and then, through it, for Welsh Government to make sure that, particularly on the cross-border issues that Elin rightly highlighted, we have a national view of it as well. However, there is not just one spot on the map where you can say, ‘All the responsibility rests there and that is where it should be discharged’. There is a dispersed responsibility, and we need all aspects of the system to be discharging those responsibilities to make these plans as good as they can be.

[24] **David Rees:** Leighton is next.

[25] **Leighton Andrews:** I accept that, but if you take some areas—and I hope that I get this right—such as neuroendocrine tumours, NETs, there are very limited areas of expertise within Wales. In fact, as I recall, there is a leading consultant in Cardiff who, until recently, was able to support patients in Cwm Taf as well as Cardiff and the Vale but is no longer able to do so simply because of pressure—perfectly understandable reasons. That suggests to me that, in the area of cancer specifically and in particular with some very hard-to-diagnose and hard-to-identify cancers, you actually need a lot more national input and determination, strategically, than you do with more routine, acute or other chronic conditions. I just want to ask about that.

[26] **Mark Drakeford:** I will probably ask Dr Jones to say more on this, but I think that the picture is this: most cancers occur at a population-based level that means that local health boards have to provide that service. So, breast cancer, cervical cancer, lung cancer—these occur with a frequency that means that local health boards have to be able to provide a service on that population basis. There are—and it is an important point, I think, that Leighton was making—rarer forms of cancer, and local health boards will never be able to run a service themselves to respond to the small number of people who will get them.

09:30

[27] The Welsh Health Specialised Services Committee is the mechanism that we use to commission services for people who have those rarer forms of cancer. It is owned by the health boards and its committee is made up of the chief executives of health boards and it is its job to make sure that there is a service available for people who cannot be served. So, in that sense, there is already a national approach to those things, but Chris will tell you more.

[28] **Dr Jones:** I would say that the cancer implementation group itself represents a strengthening of a national perspective, but also I think that it serves to connect a number of other national systems in the sense that it receives advice on cancer from the National Specialist Advisory Group for Cancer, and I would expect that group to provide advice about the pattern of services that should be available for the diagnosis and treatment of neuroendocrine cancers. It then discharges its responsibilities to health boards, but in many cases, particularly where there is a network aspect, through the networks. So, the networks, in a sense, become like the operational arm of the cancer implementation group and, again, if there is an issue about one health board not being able to provide a service that another should provide, I would see that as a network issue, but it can be accelerated or escalated, if necessary, to the cancer implementation group, which can consider whether it needs to be dealt with elsewhere. So, if it is a WHSSC issue and WHSSC is not sighted on an issue, then the cancer implementation group can link to WHSSC. If it is for the south Wales collaborative working to consider this in the service planning and service-change-type context, then it can talk to that context as well. However, it connects up a number of national perspectives. So, issues like that should be effectively dealt with.

[29] **Kirsty Williams:** Are you satisfied that the attitude that WHSSC takes to commissioning these types of services for those with rarer cancers is as robust as it should be

and therefore offers equity of quality treatment in how it commissions those services? Neuroendocrine tumours are a very good example of where WHSSC does not commission a Wales-wide service. Those who are lucky enough to live in Cardiff and in the Cardiff and Vale area get access to a very expert service and those in north Wales get access to an expert service in England, but if you live in Cwm Taf or Swansea or Powys, it is hit or miss in terms of the nature of the service that you would receive. I am just wondering how robust you think WHSSC is in commissioning those services for rarer cancers. We know from the cancer survey that the rarer your type of cancer, the less likely you are to be satisfied with the quality of your treatment, so that suggests that we have an issue here about how we deal with people with rarer cancers or those who require specialist treatment that may or may not be available inside or outside Wales, and I am not referring to untested drugs, but to procedures such as radiotherapy that have been signed off by the National Institute for Health and Care Excellence as being effective treatments. How convinced are we that what WHSSC is doing is robust?

[30] **Dr Jones:** WHSSC does have a list of special conditions that it acts as a commissioner for. I think that that list can be revisited at any time. The rare diseases plan is very significant in that respect because I think that there are a lot of actions in that plan for WHSSC, as part of a broader community, in terms of how we deal with these conditions. I find it difficult to know how to judge how effective WHSSC is. I am not sure that neuroendocrine tumours are an issue for WHSSC at present. They are not on the WHSSC list—

[31] **Kirsty Williams:** No, they are not.

