



Cynulliad Cenedlaethol Cymru The National Assembly for Wales

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

**Dydd Mercher, 18 Mehefin 2014
Wednesday, 18 June 2014**

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

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

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

Aelodau'r pwyllgor yn bresennol
Committee members in attendance

Leighton Andrews	Llafur Labour
Rebecca Evans	Llafur Labour
Janet Finch-Saunders	Ceidwadwyr Cymreig Welsh Conservatives
Elin Jones	Plaid Cymru The Party of Wales
Darren Millar	Ceidwadwyr Cymreig Welsh Conservatives
Gwyn R. Price	Llafur Labour
David Rees	Llafur (Cadeirydd y Pwyllgor) Labour (Committee Chair)
Lindsay Whittle	Plaid Cymru The Party of Wales

Eraill yn bresennol
Others in attendance

Dr Sharon Hillier	Dirprwy Gyfarwyddwr Sgrinio, Iechyd Cyhoeddus Cymru Deputy Director of Screening, Public Health Wales
Dr Dyfed Huws	Cyfarwyddwr Uned Gwybodaeth ac Arolygaeth Canser Cymru Director of the Welsh Cancer Intelligence and Surveillance Unit
Dr Pat Riordan	Cyfarwyddwr Iechyd a Gwella Gofal Iechyd, Iechyd Cyhoeddus Cymru Director of Health and Healthcare Improvement, Public Health Wales

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

Stephen Boyce	Y Gwasanaeth Ymchwil Research Service
Helen Finlayson	Clerc Clerk
Victoria Paris	Y Gwasanaeth Ymchwil Research Service
Sarah Sargent	Dirprwy Glerc Deputy Clerk

Dechreuodd y cyfarfod am 09:33.

The meeting began at 09:33.

Cyflwyniad, Ymddiheuriadau a Dirprwyon
Introductions, Apologies and Substitutions

[1] **David Rees:** Good morning. I welcome Members to this morning's meeting of the Health and Social Care Committee. We will be continuing our inquiry into the Welsh Government's cancer delivery plan. Our first evidence session this morning will be taking

place shortly. I remind Members that the meeting is bilingual. If you wish to use your headphones, simultaneous translation, which is from Welsh to English, is on channel 1, and amplification is actually on channel 0. I also remind Members to please turn your mobile phones off, or put them on silent, along with any other electronic devices that may interfere with the broadcasting equipment. There is no fire alarm scheduled this morning, so, if one does occur, please follow the direction of the ushers. We have not received apologies this morning.

09:34

Ymchwiliad i'r Cynnydd a Wnaed hyd yma ar Weithredu Cynllun Cyflawni ar gyfer Cancer Llywodraeth Cymru: Sesiwn Dystiolaeth 6
Inquiry into Progress Made to Date on Implementing the Welsh Government's Cancer Delivery Plan: Evidence Session 6

[2] **David Rees:** I welcome Sharon Hillier, the deputy director of screening at Public Health Wales, Dr Pat Riordan, director of health and healthcare improvement at Public Health Wales, and Dr Dyfed Huws, director of the Wales Cancer Intelligence Surveillance Unit, which is also at Public Health Wales, is it not?

[3] **Dr Huws:** Yes.

[4] **David Rees:** Thank you for the written evidence that we have received. Clearly, as always tends to be the case, written evidence leads to questions, and we will now, hopefully, be going straight into questions, if that is okay with you. We will start with Gwyn Price.

[5] **Gwyn R. Price:** Thank you, Chair. Good morning to you all. Could you tell me, in your view, whether you agree with the previous witnesses that a more integrated all-Wales approach is needed to ensure the delivery of the plan and that an overarching strategy plan delivery and performance monitoring body that is clinically led and brings all LHBs together with authorities should be established?

[6] **Dr Riordan:** I would agree with that. I think it is absolutely fundamental that the whole system across Wales—the health system and the public health system—works together in unity. It is absolutely fundamental that we work together as agencies in relation to the prevention of cancer and that we work together along the total clinical pathway for cancer, which, of course, starts with prevention and then leads into primary care, treatment within the acute sector, secondary care, and, for the more complex cancers, tertiary care as well. Then, obviously, and unfortunately, we have to consider the important role of end-of-life care as well, which cuts across all of our services. So, I absolutely would agree with that.

[7] **Dr Huws:** May I add to that? I am embroiled in all of that at the moment, as a member of the Government's cancer implementation group. The boundaries are a bit blurred because, of course, I am not a Government member. It ranges from a sort of half-strategic approach to a half-operational approach, and the accountability then becomes blurred. Under that, then, you go straight to the south Wales and north Wales cancer networks, which have individuals from the health boards. In the cancer world, it goes from prevention, primary care, secondary care to tertiary care, and there is a lot of cross-border treatment within Wales, and, of course, a lot of our patients go outside Wales for treatment. From what I can see, we need to split the strategic accountability at an all-Wales level, and I think the cancer implementation group is going to look at that. Are we talking about, in terms of the implementation part, certainly, clinically led for tertiary care? That is what is happening now, a little bit. On an all-Wales basis, I have heard mention of a single cancer network that would perhaps co-ordinate the health boards. I can see that being sensible and wise, but what I do

not currently see around the table anywhere are the other bits. Most people do not turn up to appointments with oncologists saying, 'I've got cancer', do they? They come with a range of symptoms and, generally—although Wales is not doing too well here—they present in primary care, to their GP and, unfortunately, increasingly to accident and emergency departments. So, we need to involve those parts of the health system strategically, whatever happens at the implementation stage. They are not around the table at the moment. So, the short answer is 'yes', but some of the detail is as I have described.

