



Cynulliad Cenedlaethol Cymru The National Assembly for Wales

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

**Dydd Iau, 12 Mehefin 2014
Thursday, 12 June 2014**

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

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

Aelodau'r pwyllgor yn bresennol
Committee members in attendance

Leighton Andrews	Llafur Labour
Rebecca Evans	Llafur Labour
Janet Finch-Saunders	Ceidwadwyr Cymreig Welsh Conservatives
Elin Jones	Plaid Cymru The Party of Wales
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

Yr Athro/Professor John Chester	Coleg Brenhinol y Ffisigwyr Royal College of Physicians
Dr Tom Crosby	Ymddiriedolaeth GIG Felindre a Rhwydwaith Cancer De Cymru Velindre NHS Trust and the South Wales Cancer Network
Emma Greenwood	Ymchwil Cancer y DU Cancer Research UK
Rachel Hargest	Cymdeithas Brydeinig yr Oncolegwyr Llawfeddygol British Association of Surgical Oncologists
Ailsa Hayes	Coleg Nyrsio Brenhinol Royal College of Nursing
Damian Heron	Bwrdd Iechyd Lleol Prifysgol Betsi Cadwaladr a Rhwydwaith Cancer Gogledd Cymru Betsi Cadwaladr University Local Health Board and the North Wales Cancer Network
Simon Jones	Gofal Cancer Marie Curie Marie Curie Cancer Care

Hamish Laing	Bwrdd Iechyd Lleol Prifysgol Abertawe Bro Morgannwg
Dr Ian Lewis	Abertawe Bro Morgannwg Local University Health Board
	Tenovus
Dr Sian Lewis	Bwrdd Iechyd Lleol Hywel Dda
	Hywel Dda Local Health Board
Linda McCarthy	Cynghrair Canser Cymru
	Wales Cancer Alliance
Susan Morris	Cymorth Canser Macmillan
	Macmillan Cancer Support
Dr Martin O'Donnell	Coleg Brenhinol yr Ymarferwyr Cyffredinol
	Royal College of General Practitioners
Dr Alison Parry-Jones	Banc Canser Cymru
	Wales Cancer Bank
Dr Martin Rolles	Coleg Brenhinol y Radiolegwyr
	Royal College of Radiologists

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

Helen Finlayson	Ail Glerc
	Second Clerk
Victoria Paris	Y Gwasanaeth Ymchwil
	Research Service
Sarah Sargent	Dirprwy Glerc
	Deputy Clerk

Dechreuodd y cyfarfod am 09:16.
The meeting began at 09:16.

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. We will be commencing our inquiry into the implementation of the cancer delivery plan from the Welsh Government. I welcome all Members and our first three witnesses. I remind Members that the meeting is bilingual; simultaneous translation from Welsh to English is available on channel 1 and amplification is available on channel 0, if you need it. I remind Members to turn off their mobile phones or any other electronic devices that may interfere with the broadcasting equipment. There is no scheduled fire alarm this morning, so, in the event of a fire alarm, please follow the directions of the ushers. I remind witnesses that the microphones will come on automatically, so there is no need to touch anything. We have received apologies from Darren Millar, but there is no substitute.

09:17

Ymchwiliad i'r Cynnydd Hyd Yma ar Weithredu Cynllun Cyflawni ar gyfer
Canser Llywodraeth Cymru: Sesiwn Dystiolaeth 1
Inquiry into Progress Made to Date on Implementing the Welsh Government's
Cancer Delivery Plan: Evidence Session 1

[2] **David Rees:** I welcome our first three witnesses: Dr Martin O'Donnell from the Royal College of General Practitioners, Professor John Chester from the Royal College of

Physicians, and Ailsa Hayes from the Royal College of Nursing. I welcome you all and thank you for the written evidence that we have received from all three of you. We now go to questions on that, obviously, because there are some issues that we wish to raise with you. We will start off with questions from Gwyn Price.

[3] **Gwyn R. Price:** Good morning, everybody. Could you tell me whether you think that the cancer delivery plan's aspirations are appropriate, whether Wales is likely to achieve its objectives, and whether you think that the Welsh Government has provided adequate strategic direction and leadership on this matter?

[4] **David Rees:** Shall we start off with Dr O'Donnell?

[5] **Dr O'Donnell:** That is quite a large question. With regard to strategic leadership, the health boards have been trying very hard to get the primary and secondary care interface working better. The move towards locality groups helps with this, and, especially with the recent changes to the GP contract, that should have reinforced that. Overall, the aspirations and aims of the cancer delivery plan are to be applauded, and the Royal College of General Practitioners would strongly support those. The difficulty is the capability and capacity for implementation. Unfortunately, within the primary care sector, we are currently facing a recruitment and retention crisis, and the capacity is somewhat lacking. So, strategically, I would say that the biggest problem has been the difficulty in planning the transfer of care from secondary into primary and community care and the ongoing support that is required for the increasing number of survivors of cancer. Once we have gone through the treatment phase, which tends to be, as the recent patient satisfaction report pointed out, 90% plus satisfaction, which is a high level, it is afterwards, in the aftermath, that the fall-out and the ongoing planning seem to be lacking.

[6] **Professor Chester:** First of all, I think that it is doing the right thing. It is aiming to do the right things to increase survivorship, effectively, by improving mortality. It is important that we get waiting times down so that people are treated adequately, but, of course, there is the important aspect of making sure that what we are treating is not so far advanced, either by preventing it completely, or by picking it up early, and I think that those are very important things. I would echo what Dr O'Donnell said: I think that the interface between primary and secondary care is crucial. It is not as good as it could be. That does not mean that it is not good in all sorts of ways, but it could even better, I think. One thing that came to mind, particularly when Dr O'Donnell was giving an outline there was around electronic records and communication. I am sure that most people here are aware of certain waiting time targets being hit and certain waiting time targets not, and I think that one of the ways in which we could improve that is around better communication. It is not that my side of things, Dr O'Donnell's side of things and Ailsa's side of things do not want to communicate; we do. It is about having the mechanisms in place and having structures that are shared, and I think that there is some way to go with that.

[7] I am very much on the therapeutic side of things rather than prevention or early diagnosis, but, certainly, the field that I work in uses a lot of expensive drugs, and having a reliable, robust system for ensuring equity of access to those things would be a good thing. I noted with interest a document just a week or two ago suggesting that the seven different health boards and trusts should retain different panels. My personal view, and I have not had a chance to consult widely with my colleagues, is that a more unified approach would probably be better for the patients of Wales, by having a more transparent, standardised process with more clarity. I am sorry, but I have forgotten the very last aspect of your question.

[8] **David Rees:** I think that you have actually answered several points that I am sure will come up in other parts of the questions.

[9] **Gwyn R. Price:** I think, Chair, that I will not expand, because I would perhaps take other Members' questions if I did. However, the aspirations are there and you are going down the right road, but you are not sure, really—there are a couple of things that might get in the way.

[10] **Professor Chester:** There is always room for improvement.

[11] **David Rees:** What about Ailsa, from the Royal College of Nursing?

[12] **Ms Hayes:** I am also representing Velindre Cancer Centre; I am based there. Certainly, the challenges that we have are crossing boundaries and making the patient the centre and the most important person in the process within the complex therapies that we offer and the complex cancer journey. To have guidance regarding that is really important. As nurses, we struggle in ensuring that patients have access to clear pathways between all the health boards and given the complexities of care. Nurses have a major part to play in that. So, the plan definitely gives guidance to us and gives us some credibility; it recognises that clinical nurse specialists have a major part to play in cutting through boundaries and making sure that the patient accesses care quickly. It is a great aspiration. Again, as my medical colleagues have alluded to, we also struggle with funding and recognition of the value of specialist nurses within that process, and that is an ongoing challenge. The complex cancers that we sometimes deal with do not fare as well with within the cancer experience, and the survey showed that. I am sure that you will have evidence later regarding that. It is great to have the aspirations, but the recognition of the expertise that nurses can offer to the process is not always recognised, and it is hard to ensure that that is measured and valued as such.

[13] **Gwyn R. Price:** Thank you.

[14] **David Rees:** I have questions from Janet, and Lindsay to follow.

[15] **Janet Finch-Saunders:** Thank you. Good morning. I think that we are all agreed that the plan is a good plan, but a strategic plan is only as good as how it is interpreted and delivered. Macmillan Cancer Support has raised concerns about low compliance with the commitments of the plan. How do you feel that we should be ensuring that people really do get it, understand it and actually seek to deliver it?

[16] **David Rees:** Who wishes to take that?

[17] **Janet Finch-Saunders:** Oh, and also the second part of Gwyn's question was—

[18] **David Rees:** You can come back to that one—

[19] **Janet Finch-Saunders:** It was whether the Welsh Government has shown enough strategic direction and leadership.

[20] **David Rees:** So, the question is: has the Welsh Government shown the leadership you would expect in relation to the plan, how should this be implemented and what about the issues you feel—

[21] **Janet Finch-Saunders:** And strong compliance with the plan. It is pointless just writing up plans if—

[22] **Professor Chester:** Do you have any particular aspect in mind? I am not aware of the particular aspects that—

[23] **Janet Finch-Saunders:** Well, Macmillan has stated that there is low compliance with

its commitment.

[24] **Professor Chester:** Okay. I might try to generalise rather than sticking to Macmillan, if that is all right, because I do not know the particular things—. My guess would be that they were in the palliative care sector.

[25] **David Rees:** That is all right. Macmillan representatives will be coming in afterwards so they can answer that.

[26] **Professor Chester:** How is compliance? I think that, on many things, the compliance is good. On cancer waiting times, for example, the targets are met for one of the two major measures. It is not met quite so well for the other. One thing I would probably pick up on is the patchiness, for want of a better word, between the different health boards in the sense that only one or two of the six major health boards meet the targets either consistently or comfortably. I guess that, if we are wanting to talk about strategic direction from the Welsh Government, I would probably be in favour of what I would call a joined-up approach, a genuinely national approach, so that best practice is shared and so that each of the health boards does not try either to reinvent the wheel or interpret things in its own way so that there is a clear direction on the best way to do things and how we can ensure equity of access so that all patients, wherever they may be and whichever health board area they may be in, are getting the best possible approach. I do not know whether that answers the kind of thing you wanted to know.

[27] **Janet Finch Saunders:** Yes, it is just about how we can—. Many plans and strategic documents come through here, but this one is a very important one and it is concerning when you read that there is low compliance, and you think, 'How on earth are you going to meet the full compliance by the delivery date, as such, if it is highlighted now that there are concerns about low compliance, and what we can do about it?'

[28] **David Rees:** I think, to be fair, on the question on compliance, we will ask Macmillan. However, do you have any concerns about whether compliance is being achieved or the levels of compliance?

[29] **Professor Chester:** I guess that the thing that would come to my mind in direct answer to that would be around the field of acute oncology, which is somewhere where Ailsa and I interact fairly regularly. That is very different between the different health boards. There is only one health board that hits all its waiting time targets, and that may be related to acute oncology, which, for those who do not know, is about dealing with cancer patients who come in acutely ill either because of something to do with their disease or something to do with their treatment, patients who are newly diagnosed and patients who have rare, unusual or unidentified cancers. It is really important that we act quickly, either because somebody is acutely sick or because somebody needs to be moved very quickly into a management pattern, and the health boards are very different. In south-east Wales, things are done differently to how things are done in south-west Wales. They are not necessarily done the same way, and that sort of ties in to the point I was trying to make about having a uniform approach and making sure that everybody can get the same standard of care.

[30] **Ms Hayes:** I am very much part of one of the leads of the acute oncology service and I have a lot to do with the health boards as the service is developing. We have just had a fantastic experience with the Aneurin Bevan health board, where we are seeing patients coming through accident and emergency departments much more quickly, having their treatments more quickly and being identified with complex cancers. Again, it is cutting the barriers to the person coming through the front door of A&E getting through to cancer expertise. It is superb, a great model, and they have done amazing work between Velindre and Aneurin Bevan. Elsewhere, we are not seeing that. I believe that it is all work in progress. I

understand as well that, in Wales, it is unfunded whereas, elsewhere, it is funded. So, we have to create models about streamlining services, putting the patient in the centre and getting them through to expertise very quickly. So, every area is at a different stage of that process. They are very different health boards with different problems, so we need to work together, and I agree with Professor Chester about cutting through the barriers and taking a global approach to really encapsulate everybody to get the best, to get the patient through and to understand how each health board works. We have a long way to go but we are getting there and we are moving towards it. The difference that has been made by the acute oncology service is remarkable, but it is in only one health board at the moment.

09:30

[31] **David Rees:** Dr O'Donnell, do you want to add anything to that?

[32] **Dr O'Donnell:** I think that the strategic leadership part of it has perhaps been addressed by the Minister's recent statement with regard to the increase in funding that has been year-on-year attributed to cancer care, and the expansion of the cancer care services. That does not mean that more does not need to be done. The difficulty with compliance, in fairness, is the ability for people to access services—patients, and the citizens of this country have major difficulties in initial access. By that I mean that, sadly, as general practitioners, we would have to say that we are not in a position any longer to be able to offer the quality of service that our patients deserve. This is due to the fact that we have an increasingly aged population that, due to the advancing years, develops more complex needs, including cancers.

[33] Unfortunately, the GP workforce has remained virtually static over the last 10 years, since the change in the 2004 contract. The ratio of GPs to the population is 0.6—which is the lowest in all the four nations—per 1,000 patients, as opposed to our colleagues in hospital services who have a ratio of 1.9 doctors to 1,000 patients. Yet, primary care sees 90% plus of all patient contacts. Funding has greatly dropped in primary care, hence the royal college is pushing the Put Patients First campaign. In order to put patients first, we have to recognise that they wish to see somebody quickly and offer access, but if you do not have the people there, you cannot offer access. General practitioners are seeing 60-plus patients a day at the moment, and a 10-minute appointment is not enough to be able to deal with a complex presentation, to take a history—

[34] **David Rees:** I appreciate the issues of the GP; I am trying to focus on the cancer delivery plan as much as possible.

[35] **Dr O'Donnell:** However, a patient wishes to be able to come to see somebody quickly, to get referred, and if they cannot do that, and they have to wait a few weeks, then, unfortunately, we are in difficulty. We need an expansion to allow access to primary care services. Once in the system, the system is quite good. The referrals run through quite smoothly, according to our colleagues in secondary care—John, Ailsa, et cetera. The working together does tend to happen, and things move through quite reasonably once the initial referral—. The referral to treatment targets are pretty well met in most of the areas. So, overall, compliance is good, but access is, initially, poor.

[36] **David Rees:** Okay, thank you. I have questions from Lindsay and Rebecca. Is your question on this particular issue, Lindsay?

[37] **Lindsay Whittle:** Yes. Dr O'Donnell, you mentioned a recruitment and retention crisis in your opening remarks. I think that that was your word—'crisis'—so that set a little alarm bell ringing. What can be done to alleviate this crisis, because, with the best will in the world, you can have the best delivery plan, and you can have the best target, but if you do not have the specialists at the top, and the specialist nurses delivering—? Clearly, I guess that you

are going to say that it is all about money, but it is about money and training as well? That is important. It is then about equity of treatment. Professor Chester, you mentioned equity of treatment throughout Wales and sharing best practice. How is that done, please? So, I have two questions, sorry, Chair.

[38] **Dr O'Donnell:** With regard to the expansion and recruitment aspect, we have to make Wales a more attractive place for people—primary care and secondary care physicians—to work. In that aspect, there has to be some initiative taken on board to say that we actually need an expansion in training. That includes our colleagues in the Royal College of Nursing, because we need to expand our nursing workforce in the same way. They are becoming, like us, increasingly aged and top-heavy, and, unfortunately, they will fall off the list. It is very difficult to recruit younger doctors into the service, because Wales has increased rurality and difficulty in covering certain areas. It becomes less attractive to work in Wales. We need to be able to ensure that the more difficult-to-reach areas and patients have that access by taking any initiative that is required to make it feasible. Education is vital, but networking and support for physicians at all levels are essential; the more that that is done, the better.

[39] **Professor Chester:** There are two aspects there, I guess—the all-about-money aspect and the sharing-best-practice aspect. Of course, it is not all about money. It is partly about how we spend the money—do we spend it wisely and do we spend it in the most efficient way? Are we having people who are overqualified taking a job and doing a medical task that could be done by somebody else? I think that there are definite movements towards doing that kind of thing with what we call non-medical prescribers, for example in my field of chemotherapy. The other way around, do we have somebody who is not appropriately deployed? You touched on training there, so they either take longer to do the task or it has to be done again. We need to make sure that we are delivering things in the right way.

[40] With regard to sharing best practice, we have some really good examples of networking in Wales. The Wales cancer research network, which is largely about clinical trials, works extremely well. I am not saying that there is no scope for improvement, but there is definite sharing of best practice in those kinds of areas. It is not all about money, and more networking is never a bad thing in terms of sharing best practice; that would be the most straightforward answer that I could give you, I think.

[41] **David Rees:** Just to clarify that point, there are elements of good practice that we are starting to see, but not across the whole of Wales.

[42] **Professor Chester:** Yes; I do not want to seem to keep banging on about it, but acute oncology, as we said, is patchy. If everyone did things the way that they are done best in Wales, it would be a good step forward.

[43] **Lindsay Whittle:** That is quite interesting, because we will be questioning the health boards later. I will save my question for them. Thank you.

[44] **David Rees:** Rebecca is next.

[45] **Rebecca Evans:** With regard to the workforce issues with GPs, you can have as many GPs as you like, but if the skills, knowledge and expertise are not there to spot cancer and diagnose it at an early stage, then that will not have any impact at all on the delivery plan. We have heard evidence from Pancreatic Cancer UK saying that more than 40% of its patients visit GPs more than three times before a referral to hospital. In our round-table evidence sessions, we have heard from people who have gone into double figures in terms of going back to their GPs before a referral. How satisfied are you that the education and awareness are there among GPs to diagnose cancer early, and what is being done to improve

that?

[46] **Dr O'Donnell:** As I referred to earlier, the difficulty is in the amount of time that you have available for patients. If I have only 10 minutes to see you, take a history, perform an examination, find out the associated risk factors, document them and refer you through, if appropriate, for secondary care or for further tests—to facilitate an appropriate referral—the difficulty that I, as a general practitioner, face is that I am being tasked with reducing our secondary care referrals, so that we do not refer as many patients into secondary care. However, all of the sensible targets say that, with regard to cancer care, the sooner that you get in, the sooner the diagnosis is made, et cetera. You need to be able to justify why you refer someone. Often, trying to make a diagnosis is about finding the needle in a haystack. If you can make the haystack smaller by eliminating certain things, you are able to focus correctly.

[47] Pancreatic cancer, sadly, is one of the harder cancers to diagnose because it presents in a multitude of ways. It is about the difficulty in eliminating other problems. Do you investigate heart troubles? Do you investigate lung troubles? Do you investigate the stomach, liver or bowel, et cetera? Due to the increased specialism that is required for our colleagues in secondary care to be able to offer an exemplary service, we in primary care have to refer to the correct department. I would not wish to refer somebody to a cardiologist whom I suspect may have an abdominal problem, so I would do a work-up. Yes, I would bring a patient back on a couple of occasions to check their blood tests and to check their assessments, et cetera. Then, I would refer appropriately. Education is vitally important. The more that that happens, the better. Again, we talk about networking. Coming from secondary care out into primary care, a lot of our colleagues—including our nursing colleagues—offer brilliant education facilities. They come out and talk to general practitioners about the services that they offer, and about ability. However, there is a very large and complex network of education required. A general practitioner knows a little about a lot. Hospital specialists know a lot about a little. That is the difference. So, we need to keep knowing a little bit more about a lot.

[48] **Rebecca Evans:** Are there opportunities to learn more about cancer within the current structures of your continuous professional development, or does that need improvement? Also, does that rely on a particular interest in cancer on the part of the GP? As you say, there are so many different conditions to know about.

[49] **Dr O'Donnell:** 'Yes' is the simple answer to that. However, regarding CPD, the protected funding sessions are often directed by the local health board. It is only once a month that they are put on. Four of the sessions are normally attributed to the health board to direct what it wishes to have done and the rest are left to the practitioner and practices to facilitate. Once a month is not enough. Hospital colleagues, I believe, get at least a session a week for education purposes. Is that right?

[50] **Professor Chester:** In theory.

[51] **Dr O'Donnell:** In theory.

[52] **Rebecca Evans:** That is a whole other inquiry, I think. I have just one more question, which is on the awareness of the availability of diagnostic tests among GPs. We had some evidence that perhaps the awareness of the range of diagnostic tests just is not there among some GPs at the moment.

[53] **Dr O'Donnell:** I would have to agree with that. The biggest difficulty is knowing what is available in a specific locality. That is one of the reasons why locality, development and networks, et cetera, are being promoted quite a lot at the present time. You almost need a directory of services available not only to the patients, but to the physicians, the clinicians and

district nursing colleagues, et cetera, to be able to know where to refer to. However, this is interesting. We talked about patchiness. Different authorities have different policies, and different health boards have different policies, with regard to access. I know of colleagues who can refer directly for gastroscopy; in other health boards, gastroscopy is not available. So, it can be very confusing. Coming back to what John said earlier, a national directive stating that, 'This is going to be available', or a formalised directory of service, would be extremely beneficial.

[54] **David Rees:** I wish to ask about one point. Obviously, the Minister has identified the changing GP contract, as you mentioned, and the changing QOF, but also the establishment of networks or clusters where there would be a specialist. Is that one way forward, as you see it, to some of the solutions that you have identified, and having a little bit of specialism rather than knowing a little about a lot, within GP services?

09:45

[55] **Dr O'Donnell:** Having a specialist nurse consultant coming from secondary care into a network community would be a godsend, and would certainly make logical sense for development. Our nursing colleagues, I would have to say, do a lot of that currently—diabetes being a prime example of specialist nurses coming out into community care. However, with regard to cancer care, the cancer care nurses coming from the hospital to practices have also been extremely beneficial. I think that Ailsa would know more about that than I do.

[56] **David Rees:** That is the care side—I was talking more about the early diagnosis side, so you would have the specialist who would have the knowledge within that cluster.

[57] **Dr O'Donnell:** The ability to run community-based facilities, and to refer to and learn from that, would be sensible.

[58] **Leighton Andrews:** On early diagnosis, I just wanted to be clear about what your feeling is, collectively, about current waiting times for screening when a GP has indicated that there may be a need for a follow-up.

[59] **Dr O'Donnell:** Is that still with me? [*Laughter.*]

[60] **David Rees:** The problem is that early diagnosis very much focuses on the GP side of things, because once you start the referrals, secondary care comes in.

[61] **Dr O'Donnell:** On referral for screening, a lot of the screening is done through the national programmes. With the follow-up, if patients fail to attend some of the screening progresses, it is notified through the practices and the practices have procedures in place to chase up those patients. We often find that it can be extremely difficult to get the patients to engage; we send them frequent letters and reminders. However, unfortunately, one of the problems that we face in some of our areas is that a large proportion of the population still lacks the ability to understand the written word that is sent out to them.

[62] **Leighton Andrews:** Sorry; I was not as clear as I should have been. I was not talking about general screening programmes. What I was really talking about was, once a GP has a concern that there may be a problem on the basis of a patient presenting, do you have views on the current waiting times for follow-up from a specialist, in terms of identifying whether or not a cancer may be present—for example, colonoscopy, or something like that?