[32] **Dr Jones:** —so, I think that one would want to know whether the other mechanisms, which are the cancer networks, the cancer implementation group and the advisory structures, would be effectively dealing with these issues.

[33] **Leighton Andrews:** Could I make a suggestion?

[34] **David Rees:** Kirsty, do you want to come back on that?

[35] **Kirsty Williams:** No, let Leighton make his suggestion.

[36] **Leighton Andrews:** I would like to ask the Minister whether he could go back to look at—[*Inaudible.*]—in particular and use that as a test bed in respect of WHSSC's responsiveness because I am getting representations from Cwm Taf Local Health Board on this issue and we have had representations from patients in the course of—

[37] **Mark Drakeford:** I am very happy to look at that.

[38] **Leighton Andrews:** Whatever the appropriate structure is—

[39] **David Rees:** I think that the question from the Member effectively is that this is an example of the need to look at particular types of cancers, and how the robustness of addressing those cancers across Wales and the parity of experience is being addressed.

[40] **Mark Drakeford:** I am very happy to look at that and to supply a note to the committee on that particular issue. In relation to Kirsty's actual question, which is whether WHSSC is an effective commissioning body for those rarer forms of cancer that Leighton referred to, which are beyond the ability of local health boards, I recently had a sort of exit interview with the outgoing chair of WHSSC, Professor Mike Harmer, the former deputy chief medical officer. It was a frank interview in which he pointed to a range of things that he thought that WHSSC needed to attend to and do better. He told me that he thought that the

part of WHSSC's work that it was genuinely good at was its ability to commission effectively for those rare forms of conditions on an all-Wales population basis. He said that he thought that it had genuine expertise in that area and that it was able to commission effectively clinically. He said that it knew the sort of service that it was looking for and that it had a good idea of where that service would best be secured across our border for Welsh patients in terms of the quality of the service and the accessibility of the service. He said that if he was looking at a sort of strengths and weaknesses analysis of WHSSC, he would have put that part of its work in the 'strengths' side of the equation.

[41] **Kirsty Williams:** In that conversation, did you have any discussions about the ability of WHSSC to horizon scan and proactively look at commissioning new treatments and services and then implement those services in Wales, such as peritoneal surgery, for instance, which we are currently sending people to England for? Wales certainly has the medical expertise to deliver that service in Wales, and indeed could deliver it not just for Wales but for the south-west of England as well, because it does not have a service. There are people wanting to do that but they simply cannot find a way through the system to get someone—WHSSC, probably—to proactively go out to look at how we can secure that service for Welsh patients within Wales. Do you think that it is good at being proactive in looking at new treatments that we can commission?

[42] **Mark Drakeford:** I did have that conversation with Professor Harmer. I am glossing slightly here now, really, but I think that he would say that WHSSC does make efforts in that area but that it is not as—. I do not think that he would claim that it was perfect in any way. I think that one of the things that he would have said to me was that one of the difficulties is the rapidly changing nature of some of this. Something that looks to be on the far horizon today—. The situation can change pretty quickly because a new development happens, a new technique develops, or someone is recruited to come to work in Wales who is able to do things that no-one could previously do. The picture can change very quickly. Horizon scanning is quite a hard thing to do successfully.

[43] **Kirsty Williams:** I have one more question.

[44] **David Rees:** I will come back to you on that point, Kirsty. Darren is next.

[45] **Darren Millar:** I just wanted to pick up on what has been a theme, certainly for the patients that we met in focus groups, namely the concern about the length of time that it takes to secure a diagnosis, sometimes, for cancer. It seems to me that there are three issues that patients are particularly concerned about. One is patient education and another is GP training, and their ability to spot the symptoms of cancer. It seemed that many patients showing some symptoms were attending a GP appointment three, four, five or even many more times. Another concern, of course, is the delay in being able to access a diagnostic test. I appreciate that, in addition to those, you have the screening programmes across Wales, all of which are missing their targets at the moment, although the cervical cancer screening programme is just below it. I just wonder—I can see you pulling a bit of a face there. You mentioned the standards in your paper, Minister, in terms of the cancer targets. You seem satisfied that the standards are being met, but, actually, the national cancer target for breast cancer, for example, is 80%, but Public Health Wales told us that just 71.5% of people are screened. It told us that, for cervical cancer, there is an 80% target, but that it is just under that for the percentage of people being screened and that the figure for bowel cancer is 48% compared with the national target of 60%. I just wonder what specific action you are taking on those fronts: so, on patient education; GP training and refreshed GP training on a regular basis, because it appears to be inconsistent in different parts of Wales; direct action to drive up screening rates, particularly in some of the deprived communities because there does seem to be a very clear link between deprivation and low take-up of screening; and, when it comes to diagnostic tests, we know that the waiting time targets are not being hit.