[8] With regard to public health in the wider sense—population approach and prevention—the cancer world, perhaps, needs to talk less to itself and more to those other parts of the health system, as I alluded to, more to us, and then out to the executive directors of public health locally, who sit on the health boards. We have a direct line to them and to their teams, as a part of Public Health Wales. We know them, we have our links and they use our data, and so on. I cannot speak for them, but I am sure that, as part of the public health system, interfacing more nationally, both operationally and strategically, could really push things along.

[9] **Dr Hillier:** From a screening perspective, the screening division of Public Health Wales manages and governs the cancer screening programmes across Wales—breast cancer screening, cervical screening and bowel screening. I think that is a very good example of how, strategically and operationally, we look across Wales. It is a service for all eligible patients in Wales, so we govern it so that people, wherever they live in Wales, have access to the same screening tests and the same screening treatment. We work very closely both on the uptake—and, for that bit, we work with our public health colleagues, our directors of public health and local teams in terms of the population—and across through to the health boards to ensure that, once the person is diagnosed, they are referred quickly into that care. So, it is looking at that pathway of screening and ensuring that we are the link, if you like, in terms of our partners to ensure that that pathway is the best for our population in relation to the cancer screening programmes. We have quite well established links, which we are talking about here, really, looking at that focus.

[10] **David Rees:** In relation to the screening, obviously, your paper focused a lot on screening and on information aspects. You have just said that there is a strategic look at how you deliver screening across Wales, but is there a strategic look at some of the difficult areas to target, because some of the figures that you quote are quite low, and you identify areas of deprivation in particular that are difficult to hit? There are also other groups of people who are also hard to hit as far as information and prevention is concerned. You mentioned prevention, Dr Riordan, which is clearly important. So, should we also be looking at a strategic way of looking at where those issues are and how we tackle them across Wales? I am sure that the difficulties in one health board will be similar to those in another health board.

[11] **Dr Hillier:** They are, and that is something that we are taking forward. The three cancer screening programmes have different aims, some of which are about prevention. Cervical screening is a prevention programme—it prevents invasive cancers from developing. Breast screening is about early diagnosis of cancers to reduce mortality from breast cancer. Bowel screening is about identifying early, again, but also, if polyps are there, they are removed, so there is a preventive part to that, so that the patient will not develop cancers in the future. So, there are different aims in that.

[12] With regard to the cervical cancer programme, we have very good uptake and coverage in Wales compared with the other countries in the UK. Our target is 80% coverage among 25 to 64-year-olds. We are at 79.3%, so we are not quite at the target, but, when you look at the coverage for other parts of the UK, we are the highest. That is not saying that we are complacent. It is a good percentage, but we need to work more on that. Our breast

screening uptake reaches our target of 70%; it is just over 70%. It is our bowel screening that we are unhappy with, because the target is 60% and we are not reaching that, and we have never reached that consistently. The last figures showed that we had reached about 50%. So, of our screening programmes, that is the one area that we are absolutely focused on.

[13] What we are doing with that is that we have looked at deprivation, and, actually, there is a relationship with deprivation for all our cancer screening programmes: the populations that are most deprived have a lower uptake than the populations that are least deprived. That is uncomfortable, but that is not unexpected of a public health intervention. It is a good, over 10% difference. For breast and cervical screening, of course, we are just inviting women, so we can look at deprivation only. When you look at bowel screening, the men are—if you look at the uptake as sloping upwards from the most deprived to the least deprived—10% lower again. So, among men in the most deprived communities, uptake may be about 35%. That is in contrast to women in the least deprived communities, who are reaching 60% uptake. So, in some populations in Wales, we are hitting our uptake rate. So, that is one factor that we have looked at; we have mapped it, we have looked at different areas and we are aware of that.

[14] So, what we are taking forward in the screening division—. We are aware of this and we can describe it; we now want to see what we do about it. Unfortunately, when you go to the literature or you go to the library, there is no book on the shelf that says, ‘This is how you reduce inequalities in a screening programme’. So, we have reviewed the literature and what we want in the literature is to provide clear, consistent and appropriate messages to the population. That is the strategic look that we are looking at. So, we have developed key messages for our screening programmes, and we are now using our partners to make sure that those key messages go out in a consistent way.

[15] We have a screening engagement team within the screening division, and that is going out across Wales. That team is looking at general uptake and then this work on inequalities. It is a small team, but we are using the partnerships with health boards and Communities First, and the people who are trusted in the community, to get the key messages out there, so that, when you are talking about bowel screening in particular, wherever you are, you are getting the same message about it. That has been set up using the Making Every Contact Count method in terms of the key messages; I have some copies of the information here. The first bit is, ‘Don’t ignore your bowel screening—it could save your life’, so, if you read that sentence up front, you would know what it is about, but then we have structures, some information and some more detailed information, so it is layered. The last bit is other general public health messages. So that, if you like, is our strategic look and it is about increasing uptake, but also looking at increasing inequalities.

09:45

[16] In July this year, we have a screening for life campaign, in which, again, we will be working with our partners. We have a community pharmacy campaign. In July, pharmacists in Wales will be providing bowel screening stickers and information packs in medications that people have and they will be doing questionnaires. So, again, it is about those people, locally, getting those key message to the different people to whom it is more difficult to get. Some groups, because we have an established link to our farmers union in Wales, have come to us and asked, ‘What can we do with screening?’ We have the Royal Welsh Show, but the farmers union works with us very closely.