[63] **Dr O'Donnell:** It is interesting that you picked colonoscopy, as it is the one area that can create some difficulty—as well as urology, sorry. Once a potential diagnosis is made, the referral process identifies whether it is an urgent case. If we identify it as urgent, I would have

to say that our colleagues in secondary care facilitate it and are often back in contact and ringing us up to try to make sure that things are dealt with. If it is a case of 'I'm not sure' and it is put through as a more routine case, our colleagues in gastroenterology have questionnaires that they send out to the patients and they ascribe priority as a result. It is a useful tool, because it picks up suspected cancers quite well, if it is filled in and returned.

[64] **So**, again, it comes back to the ability to interpret, understand and fill in the forms, which people are not very keen to do. There was a suggestion that GPs should do that on the desktop. Unfortunately, filling the form in takes about 12 minutes, which is longer than my appointments. If it is sent through as a routine case, there can, unfortunately, be delays in the system. Urgent cases are no problem.

[65] **David Rees:** Elin, do you have a question?

[66] **Elin Jones:** Yes, to follow up on the waiting times for diagnostic tests. I accept what you say, that you are quite happy with urgent cases. However, the length of waiting times for many of the scans that are involved in cancer detection is quite long in Wales compared to the NHS in Scotland and England. Do you have any comments to make as to how you think that can be improved or where you think the problem lies with the ability to test quicker in the system? I think that it is something like 50% of people will get their diagnostic tests, generally, in around 12 weeks, but in Scotland and England, the percentages are in the 90s for tests undertaken within that particular time. So, there is something that is different in Wales to what is happening in Scotland and England.

[67] I was particularly concerned about something that you said as a GP about the difference between local health boards in being able to refer for some scans or tests. It seemed particularly concerning to me that some health boards put obstacles in the way of a GP being able to refer for tests. Maybe you could just expand on that. Then, on screening—

[68] **David Rees:** I will come back to you, Elin. I ask you to deal with that one first.

[69] **Dr O'Donnell:** I do not see it as health boards particularly putting obstacles in the way. What tends to happen is that health boards are tasked with reasonable management of their resources and, in trying to facilitate the referral processes, they will often have pathways—I was trying to think of the right word there—in place and ask that these pathways are used for referral purposes. Pathways in some health boards are developed locally and some are national pathways. So, if the local pathway says that in order to access a scan or a test, you must refer first to secondary care colleagues, then that is what happens. If in another area it says, 'Please have the scan organised first', then there is a capability to do so. The problem is that colleagues in our investigative facilities such as radiology, pathology labs, et cetera also have their guidance from their royal colleges and they say, 'Unless certain criteria are met, these scans are inappropriate'. That comes back to the question that was raised earlier: are general practitioners educated enough to be able to determine the level at which a scan should be requested? If a patient comes along with a potential diagnosis, if a scan is available will we refer for that scan simply because it is available or because it is needed as part of the process? So, I can understand the dilemmas for health boards in rationalising and utilising services appropriately. Pathways are generally a good thing, used sensibly, but there needs to be uniformity.

[70] **Elin Jones:** Why would I have expected the pathways to be consistent, at least within a clinical network? So, we have three cancer clinical networks in Wales—am I right in saying that?

[71] **Professor Chester:** That would be south-east, south-west and north.

[72] **Elin Jones:** Yes, that is it. I would have expected the clinical pathway from GP screening right through to acute oncology to be consistent within a clinical network area, not related to whichever local health board within an area, because there are probably at least two local health boards in one clinical network area. However, that is not the case, is it? Specifically, because the commissioning is still done by the local health boards, this is primarily driven by local health boards.

[73] **Dr O'Donnell:** To the best of my knowledge that is the case.

[74] **Professor Chester:** I think that you are taking it back to a point we made before and that is if we are going to be genuinely patient-centred, and we absolutely must be, then we have to think about what works best for the patients, not for primary or secondary care, this health board or that health board. We have to streamline things and adopt best practice so that the patient, wherever they may be, whatever their health board, whether they come to the GP or whether they come into A&E, is going to get the best possible approach. It goes back to—I am sorry, but I cannot remember who asked the question about strategic direction. I think that the strategic direction needs to be, 'Let us act together in Wales to get the best things for the people in Wales', rather than it depending on where you are. I think that is the biggest single strategic thing that could be done to join it all up.

[75] **Elin Jones:** Yes. You made a similar point earlier, did you not, about access to drugs, but in a different context?

[76] **Professor Chester:** It is the same thing in multiple different—

[77] **Elin Jones:** In not needing seven local health board panels to decide on individual patient requests.

[78] **David Rees:** I will ask about one point on that, just out of curiosity—we have talked about the different pathways, and I am assuming that medical professionals are involved in establishing those pathways. So, in one sense, if they are different, is that the decision of the health board management to change the pathways, or is it a clinician decision to have different pathways?

[79] **Professor Chester:** I think, as ever, it is a lot about human beings, and human beings doing things in different ways and doing them differently when they are in different combinations. Clinicians are very much involved. We are pretty good at the multidisciplinary approach in cancer. As many people will know, a lot of secondary care cancer management is based around multidisciplinary teams of surgeons, radiotherapy doctors, chemotherapy doctors, clinical nurse specialists and physiotherapists. We are very good at that. Clinician involvement, both in individual patient care and in pathways, is pretty good. One thing that we ought to probably do, if we are going to be genuinely patient centred, is to get lay people more involved in deciding pathways and telling us how they think it should work. That would be a very good thing. I am not saying that it is not done, but I am just saying that we could probably do more of it. I think about hospitals, and Dr O'Donnell thinks about general practice, but they are rather artificial divisions and we should be tying them closer together. I suspect that that is what the public would say to us we should be doing.

[80] **Ms Hayes:** I would like to add that some of the treatments we give are highly complex, which means that we have to use the expertise that are within various health boards. Sometimes, the person can get very stuck and lost between all the health boards and the multiple clinicians involved when there are multiple health boards and different services in different areas. You can very often run the risk of the person being pulled around, rather than being focused upon as the person who is going through it, especially with the rarer cancers—and we do see them. I just want to back that up—the global approach, breaking down the

barriers, working better together with our primary health care colleagues—very much so that the patient comes first. It always seems very difficult to do that, but it is the crux of the matter. It is not about where the speciality is; it is where the patient is and how we can make it better for that person to access that care.

[81] **Elin Jones:** The cancer plan talks of a key worker for an individual, who helps and leads them through the process, especially with some of the more complex cancers. I wonder whether you have experience of how that works well and how it may be patchy across Wales as well. Finally, my last question is going to be on something else, which is the national population screening programmes and whether you have views that we have got that right in Wales at the moment. Are there screening programmes that are not working particularly as effectively as they could be? Are there other screening programmes that we should be doing as well in Wales?

[82] **Ms Hayes:** Do I speak about the key worker particularly?

[83] **David Rees:** We will do key workers first.

[84] **Ms Hayes:** The key worker is fundamental, and you recognise that as such. We are getting better at cancer. These guys do amazing work in coming up with more complex treatments, but they have to be navigated. They are highly complex, very invasive in some cases, and they are done in several different places. A key worker is key; in some of the specialities, we have many and that is great. In others, we do not, and it is very difficult for those patients going through that. It has to be a priority to make sure that you never feel lost if you have cancer, that you never feel as though you do not know what is going on, and that you are always clear about where you are and whether things are good or bad. That goes on into survivorship very much. So, it is key, but it is patchy in areas for the more complex cancers—the rarer cancers. It is very difficult to quantify what a clinical nurse specialist does. I have been twice, in two different specialities, a CNS and, if you are not part of the numbers, if you are not part of the traditional nurse role, to be able to say that what you do is worth it is very difficult within the financial constraints when they are there. It is difficult for nurses to quantify that. So, we very much welcome your backing in recognising that that is a key part of a person's care.

[85] **David Rees:** In that case, we will move on to the national screening.

[86] **Professor Chester:** I would feel very nervous about giving you an expert comment on that. I am not an expert in that field and I would be very nervous about stating that. Perhaps one comment that might be useful is about the bowel screening programme, which we have touched on indirectly. However, clearly, the figures are not as good as they should be and are not even as good as they were. That is a clear problem. I am not the person to give you a solution on that, I am afraid.

10:00

[87] **David Rees:** Dr O'Donnell, perhaps you could comment on the screening, because, rather than come back to the GPs—

[88] **Dr O'Donnell:** I would probably echo what Professor Chester has said—that Public Health Wales would be in a position to answer with regard to the screening programmes. I mentioned earlier the difficulty with regard to getting patients' engagement with some of the national programmes and the difficulties with chasing them up. National advertising and national reminders are vitally important, but it is almost door-to-door chasing, sometimes, to actually get patients to engage. We have had the same difficulties with our immunisation programmes, so, unless you actually individually chase somebody there, it is always difficult

to get full compliance.

[89] I will just go back, briefly, to the key worker. On the key worker, I would echo everything that Ailsa has said—I will get your name right, yet [*Laughter.*] However, the biggest difficulty that the key worker faces in regard to patients in their home environment is the integration of health and social needs. The interface there still needs a lot of work.

[90] **David Rees:** May I expand upon that? Is that interface issue an issue of information, or is it an issue about the delivery of services and linking that to services that they require? I also wanted to ask, as we are seeing improvements in survival rates, whether we are seeing, therefore, a change in the model of care because people are living longer and that, therefore, models of care may need to be changed as a consequence of that. Are we seeing that happening?

[91] **Ms Hayes:** What I would like to add to that is, certainly, we are seeing people surviving, sometimes with long-term side effects of their cancer treatment or other treatment that they have had. That is not all just about medicine and nursing; that is about how it affects them as a whole—their whole lives. So, integration between health and social care is vital. It is about a multi-agency approach and co-ordinated working, again, with no barriers, to look at somebody at the centre. So, that is the key; it goes on.

[92] **David Rees:** Is that working?

[93] **Ms Hayes:** I would say, in my experience—I am hospital based—it can be very challenging to make that happen. In certain areas, there is a great working relationship but, sometimes, you can be held up in accessing social care for somebody. That is not all about a home package; it is about seeing the person as a whole and guiding them through their long-term health. The integration can be very difficult.

[94] **David Rees:** Okay. Rebecca, do you want to come in?

[95] **Rebecca Evans:** Yes. I want to ask you for some more information about how you collaborate and work with the third sector in Wales. Among us, we have mentioned that several organisations—quite a rich tapestry of organisations—work in cancer in Wales. How do you work alongside them and signpost and so on?

[96] **Ms Hayes:** They are vital, are they not? It is an amazing job that they do, and a lot of the NHS specialist nursing team now work for the voluntary sector. They are looking at funding some acute oncology posts. They are vital and we integrate with them very much as they are based within Velindre. My history is that I have worked within teenage cancer prior to this job. We had very much to work with the third sector in order to get that service off the ground. They have done a phenomenal job there. So, there is clear integration of value, in my experience. They may not feel that but, working on the ground, we would have great difficulty giving the care that we do without our colleagues in the third sector.

[97] **Rebecca Evans:** Do you have any concerns, though, that, in the current situation of austerity, the third sector is coming under enormous pressure? Do you have any concerns that that might have a knock-on effect on the kinds of services and support that are offered to your patients?

[98] **Ms Hayes:** Yes, absolutely. We rely on them very much—[*Inaudible.*]—care teams are now 24/7; there are not enough of them to go around, are there? It is highly complex work that we are looking at—getting somebody through that stage of their illness. So, they must struggle terribly to be able to offer the care that they do, as we all do—all disciplines here. It is getting more complicated—people are living longer and the needs are more complex. We

endeavour to be very integrated with the third sector.

[99] **Professor Chester:** If I might extend that a little bit, I think that this is sort of implicit. Macmillan Cancer Support does fantastic work and, as Ailsa said, a lot of our patients would struggle badly if it did not do the great things that it does. A lot of third sector work also goes on in cancer research. You might say, ‘Well, that’s different; that is not about caring, is it?’, but cancer research is often about the future patients rather than the current patients. As well as the wonderful work that Macmillan Cancer Support does in current cancer care, we have excellent relationships with the third sector in cancer generally, but including, in Wales, major funders such as Cancer Research UK, Cancer Research Wales and Tenovus. The list goes on. I think that we have really good relationships with those. Just as the work of things like Macmillan nurses is crucial to current patients, I think that that work with the third sector for future patients is absolutely crucial. I would say that that is one thing that we are very good at, and not something that we need to worry too much about. I am never one to be complacent, but I think that that is an area of strength.

[100] **Dr O’Donnell:** If I may add to that, I think that our third sector colleagues are extremely vital. It comes back to what I referred to before—a directory of services being available, because they are often unknown. They are very good lobby groups, because they tend to put pressure on for particular disease entities, particularly in regard to rarer cancers and trying to push things through to an exceptionality that will require treatments for individual patients. They are very good at signposting for their trials. In primary care, we work very closely with our third sector colleagues. I admit a personal bias, having had throat cancer myself and being a survivor. Without the third sector, the services supplied by our secondary care colleagues would have been somewhat lacking. The third sector is vital.

[101] **David Rees:** Thank you for that. We are running short of time and I have just one final question, if that is okay—[*Inaudible.*—]because we focus very much on understanding beyond the early stages and the diagnostics. However, you talked briefly about the individual patient funding request earlier in the session. Just as a very brief comment on the IPFR process working in Wales, do you see that it is actually working? We are aware of the issues of consistency, but I want a comment on the IPFR.

[102] **Professor Chester:** It is a very complex question; you are absolutely right. Trying to cut to the quick, I think that clinicians generally feel that it does not work very well for patients. Patients often struggle to understand the process. It is often very difficult to say to a patient, ‘Well, there is a treatment, but I don’t know whether we can get it for you. We are going to have to apply to someone’, and no matter how quickly the processes work, it takes time. That is also anxiety for the patients. The process itself is, as we have said, very variable. When it is variable, both between health boards and between patients with very similar situations, you can sometimes get a different answer to more or less the same question. I think that that limits the confidence of both the medical profession and patients in the process. I think that it is something that really needs looking at. Of course, we have to have a process whereby we limit costs. We cannot possibly afford all of the fantastic things that are coming along. We have to use them wisely, but that wise use, I think, needs an open, transparent and consistent process. My personal view—and I was also slightly nervous of talking for one’s colleagues, but I think that many of them would agree—is that we do not really have that openness, transparency and consistency that one needs.

[103] **Dr O’Donnell:** Again, I admit a bias, having previously been assistant medical director who sat on the IPFR and actually negotiated the funding. It has become nationalised so that there is now a national body, which deals with the referrals and requests. I think that it does an excellent job, but the process is complex and patients often do not understand it. It does need better explanation. There has been a lot of training done for the medical directors and all the people who sit on that. They try to facilitate it. I note that the recent report states

that access to more complex medications in Wales is better than in other areas of the UK. So, I am quite happy that things are heading in the right direction there. However, the complexity needs to be simplified.

[104] **Professor Chester:** I have to say that it is a difficult conversation. Without wanting to get into it too far, that is not the perception of the people prescribing the complex treatments.

[105] **David Rees:** Ailsa, you may have a view from the patient's point of view as well.

[106] **Ms Hayes:** This is a strange language that these gentlemen are talking at the moment. There is a lot involved. There are a lot of people involved. There are a lot of health boards involved. Sometimes, we are sending patients to England to have certain parts of the treatment done. So maintaining them as the most important person within that process is a real challenge, if that contributes to answering the question.

[107] **David Rees:** May I thank you, therefore, for your evidence this morning? You will receive a copy of the transcript to check for factual accuracy. Once again, thank you very much.

[108] Our next panel is just about to come in for the second evidence session this morning.

10:11

**Ymchwiliad i'r Cynnydd Hyd Yma ar Weithredu Cynllun Cyflawni ar gyfer
Canser Llywodraeth Cymru: Sesiwn Dystiolaeth 2
Inquiry into Progress Made to Date on Implementing the Welsh Government's
Cancer Delivery Plan: Evidence Session 2**

[109] **David Rees:** Good morning and thank you for waiting. I welcome Rachel Hargest from the British Association of Surgical Oncologists and Dr Martin Rolles from the Royal College of Radiologists. Welcome. I thank you for the evidence that has been submitted to this inquiry. The microphones will come on automatically, so you do not need to touch anything. If Welsh is spoken, you can get simultaneous translation from Welsh to English on channel 1 of the headsets.

[110] We are obviously looking into the Welsh Government's cancer delivery plan. Our Members have some questions and we will go straight to those, starting with Gwyn.

[111] **Gwyn R. Price:** Thank you, Chair. Good morning, both. Can you tell me whether the cancer plan's aspirations are appropriate and whether Wales is likely to achieve its objectives? I just have another question. Has the Welsh Government provided adequate strategic directions and leadership to you?

[112] **Ms Hargest:** I thank you on behalf of BASO for allowing us to take part in this process. As surgeons, obviously, we are key deliverers of cancer treatment, particularly for the common operable tumours. Therefore, we are very pleased as a community of surgeons that the Welsh Government has a cancer plan and is so committed to improving cancer treatment and outcomes for the people of Wales. In terms of the plan itself, speaking from a surgical point of view, although we concur with the aspirations in it, the actual crux of the matter for us is the diagnosis and treatment, and there is not a huge amount of detail in the plan about either of those aspects that particularly concern us. That is not to say that the other aspects are not very important. However, as surgeons, diagnosis, treatment, quality of treatment, follow-up and outcome are really the crux.

[113] In terms of leadership and accountability, it is our impression that this is done mainly at health board level, and that makes sense in terms of the fact that health boards are probably in the best position to know about the particular needs of their population, particularly in Wales where you have one or two large centres of urban population and then health boards covering huge more rural areas, which will have very different issues about how they deliver services perhaps to a city like Cardiff. So, in terms of practicality, health boards probably are the best mechanism for delivering this, and certainly the steps that the Welsh Government has taken in terms of making health boards very accountable—I think it is the CIG where the health boards have to answer to the Government on a fairly regular basis on how they are delivering the cancer plan in their locality—have really been a great help in focusing the minds of health boards on cancer, which might otherwise slip because, to be fair, they have other things they have to do. So, it is very important that the Government keeps the health boards to account on cancer. In terms of the plan itself, as I say, from a surgical point of view, we would like to see more about diagnosis, treatment and treatment outcomes. That is really the crux of the matter for us.

10:15

[114] **Gwyn R. Price:** The earlier the diagnosis, obviously, the better the outcomes.

[115] **Ms Hargest:** Yes. Also, in terms of the patients who do not have cancer—I was listening in to the previous group of experts—we have to be realistic about GPs, who deal with a huge amount of work. The number of people with cancer overall is not going up dramatically. Some cancers are slightly increasing; some are slightly decreasing. However, at the population level, there is not a sudden huge increase in cancer, so GPs see a lot of people with similar symptoms who will turn out not to have cancer. However, for those people, an early scan or an early diagnostic test that says, ‘Actually, no, you don’t have cancer; this is something else’, is great for the patient, because, obviously, that is a relief, but also good for the system, because if they know that it is not cancer, it is just x or y, they are less likely to be re-presenting and needing further reassurance from other parts of the health service. So, it is kind of win-win with the early diagnosis.

[116] **Gwyn R. Price:** Yes, I have had personal experience of that. It is the fear factor, is it not? It is the big ‘c’; everybody tries to avoid the big ‘c’. However, it is the fear factor, and once you hear, ‘Mr Price, I’m glad to tell you you’re not part of that’, you do not go back again.

[117] **Ms Hargest:** It is the same with our clinics. We run all the urgent suspected cancer clinics—I am a colorectal surgeon and I have colleagues in upper gastrointestinal, urology and so on. Even within those clinics, where the GPs have selected the ones who they think are suspicious, it is still between 5% and 10% who actually turn out to have cancer. So, even at our level, we are reassuring a large number of people.

[118] **David Rees:** Dr Rolles, would you like to give a view from the radiologists?

[119] **Dr Rolles:** There are two points, really, just to echo what Rachel said. The cancer delivery plan appears to me and to the college to be a commendable framework that individual health boards can then personalise and amplify certain aspects of and prioritise. Actually, a lot of existing strategic plans can fit into the cancer delivery plan. I suppose that one of the useful things about it is that it allows different health boards to know that they are concentrating on roughly the same range of subjects, which is probably useful.

[120] From a larger, strategic point of view, though, there are some aspects of cancer service development within Wales that sit outwith the scope of the cancer delivery plan.

Those are things like commissioning large new radiotherapy services across Wales, or commissioning the development of whole new hospitals et cetera. That is secondary and tertiary care; I am sure that there are similar examples to be found within primary care or the primary-secondary interface. Although the cancer delivery plan mentions using cancer networks, the Welsh Health Specialised Services Committee and things like that, there is a lack of clarity on how to escalate strategic concerns above health board level—some things clearly do not work very well just at health board level; they need a national approach. One of the things that Wales has demonstrated a weakness in is the ability to grasp things that are going to be important and takes on at an early stage. The cancer delivery plan does not necessarily help there. It is comprehensive, but it is a little bit parochial, I think, potentially. So, it has a definite function, but it has to be recognised that it has limits.

[121] **David Rees:** Okay, thank you. I have a question now from Elin.

[122] **Elin Jones:** Yes, just on early scans and early tests; you mentioned those and you also mention them in your paper, talking about the capacity in Wales to meet the demand on tests and scans. We know that the waiting times in Wales for diagnostic tests and scans are much longer than they are in the NHS in Scotland and in England. Do you have any views on how that could be improved in the current financial envelope that the NHS works within at this time? You have outlined how important it is to get those early scans, so that people who do not have cancer can go into another part of the NHS and that those who do are then progressed through the cancer pathway. How can it be improved, then—that is my question—without an answer that says ‘more money’?

[123] **Dr Rolles:** Well, more money, obviously, is always going to be part of the answer. The other thing is the appropriate use of tests. Are we doing too many tests on people who do not necessarily need them? There are issues here with the referral process, the whole primary-secondary care interface, and also GP education. So, the places where there is a perennial problem are some of the very common cancer sites, such as urological cancers and colorectal cancers, where there are a lot of patients who come to the GP with protean symptoms that, actually, in many cases, are completely benign or innocent. However, they are worrying for the patient and for the GP, and the GP has to refer them on. Actually, the diagnostic clinics and the diagnostic investigations, in terms of radiology, are rather swamped. So, there is a long wait.

[124] **Elin Jones:** You may not be able to answer this, but why would that be different in Wales from how it is in Scotland and England?

[125] **Ms Hargest:** I think there are a couple of differences. Obviously, in Wales, everything is done at health board level—the finance comes through that way, and the services are delivered that way. So, as health boards, they get their sum of money for doing certain services for that community. There is not really an incentive to do more scans or more tests, because, actually, that would cost more money, obviously. Now, there is a slightly perverse incentive, I guess, in some of the other models of how things are funded, because there, you get paid per episode. In the English NHS, for example, if a particular organisation was doing more scans, they would, presumably, generate more income. Well, that incentive is not in the Welsh NHS. In fact, it is slightly the other way.