[46] You said that there has been an extra investment of £4 million in order to help health boards hit those diagnostic targets. That is welcome cash, of course. I do not know whether it is a one-off investment or whether you are robbing Peter to pay Paul from another part of the health service. However, it would be interesting to know how you expect that to meet the demand in future and improve capacity in the longer term, given that it appears to be a single slab of cash.

[47] Finally—I know that this is a lot of questions wrapped up—

[48] **David Rees:** I will come back to you. Give him those questions first. I will come back to you.

[49] **Darren Millar:** Well, it may help the Minister to piece it all together. The one final bit is that, obviously, there is the urgent cancer waiting time target for a diagnostic test, which is 62 days. The longer target is eight weeks, compared with a six-week target in England. Is there any reason why we have a different target? I know that both targets are being missed, but is there any reason why we have a different target?

[50] **David Rees:** I think that you have had a lot of questions there, Minister.

[51] **Darren Millar:** It is all about diagnosis.

[52] **Mark Drakeford:** I will try to say something briefly on each of them and then colleagues will want to add to that. Patient education is a very important part of the cancer pathway. We know that probably the single largest difficulty in getting effective cancer treatment is late presentation by patients, and there is more that we have to do to try to persuade people on two scores. First, there is the whole prevention agenda. We know that lots of cancers need never have happened. So, everything we do on smoking cessation and so on is part of that patient education effort. However, we also need to do more to try to make sure that there is an authoritative place that patients can go in order to get information and advice. One of the things that the cancer implementation group is looking at this year is whether we should develop a single cancer hub for Wales, which would have the NHS guarantee with it. We all know that people go to the internet and all sorts of information pops up, but you have no way of knowing whether this is reliable, tested information or whether it is just someone's hokum hobby-horse that you are reading about. So, the idea of a single cancer information hub for Wales is that, if you went there, you would know that this was the best available advice and that it came tested through the NHS so you could rely on it. That is something that the implementation group is hoping to work on this year.

[53] On GP education, I must say that I think that it is a responsibility, a professional responsibility, of GPs to ensure that they keep their education up to scratch. I was a bit disconcerted by some of the stuff that I saw that the royal college had said to you, as though GPs themselves had no responsibility for ensuring that they had up-to-date information and education. There is a lot of material available to them. There are many online courses that GPs can take. There is a lot of extra attention on the cancer pathway through the new GP contract. However, to take the point that Darren said that patients had mentioned—people anxious that they were not being referred into the pathway quickly enough by GPs—in some ways, I think that the evidence does not bear that out. Of the 100 people who are referred by GPs under the 62-day urgent suspected cancer route, somewhere between 5% and 10% will turn out to have cancer. So, more than nine out of 10 of the people that GPs are sending in to the system—thank goodness—turn out not to have cancer at all.

09:45

[54] That does not suggest to me that GPs are, somehow, hanging back with regard to sending people through the system, because the vast majority of people they refer turn out not to have cancer at all. So, they seem to me to be pretty willing to refer people through the system when they think that there is something that needs to be investigated. The number of people who are being referred through the 62-day pathway has increased hugely over the last five years. There has been a 16% increase in the last 12 months, and there is nearly a two-thirds increase over the medium term. So, more and more patients are being sent by GPs into the pathway. That is not to say that there is not more that we need to do to make sure that they are properly equipped, because early diagnosis is the best thing that can be done. So, it is a sign of success that there is this huge increase in the number of people coming through the system. However, I believe that it shows that GPs are alert to it and doing a reasonable job.

[55] In the diagnosis sphere, we have put both capital and revenue into the system in order to bring down diagnostic rates. Members will be aware that the Minister for Finance yesterday made a statement in which she stated that £18 million of additional capital is being made available for health services this year, and that includes £2.5 million extra capital for diagnosis, on top of the extra capital that had been made available through the health budget. The capital money is a one-off, the revenue money is for recurring services. I expect to have detailed plans from all of the health boards within the next couple of weeks that will show me how that extra money is to be deployed. I am looking to them to provide plans that give me confidence that, with the extra money that they have and with the extra capital that will allow them to invest in services, we will see a real, rapid diminution in the number of people who are waiting for more than eight weeks.