[17] So, really, it is about those respected people in the community having those key messages out there, which will have a two-pronged result of increasing the uptake generally and focusing more on targeted groups. We have very targeted messages and we work very closely with transgender groups on screening; they say, ‘Actually, the messages are quite complex for us—female-to-male and male-to-female—so which screening programmes do we

do?’ We now have some videos on our website and leaflets specific to those. So, we are looking at it in a very strategic way, but with a view to going forward and looking at the evidence and whether that increases uptake and then rolling out. So, you would say that it is about increasing the messages and getting out there in terms of awareness.

[18] We worked closely with a local service board in Wrexham in north Wales, because that is an area that has a very low uptake of bowel screening. It gave us some money to do a campaign. We did a large campaign: we had bowel screening information on buses, we had radio campaigns and local communities involved in distributing that message. We will be evaluating that to see whether that targeted and very close focus that we had—. The mayor came to launch it, we had the Tenovus choir there and we tried to make as much noise about it as we could. There was lots of activity, but it will not be until August that we can say that the uptake has increased. So, it is about doing small pieces of work and evidencing them and then, if that works, rolling it out. However, we do have an overall strategic approach to this, looking at the targeted areas.

[19] **David Rees:** When did you start that, so that we have an idea of when you expect to have some data and we can get some information from that?

[20] **Dr Hillier:** The Wrexham campaign was in February 2014 and the key messages were released a couple of months ago, so that is kind of snowballing, but the real push on screening for life will be in July this year. It is something that we have been concerned about and looking at and doing pieces of work on and it is now building up into a direction and a way forward. We have also worked very closely with some universities to look at the data about GP use and primary care. So we are very much in the throes of giving information to people, so that they are aware, in their communities, and GP clusters now know the uptake rate. It is about working with them to get that uptake higher. It is something that we are very aware of.

[21] **Lindsay Whittle:** Would I be correct in saying that you have actually moved the goalposts? I understand that there was some considerable bad press about 12 months ago about cervical screening of women? I do not think that they were tested every three years; is it every five years now? Younger women were not being targeted at all. There were some highlighted cases—my postbag had a few and I am sure that other Assembly Members’ postbags did, as well—of younger women who, quite frankly, would clearly have been at risk, had they not taken the initiative to go to their doctors to say, ‘Look, there is something wrong’. They should have been picked up earlier, should they not?

[22] **Dr Hillier:** Yes. The decision about which screening programmes you run is a recommendation by the UK National Screening Committee. That is run by the UK, but all countries feed into it and that is where the recommendation on what to do with screening is made. We have our director of screenings on that and there is also Welsh Government membership.

[23] Screening is a population-level intervention. You must ensure that, in a screening programme at population level, you do more benefit than harm. Although screening sounds like a very positive thing, and it very much is, there absolutely are harms in screening and we have to make sure that we create more benefit than harm. So, with the decision on which age range we screen in cervical screening, we in Wales were screening 20 to 64-year-olds every three years. However, England had changed to starting with 25-year-olds and screening five yearly from ages 50 to 64 and had been doing that for quite some years. Scotland was discussing that as well, so there was variation across the UK. The evidence on which this was based was considered and went out for public consultation on the age range that we should be screening. The issue with young women is that the uptake rate is lower than among older women. The uptake in Wales was about 50% attending for screening among 20 to 25-year-

olds.

[24] However, it is about that balance of harm and benefit for that population, because we were pulling in quite a lot of young women for colposcopy but there was a view that, actually, the changes we were seeing would regress on their own. We were intervening and doing something that, actually, would potentially harm that population. We were also bringing vast numbers of people in for that, but what we were not doing so much was catching the cancers in there. So, when we talk about cervical cancer, it is about preventing cervical cancer in future. The women who were coming in with cancers were not necessarily the ones coming for the screening. So, although it feels like you are doing screening and you have this safety net, actually, it was a safety net that was not working in that population, because, as I said, the uptake was not high and we were harming—. On the balance of the population, there was more harm than benefit in that population. Actually, it needed to move to case-finding rather than screening. So, there was a net there, but it was not actually effective as it was. It is uncomfortable and there will be young women who have cancers, but the numbers are very, very small, and when you looked at the women who had cancers, they had not come for screening.

[25] It was something that had been considered by the UK National Screening Committee. It made a recommendation and it went out for wide public consultation, and people like the charities are actually supportive of that decision as well. Jo's Trust is very supportive of that decision because, in that population, the benefit was not more than the harm.

[26] **Lindsay Whittle:** I just have a quick question. Clearly, I have to accept what you say. I am not an expert in cervical cancer, obviously. However, as a layperson, I would have thought that the earlier you detect something—it is quite obvious—the quicker you can treat it. What can we do for those younger people who would clearly be missed, would they not? If they are not coming in for screening, they are going to be missed, and some of the cancers could then have developed a bit too far.

[27] **Dr Hillier:** It is about people going to their GP and the GP thinking about potential cancers and making prompt referrals. That is where we look to the younger women who had cancers. That is the bit that needs to happen. It is about case-finding, really, and that prompt referral. So, when we made that change, we also communicated to all the GPs the pathway that should happen if a young woman, or any woman actually, comes in with defined symptoms, and what to do at that point. If somebody came to their GP with symptoms, a cervical cancer smear would not be the appropriate treatment at that point. It would be colposcopy and examination. So, the safety net was not working and was not appropriate in that population. It is about the GP acting quickly now.

[28] **David Rees:** We have heard from many witnesses about the need for education for GPs to make sure that they have better awareness of some of the symptoms. Is it your view also that, if you are asking GPs to take on this additional role, there is a need for education among GPs?