[126] The other area where we probably have not done as much as England is endoscopy. We certainly do fewer endoscopies per head of population than other countries. One of the things that we have not done, really, is in terms of training our workforce. We have a very well-trained workforce, and the Welsh bowel screening programme has shown what a very high standard of colonoscopy can be achieved, but it is virtually all delivered by doctors, and we have only really utilised nurses and other non-doctor endoscopists for flexible sigmoidoscopy, which is just examining the lower part of the bowel, and for some oesophago-

gastroduodenoscopies, which is to examine the oesophagus and stomach, and they have made a huge, massive impact on the two-week rule and other, even longer term waiting patients for those two tests.

[127] The one for which we have a big problem in Wales is colonoscopy waits. Many health boards can just about get to the two to three-week urgent colonoscopy for patients who have been sent as ‘urgent suspected cancer’. Our problem, however, is with either the patients who were not referred by that route, because their symptoms were not suspicious enough, or they were of a young age, or patients who were on follow-up programmes, for whom we know that, because of their family history or something, there is a higher risk than average, or they have had a cancer or a polyp or something before, so they need follow-ups every so many months or years, and they languish on our longer routine waiting lists. It is my understanding that certain areas of the country—I am talking about the UK—have gone down the route of training more endoscopists, and particularly colonoscopists, which involves a much more technical procedure that takes longer to learn and longer to do, but which is the test that you really need to exclude a bowel cancer, or to treat polyps to prevent a bowel cancer. That is where I think Professor Chester, in his evidence earlier on, was saying that, really, you are looking at our workforce. Yes, more money would be great, but we know what economic times we are in, so nobody is really going to expect a huge tranche of money suddenly to come and for someone to say, ‘We’ll pay for 10 extra colonoscopy lists at overtime rates’; that is out of the question. However, looking at our workforce, the nurse endoscopists have proved that they can make a big difference for flexible sigmoidoscopies, a reasonable difference on oesophago-gastric cancer—or OGD investigations—and, in some parts of the country, they are making inroads for colonoscopies, but we have not really gone much down that route in Wales.

[128] X-rays and scans and MRIs and so on are a bit harder, and PET is another. In Cardiff, we have the only PET scanner, I believe. The indications for that are very tight in Wales, as to what you are allowed to scan for. That is an area that is really at the cutting edge, I guess, of diagnostics, but we are certainly barely keeping up with how the indications are progressing. To get a PET scan for people who are at the cutting edge of indications on the NHS is extremely difficult.

[129] **Dr Rolles:** PET scanning is a fairly small part of the diagnostic armamentarium, but it is very important. The evidence base for it is increasing, and I think that Wales is an outlier in the UK and in Europe in that the funded indications for PET scans are very parsimonious in Wales compared to England. The fact is that we now have only a single PET scanner, which is in Cardiff, in the whole of Wales. North Wales sends its patients to Manchester or Liverpool, I think. So, it is under strain and is pretty much at capacity. The whole thing needs to be looked at.

[130] **David Rees:** Do you know how many PET scanners there are in the UK?

[131] **Dr Rolles:** There are quite a lot.

[132] **Ms Hargest:** It is not considered a special thing to get a PET scan in certain conditions, I understand from talking to my colleagues, in England, Scotland and so on. Certainly, as a surgeon, if you are doing the really big end of surgery—the major resectional end of surgery—especially for patients who have bad prognostic features, having a PET scan might show that, actually, the huge thing that you are proposing to do will not cure this patient. The worst thing, as a surgeon, is putting somebody through something huge, and having a technical success, but finding that the disease has already advanced. That is not good for anybody. If we are going to do huge operations, we at least want it to be for the right reasons for people who are going to do well from it. The PET scan sometimes prevents you from doing operations, but that may be the best thing. There are groups of patients for whom

we cannot do that. I appreciate that they are a small number, but, for the individual patient, the 'yes' or the 'no' answer that you get after that scan makes a massive difference. It is not a minor thing.

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

[134] **Janet Finch-Saunders:** My question on this particular point has been covered by Elin, so I will move on to the next part later.

[135] **David Rees:** Lindsay is next, then.

[136] **Lindsay Whittle:** We heard from previous witnesses that recruitment and retention is at crisis point. If we are planning for this overarching, all-Wales national plan, how would you suggest we tackle the recruitment and retention problems? I appreciate that there is not an endless pot of money, but there has to be something that we can do. Do you have any ideas?

[137] **Ms Hargest:** To be honest, I do not think that it is about money with respect to retention and recruitment. I was at a meeting of the General Medical Council when it came to Wales yesterday for one of its round table meetings about the future of medical education—it is going around all of the regions. I think it is very important that, at both undergraduate level and postgraduate level, the training schemes within the universities—Cardiff, Swansea, and so on—for their medical schools and the registrar and other specialist training schemes in Wales for general practice or for hospital specialties, are of the same or of higher quality and are attractive to candidates throughout the UK. Many specialties have been recruiting their junior doctors—who are going to be the consultants and GPs of the future—through what is called national selection. It gives us a little bit less control over it, but it opens us up to a huge pool of candidates.

[138] As general surgeons, we have been working very hard on our training programme over the last five or 10 years to make it a training programme that people want to come to, and I am sure that other specialties have done the same. I think we have to be really careful, when things are difficult, not to withdraw into a parochial, barriered attitude of saying, 'We will just train Welsh schoolchildren to be Welsh medical students, to be Welsh doctors', because you are going to have attrition among your own, home-grown people, as it were, whatever you do, and, if you do that, you put up barriers to people wanting to come in at both undergraduate and postgraduate level. I think that there are a few things going on at the moment within the university sector and the postgraduate training sector that worry me and worry people like me; there is this attitude of, 'We'll just train our own youngsters to be doctors for Wales'.

10:30

[139] Apart from anything else, that is not good professionally because it does not bring in new ideas and it does not allow our people with a degree or qualification from Wales to basically be competitive on a national stage. We basically need to say, 'We are a great region. Come in; we'll really train you to the next level. We'll welcome you in at any level and we'll let you go out and back in again'. I mean, I am a Welsh girl. I trained in London and I have now come back as a consultant. Obviously, there were years in between when I could not do that but I would hate to think that there would be barriers to people like that in 10 or 20 years' time. We must not be too parochial about training, I think.

[140] **David Rees:** May I ask about that around radiology? There might be a shortage of radiologists.

[141] **Dr Rolles:** Going back to what Rachel said, there are a number of aspects to this.

There is a training scheme. What we have to recognise is that, for specialists, we are recruiting nationally and we are competing nationally. Wales is always going to have some issues competing with places such as the wealthy south-east of England, so we have to be attractive. People who come here want to be able to practice their craft to the best of their ability. They do not want to be stuck trying to do something that they feel is second-rate or out of date. That is obvious. I will get back to the radiologist thing in a second, but, in terms of training, there was quite an interesting point to illustrate the issue. Four or five years ago, there was a national recruitment round for clinical oncology trainees. Wales had vacancies but people were not applying, and there has been a concerted effort among the cancer centres in Wales to promote Wales. They have had open days, put a website out, and they are running promotional things. It is now popular and it is oversubscribed and people want to come here. So, it can be done; it just takes some effort. I think that a lot of other training schemes for other specialisms in Wales have had similar problems and have not quite reacted as well.

[142] **Ms Hargest:** It depends on the specialism. In surgery, we are very lucky. I have just taken part in the national selection process in London for surgery, and we have basically filled all our places. Obviously, there are Welsh trainees who have gone up to the next level, which is great, but we have also brought in people from outside, and a proportion of them will undoubtedly stay here as consultants in six years' time. I appreciate that we are a popular specialty. I mean, every medical student seems to want to be a surgeon until they sort of wise up a bit. *[Laughter.]* However, there are shortage specialties that medical students are not exposed to as much and, therefore, they often do not consider as careers. The two that are absolutely vital to us in cancer are radiology and pathology because we are the face that the patient sees, but they are the ones that do the really expert work behind the scenes. If they do not tell us the right things, we cannot do our job. Even in places like Cardiff, which is considered to be not too far from anywhere and which has a big hospital and all the rest of it, we have problems, and I know that small hospitals as you go further west and north have even worse problems recruiting in those two specialties particularly.

[143] **Dr Rolles:** To go back to your question about radiology, it is worth thinking about diagnostics, especially as radiology and pathology have analogous issues in that there are numerous unfilled consultant posts, so it is not about a lack of funded posts; the fact is that we cannot recruit. This is a problem across Wales, but it is exacerbated the further west you go, and it is difficult in ABMU but it is very, very difficult if you go to Hywel Dda and places like that. Part of the problem is that the nature of the specialty has changed. Whereas 15 or 20 years ago you might have had a generalist radiologist who did x-rays or scans for everything and a pathologist who would deal with all sorts of pathology, now, trainees are expected to specialise, and they are expected to specialise in one or two things. The whole nature of diagnosis and pathology and disease has become far more detailed and it is not possible really to practice as a specialist. The colleges do not support that. You are expected to train up and have a general training but then to specialise within that and to come to fruition as a new consultant with one or two areas of specialist expertise.

[144] That is something that cannot be sustained in every district general hospital, unfortunately, so the old model does not really work. People are not necessarily prepared—again, we are talking about competing nationally, and it is quite difficult for someone who has come out fizzing with new ideas and expertise to really want to work in a small district general hospital where they would be expected to do everything, when they could be working in a university hospital department somewhere else and practising their craft to the standard that they want to achieve. Part of the problem is that this is very difficult because it is an unpalatable truth, I think, politically, with the local media, with the local population and with lay groups.

[145] The trouble is that this is something that has been looming for a number of years and has not been faced up to very clearly, and we are running into a situation where there is an

imminent danger of service collapse in some parts. It is not because there are not posts; it is because no-one is going to work in these places. The unpalatable thing for many people is the fact that the only way that we are going to sustain the service is to centralise specialisms, and it means that everything is not going to be always in every district general hospital. For some aspects of diagnosis and service, there is going to have to be a bit more of a hub-and-spoke model, and people are going to have travel for some things. It comes back to recruitment and retention; if you do not have staff, you cannot run a service. If you are trying to advertise jobs that are unattractive, it is a fruitless exercise; people just will not apply.

[146] **Lindsay Whittle:** Heaven forbid—I hope that you do not think that I was advocating that we recruit only in Wales. I certainly did not mean that, and I am delighted for you to recruit across the world, really. My other question, Chair, which I asked the previous witnesses, was about best practice and how we learn from best practice not just from across Wales, but, again, from across the rest of the world.

[147] **Ms Hargest:** I think that, in Wales, one thing that has been a step forward is the introduction of peer review. We have not had it before in Wales, but, in the last 18 months to two years, the first round has started. Obviously, like all new programmes, it has its teething troubles, but the principle of doing peer review, making the results publicly available, and making the health boards responsible for the actions where problems have been identified, is a step forward. Certainly, in some of the specialties, we have seen major changes in services within a fairly short time after their services have been peer reviewed. Having said that, it is turning up some things that, as my colleague says, may not be very acceptable politically in terms of services that are either on the point of collapse or very near to it, usually due to the reasons that he has just outlined.

[148] One issue about it is that it is, literally, peer review in Wales, so only Welsh people have been allowed to peer review other Welsh people. There would be an argument for bringing in expertise from elsewhere—lots of other countries have more well-established peer-review systems. Part of peer review, apart from finding problems, is actually looking at best practice. Certainly, with the visits that I have done and with visits to us and so on, there are very good areas of practice that could be shared and maybe adopted, or adopted in an amended form, by different health boards. So, I think that peer review could be used as a tool for improving and sharing best practice within Wales.

[149] In terms of more general things, there are general issues about keeping up to date and so on—not for me personally, but I know that there are colleagues in various different specialties in different hospitals who have issues over whether they can get leave to attend professional meetings. The group that particularly has a problem with leave for professional meetings is the nurses, in that, as doctors, we have something in our contract that we can officially get that, but nurses have very little access to professional development. A lot of it relies on third sector money to pay for nurses to go for specialist training in things to keep up their skills.

[150] **David Rees:** In relation to that—I am trying to focus back on the cancer delivery plan as much as we can, because we are talking about generic issues. In your experience, therefore, of clinical nurse specialists, are there sufficient numbers? Is there sufficient training to develop those roles within the service?

[151] **Ms Hargest:** No, I think that that is an area where there has been, in a lot of places, underinvestment. Going back historically, I would say that, between about 2000 and 2007/08, there was very good investment, from central funding, in the development of extended roles for nursing. In many health boards, extra nurses—or nursing posts at a senior level within the cancer specialties were created. However, if, for whatever reason, your hospital or health board had not got someone in post, or did not have the necessary number of posts by about

2007/08, obviously, with the financial situation since then, it has not been as easy to generate new posts. I am sure that every specialty that you talk to would say, 'We could do with more nurses'; that goes without saying.

[152] The training for the nurses we do have is patchy. As I mentioned, I am a colorectal surgeon, and an awful lot of our specialist nursing posts are funded via stoma care companies, on the back of the sort of work that then later comes their way if a patient has a stoma, which a lot of cancer patients do. However, that is probably not the most robust way of funding a service sustainably. As I mentioned, companies and other third sector organisations often provide the funding for nurse training and development. There is money through the university system between the links—between health boards and their local university. That has been very useful in what is called clinical patient assessment, which is the level of training that a nurse needs to undergo in order to undertake independent consultations with a patient, and to run their own clinics. So, that has been able to be funded from within existing resources. Things that are more than that—going on individual courses and things—often depend upon soft money—third sector money, paying for oneself, or consultants paying for their nurse. It is all a bit ad hoc, really.

[153] **Dr Rolles:** Could I just enlarge on what Rachel said? Clinical nurse specialists are absolutely key—they are central to this. They fill the role of the key worker for the majority of cancer patients. They are very good value for money. They make the whole process safer, they co-ordinate the multidisciplinary team and the movement of patients between specialties—they make sure that patients do not fall through the gaps between different specialists. They keep an eye on things, and they provide a point of contact for the patient. So, it really is an extraordinary service. Some of them are nurse prescribers and can do follow-up clinics et cetera.

[154] However, the key worker role has evolved sort of by stealth, I think. It was not deliberately planned; it was not 'Let's make a bunch of people called clinical nurse specialists who can do this'. So, they tend to be senior nurses who have just taken on a sort of extra role. What we suddenly realised—a bit like with multidisciplinary teams—is that we have a bunch of people who do something that is really critically important and really very necessary, but there has never been a formal structure for developing a workforce, for funding them or for managing them. So, the whole CNS body is rather balkanised and a bit inconsistent, and there is a lack of cross-cover in places. In some places, where there are lots of them, it is great, but the reason that there are lots of them is because there has been a sort of historic enthusiasm on the part of MDTs, or individual people, for raising money and getting them in post. So, they sit within a number of different directorates, and there is often no overarching structural co-ordination or strategic or succession planning. They often sit under a variety of contracts, so some of them are employed by health boards; many of them are employed by third sector bodies like Macmillan. Their contracts may be definitive, or they may be sort of pump-priming two or three-year contracts with no great obligation to pick up things afterwards. So, it makes the whole process of establishing a sort of CNS body, which is important, very difficult. There is a real challenge, and it is not clear, at least on a Wales basis, how that is being sorted out, I do not think.

[155] **Ms Hargest:** To be fair, I do not think that it is clear in England either—

[156] **Dr Rolles:** No, but if we are going to put money anywhere in the system, that would be a very good place to start, I think.

[157] **David Rees:** I am not going to apologise for the sun, but, unfortunately, we cannot do anything about the glare at the moment—please bear with us. Janet, do you want to raise your question?

[158] **Janet Finch-Saunders:** It is really about the cancer drugs fund. There is quite often reference to that, and to what you can get in England and what is available here. What are your thoughts on that and the availability of particular cancer drugs and treatments?

10:45

[159] **Dr Rolles:** We do not have a cancer drugs fund in Wales, and that is a divisive issue. A lot of people say, 'Well, if you don't have a cancer drugs fund—

[160] **Janet Finch-Saunders:** I do not mean about the fund, but the fact that there are a number of drugs and treatments that you can apparently get in England that you cannot get here.

[161] **David Rees:** Perhaps we can look at the individual patient funding request process side of it first—what is available here in Wales—and then you can ask the question—

[162] **Janet Finch-Saunders:** No, I am asking specifically—. With respect, Mr Chairman, it is a question that is down here for us to be able to ask.

[163] **David Rees:** You can ask the question, once the question on the IPFR has been answered, which is what happens in Wales. You can then come back to something that is more comparable.

[164] **Dr Rolles:** I am happy to talk about both as an oncologist. The IPFR process and the cancer drugs fund are not strictly equivalent. That aspect has been misunderstood or misrepresented for quite a long time. The cancer drugs fund is a system in England. It is imperfect in very many respects. People complain that they want a cancer drugs fund in Wales; I think that there could be better systems. There has to be some way of dealing safely and rationally with new medications, which are often eye-wateringly expensive and may not have a huge amount of benefit. Sometimes, they do have good benefits, but it immediately becomes a bit of a hot issue.

[165] The IPFR system is not equivalent to the cancer drugs fund for the following reason: it is there specifically to deal with exceptionality, which is a poorly defined concept. Some think that the responsibility for saying what is exceptional has been abrogated from central Government and given to individual panels, which makes life very difficult because different panels clearly have different ideas about what constitutes exceptionality. That is one reason why there is inconsistency across health board IPFR panels.

[166] The thing that the IPFR system does not do, which the cancer drugs fund does do, is cover cohorts of patients. It sort of works okay if you have a patient who really is a one-off patient for some reason and there is no-one else like them; we can apply it and we can treat it as an exceptional case. However, it is a problem when you have a new treatment that comes along, where none has existed before, which is clearly going to apply to 10 or 15 patients a year from a health board. The ones that are probably going to come up, I suspect, is the new melanoma treatments that have been in the news recently. There is a bunch of patients who have never had a treatment that works and for whom a treatment comes along, but they are not exceptional because there is more than one or two of them. There is no clear pathway for a new drug to be cohort funded in that respect. The cancer drugs fund does have that. I am trying to get away from the idea that there are some drugs that are available and some that are not available. What we are talking about is groups of patients for which there needs to be a way of assessing and very quickly rationalising whether a drug should be funded or not. That fails in Wales, I think.

[167] **Janet Finch-Saunders:** We quite often hear of the postcode lottery, do we not? I

know of patients who have had to move over to England to access treatment. What more do you think the Welsh Government should be doing to ensure that there is not this inequality and patients can be treated the same here as they would if they lived over the border?

[168] **Dr Rolles:** There are several aspects to that. First of all, the fact that treatment is available in England does not necessarily mean that it is good treatment, despite what the media might say. The second thing is: what we need to do is have consistency here and efficiency of the assessment process. At the moment, we know—using specific health boards as examples—that there is a higher rate of IPFR application acceptances in ABMU and a higher rate of application per patient population in AMBU than in neighbouring health boards. So, there is clearly a bit of a positive cycle going on in some settings. That sort of thing should not really be happening. There should be consistency across the board. At the moment, the IPFR panels are a bit isolated. There has been talk within the networks of trying to get them to cross-refer, but there needs to be a wider consensus and consistency. The issue of postcode lottery is extremely divisive—it is very difficult for me, as an oncologist. I treat patients who live in AMBU and Hywel Dda areas—I get patients with exactly the same indications, but I know that my IPFR request is more likely to be accepted in AMBU and less likely to be accepted in Hywel Dda. That is—

[169] **Janet Finch-Saunders:** Unfair.

[170] **Dr Rolles:** There has to be equity. There is clearly a lack of that, in some respects, at the moment.

[171] **David Rees:** Rachel, do you want to comment?

[172] **Ms Hargest:** Although I obviously do not have much to do with the prescribing of drugs, similar principles apply to new technologies as well. Particularly in the cancer field, one of our big issues is the treatment of the rare tumour pseudomyxoma and the far more common situation of peritoneal carcinomatosis, from colorectal cancer usually. We have quite labyrinthine procedures in terms of whether we go through the Welsh Health Specialised Services Committee or whether we go through an IPFR; it is about how we actually get a patient to the place that they need to be or whether it is a service that we should be providing in Wales. We have to be very clear about how the Welsh Government looks at this. I know that there has been other work on specialised services and that you have carried out consultations on that.

[173] However, essentially, if something has been approved by NICE, we have to find some way to make that available to the people of Wales. If it is something excessively rare, then, sure, the most efficient way of doing it might be to buy that service from England, Scotland, Ireland or wherever, but there are things that are not quite so excessively rare for which we could have one, two or three centres in Wales providing that service. We would obviously have to take advice from the Department of Health in England and its modelling of the populations and the centres needed for each specific thing, and sometimes they are very simple things. In terms of cancer, the one that I am particularly interested in is a big thing that would require infrastructure resources, but there are other quite small things, not necessarily to do with cancer, for which you will see differences in terms of those health boards that will give something and those that will not.

[174] There needs to be some sort of equity about it. If things are not approved by NICE, such as the new drugs that have not yet been through a process, that is a different issue. Some sort of fund or a more transparent and equitable IPFR process is the way to deal with non-NICE approved things. However, if it is NICE approved, we should not really have to waste patients' time and all of the anxiety of putting them through a long approval process while not knowing whether they can have this treatment funded when it has been NICE approved.

There are two different issues there.

[175] **David Rees:** Janet, do you want to come back in?

[176] **Janet Finch-Saunders:** No, it is fine.

[177] **David Rees:** Okay. Kirsty is next.

[178] **Kirsty Williams:** I take your point that the non-NICE-approved stuff is very difficult and highly controversial, but I am just wondering what your assessment is of take-up in Wales of NICE-approved interventions. What is the scale of that problem, whether that is in terms of drug or non-drug treatments? For instance, my understanding of the peritoneal stuff is that that service is approved and it has been commissioned in England, and yet, Welsh Government has said ‘no’ to commissioning a service here in Wales and so people have to go through the IPFR process, which is massively hit-and-miss about who gets it or not. I am just wondering what the scale of that problem is.

[179] **Ms Hargest:** I will deal with the technologies quickly, if that is okay. Some things we took up very quickly. Wales took up laparoscopic surgery very quickly and, as a whole, we have better rates of offering and completing laparoscopic colorectal surgery to patients in Wales than on average in England. England is very patchy—there are excellent centres but there is no uniform coverage—whereas, in Wales, every health board has the ability to deliver laparoscopic surgery for suitable patients. That has been a great success; it was funded and organised in a very strategic way and the training has been rolled out.

[180] There are other things on which we have been slower on the uptake. A robot has now been purchased and will be used for some of the urology cancers, and maybe others as well. However, peritoneal carcinomatosis is the next big problem as I see it—well, not just me, but surgeons see it as the next big problem.

[181] The other thing is that the indications have massively increased. This is new knowledge. Five or 10 years ago, one would have said that there is nothing much that can be done for these patients, maybe a bit of chemotherapy but that was all that could be done. Now, there is evidence that other things can be done. To be honest, the existing centres in England will not be able to cope with that volume of work. They want there to be more centres and they are very prepared—I have been to look into this in quite a lot detail—to help us set up a centre, to mentor us, to make sure that we had sensible governance arrangements, to link in with us for a period of time and to make sure that we were doing the right patients in the right way, but, obviously, there needs to be a certain amount of investment and will to actually make that happen, or else we have to just keep filling in one form after another every time a patient comes along. With that you obviously do not want to bother the centre with people whom it is going to turn down; so, you probably have a slightly different threshold for considering whether someone should be sent up and put through this process, because you do not want to send someone to whom they will say, ‘Actually, this is not suitable’, whereas if you had a more professional forum for discussing that with them, as more of a mentoring arrangement, we as a community would learn where the field is going and how to judge which patients would benefit from this. It is an emerging field. No-one really knows at the moment exactly how many patients are going to need this.