[56] **Darren Millar:** I would like to pick up on a couple of those points. You mentioned that only between 5% and 10% of those people referred as urgent actually turn out to have cancer and, therefore, that gives you some assurances that people are being referred sufficiently quickly. However, with regard to the 5% to 10% how many times have they visited their GP? Do we have any way to measure that? Would it not be useful to find out precisely how many times they have had to visit their GP prior to having a referral? That is the real test here, is it not? It is not actually the proportion of people who turn out to have cancer; it is what proportion of that 5% to 10% have actually presented to their GP and on how many occasions they have presented to their GP prior to be referred into the pathway.

[57] Secondly, in terms of the 16% increase in referrals to the urgent pathway, do you not accept that part of that will be as a result of the very long diagnostic waiting times in the first place? GPs are simply trying to ensure that there is rapid access to a test, in addition to the general demographic pressures across Wales. So, I cannot see, Minister, how you can have those assurances without having the data available to you to say very clearly that, when people are diagnosed, they have had one, two, three, four, five, six or however many visits to a GP. We know that people are turning up much more regularly in accident and emergency departments with advanced cancer these days—that is the evidence that has been given to the committee. It is much more than it used to be. I am not quite sure why that is, but clearly we need to understand that a little bit more in order that we can help to prevent some of the unnecessary pressure on our unscheduled care services in our hospitals. So, I am not quite sure that you are measuring the right things in order to give yourself the assurance. Do you accept that there needs to be better measurement?

[58] **Mark Drakeford:** I will probably ask Dr Jones to deal with the question of whether it would be a sensible use of the system to measure how many times people have been to their GP beforehand. However, Darren is trying to have it both ways—not, maybe, unexpectedly. In the first question, he wants to suggest that people are not being presented quickly enough and he then wants to say that the reason that there is a rise in the number of people going into the 62-day pathway is that people are coming in very quickly.

[59] I will just take the second one, because I think that the suggestion really does not bear any examination. Of the people who are referred on the 62-day pathway, more than nine out of 10 will be seen within 62 days. So, the idea that they need to be referred quickly in order to get over delays in diagnosis really does not stand up to any sort of examination, because they are being seen very quickly indeed. Interestingly, when I was in Velindre Cancer Centre on Friday of this week, Professor Rosemary Kennedy, the chair of the board, was explaining to me that they had recently done a piece of work with people who have been through the Velindre system, asking patients about their own experience. One of the strong themes coming back from patients, she said, who have had the treatment now and are out the other side of it, is that, in quite significant numbers, they say that they felt that their experience was rushed. They wished that they had had more time along the pathway to pause, ask questions, find out what was happening, and make different sorts of decisions. Our system is designed to be quick, however, and there are very good reasons why it is, but for some patients, it was quite a theme, she said—it feels like you are being pushed along a pathway in which speed is more important than individual patient experience. I will ask Dr Jones about the issue of GPs and referrals.

[60] **Dr Jones:** If I can comment on the GP visits issue, and also perhaps on the staging issue at diagnosis, I do not feel that counting the number of times that someone sees a GP would necessarily be a useful quality marker, really, because I think that it depends on how valuable those visits are and what is done during the visits. So, if the GP has done the right tests and investigations and has seen the patient frequently over a short period of time, you might expect there to be quite a lot of visits. If someone is being properly worked up for an early referral, I am not sure that seeing someone more than once or twice is necessarily a bad thing. So, I am not sure about that. I think that a more rounded approach is in the more reflective approach that is now being introduced into the GP contract, which is that, when someone does present with a cancer, the GP at locality level reflects on the process that led to that diagnosis. That is in place now for lung cancer and gastrointestinal cancers. I think that that might provide a more rounded approach. It may actually be a reflection of the way in which the patient presented, the way that the surgery responded and a discussion about that. I think that better learning would come from that approach, personally.

[61] However, I agree with you on the second point, about staging. We do want to drive down the proportion of patients whose diagnosed cancer is at a later stage. So, the first stage in that is to measure the staging at the presentation. One success of the cancer implementation group over the last year has been to see a significant increase in the percentage of patients diagnosed with cancer who have their staging recorded on CaNISC; actually, I think that we are now recording this stage on diagnosis in around 73% of people, which is the highest of all the UK countries. That represents a very significant increase over the last year. It is only when we have that measure in place as a baseline that we can start to drive down through transformed services the percentage that arrives with a late-stage cancer, because I agree with you that we want to drive that percentage down.

[62] **David Rees:** I am going to want to move on; the Minister is only here until 10.15 a.m.