[29] **Dr Hillier:** I would not argue that it is an additional role. It is about having awareness of their population. When we had screening, there were women who needed to come through that way. We were very clear that, when we made the change, we had to ensure that there were very good communications out there. We have very good links with GPs. We have a screening link into all the GP practices in Wales, so we are able to push information in that way. That is something that we did as part of the change in awareness of it.

[30] **Dr Riordan:** Chair, I just have a comment. Yes, GPs have got to have their awareness raised in terms of the common signs and symptoms and also early referral, but there is something about the evidence that says that we need to empower the population to be

aware of their own signs and symptoms and not ignore them, such as the simple messages around, for example, blood in your poo. You need to empower that population to say, ‘Look, I need to do something about this. I have a right to go to my GP and say that this is something that I am concerned about. I am worried about it. Do I need to do something?’ Particularly in men, there is a tendency to put things to one side and ignore some very common signs and symptoms. We know that, if we educate the population to be empowered and feel, ‘I am not wasting my GP’s time; I have that power to control my own health and wellbeing’, then we know that there is a more common approach, if you like, to dealing with it.

[31] **Dr Huws:** May I add to that? This exemplifies exactly why our data are so useful. We perform one of the four statutory duties of Public Health Wales, to find each case of cancer in the resident population of Wales—that includes those treated, diagnosed, and/or treated across the border or elsewhere. So, we build a population approach for the people of Wales. That is why we are able to produce something like the document that we have here. Some of you may be aware of the official statistics that we produce on mortality, combining the Office of National Statistics data on deaths and survival. No-one else is able to do that. We do that by collecting the information from various sources, including from our colleagues in screening. So, we build up the register, if you like, and then we have a whole picture, each year, of all our cases—obviously, we will miss one or two. For example, in this case, we are talking about cervical cancer and it is not just about screening, of course; it is about prevention and sexual health. It is papillomavirus-related of course. We can then look at the screen detected and the non-screen detected. Something that we are doing with lung cancer, for example, which is something that we are focusing on this year, is looking to see whether there are any shifts into earlier diagnosis. So, we would be able to see if those people who presented with later stages of cervical cancer, for example, tended to present not to their GP, but to A&E, and whether GPs were picking up earlier stages.

[32] Additionally, we are involved in international research with our data. Patient confidentiality issues are, of course, taken care of. That might sound too glamorous and not the business here, but it has actually helped us to see, by comparing with other countries, and other countries within the UK, why certain problems are happening here or just illuminating in general. So, for example, in the international cancer benchmarking partnership studies—we are on to module five now—in the second module, we found that in Wales, particularly, it was more of a population issue, as you have said, Pat, rather than the GPs. Compared to Scandinavia and some Commonwealth countries—I think Canada and Australia were two—our people tend to get quite embarrassed about symptoms. They are as aware as other countries of cancer symptoms—it is important that we know that, so that we do not go off spending loads of money on the wrong campaign—but, for some reason, they are embarrassed about these symptoms; they worry about wasting the doctor’s time. This is fact now, it is not us supposing this; the research has shown this, so it is really important that we take part in this. They are also worried about what the doctor might find. So, they are worried that it may well be cancer, but they are scared of that or whatever. The researchers have scored all of these things and we tended to have the highest population score of people who were concerned about the barriers. Hence, overall, in several cancers, not just in this, we tend to present later.

10:00

[33] For certain cancers, other factors are involved within the health system, but on the subject of cervical cancer, that is some of the work that we can do. So, it is about drilling down to the detail and understanding that we give you the headline figures, but with further research, if we can have the resources to do that, we can really find out what the issues are and address them.

[34] **David Rees:** I have questions from Elin and from Darren.

[35] **Elin Jones:** Mae fy nghwestiwn i'n gysylltiedig â'r cwestiwn a ofynnodd Lindsay am y rhaglen sgrinio ac oedran. Hoffwn gyfeirio at y rhaglen sgrinio am ganser y fron ac, wrth gwrs, mae'r rhaglen sgrinio honno'n gorffen pan fyddant yn 70 oed. Rwyf yn sicr wedi dod ar draws menywod sy'n meddwl bod eu risg ar ôl 70 oed yn llawer llai ac, felly, bod yr oedran 70 yn arwyddocaol o ran y penderfyniad ynghylch risg iddyn nhw fel menywod. A ydych yn credu bod y rhaglen sgrinio yn gorffen am 70 yn briodol, o ran lefel y risg, neu ai adnoddau sydd yn gyrru'r penderfyniad i orffen y rhaglen sgrinio genedlaethol pan fyddant yn 70 oed? Yn gysylltiedig â hynny, a ydych yn gwneud gwaith gyda'r boblogaeth honno o fenywod dros 70 oed sydd angen gwybod bod lefel y risg yn parhau ar ôl 70 hefyd?

Elin Jones: My question is related to the question that Lindsay asked about the screening programme and age. I just want to refer to the breast cancer screening programme and, of course, that screening programme finishes at age 70. I have come across women who think that their risk after the age of 70 is a lot less and, therefore, that the age of 70 is quite significant in the decision around risk for them as women. Do you believe that the screening programme finishing at 70 is appropriate, in terms of the level of risk, or is it resources that are driving the decision to finish that national screening programme at age 70? Connected to that, are you doing work with that population of women over the age of 70, who need to know that the level of risk continues after the age of 70?