[182] **Dr Rolles:** In terms of drugs, I think that I am right in saying that if NICE or the All Wales Medicines Strategy Group approve a drug, health boards are obliged to shoulder the cost and get on and deliver it. It does not quite have the same infrastructure issues, or long-term training sorts of issues, as non-systemic treatments. That is relatively simple. There is a particular problem, however, and, again, it is these patients who fall between the stool of the IPFR panel and NICE. If NICE is doing a drug appraisal, which often takes nine months or a

year, IPFR panels feel that it is not acceptable as NICE is looking at it. However, if NICE has not approved it yet, there is going to be a hiatus when things occur. So, this is another hole in the system, where patients can fall through.

[183] In terms of other non-surgical, but non-pharma treatments, radiotherapy is a really big one, which is a very major part of all cancer treatments. NICE looks at radiotherapy, or tries to do so; it does not do very well at it. I think that it is one of these things that—. With major surgical or radiotherapy treatments, to build up the workforce it takes years to build up the expertise, and actually infrastructure takes a long time. If we know that something is very likely to come along, we should not just be waiting for NICE to say, 'Yes, do it', because it will then take another four or five years to get the service up and running. If there is a general consensus around the country or the world that something is a good thing and is likely to happen, we should really be getting on with it anyway. Otherwise, we will always be very much on the back foot.

[184] **Kirsty Williams:** I am just interested in why it worked for laparoscopic surgery. Someone took a lead and said, 'This is what we are going to do, and we are going to make this available', and it has worked really well. On the peritoneal stuff, we do not seem to be getting anywhere and I am just wondering what the crucial difference is because we are obviously capable of doing it, and we can do it.

[185] **Ms Hargest:** I think that there were two issues. First, laparoscopic surgery applies to a huge number of people. It also had financial savings in terms of length of stay and so on. So, really, every sort of constituency, whether it was the health board that liked the idea of reduced length of stay or things like a reduction in painkillers, or another body that liked the idea of potentially reduced time off work, all the different social and health bodies were going to gain something out of that. Colorectal cancer is one of the commonest cancers. I think that it is about 45% of patients in Wales that have their surgery laparoscopically. So, it is getting near to half of the patients, which is probably what it will be because, obviously, it is not suitable for everyone. That is a huge number of people. Things like the peritoneal carcinomatosis are a different issue because they are much smaller in number. The other thing is that although we did not have a specifically trained workforce for laparoscopic colorectal surgery, you have a huge pool of highly trained surgeons, many of whom were undertaking laparoscopic surgery for other conditions. A lot of the equipment and a lot of the things like nursing expertise, and so on, were already in place. So, really, it was just taking something to a higher level, and then by having a strategic training programme and the ability not only to train consultants, but to train junior doctors as part of their registrar training, so that when they came out they were ready to go, is probably different to colorectal peritoneal metastases, where there will be a surgical aspect.

11:00

[186] However, there will also be a huge knock-on effect for pharmacy infrastructure, nursing, anaesthetic and intensive care, all of which are very expensive specialties, and the cost per patient will be huge compared to something like laparoscopic surgery, where the costs per patient are not really that big. But, you know, we have done it for one thing, so I am sure that we could do it for another. I think that, with a lot of these things, there is demand from the patient groups. We cannot ignore that.

[187] **Dr Rolles:** There is a particular issue, I think, with a lack of incentive for a health board in Wales or a hospital to develop a new service that is going to be much more expensive than the existing one. It is always a big incentive if they can make things more efficient, and it is a bit more facilitated in England because they have a tariff system and, quite often, if there is a tariff they can charge more for it and they know that they are actually going to get financial benefits from putting it in place and, to some extent, there is

competition with neighbouring primary care trusts et cetera. That does not exist in Wales.

[188] **Ms Hargest:** In Cardiff, we have the interest and potentially the expertise to do it. I mean, I have not discussed it with our health board, but I can imagine that it would be horrified by the thought that we would bring in patients without a funding stream, because money does not follow the patient in Wales. That is one of the biggest strategic problems with doing anything that is expensive and new, unless there is a separate funding stream identified for it.

[189] **David Rees:** You identified that laparoscopic surgery was actually a strategic decision. Do you therefore see a lack of strategic vision on those other aspects you were talking about?

[190] **Ms Hargest:** I think that it is very difficult for politicians and even for medical people who are not in a particular field to know what the next big thing is. Even with the two of us sitting here, I do not know what the next big thing is in his field and nor he in mine, so it is really about getting the right advice from people who are able to see what is on the horizon and what will be important in terms of delivery and, also, not getting carried along with things for which there is a short burst of enthusiasm but that then disappear, because you can waste an awful lot of time and money on those. So, I appreciate that it is very difficult for whoever is organising or funding healthcare to actually know where to invest.

[191] However, I think that, with some of these things, there is enough evidence now from Europe, America and, indeed, from England that this is not just a sort of temporary enthusiasm that is going to disappear; this is something that is increasing continuously and longer term results are backing up the shorter term results, and we have to decide at what point we get on to this. Or do we say, 'We're never going to provide this in Wales, but we'll have a very simple system: if you meet these criteria, you will go to Basingstoke or London or wherever'? That is a perfectly acceptable solution, particularly for very rare things, but it needs to be clear so that, when I see a patient in clinic, I can say, 'You fall into this category and basically it's a formality that I write to so-and-so and you will be sent an appointment within two weeks', like I would if I were an English surgeon. The problem is falling in between those two. As I say, we are not so unrealistic as to think that every last thing has to be provided in Wales, because we appreciate that some things are very rare and are better dealt with maybe in one centre in the whole of the UK, but there are things that we either should provide or for which we should have a very clear understanding that, 'You will go to centre X; we have an arrangement with them and it will be automatic'.

[192] **David Rees:** Okay, thank you. Time is almost up, but I am going to use the Chair's privilege of asking the final question. We have not talked about what happens post-operation or post-treatment and the care model. Obviously, we are seeing survival rates improving, so there is an issue of changes to the service we are providing. Perhaps the—[Inaudible.]—has views on that. Do you have any comments on the longer term model of care, particularly with regard to helping people with information and guidance that is perhaps beyond just medical treatment as well?

[193] **Ms Hargest:** The key worker concept has been a very good thing in helping patients through their cancer pathway, as it were, and really looking at that and bringing patients out the other side. We certainly have used a model that I think other people have used, where our key workers are our clinical nurse specialists, who will then run follow-up clinics. So, the patients have already established a rapport with those individuals, who will then follow them up for five years. That has been very good from a patient point of view and a patient feedback point of view, because they already have confidence in those people. They know them as people and they have met their families during the crisis point.

[194] The other thing is that that is a very good model, coming back to issues about the workforce and so on, because putting a lot of that follow-up work into the hands of clinical nurse specialists has proved economically helpful in terms of freeing up more slots in consultant clinics for newer patients. So, I think that for people who need follow-up appointments, scans and so on, looking at those kinds of newer models of care—. I know that some of the breast surgeons are looking at radiography and radiology-led follow-ups with regular mammograms for five years after treatment as a way of making sure that those patients do not fall out of the system, but, on the other hand, do not have to go to an acute clinic all the time.

[195] We are very reliant on the third sector, and Macmillan, in particular, has been a huge benefit in terms of things like helping patients with issues about finances, getting back to work and those sorts of things that are not strictly medical issues, but are all to do with survivorship and quality of life. I do not really see how we could do without the third sector at that end of the journey, as it were.

[196] **David Rees:** What about you, Dr Rolles?

[197] **Dr Rolles:** The third sector is very important. I think that one of the points brought out by the Macmillan cancer patient experience survey was about survivorship and the feeling of support. There is a bit of a capacity issue in terms of cancer patient follow-up in hospitals. Historically, patients have been followed up for many years regularly, often with little evidence base in terms of whether it improves survival, picking up recurrent disease or whatever. In fact, the amount of follow-up, to some extent, reduces capacity for seeing new patients quickly. So, there are quite clear guidelines from colleges and specialist groups about how patients should be followed up, and this is on an evidence basis. So, for example, in breast cancer, we used to see patients every six months for five years. Now they are discharged six weeks after they begin their radiotherapy, but they have an open phone line to a CNS and they can self-refer, and they have their annual mammograms. So, there is a general impetus to put the onus back on the patient and back on primary care, but on the understanding that there is a direct line in. They do not have to come through a long-winded patient referral system.

[198] This varies and is individualised for different cancer sites and, obviously, it is individualised for patients, but what that does not take into account, necessarily, is the patient's needs from a psychological and spiritual point of view, and, clearly, post-treatment there may be some quite significant issues. This is really where primary care is important, clinical nurse specialist input is very important, and third sector support from organisations such as Macmillan and Maggie's and patient self-support groups is really necessary. There are clearly some very medical problems associated with post-cancer treatments, but there are also some quite significant non-medical problems, and I think that there is a general move, and this is reasonable, to try to de-medicalise some of the patients' existence after they have finished their treatment.

[199] **David Rees:** Okay. Thank you very much. May I thank you both for attending this morning and giving us your evidence? You will receive a copy of the transcript to check for any factual inaccuracies. So, I thank you once again.

[200] I would now like to suggest to Members that we have a break.

*Gohiriwyd y cyfarfod rhwng 11:08 ac 11:19.
The meeting adjourned between 11:08 and 11:19.*

**Ymchwiliad i'r Cynnydd hyd yma ar Weithredu Cynllun Cyflawni ar gyfer
Canser Llywodraeth Cymru: Sesiwn Dystiolaeth 3
Inquiry into Progress Made to Date on Implementing the Welsh Government's
Cancer Delivery Plan: Evidence Session 3**

[201] **David Rees:** I welcome Members back to this morning's session, in which we now go to the third set of witnesses in our inquiry into the Welsh Government's cancer delivery plan. I welcome Emma Greenwood from Cancer Research UK and Dr Alison Parry-Jones from the Wales Cancer Bank. Thank you for the written evidence that we received for this inquiry. Just to inform you, the microphones will come on automatically, so there is no need to touch anything. There is no fire alarm scheduled, so, if it goes off, please follow the ushers.

[202] Based on the evidence, obviously, we have some questions—I am sure that you have been following the progress this morning so far. We will start off with Gwyn Price.

[203] **Gwyn R. Price:** Good morning to you both. Could you tell me whether the cancer delivery plan aspirations are appropriate and whether Wales is likely to achieve its objectives, in your opinion, in the plan?

[204] **Dr Parry-Jones:** Certainly, as far as the cancer bank and the target that has been put in as a research element of the cancer delivery plan are concerned, it was an aspirational figure when it was put in. I am glad to say that we are getting towards that figure. It is very reliant on resource funding. All of the consents that we facilitated in the cancer bank are via specifically funded posts from the National Institute for Social Care and Health Research. So, the activity that is documented is funded activity, rather than being done through individual health board input. Having said that, activity is increasing and has been increasing year on year. So, from our point of view, it is something that is becoming more achievable, assuming that we can keep the current level of funding that we have from NISCHR or unless we find an alternative method of integrating this more fully with NHS routine practice, so that it becomes less of a research activity and more of an ingrained routine activity within the health board.

[205] **Ms Greenwood:** In terms of the aspiration initially set, we absolutely think that it was appropriate at the time, and it is a good starting point for trying to increase and promote more research across Wales. What we have been reflecting on is how much further we can go to deliver more on that. While we have seen an increase in recruitment to clinical trials in Wales, there is inequitable access to trials across Wales. So, while, overall, performance is much better, there are obviously some patches where more could be done to better embed clinical trials. So, we would probably like to see more collaboration between local health boards, trusts and universities and some sort of standardisation across health boards so that, when you are trying to run a multi-site trial, you do not have to navigate various different arrangements, depending on which site you go to, so that patients can access trials regardless of where in the country they are based.

[206] The other thing that we would really like to try to move towards is a better link up in terms of the translation of those research results into practice. It is something that we hear from patients a lot of the time: if they have been involved in trials or they have heard about trials that have been going on, it is about making sure that, where those trials have proven that an intervention or a screening technology or whatever they have been looking at is effective and should be available on the NHS, there is a better join up with proposals and plans to get those innovations embedded. So, particularly in areas such as radiotherapy, where we are seeing lots of new and exciting innovations, technologies and techniques coming down the line, there needs to be some sort of national co-ordination so that the results of that research are then embedded.

[207] **Gwyn R. Price:** So, would you agree with some of the witnesses who have said that a more integrated, all-Wales approach is the way forward—sharing your experiences and pooling resources, or whatever? Would you agree with that?

[208] **Ms Greenwood:** Certainly, from our perspective, that is definitely something that we would welcome. I suppose, building on that slightly, the other thing is that, in the majority of cancer studies, you are normally talking about a UK-wide trial or study, and it is very rare that we are doing research that does not involve the other nations in some way, whether it is access to data sets that need to be linked up or recruiting enough patients to ensure that there is a valid number on a trial. So, in addition to more co-ordination in Wales at the national level across research through to innovation, access to treatments, and just service delivery in the NHS—so, pathology, radiotherapy and access to MRI scanners—we would like more co-ordination across the UK. It does already happen, but, again, more could be done in that area.

[209] **Dr Parry-Jones:** I absolutely agree. We are very much a resource for the people of Wales by the people of Wales. It does really require an integrated effort across all health boards. It comes down to things like having so many disparate IT systems when it comes to being able to access. IT is a major bugbear. It is not easy to get information. So, I think that a more complete integration of research within the health boards, but also between the health boards, would be hugely helpful.

[210] **David Rees:** May I ask one question on that? You mentioned the trials and you mentioned some of the diagnostics related to that. Is there a concern, because of the waiting times that we have at the moment on diagnostics, about whether trials will go ahead or not in Wales?

[211] **Ms Greenwood:** I have not heard of a concern that links those two issues. We do sometimes hear from patients that—it is a UK-wide challenge—the time that it takes to set up a clinical trial can be unduly and unnecessarily long. A lot of that has been related to the regulatory environment, the fact that different NHS organisations all have a different set of governance checks that they need to run through and, traditionally, the UK has not been the fastest at getting trials set up. So, we do hear from patients that it is frustrating that there might be a trial that they are keen to be involved in that they have heard about and, for whatever reason, if we are not as quick as other countries, patients in the UK are missing out. I do not think that that is actually linked to service delivery around diagnostic tests and stuff. There is a lot that has been done; the Health Research Authority has been fantastic in trying to transform that, and it works across the whole of the UK. It looks at research ethics committees and regulation. However, there is certainly more that could be done for the health service to be more aware of trials that are going on.

[212] GP practices, we know, are not necessarily fantastic at informing their patients about potential trials that they could get involved in. When you are thinking about such things as access to diagnostics and maybe some of the new screening technologies, that is when you are thinking about recruiting potentially healthy patients into the trial, so not cancer patients. For example, when we were running the bowel scope screening trial, which was testing a new intervention that could, potentially, be put into the national screening programmes for bowel cancer, that required going out to healthy people. So, it absolutely depends on the buy-in from GP practices, because they hold the patient records and have to assist us in identifying patients to recruit. I think that if we did have a health service that was a bit more aligned with and in tune with that agenda, it would help facilitate and speed up the research effort.

[213] **David Rees:** Okay, thank you. Elin is next.

[214] **Elin Jones:** I was going to ask you about screening and screening programmes. Your paper, in particular, refers to the bowel scope screening, so I just want you to elaborate for us

on how you think that the screening programmes in Wales should be adapted, renewed or changed in any way.

[215] **Ms Greenwood:** I think that, specifically, our focus for Wales would absolutely be the bowel screening programme. We know from the data that survival rates for colorectal cancer patients are poorer in Wales than in most other countries in Europe. So, there are a couple of things that we would particularly focus on. There is something about increasing uptake within the existing programme. I think that the last annual figure that we had was showing that uptake was around 50%. So, there should be work across Wales to understand the different rates in uptake, and, if there are certain areas that, perhaps, are performing less well, to really understand at the local level what the reasons behind that might be—so, say, whether there are inequalities issues and different socioeconomic groups are experiencing different uptake—so that we can understand that a bit better. Potentially, it is around public awareness campaigns so that people understand why they are being invited to these screening programmes. Cancer Research UK is actually piloting in England at two sites a change in the information that goes out to patients when they are invited to take part in bowel cancer screening to see whether that has any impact on the uptake rate. So, there are things that you can do in those areas.

[216] In addition to that, the test that I just referred to that was in the clinical trial has shown itself to be effective, both clinically and in terms of cost, for the NHS, and we would like to see a bowel scope test integrated into the Welsh bowel screening programme.

11:30

[217] I think that that in itself requires the whole service being ready to be able to incorporate that. So, there are issues around endoscopy that would need to be looked at, but we would like to see plans put in place for that national roll-out, because we know from the trials that that could have a huge impact on patients.

[218] **Elin Jones:** Is there anything else in terms of screening, or is that the kind of immediate priority to be included in the population screening?

[219] **Ms Greenwood:** From our perspective, yes.

[220] **Dr Parry-Jones:** I do not know. It is not really something that we would—.

[221] **Lindsay Whittle:** You have done some benchmarking. You would highlight the fact that we are lagging way behind other countries, at least in Europe, and, possibly, the world, I suppose—it depends which part of the world you go to. How can we learn from best practice?

[222] **Ms Greenwood:** That is a question. What we have done through various different studies—historically, because of the great data sets that we capture across the UK, we are quite confident in our ability to be able to compare—is to look at other countries that also capture data to the same levels, so that it is comparable, and that have similar health service delivery systems to us. The one that I will refer to is the international cancer benchmarking programme. I think that that is the first time really that we have not only looked at the differences in survival rates, but actually tried to break that down a little bit more across the patient pathway, and look at international comparisons and how health services are working differently.

[223] The caveat is that this is all still emerging, and I think that there are various papers in train, in terms of publications. However, essentially, what we are seeing—this is kind of a UK-wide issue—is that we are diagnosing later, at a later stage in the disease. If you unpick that a little bit, some of the qualitative evidence is showing that that is due to a number of

reasons. Certainly, there is something about the culture of patients in the UK—you know, the stiff upper lip, which often comes up as a reason for patients just not going to their GPs, for whatever reason. Some people just do not want to waste GPs' time. So, there is something there, once the general public is aware of signs and symptoms that could indicate cancer, about them actually presenting at their GP.

[224] There is definitely something about GPs' ability to then access diagnostic tests. We know that about a quarter of patients are diagnosed through emergency routes, which is suggesting that, for whatever reason, diagnosis is not being made through the GP route. Now, that might be that patients have not gone to their GPs at all and are just presenting through emergency routes, but we also know that GPs are sometimes using that route to get quicker access to diagnostic tests. So, there is absolutely something in there about GPs and the system being able to access those diagnostic tests more quickly for those patients who need an urgent referral. There is also something about access to treatments, which, undoubtedly, needs to be unpicked a bit more. However, we do have different rates of access to certain drugs, and there is more that we can do in access to innovative radiotherapy.

[225] So, I think that the two focus areas would absolutely have to be getting the system to be better at diagnosing patients quicker—getting patients in to the GPs quicker—and getting access to diagnostics. Then I think that there is something that we need to look at around what treatment options we are then providing for our patients. It seems to be, emerging from the data, that there is a difference across the countries, and the UK seems to, certainly, offer fewer treatment options to older patients. So, there is a potential inequality there that we need to understand a bit more. Again, that might be a cultural thing—it might be that patients in the UK do not want to take up some of those options. However, I think that there is definitely something in there about whether we are offering the same to our older population of patients as is offered in other countries.

[226] **Lindsay Whittle:** I just have a quick supplementary question, Chair. I wonder whether any research has been done on self-diagnosis. They say that a little knowledge is dangerous; if you go onto the internet, you would probably fear that you have many illnesses yourself. However, I am sure that it must have some advantages as well—people identifying, possibly, an illness, and then going to their GP. Has any research been done on that?

[227] **Ms Greenwood:** I am not sure whether any research has been done on the impact that that could have. I know that some of the things that the international programme is pulling out are around those health systems where you do not have to go via a GP to get access to diagnostic tests, and the impact that that has. In some countries you can go directly, essentially, to a diagnostic service yourself, present and have access to tests in that way. Obviously, in the UK we have GPs as a kind of gatekeeper, almost. Absolutely, more research needs to be done to understand that and the potential impact that that could have.

[228] **David Rees:** On that point, are systems in those countries that you are talking about like the NHS, free at the point of service, or are they where people pay privately for access to those diagnostic services?

[229] **Ms Greenwood:** It is a variety of models. Again, I think that it does need a bit more exploration. There is certainly a sense among some researchers that, in terms of the public patient view of the health service, if you are paying for your GP appointment or your test, it might change your attitude to your approach to the service. So, there is some research, and more needs to be done around whether, if you are paying, you are more likely to be more forthright if your GP is a bit dismissive, perhaps, of your symptoms. If you know that there is something not quite right and you are paying for that service, as a patient does that mean that you are more engaged in that process and willing to be a bit more forthright about the fact that you think that there is something that needs further investigation? So, yes; all of these things

absolutely need to be unpicked a bit more.

[230] **David Rees:** I have Kirsty, Leighton and Janet to come in. Is it on this topic?

[231] **Kirsty Williams:** No.

[232] **David Rees:** Is your question on this topic, Leighton?

[233] **Leighton Andrews:** Yes. Earlier, we heard from a GP who said that, if he was making a referral for a colonoscopy, he might have two forms of categorisation: urgent and less urgent. Is that a distinction that you feel comfortable with, or is that, potentially, culturally difficult in that it may be a GP colluding with a patient?

[234] **Ms Greenwood:** I think that those pathways are in place for a valid reason. You have to be able to distinguish within the system so that the system is not overloaded and that patients are going through the right routes. I think that we are starting to see, from some of the data—this is why we are highlighting the value of collection of data and the capacity for the system to be able to analyse those and understand what is going on—is that some GPs are feeling that even that urgent referral route is not fast enough. There are patients sitting with them for whom they would like to have access to tests even more quickly, and that is not happening.

[235] I think, actually, that the biggest challenge that we have heard about is when you have someone presenting with perhaps a vaguer set of symptoms. Actually, by and large, the system tends to work quite well if you tick all of the boxes almost, with the kind of symptoms to look for, say, in a colorectal case; then you do actually run through the system quite smoothly and quickly. It is when patients present with a more vague set of symptoms, and they kind of know themselves that something is not quite right but the GP is not able to fit them into a particular route for diagnosis, that we are starting to see more of the challenges. Certainly, with the patient experience survey, patients are kind of self-reporting on how they have travelled through the pathway. It is where they say, ‘I went to the GP two or three times; something wasn’t quite right’, but the GP was not able to quickly put them into those routes of referral.

[236] **Kirsty Williams:** I want to look at the issue of access to clinical trials, because we know that patients do better if they have that access. I recently attended a presentation where clinicians were expressing concern about the ability for Wales to continue to participate in trials, because of a lack of access to certain drugs, which are the international norm. The prescription of those drugs is a prerequisite for being part of the trial, but because they may not be approved for use here that potentially jeopardises the trial. I am wondering whether you have any views on that. Of course, some of the answers to expensive new drugs—stratified medicine—have long been talked about as the answer to some of these problems, and I am just wondering what we can do about the Wales Cancer Bank, or the role of the Wales Cancer Bank, in trying to move us more quickly along the path of stratified medicine.