[63] **Darren Millar:** Yes, but there are still two questions.

[64] **David Rees:** I will come back to you, if there is a chance. I have Lynne on this point.

[65] **Lynne Neagle:** I was just interested in what Dr Jones was saying about the local GP learning experience based on where they evaluate how they handled particular cases. I was just interested in knowing a little bit more about that, to be assured, really, that GPs would not learn from it and then not do anything about it. What sorts of checks and balances are in place to ensure that, if patterns of problems are identified, they will be tackled?

[66] **Dr Jones:** Although I recognise that that is a clinical question, I think that the Minister and Grant may be better placed to address it, in many ways, because they have been working on the contract more closely.

[67] **Mark Drakeford:** This year's contract requires that, for this calendar year, all cases of lung cancer and gastrointestinal cancer will have to be reviewed in every practice. That is the first time that we will have done that, and we have chosen lung cancer in particular because we know that it is a particular area of concern in Wales. So, every case that is identified in that surgery will have to be reviewed during the year, and the checks and balances in the system, I think, will come through the clusters. You will know that the other big change in the GP contract for this year is that GPs have to meet at least four times a year in these new clusters. There will be 64 clusters across Wales. The point is that, if I am a GP in one surgery and we have one pattern, and you are coming from a different surgery and you have a different pattern, there is a clinical opportunity for people to share that information. The idea is that I would not want to be the surgery that had figures that looked like they were not as good as they should be compared with everyone else in the cluster. So, there is a bit of peer review in it all, which we think is one of the key ways in which you get professionals to attend to their practice, to learn the lessons from the reviews and to do things better from that point on. So, every practice must do this, every practice will then be part of a cluster and that cluster will act as a peer review mechanism to drive up performance, and not allow it just to be some interesting information that you do nothing about.

[68] **Lynne Neagle:** You do not think that there is a danger there of cosiness and everybody sort of—

[69] **Mark Drakeford:** Personally, I am very committed to peer review. I think that it is a very strong mechanism for ensuring improvement, but it must have some grit in it as well, otherwise, the danger is, 'I don't criticise you if you don't criticise me'. So, the clusters themselves will be reporting beyond them, so there will be another tier where we can make sure—. All health boards have primary care advisers and things through which they will supervise the work of the clusters. However, it is a danger.

[70] **Dr Jones:** Could I just comment? That type of mechanism helps to create a spirit of openness, because the last thing that one wants if something has gone wrong in a practice is for that practice to close ranks, to keep it within the practice, not really to learn from it and share the learning. So, I think that this visible sharing of experience creates an open culture in which improvement can flourish. I think, also, that the measures that I describe around the staging and diagnosis can, in time, be measured at cluster level as well. So, we can start to assess and think about how we gain some assurance about the impact of this proposal.

[71] **David Rees:** I have Leighton on this point.

[72] **Leighton Andrews:** I think that what you are doing through the contract to measure those two areas of cancer is really interesting. How are you going to report that information back at an all-Wales level and how quickly will you be able to do that?

[73] **Mark Drakeford:** It is for this calendar year, so it is every case in this calendar year. It will be into next year by the time that all those data become available. We will aggregate the data up through the clusters and then to the all-Wales level. It will certainly be of interest to the cancer implementation group, but because the contract is so different this time and because we are keen to learn whether we are getting the value from the contract that we hope to get, then the chief medical officer herself will be looking to see whether we are getting information through it that allows us to make conclusions at that all-Wales level.

[74] **Leighton Andrews:** Is the technology in place to allow you to do it swiftly—in real time?

[75] **Mark Drakeford:** I could find out. I do not know the answer.

[76] **David Rees:** We have questions now on some other areas from Rebecca, Lindsay, Kirsty, Elin and Lynne—you can see that you have got a lot of questions coming.

[77] **Rebecca Evans:** I wanted to ask you about cancer research, because we have heard a great deal about that during this inquiry. What action are you taking to ensure that research is or remains high on the agenda and that it is being planned in a strategic way, in collaboration with service delivery and your key priorities?

[78] **Mark Drakeford:** I will answer this very briefly, given that there are more questions, and then ask Carys to give you some of the detail. There are 408 open, high-quality clinical trials in Wales today; 38% of those are in the field of cancer. So, cancer research and the applied nature of cancer research, is a real strength of the Welsh NHS. All the guidance that NICE provides in the cancer field is produced at Velindre for the whole of the United Kingdom, so we have some real strength in this area, and we are very keen to preserve and promote them for the future. Carys will tell you a bit more.