[36] Os gallaf, gofynnaf un cwestiwn arall. Wrth gwrs, y rhaglenni sgrinio sy'n cael eu trafod fan hyn ar hyn o bryd, ond yn dilyn y rhaglenni sgrinio, mae'r *diagnostics* yn digwydd. Rydych wedi son am *colonoscopies* yn barod ac y mae'r amseroedd aros ar gyfer *diagnostics* a phroffion *diagnostics* yn weddol o sylweddol 'nawr yng Nghymru. Rwyf yn meddwl bod tua 40% o bobl yn aros dros 12 wythnos am *colonoscopy*. Felly, fel pobl sy'n ymwneud â iechyd cyhoeddus, a oes gennych farn ar, neu unrhyw gynigion ynglŷn ag, a yw'r lefel honno o *diagnostics* ac amseroedd aros ar gyfer *diagnostics* yn briodol ar gyfer atal y cancer rhag datblygu?

If I may, I will ask one other question. Of course, it is the screening programmes that are being discussed here at the moment, but following the screening programmes, diagnostics happen. You have talked about colonoscopies already and the waiting times for diagnostic tests are quite significant and long in Wales now. I think that around 40% of people wait over 12 weeks for a colonoscopy. So, as people who are involved in public health, do you have an opinion, or any suggestions, in terms of whether that level of diagnostics and waiting times for diagnostics are appropriate for stopping the cancer from developing?

[37] **David Rees:** Could you deal with the age question on breast cancer first, and then we will go on to the question on diagnostics?

[38] **Dr Hillier:** The breast screening programme in Wales, as across the UK, is that we call and re-call women aged 50 to 70 every three years. However, from 70, women can self-refer and we make that well-known to them. The issue is not about resources, but about evidence base. So, we are going back to the aim of the breast screening programme, which is to reduce mortality from breast cancer; it is not to identify breast cancer per se, but to reduce mortality. If you identify it, then by doing that, you reduce their mortality. The evidence for that in older women is not there currently. That is the issue with it. It is about mortality; it is not necessarily that the breast cancer will increase their mortality from breast cancer itself. England is doing a large study on this—a randomised controlled trial—and it is probably one of the largest it can be. They are randomising women in the earlier age group, the 47 to 50-year-olds. They are doing an additional screening and half the women will be from 47 to 50 and then the other half will be over 70, in order to answer that question. It will not be until we have that evidence that we can make that recommendation. So, it is not an issue of resource issue, but the evidence base on which that is based.

[39] **Elin Jones:** May I ask a quick question? On self-referral among over 70s, what is the level of self-referral? Does it drop significantly from the numbers that were being referred or invited?

[40] **Dr Hillier:** Yes. From the top of my head, I could not tell you what the percentage is, but not all people self-refer. They are made aware of that in all of our posters and information, so that is awareness. Breast cancer does increase as you get older and that is the message that we probably need to make a little bit stronger, but the aim of the screening programme is to reduce mortality, and that is the evidence on which that is based.

[41] **David Rees:** Do you have the numbers for the self-referrals?

[42] **Elin Jones:** It would be interesting to see them.

[43] **Dr Hillier:** I can send them; they are there. I am sorry—they are just not one of the figures in my head.

[44] **David Rees:** A note would be fine.

[45] **Dr Riordan:** I think that one of the essential things about the older age group of women is that, as with all women, they get screened and they get a diagnosis of breast cancer, but often these women who are in the older age groups may be subject to some fairly aggressive treatment and it may be that the evidence would suggest that these women, who have that diagnosis and that label for the later part of their lives, would go on to die not of their breast cancer, but of other diseases. As with other cancers, there is a risk in terms of over-intervention; that is the risk of any screening programme. You have to weigh up, if you like, the checks and balances in that screening programme to say, 'Are we doing more harm than good by identifying an early stage breast cancer in a woman aged 75 who may go on to have that label and psychology?'. We have to understand the psychology of that diagnosis, which is powerful, in relation to the harm that we may do in relation to the benefit to her as she progresses through her older years.

[46] **Dr Huws:** Gadeirydd, hoffwn ategu'r wybodaeth y mae fy nghyfoedion wedi sôn amdani ynghylch cwestiwn Elin Jones. Bwriad y rhaglen sgrinio yw lleihau marwolaeth. O ran goroesedd—'survival'—mae yna lun pwysig yn cael ei ddangos. Soniais am sut mae gwybodaeth bwysig yn dod o'n dyletswyddau statudol a pha mor ddefnyddiol a phwysig yw hynny i oroesi cancer yn gyffredinol.

Dr Huws: Chair, I wish to add to the information that my colleagues have given in response to Elin Jones's question. The intention of the screening programme is to reduce mortality. However, in terms of survival, there is an important picture being portrayed. I mentioned how important information comes from our statutory duties and how useful and important that is for cancer survival in general.

[47] Mae gen i bapur o'r gwaith ymchwil yr ydym wedi cyfrannu ato, ac mae'n cymharu lefelau goroesedd cancer y fron rhwng y gwledydd y soniais amdanynt ac yn torri'r wybodaeth i lawr yng ngwledydd y Deyrnas Unedig. Yr hyn sy'n bwysig i sylweddoli yw a yw'r sbectrum o safle neu safon y diagnosis o ganser y fron—hynny yw, a yw'r cancer yn cael ei ddal yn gynnar, yn ganolig neu'n hwyrach, neu yn 'stage 1 to 4'—yn debyg yng Nghymru i'r gwledydd

I have a paper from the research work that we have contributed to, and it compares breast cancer survival rates between those countries that I was talking about and breaks down that information within the UK countries. What is important to understand is whether the spectrum of the site or standard of the breast cancer diagnosis—that is, whether the cancer is caught early, in the medium term or at a later date, or at stages 1 to 4—is similar in Wales to the other countries.

eraill.