[237] **Dr Parry-Jones:** I will pick up on the stratified medicine issue first. Certainly, as you say, it has been talked about for a while, and I am hoping that we are actually getting much closer—in certain areas, we are already there. It will depend on samples being available to be tested, and I think that we have to be careful in Wales that we are not left behind in this. With the genomics initiatives that are happening in England and in Scotland, they are certainly grasping the nettle and recognising that this needs to be taken forward. Unfortunately, again, it requires resource. The technology from the genetics service, though it is reducing in cost, is still relatively high if you are running a complete gene sequence. I think that tissue banks have an important role to play in ensuring that access to tissue, or the pathway for the tissue, is relatively smooth. Nevertheless, we rely hugely on pathology departments. Pathology

departments have undergone huge restructuring in the last couple of years, and it is still ongoing with the query about what is happening to the south Wales service. It is often the cinderella service in hospitals, and it is sometimes difficult, as they are so under-resourced, to persuade them that they are able to help with the pipeline for the tissue, possibly through the tissue banks, to the genetics service. So, that is one issue that I do think we have to watch and be careful of, and we have to try to facilitate it.

[238] We are trying, at the moment, to look retrospectively at about 3,000 of our tissue samples. So, with a lot of the work with the Cancer Research UK stratified medicine, for which Cardiff is a clinical hub through the Wales Cancer Bank, that is more prospective, especially now with the phase 2, which is focused on late-stage lung patients, and, hopefully, the new matrix trial will come on board in the next few months. However, that is a very prospective issue of getting a sample tested quickly, so that the patient can be offered the trial within their treatment pathway.

[239] We started to look at a large cohort of samples, with funding from Cancer Research Wales, to go back to look at tissue samples that we have from the last five, six or seven years, to look at the genetics of those tumours and to be able then to correlate with the treatment information that we have and the outcome information, to see if we can start seeing patterns back that will help to inform going forward, to see where there are drugs that would maybe impact on a certain genetic pathway. If we can start to identify these cohorts of patients and find out why one cohort responded and the other did not with what looked like a very similar tumour, then we can maybe start to inform the process prospectively. However, I think that we have to be involved in this; it is imperative, I think, for the patients, because there are such huge differences within these tumours that you cannot see by looking down a microscope. The work is needed and the investment is needed to take this forward.

[240] **David Rees:** May I ask you one question on that? You talked about the pathology aspects, and you said that it was a poor relation, effectively. Is there a problem there, because we heard earlier that there might be a problem in recruiting to those areas? Or is it a problem of under-resourcing in those areas?

[241] **Dr Parry-Jones:** I know that certain hospitals do have a problem recruiting pathologists. It is not such an issue in the larger centres, certainly in Cardiff, but, again, there has been restructuring, in which pathology departments have merged—smaller departments have merged. So, I think that there is one pathology service in north Wales, and in west Wales it is moving more towards Swansea. I know that, at the moment, there is a pathology service in Carmarthen, but whether that remains there, or is centralised in Swansea—. It is the same with the south-east. I think that it is a combination that includes being able to recruit high-quality pathologists—a lot of the posts are filled at the moment with a lot of foreign locum staff, and while that is not necessarily a bad thing, it is not necessarily as good as it can be in certain areas. Certainly, there is also a resource implication because they are generally underfunded departments.

11:45

[242] **David Rees:** Emma, do you wish to respond to the clinical trials?

[243] **Ms Greenwood:** Cancer Research UK funds quite a significant portfolio of cancer trials. I have to say that, with this issue where you might want to fund a trial and you are looking at potentially a new, innovative treatment and you have to therefore compare it against the gold standard—and I think that what you are asking is that if that gold standard is not available in Wales, for whatever reason, whether that proves to be a challenge—it is not an issue that we have picked up on hugely yet. It is certainly something that the pharmaceutical industry has raised and flagged to us as coming down the line. I think that that

is just a reflection of the fact that we are increasingly developing much more stratified medicines, which are much more targeted. They are going to be in a position where, increasingly, the drugs that they are looking to trial—their newer drugs—are going to be compared against innovations that we have not yet taken up in the health service. There might be a very valid reason that those perceived gold standards that they want to test against have not yet been taken up. If they have been through an assessment by NICE and they are not found to be cost-effective on the NHS, it might be completely legitimate that they are not available. In those circumstances, there is a role for industry, if they want to be testing those innovations, around covering the cost of both of those drugs in those trials. It is not something that is currently a huge issue, but I think that, increasingly, it could be. I can understand why it would be raised as a concern.

[244] For us, the other thing to just flag is that it is not just about drugs trials. Actually, an area that we are increasingly starting to see a bit of challenge with is us trialling new innovations in radiotherapy because that is an area where there has been underinvestment across the UK, mainly because, around 20 years ago, everyone felt that the future was purely in drugs, and radiotherapy became a bit of a cinderella of treatments, and little research was done into it. We are now completely trying to pick up the pace again. We have trials potentially coming down the line into intensity-modulated radiation therapy and stereotactic ablative radiotherapy—some of these really exciting new technologies to the patients. If they are not readily available on the NHS, the cost of running those trials will then be huge. Unlike drugs trials, where the pharmaceutical industry is actually pretty fantastic in that it does tend to pay for quite a lot for the availability of these drugs, we are not seeing that same lead from radiotherapy manufacturers. Once an NHS body has bought a machine, it is kind of hands off. I think that that is an area where, across trials, we probably need to really think about this. It goes back to that point about better integration across planning for research, innovation and integration so that, really, the NHS is looking at these things holistically so that you do not have a situation where you want to trial your innovations. However, the reality is that the NHS is nowhere near being able to take that forward.

[245] **Janet Finch-Saunders:** What actions do you feel that the Welsh Government should be taking to ensure that cancer research stays consistently on the agenda, and does the role of the regional cancer network need revising in order to provide sufficient oversight and co-ordination of research?

[246] **Ms Greenwood:** Yes, that is the crux of the question, is it not? Given that we are talking specifically about cancer research, the fact that we have the vehicle of a cancer plan or strategy that ties together all streams of the cancer pathway does offer us a really unique opportunity, actually, in cancer to really be able to set that out. I suppose that what is really needed is not only a focus on just the research element of the pathways—so, not just National Institute for Social Care and Health Research, I suppose, focusing on that element—but all parts of the healthcare pathway really taking that into mind when considering service delivery and what the key priorities are. So, it all comes back to looking at the data and, I suppose, looking at survival rates, where you really want to focus effort, and, if you are thinking about something like bowel or lung, or where the key focus is, tying in that theme through the plans for research and prioritisation.

[247] However, going back to the point that Alison made, it absolutely requires, in making sure that, if we want to be world leading in stratified medicine—thinking that, 10 years down the line, that is going to be the reality—we plan not just for the research now, but for the service delivery. If we do not have the pathologists to deliver it or if we do not have the clinical data that are able to tie up with some of the stuff that we are generating through tissue banking so that we can deliver those changes for patients through the service and not just in research trials, the reality is that we will be doing all this amazing research and it will not be translating into patient benefit. So, I think that it requires the Government to lead on setting

that sort of vision and strategy, and making sure that that is integrated across all of those strands, but also that responsibility is being taken within each local health board so that they are planning and can see what that translates to in practice on the ground.

[248] **Janet Finch-Saunders:** Would you like to see greater compliance, implementation of the plan and a more consistent approach across Wales?

[249] **Ms Greenwood:** Yes, I think that it is carrots and sticks, is it not? However, there is something about collecting data and holding to account those health boards where the recruitment is not as good as it could be, or what have you. I think that it is important that you do not lose sight of the unique challenges that are happening at local level, and everywhere will be different, and it is absolutely right that certain trials are going to run only on certain sites and that some sites may have a focus on particular cancer types or particular challenges that they may be facing in earlier diagnosis for access to treatments. So, it cannot be one size fits all; there still has to be that ability for each local health board to take the national priorities and develop a plan that works for it. However, I think that better accountability and holding them to account on what those plans are would be welcomed.

[250] **Dr Parry-Jones:** I would agree with an awful lot of that. It does go back to the integration and, obviously, having the cancer delivery plan focuses people's attention on it. I would love to see a lot of this activity become more routine, rather than being badged as a research project and, therefore, slightly on the periphery to try to get a real culture of research within the NHS. It is not a small thing to achieve, but I think that it would be a huge step forward to try to integrate this as fully as we can. Certainly, from our point of view, when the plan came out, we had the health boards saying to us, 'Well, you've got cancer bank activity in our health boards. You'll take care of that. We don't need to think about that particular part of the cancer delivery plan'. That is fine, as long as I have the resource to keep those nurses in these posts, which, with the NISCHR re-commissioning and restructuring, may not be the case after April next year. We may be facing a reduction in funding; I really do not know at the moment. We are going to become part of a cancer centre within Wales within the restructuring. So, it may be that we cannot keep our consenting levels as they are now, and if the health boards do not take this on and run with it as something that they need to do, these lines are going to start going down instead of continuing to go up.

[251] Cwm Taf did come to us to see how we could work together to try to achieve this, but a lot of the departments are saying, 'Well, if that hospital has a Wales Cancer Bank-funded nurse, it can achieve it. I could achieve it if you gave me a Wales Cancer Bank-funded nurse as well'. There is not quite the ownership that the health boards are taking on with this particular target. They are very much seeing it as being achieved by us with the NISCHR funding and the CRW funding. So, it is not really something that they have picked up and are running with at the moment, I have to say.

[252] **Janet Finch-Saunders:** Okay, thank you.

[253] **David Rees:** So, can I say, therefore, that the health boards have their plans and they rely upon you to deliver part of those plans, but it sounds as though only one health board is currently talking to you?

[254] **Dr Parry-Jones:** We have dialogue with all of the health boards through the staff that we have employed there, but, certainly, since the delivery plan came out, it has been only one health board that has actively come to us—because we did not have staff based in that health board—to say, 'Right, we do want to become involved. How do we do that in partnership with you?' I did not have any more funding or substantial enough funding to give it to be able to achieve this. It has now started consenting. We have a bit of a mixed model going there, in which we have two consultants who are very interested and are actually doing

the consenting themselves, and then we take one of our nurses from Cardiff to Prince Charles Hospital once a week to consent as well. So, the figures for Cwm Taf will increase next year, but most of the other health boards have very much taken the view that, 'We will take care of this; the staff that we have in place will be sufficient to hit the 20% target', which, in Cardiff and the Vale, it is, and in Aneurin Bevan it is very close as well, but some of the others are much further behind.

[255] **David Rees:** Thank you. You have talked a lot about—well, you started off, actually—the IT system, in one sense, which is obviously about electronic data, because, to deliver some of the research data is critical. Are the data robust enough in Wales, and how easy is it to access them? If we are talking about research, that is going to be critical.

[256] **Dr Parry-Jones:** It is. The cancer network information system Cymru—which is the all-Wales cancer data system—was very much a leader in its field. I do feel that it has slipped behind in the last few years. I know that there were queries about how that was going to be taken forward. It has the capacity to be a wonderful resource. It does not always necessarily deliver, and, from a research point of view, because it was set up as a clinical system and the priority is clearly still clinically based, it can be quite difficult to ask for changes to be made to it for a research purpose and to get information from it for research purposes, because they really do not see that as a priority. The clinical side to it is the priority.

[257] The laboratory information management system—the LIM system—is being adopted throughout Wales very slowly, but it is being adopted. Again, that would hopefully have a positive impact, depending on how available it is for accessing information. There is a huge disconnect between the university systems and the hospital NHS systems. You have to have two separate PCs to be able to access them; you cannot get information easily from one to the other. I know that the trials sometimes have difficulty in accessing the information they need from the hospital systems, for various perceived governance issues. So, it is not easy, from an IT standpoint; we really do need to try. From a cancer point of view, if CaNISC is going to be taken forward, then it needs to be taken forward and implemented for a research arena as well as for a clinical arena.

[258] **Ms Greenwood:** The only thing that I would add—and I was at a two-day data conference at the start of this week—is that it is a real struggle at the moment for researchers to access the data sets that they want to link together. So, I think that a lot of this relates to some of the fallout from the proposed Care.data upload in England. However, normally, as I have said, our research studies are looking UK-wide. So, if there is a need to access data in order to identify people to recruit for trials, or to run population-scale epidemiological studies, as soon as you really need to access UK-wide data sets and multiple data sets and link them, the governance at the moment is just ridiculous given the amount of red tape. We have some researchers who want to run projects that look at earlier diagnosis and where the delays in the system are who have been waiting months to get access. That is very much a UK-wide problem that needs a solution, which is that we need to have a clear statement of intent around the fact that researchers really should be able to get access to these data. They are running ethically approved studies, so they should not be experiencing these sorts of delays, because they are really holding up the research question.

[259] The other thing that I would flag up is something that we are doing a lot of work on, and that is the European data protection regulation, which is currently going through. If brought in, that would completely replace our own legislation—things like the data protection Act—because it is a regulation and not a directive, so we would have to implement it as stated.

12:00

[260] As currently drafted, it would essentially mean that we were unable to run most of our population studies. It would make it impossible to collect data through things like cancer registries. It would derail a lot of what we are doing. So, obviously, we are working very hard to try to get that changed, but anything that we can do in terms of UK representations to the EU to really make clear the scale of that problem would be good so that we can try to ensure that it amends that piece of legislation before it goes through. With regard to a lot of what we are talking about around stratified medicine, genomics, and really understanding what is going on with our survival rates, if that went through, it would not happen.

[261] **David Rees:** Thank you. That is something for our new Members of the European Parliament to take up, perhaps. Do any other Members have questions? No. Therefore, thank you very much for your evidence this morning. You will receive a copy of the transcript to correct any factual inaccuracies that may exist. Once again, thank you very much.

[262] I now propose that we break for lunch. We will reconvene at 1.10 p.m.

*Gohiriwyd y cyfarfod rhwng 12:01 ac 13:13.
The meeting adjourned between 12:01 and 13:13.*

**Ymchwiliad i'r Cynnydd Hyd Yma ar Weithredu Cynllun Cyflawni ar gyfer
Canser Llywodraeth Cymru: Sesiwn Dystiolaeth 4
Inquiry into Progress Made to Date on Implementing the Welsh Government's
Cancer Delivery Plan: Evidence Session 4**

[263] **David Rees:** Welcome back to Members to today's session of the Health and Social Care Committee, in which we are continuing our inquiry into the Government's cancer delivery plan. At this afternoon's session, we have representatives of the third sector. Before we go into that, I would like to give officially the apologies of Lynne Neagle for today's meeting, and we have no substitute for Lynne.

[264] We have four representatives. We have Susan Morris from Macmillan Cancer Support, Simon Jones from Marie Curie Cancer Care, Dr Ian Lewis from Tenovus and Linda McCarthy representing the Wales Cancer Alliance. Good afternoon. May I thank you for the written evidence that you provided in advance of this meeting? Clearly, as I tell all witnesses, when you write something, you tend to leave options for questions to be pursued, so we have some questions for you. We will start with Gwyn Price.

[265] **Gwyn R. Price:** Thank you, Chair. Good afternoon, everybody. Could you give me your observations on whether the cancer care delivery plan aspirations are appropriate and whether Wales is likely to achieve its objectives? Whoever wants to kick off, off you go.

13:15

[266] **Ms Morris:** In terms of the delivery plan, both as Macmillan and an alliance, we certainly welcomed it—we welcome the direction. I think that the aspirations are right; we do need to make sure that we have the best cancer care for patients in Wales. In terms of its implementation, we thought that the inquiry by this committee was very timely, two years on. It was published in December 2012, so, now is the time to look back, to review what has been achieved and to see where there are gaps and what we need to do to make sure that, by the deadline of the cancer delivery plan, five years on, in 2016, those things will have been achieved, or to see whether we are on track and what we need to do to make sure that we are making those changes and improvements along the way.

[267] **Gwyn R. Price:** Does anybody else want to comment on that?

[268] **Dr I. Lewis:** To echo what Susan said, the cancer delivery plan sets out all the correct objectives and the correct themes, and it is good to see that it is a holistic programme. So, it runs right from prevention through to end-of-life care or survivorship. I think that, at the moment, it is good to see that the direction of travel is certainly in the right direction, although there is a lot of work to be done to make sure that the principles in the cancer delivery plan are adhered to by the individual health boards and that the correct oversight is in place—I am sure that we will cover that a bit more later. Just broadly speaking—I am sure that I speak for my colleagues at the table—the third sector is really committed to working to ensure that the vision of the cancer delivery plan is something that is achieved.

[269] **Gwyn R. Price:** Would you agree with other witnesses—

[270] **David Rees:** Simon, did you want to come in?

[271] **Mr Jones:** Obviously, I will stick to the end-of-life issues. In terms of your questions on the aspirations in the plan, one could not argue with them, and one would be very supportive of them. They are those that you would wish to see there. I am sure that we will get into some questions around whether there might be some other issues that should be included and the extent to which those aspirations are being met.

[272] **Ms McCarthy:** From the Wales Cancer Alliance perspective, we recognise the progress and everything that has been made to date, and really respect the setting up of the cancer implementation board. Our concerns would be a lack of resources and an overarching drive to implement the plan fully within the time frame. Our concern is there.

[273] **Gwyn R. Price:** I wonder if I could just follow on from that, Chair. Other witnesses have stated that a more integrated, all-Wales approach is needed, so that we connect up. Would you agree with their comments?

[274] **Dr I. Lewis:** Certainly. I know that some of the people who have given evidence today have talked about the importance of local health boards also taking responsibility for what is delivered in their areas, particularly where certain geographical areas require different types of services or a change in emphasis. However, there is much in cancer care that needs to be co-ordinated in a strategic manner and in an all-Wales manner, and there are examples where all-Wales approaches have actually led to some very positive changes in the way care is delivered. Wales is, as you know, a relatively small country, and I think that there certainly should be an ability there to provide all-Wales solutions—and we have lots of great all-Wales structures already in place, like the Wales Cancer Trials Network, the Wales Cancer Bank, National Institute for Social Care and Health Research and Public Health Wales; all these things that really should be feeding into the delivery of this plan.

[275] **Ms Morris:** I would echo that, in that it is important that there are local delivery plans and that local issues can be tackled, as, quite rightly, there will be local priorities. However, cancer is a hugely complex disease and, often, patients have to travel across a number of different health board areas and between hospitals, and you need to make sure that there is a co-ordination and co-ordinated care and priorities across those different health board regions. Some things, as Ian has just said, need to be tackled on all-Wales basis. So, I think that there is a difference between having local planning, which is absolutely right, and local innovation, but I think that, if we need to make the next leap and have a really strategic approach to taking cancer to the next level, across a whole range of services, that can only be done on a much bigger scale than individual local health boards. It has to be all-Wales and national.

[276] **Mr Jones:** End-of-life care is a good example of where the central co-ordination, or a

co-ordinating approach, has worked. Obviously, since the Sugar report in 2008, and then the establishment of the palliative care implementation board, there has been a central, strategic and, to a significant extent, resource-led approach, and it is something that my colleagues in Marie Curie in England would be envious of in terms of the 24/7 consultant cover, the clinical nurse specialist cover and the co-ordination between third sector providers. There is always more that you can do, but it is a good example of where a significant degree of central co-ordination driven, in the main, by the service, has worked.

[277] **Ms McCarthy:** As you are fully aware, each health board produces action plans and reports, but those are completed in isolation. As that continues to go on in isolation, I believe that we will see variation in support and care for those patients in different areas of Wales. That needs to be co-ordinated. Equally, there needs to be an overview and a recognition of where each LHB is now, using the necessary data available. That business acumen needs to come into play to identify what the targets are in order to achieve the goals of the cancer plan. There has to be an overview. Each health board will probably have a different starting point, from point A, because that is what they are producing at the moment, but we want everyone to be sharing best practice and to be achieving the necessary milestones along a project plan, working perhaps to different targets that are aspirational but realistic for those health boards to achieve. That would then bring a massive step change to drive change and deliver the goal of the Welsh Government.

[278] **David Rees:** Do you believe that health boards are in a position where they are publishing the information, so that they know where they are now? Is the situation that the information is transparent, or not, as to where they are with regard to the plan now?

[279] **Ms McCarthy:** I do not believe that, to a layman reading those reports, those reports are consistent. The templates have changed on different occasions, but the information and completion of those reports varies considerably. For me, there are no specific goals. There are overriding goals of achievement, but, to measure the outcomes, you need those targets. Those targets in themselves can be motivational as success is achieved, but how do you measure that progress to see that you are on track, unless there is a group of people measuring how that particular health board is doing and holding it to account when it is not making the appropriate progress? The plans and reports that are being issued at the moment have such variance in their completion that some work definitely needs to be done. However, the health boards also need to be held to account when progress is not being achieved.

[280] **David Rees:** Do you agree that there is a group of people that is able to hold them to account at this point in time? Should the Welsh Government be those people?

[281] **Ms McCarthy:** I do not believe that we have national leadership for performance and being held to account. The cancer implementation group meets four times a year for two hours, and the agendas are extremely full. There is no opportunity, really, apart from top-line thinking, of going and looking at implementation across individual health boards. Therefore, the Wales Cancer Alliance perceives that we need another structure, which could be the cancer implementation group, but that group needs much greater resources in order to deliver the plan.

[282] **David Rees:** Leighton, do you have a question on this particular topic?

[283] **Leighton Andrews:** A number of you in your evidence have suggested that there are issues around leadership, governance and structure. Leaving the Minister aside for a moment, from your point of view, who do you see as the key individual who is supposed to be providing that leadership within the system?

[284] **Ms McCarthy:** I personally do not believe that it is necessarily one individual.

Certainly, the clinical lead is essential, but I do not believe that it necessarily has to be one individual.

[285] **Ms Morris:** At the moment, the cancer implementation group is chaired by Paul Roberts, the chief executive of Abertawe Bro Morgannwg University Local Health Board. There are a number of representatives from the Welsh Government on that: the deputy chief medical officer and the policy lead are also on that. The role of that group needs to be made very clear in terms of performance management. In terms of holding health boards to account, I understand and welcome the ideas of openness and transparency and the publication of local delivery plans and annual reports, but I do not think that that is enough in terms of local people being able to hold health boards to account. I think there has to be stronger, clearer and more direct scrutiny of those reports and that progress as well. As Linda has just said, there needs to be consistency in terms of what is recorded and what is measured, and how that information is presented.

[286] **Elin Jones:** I accept your description of what you say is happening now, but how do you get national accountability for local health board plans? Where is the driver if one health board is, sadly, not performing as well as another health board? Where is the driver to make sure that they are all performing as well as each other? If it is not an individual, and currently it is not the cancer implementation monitoring group, how do we get this consistency of performance unless we take it away from the health boards and have a national plan that is delivered the same way throughout Wales, where you say, 'You will deliver it in this way in every single area'?

[287] **Ms Morris:** Ultimately, the responsibility for and scrutiny of performance management will rest with Welsh Government to make sure that health boards are delivering against the objectives and the other requirements that it has set. What we have experienced over the last few years, as Linda has said, is that it has been very much left at a local level, whereas we think there needs to be a much stronger push around national structures and national planning arrangements to pull things together to provide that consistency of priorities, and then measurement against those targets and priorities.