[79] **Ms Thomas:** On top of that, there are very impressive figures: 18.7% of people with cancer are recruited into clinical trials. That is a very impressive rate compared with that of other disease areas.

10:00

[80] However, in terms of answering your question more directly, NISCHR, in Welsh Government, is one of the 22 partners of the national cancer research initiative, which is a UK consortium of 20 key funders in cancer. So, we are talking about the Medical Research Council, Cancer Research UK et cetera. This is a really important forum for setting direction and making sure that the money that goes into cancer research across the UK is used to the maximum effect. It also enables us to bring cancer funding for research into Wales. There are a number of levels to the way that the initiative works, and a lot of our cancer researchers, our leading researchers in cancer, play into different fora to try to drive the UK agenda.

[81] **Rebecca Evans:** We had some concerns raised with us that the restructuring of NISCHR would have a negative effect on clinical trials and on tissue donation targets. Could you respond to that and perhaps comment on whether you would intend to maintain funding in this area?

[82] **Ms Thomas:** Currently, the NISCHR restructuring is definitely a live issue. The way that the restructuring is planned strategically is that it is meant to make more streamlined and cohesive the way that cancer research and research generally are organised in Wales. NISCHR has no plans to reduce the funding for cancer research. However, a number of aspects of the NISCHR infrastructure are out for commissioning at the moment, and, in order to support the best research and the most excellent research, that is a competitive process and applications are being invited. We have encouraged a bid from the cancer research community, and I understand that this is working together at the moment. We are hoping to draw together some of the major initiatives where we have already put significant money into cancer research. That includes the cancer research group, for instance, on palliative care, the cancer bank and many others. We are bringing together the cancer researchers to outline their priorities. Obviously, there will be a competitive process, which will take place in the autumn.

[83] **Rebecca Evans:** Okay, thank you. I have one more question, if I may. We know that

some changes are afoot on a European level in this area. What impact do you think those might have on our ability to undertake research in Wales?

[84] **Mark Drakeford:** I thank Rebecca for that question because there are some very significant changes currently being negotiated at a European level, which are of real concern to us in Wales and to the UK as a whole. They are data protection regulations that have been worked through at a European level. The draft regulations were ones that the UK Government supported, and so did we. However, the Parliament has recently amended those regulations significantly, particularly articles 81 and 83, which, if they go through as currently formulated, would make much of the research that we do in Wales at worst illegal and at best unworkable. So, we are working with the Ministry of Justice, which is the lead UK body, here in Wales to try to get some of those changes reversed. It is now at what they call the trialogue stage in Europe, so it is discussion between the Parliament, the Commission and the Council of Ministers.<sup>1</sup> We would be very happy, Chair, to provide you with a note on that, because I know that, in this Assembly, this committee has some responsibilities for European dimensions of health policy. If, when you see the note, you think that it is something on which you would be willing to write to the Ministry of Justice as well, I think that that would be very helpful.

[85] **David Rees:** We would be happy to receive that, Minister. Is that okay, Rebecca? Lindsay is next.

[86] **Lindsay Whittle:** Thank you, Chair. Good morning, Minister. Clearly, everybody here would agree that all cancer patients should have equitable treatment throughout the whole of Wales. However, we know that that is not the case. We have had evidence that that is not the case. Not everyone has a care plan. Not everyone has a key worker. In fact, I think that the evidence is that only 66% of patients have been allocated a key worker and 22% of patients have a care plan. I will not even go down the road of specialist care cancer nurses, because many of those are often acting as key workers as well. What are your plans to perhaps improve upon those figures? The recruitment and retention of key workers throughout the whole of Wales is another issue, if you have time.

[87] **Mark Drakeford:** Thank you, Lindsay. Briefly, 66% of patients in the Macmillan cancer experience survey said that they had a key worker, but 88% of them could name their specialist nurse. For some health boards, there has been a bit of a lack of clarity as to the distinction between those two roles. As a result of the study, work has gone on over the past few months and, within the next few weeks, we will issue fresh guidance to all health boards, giving a clearer definition of what the role of a key worker should be and who should be identified as one. Our ambition is that every cancer patient in Wales has a key worker and knows who their key worker is, and that the key worker takes an interest in clinical and non-clinical aspects of that patient's care. If you look at the survey, you will see that there is a strong correlation between satisfaction with the experience that you have as a cancer patient and having a key worker. They really do go one with the other. We want to drive up satisfaction levels even higher than they were in that last survey. Getting a better key-worker approach more consistently across Wales is a very important part of that. There is a lot of work going on with the third sector as well as with clinicians to try to make sure that that happens.