[48] Buasech yn disgwyl bod sgrinio'n cyfrannu at hyn, ond, hefyd, mae'n dangos nad ydym yn ffôl o ran y rhai sy'n mynd i gyfeirio eu hunain neu sy'n dod at y meddyg teulu gyda symptomau, sef rhywbeth nad yw'r rhaglen yn ymwneud ag ef o gwbl. Er ein anhawsterau gyda chanserau eraill, felly, rydym yn dangos bod y lefel lle mae pobl yn cael eu dal neu'n cyflwyno i'r meddyg teulu arni yn eithaf da o'i chymharu ag eraill.

You would expect that screening would contribute to that, but, also, it shows that we are not bad in terms of those who refer themselves for screening or go to the general practitioner with symptoms, which is something that this programme does not engage with. Even though there are difficulties with other cancers, therefore, we are showing that the level at which people are being caught or presenting themselves to GPs is good compared with other places.

[49] Lle'r oeddem yn syrthio i lawr, oherwydd mae'r papur hwn yn edrych ar orosedd cancer hyd at gwpwl o flynyddoedd neu dair blynedd yn ôl—mae pethau'n newid, wrth gwrs, ac mae'n rhaid ichi aros i weld beth yw goroesedd pobl achos mae'n rhaid ichi ddisgwyl i'r blynyddoedd fynd heibio ar ôl iddynt gael diagnosis—oedd bod gennym broblem, os oeddech yn dal cancer yn fuan neu ar ôl i'r cancer daenu ychydig bach neu ar ôl iddo daenu'n fawr, roedd angen gwella ansawdd y gofal arnom ar bob lefel fel bod ein goroesedd yn cyfateb â goroesedd gwledydd eraill. Fodd bynnag, rydym yn gwybod bod hynny wedi digwydd ers y data hwn.

Where we were falling down, because this is looking at cancer survival up until a couple of years ago, or three years ago—of course, things change, and you have to wait to see what people's survival rates are, because you have to wait for the years to pass after they have been diagnosed—is that there were problems, if you were catching cancer early, or if the cancer had spread a little bit or if it had spread on a larger scale, there was a need to improve the standard of care at every level so that our survival rates would correspond to those of other countries. However, we know that that has happened since these data were published.

[50] **David Rees:** May I come back to the second part of Elin's question, on waiting times, and the question on diagnostics?

[51] **Dr Hillier:** With the cancer screening programmes, we are responsible up until the point that the person is diagnosed with cancer. So, for bowel screening, in terms of the colonoscopy, the pathway is that somebody undertakes the test at home, and if blood is identified in the faeces on the card, then they are offered a colonoscopy. That is delivered across Wales by screening colonoscopists in the health boards; these are colonoscopists who have undertaken additional procedures and have fulfilled the criteria to be screening colonoscopists. The waiting time on that is something that we are constantly and actively monitoring, because that is one of our concerns. We have standards in terms of how quickly that person goes through to that aspect. With screening, it is important to note as well that we always have harm at the forefront of our minds, because we are asking well people to do something and then suddenly, we might say, 'Actually, there is blood in your faeces, we need you to go and have a colonoscopy'. If they have to wait for quite a long time, that is an anxious wait for them that we have caused. So, that is something that we are very aware of. Really, the capacity of that is something that we struggle with in Wales and we are very actively tackling that at the minute. There is always a balance to be struck between screening patients and symptomatic patients. We know that it is not because the unit is not doing anything; it is actually very busy with the symptomatic as well. So, we are in active conversations on that, currently, to ensure that our screening patients have that colonoscopy quickly, because we are very aware of that as the pathway. So, the capacity is an issue.

[52] **David Rees:** Leighton, is your question on this particular point?

[53] **Leighton Andrews:** Yes, it is on this point. When we had, I think it was the British Medical Association last week, talking on this specific point, or the GP who came in anyway, who spoke about two routes to colonoscopy, as a GP, he would have what he would regard as an urgent list and a less urgent list. Are you comfortable, as Public Health Wales, with that differentiation?

[54] **Dr Hillier:** Those that come through the screening pathway go through on the urgent list because they are suspected cancers. I think that there is work now looking at a different pilot, which is a simplified version of that, which I am aware of.

[55] **Leighton Andrews:** So, do you have any data on those who have been through an urgent pathway and those who have been through a non-urgent pathway? Can you tell whether a percentage of those coming through via the non-urgent pathway are subsequently found to have been, arguably, urgent?

[56] **Dr Hillier:** Through us, if they are screen detected, they are query cancer. So that is—. We have standards in terms of timeliness that we need to reach with the health boards. So, we do not have two pathways within screening patients that go down two levels. They go through the same pathway.

[57] **Leighton Andrews:** I am not talking about screening. This is about patients presenting with symptoms and being referred.

[58] **Dr Riordan:** That sort of information—correct me if I am wrong—would not be collected by the Welsh Cancer Intelligence and Surveillance Unit, per se, but should be held at health board level. I am assuming that the monitoring of that is done within the health board level itself. So, the acute trusts should be able to disaggregate that information so that you have those who are referred through the urgent pathway and those who are just a normal wait. However, I am not aware, within our cancer intelligence unit—Dyfed, correct me if I am wrong—that they submit that information to us nationally.

[59] **David Rees:** Dr Huws, you have a chance to correct her if she is wrong. [*Laughter.*]

[60] **Dr Riordan:** Certainly, that is what I assume.