[288] **Ms McCarthy:** Currently, on a number of the action plans and reports, not all actions within the cancer plan are even addressed.

[289] **Elin Jones:** In some of the local plans.

[290] **Ms McCarthy:** Yes. So, while it is recognised, for a national drive and to achieve a real step change in delivery, there will be local variations because of that local populous need, each local health board should be absolutely aware of the specific expectations and goals of achievement that are expected.

[291] **Leighton Andrews:** Are you really saying that the health board structure does not properly support—. Is it the right structure for addressing issues to do with cancer?

[292] **Ms Morris:** We think it is probably both/and. You need to have local action planning, you need to have local scrutiny, you need to have transparency and you also need to have annual reports so that people can measure progress. However, it is not enough on its own. You also need a much higher level and a national ability to scrutinise what is done and to plan services—not just to look back on performance, but to plan ahead. The committee heard this morning that there are a number of areas where things need to be taken forward on an all-Wales basis, not just on a local health board basis. Cancer is not quite unique, but it is one of those areas where the disease and its treatment are very complex, and it can involve you, particularly in south Wales, going from Haverfordwest in Pembrokeshire or Aberystwyth, for example, to Swansea and even to Cardiff for different aspects of the

treatment. A health board cannot plan that on its own; it has to be done very much more in co-operation. You cannot then have different standards between north Wales and south Wales. So, there is a need to take particularly some of the more complex treatments and technologies into an all-Wales planning process.

[293] **Dr I. Lewis:** Along with the health boards, we need to take a much more holistic view of the plan. The health boards are one aspect of it. A lot of the big issues that we have in Wales are around the uptake of screening, and prevention is going to be the biggest thing for us.

13:30

[294] We all know the issues we have currently and, in particular, we have some worrying issues with our young people in Wales. The health boards are a component of that, but we need to have a bigger view, more of a helicopter view. It is not just prevention, but something that overarches all of this really, namely research. It is not just research in terms of clinical trials and in terms of treatments, but research into how we make prevention more palatable for young people, how we encourage people from poorer areas to take up screening and how we provide better ways of providing support to the increasing number of people surviving with cancer. So, there needs to be much more of a helicopter view that sits above the health boards, I would argue.

[295] **Leighton Andrews:** I just want to understand that a bit more. You talked about research there, but a lot of what you were talking about was not what we would normally term 'cancer research'. It was about public health research, in a sense, in order that your social marketing is reaching particular target groups. That seems to me something that you would not want done at health board level.

[296] **Dr I. Lewis:** No, but we would certainly need buy-in from health boards to allow the health practitioners who can be really innovating in those areas to have the time to conduct that research. Currently, there is protected time for, say, oncologists and surgical staff to take part in trials and research projects. However, actually, a lot of the things we can learn that would be really beneficial to patients today could come from nutritionists, nurse specialists and physiotherapists. There are lots of models of best practice internationally that we could be learning from, but we also have an opportunity to do other types of research to develop our own best practice and to allow that to spread across the world as well. There is a big onus in the cancer delivery plan on prevention and, at the moment, the things we are doing have not solved it. So, I would argue that there is still more research to be done to improve that.

[297] **Leighton Andrews:** Well, researchers always want more research. At the end of the day, somebody has got to take decisions on the basis of what we know already—

[298] **Dr I. Lewis:** Absolutely.

[299] **Leighton Andrews:** —so, presumably, we know what good practice is around the world and where those things that you identified as problems are actually being tackled appropriately. So, why do we not just import that best practice?

[300] **Dr I. Lewis:** Absolutely. I totally agree with you. I think that, quite often, our frustration in the past, as I will admit here as a research funder, has been that, sometimes, the discoveries that we have funded have not necessarily been put into practice. I agree with you to a large extent that there are models of best practice that are not being utilised. We know about the issues of rurality in Wales, for example, and we have not quite cracked that problem. However, why are we not looking at how Canada, Texas or Australia solve that? There are certainly models that we need to be learning from and implementing in Wales.

However, I also think that we are in a really good place to be a test bed for research ourselves. We punch above our weight in terms of publications and research output in Wales, when you go by the population we have and the amount of investment we have. We punch well above our weight.

[301] **Elin Jones:** I just want to go back to the issue of local health board and national planning accountability. Is a halfway house the clinical network map? You have three, do you not? There is one based around Swansea for the west—

[302] **Ms Morris:** There are two—

[303] **Elin Jones:** Oh, there are two now—

[304] **Ms McCarthy:** One in the north and one in the south.

[305] **Elin Jones:** Oh, that is how it works. Would that be a kind of halfway house between national and local where you plan and implement and break down some of these barriers of access and consistency?

[306] **Mr Jones:** I think that there is a huge amount of complexity around accountabilities and responsibilities. It is a very difficult question to give a simple answer to by saying, 'This is the person. That is the structure', because accountabilities and responsibilities, particularly in the field of cancer, which, as people have said, has such a complex care pathway—. There are going to be accountabilities and responsibilities at an individual clinician level, at the clinical team level, at a clinical speciality level—moving all the way up through the pathway. I think that what is behind the thrust of your questioning is whether there is a way of ensuring that the gaps are not so big that things slip between them either in terms of best practice or a piece of research that needs to be done with volunteers across the whole of Wales in order to get the critical mass or indeed in terms of measuring performance. I think that that leads us to recognising where accountabilities and responsibilities are, and where they are appropriately lodged, and then ensuring that there is transparency about them being there, and that they work together well. There is no particular reason as to why the current system cannot make that work, I do not think. However, it is impossible to say that this person, or that group, has the totality of accountability and responsibility because it is going to be spread through the system. The problem, I think, with the original question, Leighton, is when you said 'leaving out the Minister', because, ultimately, that is where you will end up—with the Minister and the chief executive of the NHS sitting on the side of the chief medical officer, I suspect, from a clinical perspective. It is almost impossible to answer that question with a simple, 'This is the thing; that's how it'll work', because of these huge—. I suppose that that is the case across all clinical care, but particularly in cancer.

[307] **Ms McCarthy:** Elin, I would say that you are right to recognise the role and value of the networks, but the alliance believes that, actually, it is an overarching driver that is needed to achieve the step change. So, for working across health boards et cetera, yes, you have your networks, but, actually, the driving leadership needs to be another body. If you think about the membership of the cancer implementation group, you will know that each member brings their level of skill and expertise. However, there is no business element within CIG. There are no project managers looking at each of the actions required of the plan and identifying all of those different milestones along the way to actually be able to respond immediately to the committee's question of whether we are going to achieve completion of delivery of the plan by 2016.

[308] **David Rees:** I have questions now from Lindsay and Kirsty, and Leighton wants to come back in as well.

[309] **Lindsay Whittle:** First of all, I want to place on record my thanks to your organisations and all of the staff and volunteers for all of the good work that you do in Wales. Without you, Wales would be a much poorer place. From my experience, as an elected representative for perhaps too many years, I have received nothing but extremely positive feedback. I hope that you can feed that back to those staff and volunteers in your organisations.

[310] I want to ask you about the equity of service for children and young people in particular, people with the rarer cancers and, going back to Simon Jones's point, about the end-of-life care. I have direct experience of some of the good practice that exists in Wales, but I do not know whether it happens everywhere in Wales—and I am sure that it does not. How can we resolve that, do you think? Is it through this centralisation of specialism?

[311] **Mr Jones:** Would you like me to kick off?

[312] **David Rees:** Yes, please.

[313] **Mr Jones:** From the perspective of end-of-life care—and I will not go through all of it because you have it before you—if I wanted to leave one particular message, it would be around equity of access, because once you get into the system, there is generally very good and well-co-ordinated support. There will always be an issue around the level of resource to provide the amount of support that is needed. That will always, of course, be an issue. However, we do have some concerns. It is quite complex because it is very difficult to predict when someone has reached the last 12 months of their life—albeit cancer has a much more predictable trajectory than many diseases—and you need to be thinking about end-of-life care and palliative care. That is also complicated because people quite often do not want to recognise that. We do not need to go into that; you will understand that well. However, it still remains the fact that, according to the figures that we have from NHS Wales, 46% of people in their last year of life in 2012 had some form of specialist palliative care. That tells a story, but I think that our view is that we need to look behind that at the reality of that story: whether the people who need specialist services are not getting access to them, and what the reason for that is.

[314] The other area of concern, again being careful about data and the need to get behind them and to do more work, is that there appear to be statistically valid trends around deprivation and, say, the difference between emergency admissions and elective admissions. Intuitively, you think that an elective admission is as a result of a better managed care pathway, if you like, than the pathway of someone being admitted at an acute hospital via the blue-light service. We have some concerns around the equity of access, and we think that it is an area that would justify a good look to see why that appears to be the case.

[315] **David Rees:** Susan, do you want to add anything?

[316] **Ms Morris:** In terms of end-of-life care, to echo some of the things that Simon has just said, we know already from the figures that too many people still die not in the place of their choice and that more could be done to help people to do so, whether that is in their own home or a care home—whatever their place of choice is. I think that we have made good progress, but there is still some way to go to make sure that people get equitable access to the service.

[317] **Ms McCarthy:** Are you asking about equity of access or equity of service? Could you remind me of your question?

[318] **Lindsay Whittle:** It was on equity of access to the service—although it is a bit of both, really, I suppose.

[319] **Ms McCarthy:** No; I have nothing to add—

[320] **Mr Jones:** You also asked about young people and rare cancers.

[321] **Lindsay Whittle:** Yes.

[322] **Ms Morris:** There was not a lot in the cancer delivery plan around children and young people, and I know that our colleagues in the alliance—CLIC Sargent and the Teenage Cancer Trust particularly—have raised that on a number of issues. I know that they are keen to make sure that they are not forgotten or hidden as part of the delivery plan. They are keen that the standards are published—and I think that they have been published—adhered to and achieved.

[323] In terms of the rarer cancers, again, from the patient experience survey that was published in January of this year by Macmillan and the Welsh Government—it was a very large survey; 7,500 people responded out of around 11,000—we know that the people with the rarer cancers had the worst experience—so, particularly things like sarcoma and, as I say, the rarer cancers. We also know from the survey information that there was a significant difference between people who had a clinical nurse specialist and those who did not. In most cases, people who had a clinical nurse specialist rated their care nearly 20% higher than those who did not have access to one. Often, it is people with rarer cancers who do not have access to clinical nurse specialists in the same way. We have already heard that it is, often, the key people or key workers who can help to make a very complicated and difficult journey much easier for the patient and their family. So, there is, clearly, an issue around that that we must not forget.

[324] **David Rees:** Okay, Lindsay?

[325] **Lindsay Whittle:** Yes, thank you.

[326] **Kirsty Williams:** If I may, I would like to go back to this issue around the CIG and making things happen on the ground. Linda, you said that some of the annual reports and plans that are published are less than adequate—that is plain for people to see. I am just wondering whether there is a process in the CIG where people's plans are actively looked at and what the consequences are if the plans are inadequate. It is not a secret that they are not adequate—it is open—and I am just wondering whether the CIG takes an active role in scrutinising those plans and scrutinising action against those plans. What are the consequences for local health boards if their written plans, or the implementation of their written plans, are inadequate? How can the CIG work if it is chaired by a chief executive of a local health board that may have the worst record in delivering cancer services and waiting times anyway?

[327] **Ms McCarthy:** That was quite a big statement. I have already mentioned the consistency of the reports. The fundamental need that I mentioned earlier is about where the consistency, leadership and driving force are to hold people to account equally. I do not see evidence of that, because the responsibility for delivery sits with the chief executives of the health boards and not with the CIG. Consequently, to use a business term, where does performance management sit? Where are the data to identify specific actions by those health boards to improve their achievements? Who is driving that recognition of best practice—there is a lot of it out there—and sharing that support of best practice to improve performance where it is not so good?

13:45

[328] **David Rees:** I take it from the answer that—[*Inaudible.*]

[329] **Ms McCarthy:** No, and I would say nor do they have the time to do it.

[330] **Kirsty Williams:** Somebody has to be able to do it.

[331] **Ms McCarthy:** The Welsh Government cancer plan says that accountability sits with the health boards.

[332] **Kirsty Williams:** Okay, that is clear.

[333] **Ms Morris:** The cancer implementation group receives the annual reports and the first of the local delivery plans as they are made. As a cancer alliance, we were also asked by the Minister to comment on the cancer delivery plans. We did send back a comment that there was variation and that they needed to be more consistent and needed to cover all the areas. So, I think that it is something that we would consistently say and keep on saying, really, as well.

[334] **David Rees:** However, if you were asked to comment, how did you ensure that the comments were taken on board and responded to? Are you able to assure yourselves that that has been the case?

[335] **Ms Morris:** We have not seen the next round of local delivery plans as yet, but this year, at the cancer implementation group in March, a number of priorities were presented and we, again, will be commenting on those priorities. We would hope that those were very clear in any future plans.

[336] **Leighton Andrews:** I am quite clear from what you said what the problems are with the current system, but I am not at all clear about what you really want to replace it or to add to it. I think that that is what I am grappling with in listening to what you are saying. The reality, I suspect, is that no chief executive in the health service or in a health board in Wales has sufficient time to do, probably, all the things that we task them with. So, to me that says that cancer may be such a particular set of complex issues that the health board structure may not be right for it. In a sense, in response to Elin, you were saying that it is about bolstering the implementation groups and so on. At the end of the day, to what extent do we really need local delivery plans at all? We need implementation plans and we need delivery plans, but how local do those need to be? Those local plans, presumably, take somebody several months to draw up, take you several months or whatever to critique and then it takes them time to respond to you. By the time all that has happened, have we not passed the point of delivery? We can, it seems to me, create too many bureaucratic elements within a system to make it manageable.

[337] **Ms Morris:** I think that we do need a national action team or a planning team—I do not know what you would call it. We currently have two cancer networks. There is a question mark over whether they are helpful or not.

[338] Regarding your earlier question, at the moment, the cancer networks are more collaborative; they do not really have a performance-management remit or a clear planning remit. It is much more on a collaborative basis across the networks. Certain things, such as access to new technologies, sit outside those network planning fora, and certainly sit outside the cancer implementation group. So, it is multi layered. There needs to be a team that really looks at that, at those priorities, what needs to be delivered and then performance against them.

[339] **Mr Jones:** I want to make two points, too. I suppose that you could argue that this is in defence of the local perspective. In whatever structure, there will need to be something that

takes account of specific local circumstances, let us say. The difference between lung cancer rates and the age profile rates across Wales will have an impact on local delivery plans.

[340] The other thing that we should never lose sight of is that someone needs to take ownership of what happens to an individual patient. That is particularly important, as has been mentioned already, if someone is living in Milford Haven but coming to Velindre for treatment. That patient cannot fall between the cracks in terms of care, and the speed at which the care is delivered. This does not give an answer, but, whatever the solution is, it has to be something that, one, takes account of specifics that are more local than national, and, two, holds the ring on individual patients and accountability for individual patients.

[341] **Leighton Andrews:** That suggests that there may be a range of different functions that are best pursued at different levels. If you are talking about the management of an individual, through a key worker or whatever, that is one set of functions. If you are talking about the local differences in relation to lung cancer rates here and there, that is a totally different set of issues to be tackled. They do not necessarily need to be managed within the same group, do they?

[342] **Ms Morris:** I think that you need both: you need local planning and a national overview of planning as well. There are different issues and some issues need to be tackled on a local level, taking account of very different circumstances.

[343] **Leighton Andrews:** But you do not need to plan the local level for the key worker at the same level as you plan the public information campaign on tackling lung cancer, do you?

[344] **Ms Morris:** No, but even with a key worker you need consistency in guidelines and policies, otherwise people will end up with something that is very different.

[345] **Leighton Andrews:** I accept that.

[346] **Ms McCarthy:** It was proven in the patient experience survey that how it is delivered differs hugely across the health boards.

[347] **Leighton Andrews:** I just think that we need to know what we mean by 'local'. We are asking one structure to deliver lots of different things locally, when it does not need to do that.

[348] **Elin Jones:** The local circumstances issues that you raise—socioeconomic, age profile—are primarily public health issues, are they not, in terms of screening, education and promotion in particular areas? They are not about whether an individual in the Rhondda or in Ceredigion is diagnosed with lung cancer. At that point, it should be the same, should it not?

[349] **Ms Morris:** When we say 'local', it is the local health boards—as in the seven—not the local authorities.

[350] **Elin Jones:** I understand that.

[351] **Mr Jones:** They are public health issues that then have enormous consequences for the health services in those localities, in terms of where resources need to be put. They sit at that level but they are very operational as well.

[352] **David Rees:** Kirsty, do you want to come back in here?

[353] **Kirsty Williams:** What they seemed to do across the border—I do not like the word 'czar'—was appoint a high-profile and well-respected individual who was clearly identifiable

as the person who was the national strategic lead for a step change in cancer services. Whether it is down to the job, or whether it is the personality of Mike Richards, there was one person whose job it was to knock heads together if clinicians in the field were not doing the right thing or were not co-operating. He really was the focus for driving change. Do we need a similar person, to take the plan and to say, ‘Right, I am going to work with people at whatever level—in the CIG, in the networks or in the LHBs—to really drive this forward’? Is that what we need?

[354] **Ms McCarthy:** We need that overarching person or group. Mike Richards had a significant cancer action team around him. So, it has to be a body of people able to do things, not just one person.

[355] **David Rees:** Ian, did you have a comment?

[356] **Dr I. Lewis:** Yes. From our point of view, as third sector providers, we are service deliverers as well. We are service deliverers and we are often innovators. We really want to help. We really want to work with health boards. For us, it is very time consuming to go around the seven health boards when we operate all-Wales systems and structures. We want to be able to talk to a body or a person at a strategic level when we are planning our five-year strategies, to make sure that they align with the strategies of the health boards or an all-Wales cancer system. That would make life for us a lot easier.

[357] **David Rees:** Rebecca, did you have a question?

[358] **Rebecca Evans:** Yes. It is on a different issue, if we are all ready to move on.

[359] **David Rees:** That is fine. We have moved on. We have five minutes left to move on; it is okay.

[360] **Rebecca Evans:** I just want to get your take on the role of GPs in detecting cancer quickly. We had a representative from the Royal College of General Practitioners with us this morning. I do not think that I am wrong in suggesting that his view was that, if they had more time to spend with patients, there would be earlier detection, in the sense of more thorough investigations and so on. Is that a view that you share? Also, is there something about the education of GPs, in terms of their awareness of cancer and so on and the skills that they have to diagnose it?

[361] **Mr Jones:** I will say a word at the end, because it is not the diagnosis that is the end; it is the end-of-life stuff that is—.

[362] **Dr I. Lewis:** I think that GPs are vital. I could not necessarily comment on the education provided to GPs, but there is definitely something around improved education of the public on what those signs and symptoms might be and around giving people a degree of empowerment to go to the GP. I know that Tenovus, along with the Welsh Government, funded a Welsh component of the international cancer benchmarking partnership—this was mentioned this morning—which showed that people do not feel empowered to go to their GPs, because they do not like to bother them. So, there is definitely some work to be done there. That is a great example of where some research has highlighted an issue that needs to be put into practice somehow through some form of public awareness campaign. However, I think that that empowerment and that lack of knowledge and health literacy, which is a massive problem in Wales, is compounding the issue of social deprivation and the high instances of cancer in hard-to-reach groups.

[363] **Ms Morris:** I just have some quick comments. Macmillan has been working UK-wide on developing electronic risk assessment tools for GPs and cancer decision support tools

that can sit in their information systems that will help them to question mark or spot the signs and symptoms of cancer and question whether there should be a referral. It is something that we are hoping will be available to more GPs in Wales. We are working with various colleagues at the moment to look at that. So, there is help and support that can be given to GPs to look at risk assessment and tools and when to refer on, particularly for cancer.

[364] The second issue around GP updating and education is that, again, we have been working to try to support GPs and to provide education sessions to update them on the signs and symptoms of cancer and referral, and to update them on protocols and guidelines.

[365] It is something that can be helped but, as the GP quite rightly said this morning, time is very limited in terms of the consultation. I know that they are already under extreme pressure. So, it is about whatever we can do to help, because that is an absolutely critical part of the journey. We know that too many people are not being referred quickly enough but, also, as Ian said, it is sometimes patient delays that cause the problems.

[366] **Mr Jones:** I know that it was not your question but, if I may, I will take the opportunity to say that, in terms of end of life, they are absolutely central. We are doing some work with the royal college on the quality of life at the end of life. A significant indicator would be the involvement not just of the GP but of the wider community team—which is not just clinical—and the ability for that to support you to die where you want to die, which is at home. It is absolutely critical that we do whatever we can to support and resource GPs to fill a really important role.

[367] **Ms McCarthy:** Something that was shared with me, which might be helpful, is that the average GP will only see about 10 cancer patients a year. Therefore, I think that it is a challenge for all as to how to build expertise and skills in the recognition of symptoms. So, the assessment tools that Susan referred to will be hugely beneficial for that.

[368] To digress ever so slightly, GPs, or staff within the GP practice, will probably end up being key workers for patients when they are discharged from hospital. Consequently, there is a lot of work that needs to be developed there for the key worker role of signposting people, so that they can access all of the various services throughout Wales. It is not purely about ‘huge’ on the early diagnosis side; equally, it goes beyond that too, for survivorship.

[369] **Rebecca Evans:** Could I ask about the decision support tool that you mentioned? Does that also include information about the various diagnostic tests that are available? We heard that GPs are not always aware of the diagnostic tests that are out there. Since we are short on time, I will ask my other question on diagnostic testing, which is to seek your view on the current funding for diagnostic tests.

[370] **David Rees:** Short answers, please.

[371] **Ms Morris:** May I do the CDS tool quickly?

[372] **David Rees:** Yes.

[373] **Ms Morris:** No, it does not include diagnostics; it just tells you. There are two: one has an age profile and risk factor and the other is another tool that is based on symptoms. So, if you present to the GP three times with antibiotics or with a particular issue and there are a number of other risk factors that come up in the coding, the tool might suggest to the GP, ‘Do you need to refer to cancer?’ So, it takes the clinical coding, but it is only as good as the clinical coding. It is a help and a prompt, and it is up to the GP to make those clinical decisions. So, no; it is not linked naturally to diagnostics.

14:00

[374] **Dr I. Lewis:** On diagnostics, really quickly, demand for diagnostics is going to get greater, as we know more hallmarks of cancer and there are more markers and things that we can look for, but we need to get better at stratifying risks, so, identifying who are the people who will benefit most from screening or diagnostics.

[375] **David Rees:** I call on Rebecca.

[376] **Rebecca Evans:** Since you have given me a prompt, I can continue. I wanted to ask about the appropriateness of genetic testing for people in terms of cancer and, I suppose, where you think that we are with that, and where we should go. We had that in our round table with patients. It was a big concern that family members should be able to be informed, really, about the risks and so on.

[377] **Ms McCarthy:** Family members to be informed: that is the big challenging area of genetics because some people in a family may not want to know. It is a very personal decision, and, actually, some of those family members may actually have to be part of the genetic assessment. It is over to you on the research side, Ian.