[88] You are right to say that there are some recruitment hotspots in the cancer field as well as in other places. The recruitment of radiographers is one of them. We have an annual commissioning plan for training the people that we need for the future, which includes radiography. We will be looking to see whether we can put more people into training so that we get more people out to work in the Welsh NHS.

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<sup>1</sup> The trialogue is expected to start in September 2014.

[89] **Lindsay Whittle:** What about the care plans?

[90] **Mark Drakeford:** In terms of care plans, 22% of patients in the cancer experience survey said that they had a written care plan, but 88% of them said that they had all of the information that they needed to help them with their condition as part of the treatment that they had. We want to raise the number of people who have written care plans. I just think that we need to be clear—it is not that only 22% of people have a care plan; everyone has a plan for their care, but did they have a written care plan in the format that the survey was describing? We want it to be more than 22%, but we do need to recognise that not everyone will want to have their information just in one set way. Some people will prefer to get the information that they need in a dialogue with their key worker, through discussion with their clinician, getting information that the third sector provides, and so on. It is an issue, and we need to improve the level. It is not identical to saying that if we had 100% written care plans, the whole issue of making sure that patients have the information that they need would be solved.

[91] **Lindsay Whittle:** Okay. I will not pursue it any further at the minute.

[92] **David Rees:** On that particular point, Minister, you highlighted the concerns about some people wanting to take a bit longer and to have more time to think about the issues. For example, I have friends who have raised the point about consideration and thinking. When you get a diagnosis, you do not necessarily hear everything that is being said. Surely, we should be looking far more, again, for some form of written care plan, on a wider basis, to ensure that people have an opportunity to digest the information and everything else.

[93] **Mark Drakeford:** You make a very important point, Chair. Probably all of us have had letters from people asking, ‘Why wasn’t I told something at certain points?’. When you go back through the history, what you find quite often is that people were told, but they were told at a point where it was impossible for them to hear or to retain the information that they were given. These are very traumatic experiences for people. Therefore, a lot of work is going on, and our third sector colleagues are particularly good at some of this: trying to make sure that we provide information to people in a way that does not require them to look at it there and then, and that they can take it away with them, reflect on it when the moment is right for them, or that they can be signposted at that point to the information that they will be able to use in the future. We have learned quite definitely that it is not enough simply to tell someone something and assume that, because you have said it, they have heard it, and even if they have heard it, there is a question as to whether they will be able to retain it for the day when it will be useful for them.

[94] **David Rees:** Okay. I have Kirsty next.

[95] **Kirsty Williams:** Minister, I appreciate that the consultation on the individual patient funding requests review only closed this week, but when will you be in a position to bring forward action to improve the quality of the IPFR process? Consistently throughout this review, we have had ongoing concerns about how that system works. Have you closed your mind to a national system for individual patient funding requests, or have you given any consideration to a more clinically led system, perhaps akin to what they have in Scotland, where clinicians certainly seem to be much more at the fore of making decisions about novel drugs and access to them?

[96] **Mark Drakeford:** I have not closed my mind to anything, as yet, because, as Kirsty said, the consultation is just about to end. I did ask the expert panel that drew up the report to look very specifically at the issue of a national panel and you will know that it rejected that idea; it did not think that that was the best way to achieve what we all want to achieve, which

is greater consistency of decision making across Wales. It suggests a different way of doing it, which is that we should make better use of the All Wales Therapeutics and Toxicology Centre, which is the operational arm of the All Wales Medicines Strategy Group and where the AWMSG gets all of its advice.

[97] What the report says is that all of the decisions that are being made at the individual panels should be reported through the centre. That would mean that the centre would be able to spot much more quickly than we have in the past those drugs for which there are multiple applications going through panels, and where using the IPFR route might not be the most sensible, because if that drug is being approved that often, the idea that it is exceptional begins to break down. Therefore, what the centre will be able to do is identify those more quickly to get advice, through the AWMSG, so that it would cease to be an IPFR route and it would be made by clinicians using the advice that AWMSG will provide, so that clinicians know when that drug is likely to be effective and the circumstances in which it would not deliver the benefits that were being looked for.

[98] I am going to look carefully at the responses to the consultation to see whether they support the view taken by the panel, or whether there are alternatives. I am hoping that, by the early autumn, we will be in a position to say something on that.