[61] **Dr Huws:** Pat, rwyd ti'n gywir, heblaw, nid ydym yn casglu'r wybodaeth honno a'i rhoi yn ein cofrestr canr, ond mae gennym fynediad at ffynonellau eraill o ddata. Wrth gwrs, ni fedrwn wneud popeth ar yr un pryd. Felly, nid ydym yn gwneud hyn yn arferol o flwyddyn i flwyddyn—ni welwch chi'r wybodaeth yn ein gwaith craidd.

Dr Huws: Pat, you are correct, except, we do not collect that information and put it in our cancer register, but we do have access to other sources of data. Of course, we cannot do everything at the same time. So, we do not do this on a year to year basis—you will not see that information in our core work.

[62] Mae'r tîm wedi gwneud gwaith arbrolfol yn cysylltu gwybodaeth ein cofrestr â ffynonellau data ysbyty. Rydym yn gobeithio cysylltu'r ffynonellau data gofal cynradd, a meddyg teulu yn enwedig, i astudio hyn. Felly, rydym yn gallu cael gafael ar y wybodaeth ac rydym yn gobeithio cydweithredu mwy gyda'n partneriaid o fewn yr NHS ar hyn. Rydym yn gallu dweud, trwy

The team has conducted experimental work linking information in our register with hospital data sources. We hope to link the primary care data sources, and especially GPs, to study this. Therefore, we can have access to this information and we hope to collaborate more with our partners within the NHS on this. We can say, through quite a bit of hard work on specific projects, what

ychedig o waith caled ar brosiectau penodol, pa lwybr mae pobl wedi ei ddilyn i ddod at eu diagnosis. Felly, yn rhannol, i ateb eich cwestiwn, Leighton, rydym yn gallu edrych ar hyn. Mae'r gwaith arbrofol wedi cael ei wneud ar gancr y coluddyn a'r ysgyfaint ac rydym yn symud ymlaen â'r gwaith hwnnw yn fwy pendant, i'w gyhoeddi a'i rannu â chi a phobl eraill yng Nghymru.

pathway people have followed to reach the diagnosis. So, in part, to answer your question, Leighton, we can look at that. The experimental work has been undertaken on colon cancer and lung cancer and we are moving forward with that work to publish and share it with you and other people in Wales.

10:15

[63] Mae'n fwy manwl o ran yr ysgyfaint. Rydym yn gwybod yn fras nad yw jest dros hanner y cleifion cancr yr ysgyfaint yn mynd drwy eu meddyg teulu o gwbl o ran diagnosis, na thrwy gael eu hanfon ymlaen i'r ysbyty. Maent yn ymddangos yn yr adran frys, ac nid yw hynny'n beth da. Mae'r bobl sy'n ymddangos yn yr adran frys yn gwneud yn waeth. Mae canran uchel iawn yn marw o fewn blwyddyn neu lai. Rydym yn trio peidio hybu gormod ar hynny, ond ein gwybodaeth ni sy'n golygu y medrwn edrych ar hynny. Heb hynny, nid ydym yn gwybod lle i weithredu i wneud rhywbeth am y peth.

It is more detailed work on lung cancer. We know, generally, that just over half of lung cancer patients do not go through their GP at all in terms of diagnosis or through any referral to hospital. They present themselves to the emergency department, and that is not good. People who present themselves in A&E do worse. A high percentage will die within a year or less. We try not to promote that too much, but our information means that we can look at that. Without that, we do not know where to take action to do something about it.

[64] Rydym yn gobeithio manylu ar hynny o ran canser yr ysgyfaint i edrych ymhellach ar beth sy'n mynd ymlaen. Wedyn, rwy'n gobeithio y byddwn yn gallu bwydo'r wybodaeth honno i'r byrddau iechyd ac efallai i gorff mwy strategol cenedlaethol a fydd wedyn yn edrych ar y dystiolaeth ymchwil o ran beth sy'n gweithio, nid jest yn dod i fyny gyda rhyw brosiect rydym wedi ei greu, ond yn edrych ar beth sy'n gweithio er mwyn gwneud rhywbeth ynglŷn â hynny.

We hope to do more detailed work on lung cancer and look further at what is happening. Then, I hope that we will be able to feed that information to the health boards and perhaps to a more strategic, national body that will then look at the research evidence about what is working, not just come up with any project that we have created, but look at what is working to do something about that.

[65] **Elin Jones:** In your response on colonoscopy, you said that you are taking actions to try to improve the time from the screening result to the call for colonoscopy, which can be a very worrying time in terms of the psychology of cancer. It struck me that you go from a national screening programme into the health board variations that exist in Wales. Have you given any consideration, because of your responsibility for everything up to the diagnosis of cancer, to undertaking in some way, maybe with the south Wales cancer network and the north Wales one, the diagnostics that follow on from the screening, so that it is part of a national response to the screening? I just wanted to ask another question quickly. Is there a particular statistic, in terms of cancer diagnosis, as a result of the screening? For example, is it a 20% positive cancer diagnosis?

[66] **Dr Hillier:** In terms of breast cancer, we diagnose about half of breast cancers in Wales through the screening pathways—about 1,000 a year. In terms of bowel cancer, we are diagnosing just over 240 a year, which is a much smaller percentage of the bowel cancers that are in our population in Wales. For cervical cancers, in terms of the incidence, there has been

a real reduction over the last two years, but last year it went back up to the normal level. Last year, we had around 174 cervical cancers. I do not know off the top of my head how many of those came through the screening pathway, but it is something I can find out. Sorry, I have forgotten the first question.