[378] **Dr I. Lewis:** Again, as with diagnostics, the more things that we will be able to test for, the greater the demand will be. Historically, it has been a small number of individual genes that we look for; now, it is much more recognised that it is an interplay of lots of genes. So, it is becoming much more complicated. Again, demand could increase, but it is about identifying the ones that are truly a risk factor. The important thing, of course, when that is identified, is providing that individual and the family, potentially, with the correct support, because, once told that you have an increased risk of cancer, what do you do with that? Do you have preventive treatments, do you have increased screening? It is all of these options. You want to give people the knowledge that there might be an increased risk, but you do not want to do harm at the same time in increasing their levels of anxiety.

[379] **David Rees:** Time is catching us up, I am sorry to say. We have spent a lot of time on governance, so we have not actually discussed the information aspects as to how we provide information and support and which element of that plan is working or not working. We also have not asked the question on the surveys. I was going to ask a quick question on the iWantGreatCare survey and the effectiveness of it. I will give you a chance to answer that one.

[380] **Mr Jones:** I refer you to—I think that I attached it to the stuff we provided—the report that we did recently, ‘Listening to Dying People in Wales’. We think that iWantGreatCare serves an important purpose. It actually captures information from only people who are in direct contact with specialist palliative care services. That, as we know—as I have mentioned earlier—is something like 46%. That is from the figures that we have of people dying with a cancer diagnosis. It is as low as 5% for people dying of a non-cancer disease. So, we do think that there is space for getting greater information that does a number of things: seeks to give us assurance that what we are doing is good; gives us information on what we might be doing that people want and need; and aims always to enable those who plan and deliver services to improve. So, we think that it serves a purpose and it is great as far as it goes, but there is room for more.

[381] **David Rees:** Thank you. I am going to give it another two minutes, Susan. Do you want to say anything on the issue about information provision, because clearly it is a major concept of being able to help people and support them during this period of time? Are there issues around the cancer plan relating to that?

[382] **Ms Morris:** Yes. We think that person-centred care is absolutely essential. It is the right way to go, but, to make sure that people get the support that they need, they need to have information wrapped around the whole of the treatment, and we want to make sure that they get proper assessment of their needs, a key worker and a care plan as a result of it to help them to get through.

[383] **David Rees:** Is that working? I think that the question is whether that element is working at this point in time.

[384] **Ms Morris:** It is being implemented slowly. We need to make sure that that is speeded up and is consistent for everyone because we know that, at the moment, only 22% of people have been offered a written care plan. That came out through the patient experience survey. Again, with things like being signposted to financial advice, it is less than half of the people who said that they need it. There is significant variation across health boards, services and hospitals again. Some of the commitments in the plan need to be delivered. We are on the road but we are nowhere near achieving what is set out in there yet.

[385] **Ms McCarthy:** May I also add that consistency is lacking in the information that patients are given? Consequently, a patient, particularly one crossing different health boards et cetera, can receive different types of information about the same issue.

[386] **David Rees:** Okay. Thank you for that information and thank you for your time this afternoon and the evidence you provided. You will receive a copy of the transcript to check for factual accuracy. Thank you once again for attending today.

[387] **Elin Jones:** May I just ask about the next set of witnesses? Are they clinical managers in their health boards or are they just clinicians?

[388] **David Rees:** Mr Hamish Laing, for example, is a clinical director. I know that. Tom Crosby is the clinical director of Velindre as well, but I am not sure about the other two. I will ask them to introduce themselves with their positions.

[389] **Elin Jones:** Yes. I just want to understand whether they are responsible for the service or whether they are just clinicians delivering a cancer service.

[390] **David Rees:** I will ask them to introduce themselves and their position within the health board. We will know then, Elin.

[391] **Janet Finch-Saunders:** Do you know—[*Inaudible.*]

[392] **David Rees:** We are in public session, remember.

14:07

**Ymchwiliad i'r Cynnydd Hyd Yma ar Weithredu Cynllun Cyflawni ar gyfer
Canser Llywodraeth Cymru: Sesiwn Dystiolaeth 5
Inquiry into Progress Made to Date on Implementing the Welsh Government's
Cancer Delivery Plan: Evidence Session 5**

[393] **David Rees:** Good afternoon, and thank you for coming. I am going to ask you in a minute to introduce yourselves, going from left to right, and also to state your position within the health board. I am just waiting for a colleague to come back. In the meantime, the microphones will come on automatically; there is no need to touch them. Simultaneous translation from Welsh to English is on channel 1, if you need it. There is no scheduled fire

alarm so, if it goes off, please follow the directions of the ushers. I forgot to remind Members, if you went out at lunchtime and left your phones on, that you should please turn them off. We will get on with things now.

[394] **Mr Heron:** Good afternoon. My name is Damian Heron. I am the director of the north Wales cancer network. I am also the associate chief of staff for operations for cancer in Betsi Cadwaladr University Local Health Board.

[395] **Dr S. Lewis:** I am Sian Lewis. I am a clinical haematologist, and I am also clinical director for acute services in Hywel Dda Local Health Board.

[396] **Dr Crosby:** I am Tom Crosby. I am an oncologist in Velindre. I am clinical director there, but I am medical director of the south Wales cancer network.

[397] **Mr Laing:** I am Hamish Laing. I am a surgical oncologist in Abertawe Bro Morgannwg University Local Health Board, but I am medical director and, just to declare an interest, I am also on the professional advisory board for the Maggie's Cancer Care charity.

[398] **David Rees:** Thank you very much, and may I thank those health boards that have submitted written evidence prior to today's session? We have some questions and we would like to go straight to those, if that is okay. We will start off with Gwyn Price.

[399] **Gwyn R. Price:** Good afternoon, everybody. I wonder whether you could give me your opinion on whether the cancer care delivery plan aspirations are appropriate and whether Wales is likely to achieve the objectives in those. That is to anybody.

[400] **Mr Heron:** I am happy to start and keep to the sequence. I think that the plan has a lot to commend in it. I think that the themes in it are appropriate. I think that, for some of those themes, however, the timescale is probably too tight. For example, things like cancer survival and so on are longer term targets. However, they are there and, certainly in my opinion, the plan is a reasonable plan to follow through.

[401] **Dr S. Lewis:** I think that I would probably just reiterate that. It is very useful to have it written down in a single place with priority headings. However, again, some of this is about a journey. It does not end in 2016.

[402] **David Rees:** You only need to speak if you want to say something different.

[403] **Dr Crosby:** I think that it is quite a clear vision, actually. Most of us involved with cancer services have seen that the cancer plan contains most things that we want to achieve. We can always argue about the priorities. [*Inaudible.*]—prevention, reducing smoking, reducing obesity, reducing alcohol. That is going to change things over many years, and even decades, rather than within five years.

[404] **Mr Laing:** The only thing that I would say is that I do not think that there is anything in the plan that we would not expect to be there. We would be fully supportive of the content of the plan.

[405] **Gwyn R. Price:** Could I just follow up on that? Other witnesses have suggested and stated that a more integrated, all-Wales approach is needed so we get the joined-up thing right. Local is okay, but they believe that more of a Wales approach is needed. Would you agree with them?

[406] **Mr Heron:** I certainly would. I think that, because of the type of disease that cancer is and when we look at the size of Wales, there is a need for a more integrated approach at a

national level. There are too many opportunities for variation as we are now and that is something that I certainly think that, clinically, we are not happy with and we want to address.

[407] **Gwyn R. Price:** Thank you. Do you all agree with that?

[408] **Dr Crosby:** Yes. Coming here this afternoon, the biggest thing that I would stress is that organisational structure around cancer services and the need for a planning, delivery and performance monitoring body. I personally think that that should be clinically led—not necessarily clinically run—and that it should sit in the NHS. I think that it is very important that the NHS takes responsibility for running its own house, as it were. However, it absolutely has to have representatives at a suitable level from health boards to tie them in and give it some authority for change. We would be much better off working together, and I think that most health boards see that, but they are fighting every day other issues such as acute care, unscheduled care and A&E emergencies. We have an ageing population. Who is planning for the huge epidemic of cancer for the next 20 or 30 years? We are already seeing vacancies in pathology, radiology and now even in oncology, and I do not think that there is any long-term strategic planning to avoid those for the future.

[409] **David Rees:** I have questions from Elin and Kirsty.

[410] **Elin Jones:** So, you are all agreed that the cancer plan is a good thing and then, from the evidence that we have heard today already—you are the last set of witnesses, so we are developing themes by now, and one of the themes is that what happened after the cancer plan was produced is that implementation was handed over to local health boards, and therein lies a lack of consistency and a lack of performance management within local health boards possibly, but certainly between local health boards, and comparison, driving up standards and leadership where maybe some local health boards are lagging behind on different areas of work in the cancer plan. Are you almost suggesting then, the two of you who answered the last part of Gwyn's question, that the model that exists currently is not a model that really works in the context of cancer and that relying solely on local implementation plans with local accountability within local health boards is not the way to deliver the aspirations of the cancer plan consistently throughout Wales?

[411] **Dr S. Lewis:** I come from Hywel Dda health board, and we are carrying out a review of our oncology services at the moment. Our solutions do not lie within Hywel Dda. They lie certainly with ABMU health board and probably, longer term, with Velindre. Oncology has various aspects to it. Some of it is about visiting a specialist doctor. In order for those specialist doctors to be really good at what they do, they need a large population size to see the numbers. So, from my health board's perspective, many of our solutions lie in collaboration; they do not lie within the health board.

[412] **Elin Jones:** So, how do we break down those barriers? If we think about the south Wales clinical network now with four or five health boards, probably, in that, how do we break down the potential barriers from the local health board commissioning and paying for services and the access to the specialist services that you refer to?

[413] **Mr Laing:** I think that this is not a question unique to cancer, and you will be aware of the south Wales programme, which will lead to patients moving across health boards more than they do now, perhaps, for some specialist services or particular parts of the pathway. I think that, in cancer, we see a lot of patients whose pathway spans more than one health board.

14:15

[414] It remains the case that the individual health board is going to be accountable for the

delivery of the care that is occurring in its own health board, and so the question, really, is one of how well you co-ordinate between the health boards, to ensure that the pathway works well, because it is inevitable. As we centralise some more aspects of cancer—and I would just make the point that cancer is much more than just oncology; there is surgery, diagnostics and so on—and as we centralise components of that, because we think that we will get better outcomes, we will see more people spanning the different boundaries that exist.

[415] I think that there are many components to the answer. We have to have it that the health board is accountable for what it is doing; it is part of it. We have a cancer network, and the cancer network has the potential to co-ordinate and oversee care across the whole of south Wales, and we have a separate network in the north. I would say that it probably does not yet have some of the infrastructure or, if you like, the power, the levers to do it as well as it might, and Tom may want to comment on that. Some degree of oversight above the health board is, I think, important for the delivery, but we cannot get away from the fact that we have to hold me, in ABMU, accountable for what happens in ABMU—that is my job: to be accountable for that.

[416] **Dr Crosby:** I would support all of that. First of all, it is not just about oncology and surgery; it is not just about secondary care. A lot of the care and many of the improvements in cancer outcomes are going to come from primary care, community-based care, prevention and early diagnosis. Clearly, that is going to be delivered at health board level. But, what all of this is around is being strategic in Wales—we are only 3 million people, and are we using all of these organisations to the best of our ability? We have a network, we have a national specialist advisory group, we have WHSSC, we have different health boards, and, yes, the network as it exists at the moment is an advisory group that tries to tell these big health boards, ‘You’re better off together’, but they are fighting A&E problems, waits, and acute emergencies day by day. So, I think that it needs that overarching, strategic group to bring those health boards together with authority.

[417] Nearly all treatments start off with an appraisal of the process. You then need to commission it, you then need to implement it and then you need to performance manage. I think that there is a role for a planning and strategic group—a clinically led, strategic group—that oversees all of those steps in the pathway of the delivery of excellence.

[418] **David Rees:** Is that okay, Elin?

[419] **Elin Jones:** That is fine.

[420] **David Rees:** Kirsty is next.

[421] **Kirsty Williams:** Does that group look like the Mike Richards-type lead, with a group of people below that to make that happen across Wales?

[422] **Dr Crosby:** Yes. I think that it should be clinically there, but it certainly is not about a person; it is about having a structure around it. We have roles, and we have excellent clinical leads—an abundance of clinical leads—across all the health boards whom we can bring together. What it really needs is to tie in the health boards at a level that has authority, so that, if it is not chief executives, it is directors of planning or directors of finance, who see the benefits of coming together and planning services together, rather than individually, be it for individual medicines, technologies or services, all with the same implications.

[423] **Kirsty Williams:** May I ask you about cancer delivery plan area 3 and delivering fast, effective treatment and care? I am just wondering whether the way the money flows around the system, rather than following the patient, is a barrier to developing some of the services that we need to develop, but which cannot be commissioned on an LHB basis as they

need to have a wider group of patients, for instance, services for some of the very rare things. I have a particular interest in the peritoneal surgery service or there are, for instance, people suffering from neuroendocrine tumours—there is a specialist service in Cardiff that is packed to the gunwales, which means that people outside Cardiff cannot necessarily get in to that specialist service. What are the barriers, and how can we rearrange how money flows around the system to be able to commission those more complex, rarer services for people?

[424] **Mr Heron:** Perhaps I may respond to that. In north Wales, of course, we have a slightly different angle on that, in that we have to send a lot of those patients to England, and, therefore, that service is commissioned by WHSSC—and a lot of these services are commissioned by WHSSC. I think that that is quite ill defined at times. I think that the process could be a swifter and simpler one, which I think would respond to your point, but this comes back to Tom's point that WHSSC is picking up a range of different specialist issues on which—and I do not wish to do it a disservice—it is not necessarily expert, but it has the money. In a way, once again, if that could be delegated to an appropriate group of experts, we might have a better chance of ensuring that there is access for all to the right level of treatment. Another observation I would also make about WHSSC is that it adds to time for patients in that there is a decision-making process, which is not always that quick or well informed. That is something that we could address as well.

[425] **Mr Laing:** My specialism is sarcoma, which is one of the very rare cancers. That is a service that is commissioned by WHSSC, so, if you like, the money is moving around the system with the patient there. It is only the secondary care component, of course, not the primary care component. I would echo a number of Damian's observations about how that can sometimes work. Broadly, it has helped a lot, and it has allowed us to develop a co-ordinated system across south Wales. There are teething problems with it, but it is not the money that is obstructing that. So, there is a model for the rare cancers, but that is 1% of all cancer; it is the other 99% that we really need to focus on.

[426] **Dr Crosby:** It is probably about 40% to 50% of cancers, because there are a lot of cancers, such as colorectal cancer and breast cancer, that are predominantly managed within a health board population. If it goes to WHSSC, then WHSSC clearly needs to be more robust, and I have given evidence previously about the appraisals of technologies and treatments that need to be more rigorous. However, for things like neuroendocrine disease and those regional services, there is no structure at the moment for cross-health board planning, and it does drive you to tears to know that the money has to follow the patient in the end. We do not have a system for that to occur. With neuroendocrine services, it would be much better for a very specialist service in Cardiff to offer that advice and for patients to be managed locally. However, you can try to get the money to follow patients, but it just does not happen. The model at the moment is to break up that service.

[427] So, WHSSC has its merits, where it does commission some services, but it commissions PET scans and not endoscopic ultrasound, and it does the liver, but not the pancreas. It is relatively ad hoc in terms of the issues that it does take on. It needs to be either more widespread or, as Damian said, a slightly different, modified system. WHSSC needs to have clinical engagement and oversight of the work that it takes on.

[428] **David Rees:** Janet, do you have a question?

[429] **Janet Finch-Saunders:** In your opinion, is there a need for an overarching, national, all-Wales structure for planning, accountability and performance? That will lead on to another question that I have to ask you.

[430] **Dr Crosby:** Yes.

[431] **Janet Finch-Saunders:** Is that the opinion of all four of you? I see that it is. My reason for asking that is that, particularly with metastatic cancer, there is a reference in the papers to the fact that all LHBs must plan and deliver services for this particular range of patients, but only Velindre has made reference to that in its local cancer delivery report. Once again, this is just one area, but the message we seem to have heard here today, loud and clear, is that there is a lack of joined-up services and a lack of consistency. In some areas, you can access things, but in other areas, you cannot. How should the Welsh Government be providing support in this regard?

[432] **Dr Crosby:** Obviously, a significant proportion of patients will either present with or develop metastatic disease, so a lot of that care has to be delivered close to home. There are weaknesses in the system in some of the support structures around managing patients with advanced disease. The information systems are not set up to collect information about secondary episodes of care. We did have a good system called CaNISC—the Cancer Network Information System Cymru—which collected information about primary diagnoses, but it would not be able to tell you how many patients have metastatic disease or what their outcomes are. So, I would say that the Welsh Government needs to have a tighter relationship and contractual arrangements with the support bodies that support cancer, namely the NHS Wales Informatics Service and Public Health Wales. There is a case to ask them to deliver more for the NHS rather than necessarily their own agendas.

[433] **David Rees:** We have heard in evidence today and in written evidence about diagnostics, and the difficulties people face with diagnostics and waiting times. You are representatives of health boards, so perhaps you could give us some information as to how your health boards are addressing the issue in relation to diagnostics. What we are hearing is that some people turn up and present themselves late, and as a consequence they end up with a later stage. How are you addressing the issue of diagnostics?

[434] **Dr S. Lewis:** You perhaps have two health boards here with the greatest challenges around delivering diagnostic services. I work in Hywel Dda, so I will give you an example. In radiology, we should have 17 whole-time equivalent radiologists; currently, we have 10. We have three locums, and we fill the gap by occasionally using agency staff, and we outsource. We try to outsource simple radiological investigations so that our in-house radiologists can do more complex tests such as cancer and support MDTs. That is how we try to manage it, although some of the delayed diagnoses are much more complicated than access to radiology; it is about deprivation and circumstances—it is a complex issue.

[435] Diagnostics is one of our real challenges, and we have various ways of trying to get around that. These specialties—radiology and pathology—are shortage specialties across the UK; this is not a particular Welsh issue, although for reasons of geography often it is more acute in Wales. I do not know, Damian, how you see it in—.

[436] **Mr Heron:** It sounds very familiar. I would agree with everything that Sian has just said. I would add two points that I think were in the question. One is the late presentation of disease. Our population in the UK tends to present with disease later than in other parts of Europe and the western world. I think that is partly cultural and comes back to the education of the public. I think that that is part of it. If you are late to diagnostics, it is a double-whammy, unfortunately. The other part of it is that we also have to remember that for every cancer patient we diagnose from primary care, we have probably seen 10 to 15 others who did not have cancer. So, we are in a dichotomy of promoting the public going into the health service quickly because they are worried, but then we have to get a diagnosis—we have to investigate them. So, we have a problem of a mixed message there, which we have to get over more strategically.

[437] Going back to the detail, as Sian says, these are pressure points. Recruitment is a

significant issue, particularly in north Wales for pathologists, currently. Compared with England, we have a limited number of scanners; we generally have a lower number of scanners than our comparative hospitals in England.

[438] **Mr Laing:** From ABMU and a wider health board perspective, there is a Welsh pathology collaborative that is looking at many aspects of pathology, but cellular or histopathology is one of them. We are trying to organise those services to get the very best out of the staff we have, and to make them as efficient and work as well as possible. That is working through the various pathology disciplines and making progress. There are emerging plans, particularly for south-west and south-east Wales in that regard, for trying to bring together some of the resources that we have to get better support for the individual doctors. Pathology is a specialty where you really do not want people to be working on their own; it needs peer support and peer review. That work was initially going on across south Wales, but it was agreed at the most recent meeting that it would look at some aspects of pathology in north Wales as well.

[439] In terms of radiology, there are opportunities to use technology better, so that it is possible to have reporting done in different places, for example; Sian talked about outsourcing, which is perhaps about getting reporting done in different parts of the world, but there are ways of using our radiology doctors better so that they can support each other across Wales using the technology. I know that the Welsh radiology board is considering questions of training and recruitment in radiology. England has developed radiology academies for trainees, which seem to be very successful at providing high-quality training and attracting trainees into the areas where they are located. I think that there is a question of whether there would be merit in trying to develop such a thing in Wales as a way of getting trainees to come to Wales with the expectation that they would probably stay.

14:30

[440] One final point is that people want to be able to use the latest technologies—they want to have access to the best imaging. In a market where trainees can pick and choose where they work, they are going to tend to go to the places that have the state-of-the-art technology. So, we need to keep up with that, and PET is quite a good example, but there are others.

[441] **Dr S. Lewis:** May I add one thing to that, namely the opportunities regarding innovation around information technology? A lot of these diagnostic specialties do not have to be situated in a local health board, as I think that everyone has been alluding to. However, to make it work effectively, you need really good IT. We need all of our systems to talk to each other, we need primary care to talk to secondary care and we need to have referrals that our specialists can scrutinise so that we do not, perhaps, have so many urgent patients coming in who turn out not to have cancer—we can have better scrutiny. So, good integrated IT between health boards and between primary and secondary care has huge potential and opportunities for us to become more effective.

[442] **Leighton Andrews:** What do we mean by ‘good IT’?

[443] **Dr S. Lewis:** Where secondary care can see the primary care record, for example—*[Interruption.]*

[444] **Leighton Andrews:** Okay, stop there. Does that then mean that we have to get permission from all of the patients in primary care for secondary care to have that access?

[445] **Dr S. Lewis:** I must be honest that I cannot tell you the detail of it now. Perhaps Tom has something to add.

[446] **Dr Crosby:** No; I think that we have very clear guidance around information governance that care should follow the patient and, if that information is required at a point of need, you have access to that information. I would, actually, flip it around to say that they should demand that the person who they are seeing has access to all of the information around them. It saves duplication of tests and it saves delays in the system.

[447] **Mr Laing:** At the current time, it requires the colleagues in primary care to agree that colleagues in secondary care may see the data.

[448] **Leighton Andrews:** That is what I was asking. So, it is not really a technical issue—it is more of a protocol issue.

[449] **Mr Laing:** For cellular pathology, for example—histopathology—in many parts of the UK they have now moved to digital technology. Digital technology saves you from having to store thousands of glass slides and keep them forever, and it allows you to share them. However, they have to be of a very high quality, so that is a technical issue. The technology exists, so we just need to invest in it if we see that as important, for example.

[450] **David Rees:** So, it is a mixture of both. Rebecca has the next question.

[451] **Rebecca Evans:** Other witnesses have told us that there is a variety, shall we say, in the quality and content of your health boards' delivery plans and annual reports? How would you rate your own performances?

[452] **Mr Heron:** I can certainly say that we have an annual report. As the editor of that report, I am reasonably content with the contents of it. On your second point about performance, I think that we are struggling, like most of the health boards, in terms of the cancer waiting times.

[453] **Rebecca Evans:** I meant your performance in providing a good-quality report that addresses each of the parts of the plan, rather than your performance in delivering on the plan.

[454] **Mr Heron:** I am sorry. In that case, I would say that, having written the annual report and having re-read it on the train this morning, I remain confident that it is a good report. It describes well where we are and what we need to do, and I think that it is honest in terms of deficits, where they exist, but also the things that we achieve and have achieved annually. I have to say that I am quite content with that, but I would say that, I suppose.

[455] **David Rees:** Out of curiosity, who sees that report?

[456] **Mr Heron:** It has to be approved by my board, so it sees it and signs it off, and then it is a public document that goes on the health board's website.