[99] **Lynne Neagle:** I was going to ask about key workers but, obviously, Lindsay has covered that, and I welcome what the Minister has said. May I just ask about screening rates? Obviously, we are performing well with cervical and breast cancer, but bowel screening, as you recognise in your report to the committee, could do with an improvement. You have said that Public Health Wales is looking at a strategy to improve that. Could you just tell us a little more about that and what sort of targets it is looking at?

[100] **Mark Drakeford:** Thank you, Lynne. It was a bit of a surprise to me, when I looked at some of the details, to find that the actual numbers of people who have bowel screening in Wales is three times the number of people who get breast cancer screening, for example, and one and a half times the number of people who have cervical cancer screening. About 325,000 men and women used the bowel screening service in Wales last year. So, the volumes are very big, but we are not hitting the 60% target, and neither is anywhere else in the United Kingdom.

[101] The performance of the screening service has improved over the last few months and it did hit 60% for the first time ever in February. The issue will be to see whether it can sustain that level. There is a very strong class and gender gradient in the use of that service, and it is, in the end, a voluntary service—all screening is. It is not compulsory for anybody. Men do not use it in the same rates as women do, and men in more disadvantaged communities are particularly hard to reach. That is what the Public Health Wales work is on. The people who run the service are incredibly committed to it. They are really keen to find ways in which they can provide a service in a way that would be more usable to more people. I meant to say, in answer to Darren's earlier question, that I am not sure that committee members are aware, but Public Health Wales recently provided written and oral evidence to the House of Commons Science and Technology Committee, which was doing an inquiry into screening across the United Kingdom, and I could make its paper available to committee members.

10:15

[102] It gives an overview of screening. It opens up an interesting debate about the harm that screening does, as well as its benefits. You know that in breast screening in particular, there is a pretty lively debate about whether too many women end up having surgery that they need never have had, although the Michael Marmot review of 2012 is clear that screening



does more good than harm and, therefore, it is very important, but it also rehearses some of the steps that are being taken to try to improve screening rates in bowel cancer in particular.

[103] **Lynne Neagle:** So, in terms of Public Health Wales's action in this particular area, it will specifically focus its efforts in deprived communities.

[104] **Mark Drakeford:** It is able to analyse those places and people who take up the service, so that its efforts are concentrated on those places and types of individual who are not taking up the service in great enough numbers, and its actions are focused on those people.

[105] **David Rees:** We will take up your offer to provide a paper from Public Health Wales. I am conscious of the time. Perhaps you will also add into your note your views on bowel scope screening, because the evidence was provided as to that, and the resources that are available or will be required for that. I am conscious of the time for you; Elin has the last question.

[106] **Elin Jones:** It is okay; my question has already been asked by Kirsty. However, on individual patient funding requests, it has been a consistent theme in our evidence from patients, right at the start, and then from expert clinicians, that they can see no real benefit to having local health board decision-making panels as part of the process, and I do not need to repeat the issues about when decisions are different in two local health boards when it has been the same clinician writing the report for the individual patient request. Certainly, from my perspective, I cannot see the rationale for that kind of decision making by local health board panels continuing.

[107] **Mark Drakeford:** It is an important point, and it was part of the remit of the group that we set up. It is not that they do not agree that there is a problem, their solution to it is via this centre-reporting route, rather than by a national panel, but I am sure that Members will be able to look up the merits of either way of doing it, but both are intended to be a solution to the problem that Elin has articulated.

[108] **David Rees:** We have come to the end of this session. I know that you have another scheduled event. So, thank you very much for your evidence this morning, and we thank your team for attending. You will receive a copy of the transcript to check for any factual inaccuracies that you may identify. Thank you very much.

10:18

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

[109] **David Rees:** I invite Members to note the additional information that we have received from witnesses who attended our meeting on 8 May 2014 in relation to the inquiry into orthodontic services in Wales. Is everyone happy to note that? I see that you are.

### **Cynnig o dan Reol Sefydlog 17.42(vi) i Benderfynu Gwahardd y Cyhoedd o Weddill y Cyfarfod Motion under Standing Order 17.42(vi) to Resolve to Exclude the Public from the Remainder of the Meeting**

[110] **David Rees:** I move that

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

[111] I see that Members are content with that.

*Derbyniwyd y cynnig.  
Motion agreed.*

*Daeth rhan gyhoeddus y cyfarfod i ben am 10:18.  
The public part of the meeting ended at 10:18.*