[457] **David Rees:** So, the board signs it off. Does it, therefore, sanction any actions as a consequence of that?

[458] **Mr Heron:** The report itself does not necessarily have actions, but it will identify themes for the coming year, and those sorts of aspects. So, yes, the board is accountable in signing it off, in the knowledge that it is our health board's cancer report.

[459] **David Rees:** Can those actions be traced back to the report?

[460] **Mr Heron:** Yes, because each report then has to have an update through the year, in terms of actions against objectives.

[461] **David Rees:** What about Hywel Dda?

[462] **Dr S. Lewis:** I think that it is quite difficult to rate your own report, not having systematically scrutinised it against the others. However, in terms of the annual delivery plan, we tried to align our template to that of Abertawe Bro Morgannwg University Local Health Board, because we are working closely with it and we felt that the two reports should be complementary, which was something that we had not done before.

[463] **Rebecca Evans:** Why would you not scrutinise your own report against other reports, in the sense that you have all been given the same job to do, so would it not be a good starting point to look at other reports?

[464] **Dr S. Lewis:** We certainly did that when we set out to write it and we looked at which formats were most helpful. That certainly is a process that we went through at the beginning of writing and planning it.

[465] **Dr Crosby:** There is a slightly different situation in Velindre, being a tertiary provider. We can discuss that and whether there should be even more joined-up thinking about providing amalgamation of non-surgical services. From the network point of view, I would say that they are certainly a step in the right direction. There is something about maturity, and I think that these will develop over time. However, I do not think that there is enough challenge at the moment. These do exist. I think that, last year, they were much harder to find—they were not three clicks away on the website. They were buried around it, but I would challenge you, the public and the third sector to hold health boards to account not only for what they say they are going to do in that year, but for delivery. Lastly, we undertake a peer review of cancer services, and I do not think that there has been enough clinical engagement in those local delivery plans. A lot of the clinical teams have not seen their own health boards' plans.

[466] **Rebecca Evans:** On the issue of peer review, does it clip your wings in a sense that you can only conduct peer review within Wales? Would it not make more sense to have peer review from outside?

[467] **Dr Crosby:** We do not rule out inviting reviewers from outside. We invited someone from England to peer review penile services, which are very specialist services. Ultimately, we have to put our own house in order. So, it has to be between peers working broadly within the same health system. There are occasionally times when there are personality differences between teams undergoing review and being reviewed, but, again, it is a question of maturity. Most of peer review is just holding up a mirror to that service, not telling people what to do but just maybe highlighting variations and deficits and so forth. I think that it is a fantastic system that works really well, but we are certainly not against inviting people from England where necessary. Next week, we are on a re-review, and we have invited a professor of surgery to attend the review for that reason.

[468] **Mr Laing:** I want to quickly respond to the peer review issue. I would say that we welcome peer review. Peer review should be much more widespread than just in the field of cancer. Peer review is very important in driving up standards and making sure that you are meeting standards. Provided that it is conducted properly and in the right way, it is a very positive thing even if it is identifying weaknesses. In terms of the cancer plan, we should reflect on who the audience is. I think that we often write plans as if they are just going to be read by Welsh Government and not by citizens. I would say that we could be criticised for that. I think, perhaps, that they are not written in a very citizen-centred way.

[469] I would just highlight another issue, which is that of the integrated medium-term

plans. We have been asked as health boards to move to three-year planning and integrated medium-term plans, and that is a really positive thing, too. It has been quite a challenge for us to do it in this first year but it will get easier. Really, what I have been saying to my colleagues who are developing the cancer plan is that it needs to be part of that. We do not want to end up with lots of separate plans in the board. We want to try to bring all our plans together so that they are there. Of course, there will be much more detail in other places, but we do not want to be asked to, or choosing ourselves, to develop lots of separate plans. It should describe what we are trying to do as a board in great detail for the first year and in a bit less detail for subsequent years. It applies to the quality delivery plans in other specialisms too. We really need to be able to bring those together so that we can have a comprehensive and co-ordinated plan for what we are going to do for citizens for the coming twelve months.

[470] **David Rees:** I have questions from Janet, Kirsty and Lindsay.

[471] **Janet Finch-Saunders:** I have a couple of points that I have picked up along the way and on which I would like more clarification. I know that there has been talk of all the systems working to capacity, and GPs—we only raised it on Tuesday—certainly in north Wales, are reaching crisis point. Is there scope—there are some recommendations in this—to have a clinical specialist cancer nurse in GP surgeries? How do you feel that would help and how achievable would it be to put a framework in place so that we could have clinical specialist cancer nurses in our GP surgeries?

[472] **Dr S. Lewis:** Certainly, in my health board, we are looking at developing an acute oncology service. This is a new development for us, but one of the key aspects of it is to ensure that it links into the community. It would not quite be a clinical nurse specialist as many of us understand it, as being a disease-based speciality. It would be more to do with the whole of cancer. We would be very receptive to that idea. Although, as to how the model looks, I do not have a clear idea in my mind on how it might look—the detail of it.

[473] **Janet Finch-Saunders:** Do you feel that the recruitment of those would be easier? Picking up on Rebecca's point, when we had the round-table discussion in relation to patients, there was a common thread running through that they had gone frequent times to see the GP and the GP was busy. For one lady, it took her 13 visits to the GP before he was able to diagnose. When he diagnosed—or, when he sent her off and she was diagnosed, I should say—she already knew. She knew on the fifth visit, so to speak. She felt that people were not always able to comprehend the signs from what she was saying and how she was feeling; signs that she thought fell in with some of the classic signs.

[474] **Dr S. Lewis:** I am not sure that the models I am talking about would be about the diagnostic step. The models I had envisaged are about patients who already have a diagnosis of cancer.

[475] **Dr Crosby:** As a direction of travel, it is absolutely the right way to go. Macmillan is doing a number of one-to-one projects at the moment on getting back into primary care after secondary care services. In fact, there are other examples of specialist nurses going out to clusters of GPs and talking about rectal bleeding clinics, for instance. It is going to be a direction of travel. We give primary care, obviously, quite a hard time, but they will see a few cancers every year. Most of the symptoms, even if they are strongly suggestive of cancer, will not be ultimately, as we have heard, diagnosed as cancer. So, secondary care has to be a very precious resource that we use appropriately. Gradually, as with other health services, there will have to be a shift towards primary care, and specialist nurses will have a key role. There is the independent practitioner role that we have at the moment, but we are developing GP localities and clusters at the moment, and they will have something around having specialist nurses, both for diagnostics and surveillance, in the future.

[476] **Janet Finch-Saunders:** Finally, we talk about technology, and you can probably see that it has made our lives completely different as AMs, but one of the concerns that have been raised—

[477] **Elin Jones:** She is controlling air traffic as we speak. [*Laughter.*]

[478] **Janet Finch-Saunders:** Not quite. One of the things that has come up regarding this new digital age and technology is that concerns have been raised about databases. How on earth are you going to have one integrated approach? I am not going to say ‘different health boards’, but different agencies become very precious about their own data system. Do you think that, at some stage, we should be looking to really modernise technology? You could potentially stop that barrier by becoming less precious about data sharing and more about using innovative technology and making it accessible for anyone who needs to tap into that.

[479] **Mr Heron:** I do not see it being an issue of data sharing in particular. I have not come across organisational boundaries on sharing data in particular. It is about compatibility—

[480] **Janet Finch-Saunders:** And that as well.

[481] **Mr Heron:** I think that that is where the problem is. I have worked in the health service for a very long time and I can remember everyone having an electronic health record and card being talked about for many years. Ultimately, that is what we need. It is just a big-risk project, as many IT projects in the NHS have proved to be over the years. You are absolutely right, but, in a way, I personally would not recommend a health board or even a devolved nation doing it on their own. It has to be everywhere. To give an example from north Wales, we have lots of patients who go to Liverpool and Manchester, so it has to work across the boundaries. You are absolutely right, but it is a big leap forward. That is the challenge.

[482] **Dr Crosby:** I would say that technology is catching up. There are messaging systems that are just a common language for all systems now and which will happen. In the cancer plan, there is a proposal that we should have a cancer data warehouse.

14:45

[483] We have to take factors around patients, their diseases, the treatment that they receive and their outcomes, and link those together. There are perfectly reasonable systems for pseudonymisation, to take out patient identifiable information. We have an organisation in Swansea, Sail Databank, which is an academic group that specialises in data linkage. Why is it not doing more from the NHS point of view?

[484] However, this is a task for the NHS Wales Informatics Service to bring these systems together. Nearly all chemotherapy is now prescribed electronically. It is really important that we take this information from source—from the radiotherapy machines, the surgical theatre systems and from GP demographic systems—and put this information together. I do not think that we currently have the information to tell us how good our health service is in Wales, or how much value-added it gives to what is a challenging problem in a deprived population, broadly. I do not think that we know that we have the information on performance that we should have to tell us how well we are doing, other than survival.

[485] **Mr Laing:** I would add that I think that NWIS comes in for some difficult press sometimes. It is responding to what it is being asked to do. I would urge it to really focus on systems that improve clinical care. I was in Denmark yesterday; patients there are all able to look at their own records to check that they are right and to raise concerns about them. We are

a long way off from that, but we have an opportunity. I think that we have to avoid the tendency to think of the electronic record as simply an electronic version of the paper record, and then it is just a big electronic filing cabinet. Actually, that is not very useful—it gives you the opportunity to put much more stuff in that is hard to find. So, what we have to do is build systems that improve the opportunity for clinicians to deliver good care. It is about presenting them, in a way, with decision-making tools, using the best evidence so that they know exactly what to do based on what is relevant to that patient. That may require additional investment in Wales to get us up to speed fast enough, but it would be transformational for patients, I think.

[486] **Kirsty Williams:** We heard a lot of evidence this morning about the unsatisfactory nature of the current individual patient funding request process. I wonder whether you have any comments on that, as boards that sometimes have to make those decisions. Also, what is the biggest risk that you have identified in your organisations' ability to meet the implementation of your own cancer plans?

[487] **Mr Heron:** I will certainly answer the first bit; I will have to think about the second bit. In terms of the IPFR process, the particular issue, arguably, is a particular nuance in north Wales, where some of our patients go to north-west England and are recommended drugs that we then cannot supply or fund in Wales. The main issue with the IPFR process in Wales is the variation across the country. I am well aware that my own health board has the lowest utilisation of IPFR drugs in Wales, and that is something that is clearly in the public's mind. The 'however' is that we should not be fooled that the English cancer drugs fund is the panacea that it is purported to be. A lot of the drugs that are funded will have minimum benefit and they have not been approved. I think that it raises cancer patients above all other patients and then many other patients with chronic diseases will not get the same focus.

[488] So, my observation would be that the IPFR process probably needs tweaking, to an extent, and it is probably one of those issues that could be dealt with on an all-Wales basis to eliminate local variation. However, I would not necessarily support a cancer drugs fund, either.

[489] **David Rees:** Do any of you have views on the IPFR?

[490] **Dr S. Lewis:** I think that it is a variation—

[491] **Elin Jones:** Could I just ask a question specifically about the issue that was raised this morning, which was that, in the next system after the current consultation, each individual health board does not need its own panel? There should be a national panel to decide on patient funding requests. Do you have any views on that?

[492] **Mr Heron:** In a way, that is what I am alluding to.

[493] **Elin Jones:** Okay. That is what you were saying. So, a national panel and then—

[494] **Mr Heron:** As long as it is quick.

[495] **Elin Jones:** A quick national panel. Okay.

[496] **Dr S. Lewis:** There could be some pragmatism about it, and some core guidelines so that some things can be done locally. I do not know the practicalities of it. It might be that you do not have a single system and that some are more locally based but, certainly, there needs to be consistency. Variation is a significant issue.

[497] **Dr Crosby:** I would support that, but I think that there is something much more fundamental than that. IPFR is based on a system of exceptionality, and you can only have

exceptionality if you have a negative appraisal in the first place, and then you are seeking some exception to that rule. It is a legalistic term. Certainly, obviously, if you have six or seven health boards interpreting exceptionality, you will get variations. However, much more than that, we have a number of drugs that are not licensed—they are for rarer diseases, or they are pending appraisal by the All Wales Medicines Strategy Group. These are medical cohorts of patients. At the moment, you do not have another system for unfunded drugs to use, other than IPFR. This review currently says that we need to be better at filling out forms, and that it needs to scrutinise them more. There needs to be much more fundamental reform of the IPFR system. It must not be just based around exceptionality. We have to use what limited resources we have much more strategically and joined up. That has to be in a clinically informed group of patients that will benefit most from the limited resources that we have. I do agree that, where IPFR does exist, it needs to be on an all-Wales basis.

[498] **Mr Laing:** Tom makes an important point, because to be exceptional you cannot be in a small group of patients. Yet, what we tend to find with the rapid developments in oncology is that a new treatment becomes available, and not necessarily a big group but a significant sized group of patients might benefit; they become a cohort. Therefore, they are not exceptional. It is how we deal with that group, and how we deal with patients for whom—I was dealing with this this morning—a drug has had a provisional positive approval by NICE, although it has not published its approval yet. We are being asked whether we would fund the drug, it is not yet NICE approved, but we know that it is very likely to be approved in a few weeks' time. It is those sorts of practical things. My anxiety about a national panel is its capacity, because, at the moment, these panels are being asked individually to make a lot of very difficult decisions. A national panel would be very large. That is the worry, I think. That might run the risk of it being very slow.

[499] **Kirsty Williams:** Why would it be very large?

[500] **Mr Laing:** Individually, there would be a lot of patients going to it.

[501] **Kirsty Williams:** Oh, right. Not the—

[502] **Mr Laing:** No. Sorry; the volume of the workload. The workload of the panel would be large. Alternatively, you would have to have a lot of people on it, to distribute the work.

[503] **Dr S. Lewis:** That is why you would want to take out the groups that Tom, perhaps, described better than I do—those groups where everyone would agree that it is not that it is exceptional, but just that existing systems do not allow you to fund.

[504] **David Rees:** Kirsty, would you like to move on to the second part of your question?

[505] **Kirsty Williams:** Yes. What is your biggest risk?

[506] **Mr Heron:** Yes, I have thought about that. The second-biggest—

[507] **Kirsty Williams:** I would have thought that you would have thought about that when you were writing your plan. You cannot implement your plan unless you have identified your risks.

[508] **Mr Heron:** That is a fair point. There were so many risks to choose from. I think that the biggest risk for my organisation is actually recruitment.

[509] **Kirsty Williams:** Okay. People. It is recruitment.

[510] **Dr Crosby:** For Velindre, it would be capacity and finance. It is an institutional

organisation that we are extremely proud of. We can recruit the best doctors to work there and lead innovative work, but it is a question of whether we can continue to do that for an increasing population of patients, without the appropriate finances. On the all-Wales stage, it is not moving forward in a strategic way, as an all-Wales group. I would say that that is a huge risk, because it will lead to stagnation.

[511] **Mr Laing:** I would echo both of those points. It is capacity and strategy.

[512] **Lindsay Whittle:** Thank you for spending your valuable time here today. It has been really interesting. I have two questions at either end of the spectrum on the scale of cancer care. I am of bus-pass age now, and I sometimes feel that my car gets a better MOT than I do. I think that that is a bit worrying.

[513] **Elin Jones:** I have seen your car. [*Laughter.*]

[514] **Lindsay Whittle:** It does. It gets an annual MOT test, and it can be stopped at any time by the police to also look at it. I cannot.

[515] **David Rees:** I am sure that you would be stopped at any time.

[516] **Lindsay Whittle:** Well, there we go. I think that it is important that we get to the early stages of detection, and I am wondering how you think that we can attain that. Then there is the end of life. Prior to you coming in, we had some other expert, first-class witnesses. Where would we be in Wales without the hospice care that is provided by so many organisations? I am wondering how you feel about end-of-life care within the national health service itself, and what you are doing to address that.

[517] **Mr Heron:** Taking your questions in order, in terms of a health check, to an extent, actually, we do that. I did note your age, with great respect. We do have a screening service for a variety of different diseases, and age is a key factor. There is little point having health screening for cancer before the age of 60, really. We do have national screening programmes where the tests are valid. To give you an example, with prostate cancer, the tests that we can do just are not valid enough to have an across-the-board screening programme. My clinical colleagues might disagree with me. Where we can screen and it is appropriate, we do so; we do that health check. With other aspects of cancer and diagnosis very early on, it is pot luck to an extent. We could see you one month and you might start to show symptoms the next. So, an all-organ health check is probably not that viable. However, again, my colleagues might disagree with me.

[518] In terms of end-of-life care, we rely on the hospice movement absolutely fundamentally in the UK, and certainly in Wales. We are grateful to the third sector for everything that it does in that respect. I also think that we have moved on considerably with end-of-life care and palliative care in the last five years. We have had a lot of investment and a lot of emphasis on end-of-life care; I think that it has moved on in leaps and bounds. There is far more work to do, partly because of the demographics that we know about. We have also moved away from cancer running that issue; it is much more about chronic disease, which is highly appropriate as well. So, I think that we have made a lot of progress, but that is not to be complacent. It has to be a continuum of forward movement.

[519] **Lindsay Whittle:** That is interesting.

[520] **Dr S. Lewis:** May I just add one point on the benefit of the third sector? Organisations like Macmillan and Tenovus have driven innovation into the system. They have pushed the agenda and pushed the opportunities. They fund new sorts of posts. There is a real advantage to having plural components of the sector.

[521] **Dr Crosby:** On both of the themes, we have to work better strategically, as I keep saying, but also in partnership. On your first point, around early diagnosis, it is really challenging in the UK. We have a fantastic primary care system, but it is a gatekeeping system and it is about keeping patients out of hospital. We want the patients with cancer to come in for diagnosis. However, there is some evidence that awareness campaigns that are carried out in England now are leading to somewhat earlier diagnoses, or at least elective admissions rather than presenting to accident and emergency departments, and better access to surgery, around lung cancer for instance. We are proposing to have an emphasis on lung cancer next year, which may culminate in an awareness campaign.

[522] So, at the moment, primary care will say that it will not follow NICE recommendations for telling patients with a three-week cough to have a chest x-ray, because that will flood the system. That is a NICE recommendation and that is what should happen. It is a simple test. It will have a low pick-up rate, but we know that we have later stages of presentation in the UK with the current system. I think that it is about partnership working. It is also about patients taking responsibility, and about awareness. So, we say that we need to do the right things, but we drink more, we smoke more, we exercise less at the same time as saying that we should do none of those things. We have to take some responsibility for that ourselves.

[523] I think that the same goes for end-of-life care. I think that we have a fantastic model. It is dependent on the third sector, but it is a really good partnership. I think that Sian makes a really important point, because when it has the freedom to spend, you look at the third sector and what it is investing in and that probably highlights some of the gaps that we have in our system. So, service improvement work, particularly around Macmillan initiatives, is really important. I think that we should be doing that more ourselves, obviously, within the NHS.

[524] **David Rees:** Time is upon us, but I will ask just one final question. Except for Dr Crosby, you are representatives of the health boards and, obviously, you are measured, as far as the cancer delivery plan goes, by some of the statistics that we see here on waiting times and other aspects. Are you, as clinical leaders in these areas, comfortable that the actions being identified by the health boards are tackling the issue of waiting times but also meeting the demands of the cancer plans? I am looking at ABMU because that is my area, but it also has some of the lowest figures.

[525] **Mr Laing:** The answer is that we are confident that the plans that we are putting in place will address it. As you know, we have had some difficulties in meeting some of the targets. That is down to a number of factors, but it is largely to do with capacity in one or two cancer types.

15:00

[526] Also, as you heard earlier, there are problems with recruitment—we are concerned about some likely vacancies in the oncology centre that will appear in the next few weeks that we are struggling to recruit to. So, I think that that is a concern. However, we have actually made quite a lot of progress, and we are optimistic that we will continue to make progress. We, of course, want to meet the targets, because they are quality targets. These are not arbitrary targets; they are about providing a high-quality service, which we want to do.

[527] So, yes, I think that the measures, particularly the proposed revisions to some of the measures, which I think are clinically sensible and helpful, are ones that we welcome. As you know, those are being piloted in one or two cancer types at the moment. I think that they make a bit more sense from a patient's perspective. So, we shall see how we measure up against those as we pilot them. However, it is quite a challenge to deal with some of the

demand. Neurology in particular is where we have had some difficulty, and we are putting in place plans to try to address that.

[528] **David Rees:** Hywel Dda, do you have a comment?

[529] **Dr S. Lewis:** Certainly, in the time that I have been in my post, I have seen a significant change in our approach to the pathway work. So, in terms of the performance targets, there are significant changes in place. My anticipation therefore is that the performance around that will improve. What is perhaps more important, however, is that we need a sustainable systems change in order that these patients consistently get the cancer care that they need, and that is not a single thing. It is about the cancer delivery plan, it is about the work of the networks, it is about the Welsh Government having committees such as this that are interested in it—it is all those things together that will help us to improve cancer care.

[530] **David Rees:** And Betsi.

[531] **Dr Heron:** Well, I am not a clinician anymore; I am a manager. So, I am directly responsible for this sort of thing, and all I can really say is, please do not underestimate the effort—the daily effort—that is put in to monitor patients through the system. However, I go back to the point that I made earlier: there is a massive ratio of patients who had been referred but who do not have cancer. You have to see them all quickly and diagnose them all, and get a diagnosis of it not being cancer. So, it is uphill, but there is a great deal of focus all the way through my organisation and, I am sure, all the other organisations, on always striving to meet the targets, and we are probably as frustrated as our public and our politicians in not getting there.

[532] **Dr Crosby:** As an—. Sorry, Chair.

[533] **David Rees:** Go on. I did not ask you, because you know that you have said—
[*Inaudible.*]

[534] **Dr Crosby:** Well yes, although I have been involved in looking at the outcome and the targets that we have, and they do focus on a few patients that may breach a specified date, and that has been very useful and is a very simple system, but it is not measuring the real patient experience. So, I think that we have to have outcomes that drive service improvement. We have to have clinical ownership of the waiting times. At the moment, for the last few years, that has been handed over to cancer service departments, mainly avoiding a few people breaching. Most of this is about very simple service improvement things. People need three steps before they are treated. It does not matter whether you wait three weeks, six weeks or one day; those steps still need to happen: the capacity and the use of those resources is the same. So, we have to stand back, look at the system and make it work better together. It is not just about capacity, although I accept that, in certain diagnostic areas, such as endoscopy et cetera, there are huge capacity issues. It is about having outcomes that drive service improvement and that really, truly, reflect the patient experience.

[535] **David Rees:** Okay. At that point, we will leave it. I thank you all for attending this afternoon. You will receive a copy of the transcript to check and correct any factual inaccuracies that you identify. Once again, thank you very much for your time.

15:04

Papurau i'w Nodi
Papers to Note

[536] **David Rees:** Committee members, we now move on to item 7, which is papers to note. Can we just note the minutes of 4 June, and the consolidated notes from the workshops held in relation to this inquiry, and the focus group events? They are noted. Thank you very much. In that case, before I close the meeting, I remind Members that we will next meet formally next Wednesday, when we will continue to take evidence in this inquiry into the Welsh Government's cancer delivery plan. I therefore close proceedings.

Daeth y cyfarfod i ben am 15:04.
The meeting ended at 15:04.