[67] **Elin Jones:** The first part was whether you need to own the colonoscopy diagnosis part of the process, rather than allowing it to go into the various health boards, and then into the various lists that they already run, in terms of their screening in different ways.

[68] **Dr Hillier:** In terms of the colonoscopy, screening lists happen; they do not just go into the general pile. We have screening lists, and that is when the colonoscopies occur. It is up to the point of diagnosis of a cancer. So, up to the diagnostic bit and until there is a cancer diagnosis, that comes within our remit. Once they have a diagnosis of cancer, that is when they are transferred for care into the health boards for treatment of the cancer.

[69] **Elin Jones:** So, you undertake the—

[70] **Dr Hillier:** It is until that point. It is the whole pathway until there is a cancer diagnosis. In bowel cancers there are large polyps, so the other part is that we remove the large polyps. It is not until you remove that polyp and then do the pathology on it that you understand that there is a cancer.

[71] **Elin Jones:** So, what you are saying is that for somebody in Hywel Dda or Aneurin Bevan who has been called for a colonoscopy following screening, there is absolutely no difference—it is not related at all to various waiting times in various different local health boards.

[72] **Dr Hillier:** There are different waiting times between different health boards because of their capacity. However, we have a consistent standard, and we are working very closely with all health boards to make sure that they all get within our standard. Some health boards in Wales are doing better than others in terms of their waits. However, our voice is very strong in that to try to get their rates down. So, there is a little bit of—

[73] **David Rees:** That is in relation to the patients that you send via screening.

[74] **Dr Hillier:** Yes. That is a variation that we are very aware of, and working hard to tackle.

[75] **David Rees:** I now return to Elin.

[76] **Elin Jones:** No, I am fine. I have finished.

[77] **David Rees:** I therefore turn to Darren and Janet.

[78] **Darren Millar:** Elin has taken some of my questions, but I wanted to ask you a little about how the screening programme is developed. If there is a new suggestion for cancer screening—I have heard it being suggested that prostate cancer screening should take place in Wales—how is that considered? Is it on a UK basis, or is there an option for Wales to do something differently?

[79] **Dr Hillier:** No. One of the very big pluses of screening work is that we have very close working with UK colleagues on this. Do not forget that it is not just the cancer screening programmes that we do in Wales; we actually govern the non-cancer screening programmes as well. The UK National Screening Committee considers the evidence and makes a recommendation, which then goes to the Wales screening committee for

consideration. Then a ministerial decision is made on whether we implement the recommendation in Wales. We are all basing the evidence on the same initial recommendation, but we are around the table of the UK National Screening Committee.

[80] **Darren Millar:** So, if the decision making is consistent, why is there a need for the two additional steps in Wales, with the—

[81] **Dr Hillier:** That is because we are devolved, and the health decision is a devolved power.

[82] **Darren Millar:** I understand that in terms of ministerial sign-off perhaps, but if we are going to be consistent across the whole of the UK, which is what you are suggesting we are, why is there a need for further barriers to be put in the way of a decision that, perhaps, ought to be automatic?

[83] **Dr Hillier:** I think that the barriers are not so much barriers, but it has to be right for Wales. That is more about capacity because screening is not just a test; it is a whole pathway. When we instigated bowel screening in Wales, which is the more recent cancer screening programme that we started—it has been up and running for five years—we were a little bit behind England in terms of it starting its bowel screening programme, and it was about getting the capacity right for the colonoscopies before we started the screening programme. It is no good doing the faecal occult blood test if you have nowhere to refer.

[84] **Darren Millar:** I appreciate that.

[85] **Dr Hillier:** It is about that decision, and it is a matter of whether we can do this in Wales and what we need to enable that to happen in Wales. That is the second process, if you like.

[86] **Darren Millar:** Presumably, there would be a variation in terms of access in England, time wise, to colonoscopies as well.

[87] **Dr Hillier:** Yes, there is.

[88] **Darren Millar:** So, those things would be a challenge everywhere.

[89] **Dr Hillier:** Yes, but that is the process.

[90] **Darren Millar:** What I am trying to get to is that, obviously, there is a very clear decision-making process for drugs, for example, across the UK, with NICE being the organisation that makes decisions, and then they are implemented after NICE has made a decision. Here, however, it seems to be quite a different process. I am not convinced that there needs to be a different process. I appreciate that there might be challenges in terms of capacity. There may be a higher prevalence of certain cancers as well in different parts of the UK as a whole, but if a recommendation is made and you are simply rubberstamping it again twice, what is the point of that?

[91] **Dr Hillier:** That does not institute a big delay in terms of process, because when you are starting a new screening programme, we are not talking of a week's delay here; it is a long process to setting something up. It is not a delay. It is about consideration for the population in Wales and the practicalities of how we are going forward with regard to the levers in colonoscopy and ensuring that that is a process that can happen. It is the process that happens across the UK. The UK NSC meets and the decision is referred to Scotland to decide. It is not decided by the UK NSC; it does not have the remit of making policy decisions for the devolved countries.

[92] **David Rees:** So, the situation is that it is important for patients to understand that, if they undertake the screening, there will be a follow-on process and that everything is in place, effectively. Is that the scenario that we are talking about?

[93] **Dr Hillier:** Yes. It is about making sure that the pathway is there in Wales and that is the decision. The Wales screening committee was established over the past few years in its new format. That has enabled very effective strategic leadership of that aspect for us, and very good clear communication. So, for us, in terms of the service, that has been a real plus. That committee understands where we are in Wales and knows the factors so that it is an enabler more than a restriction. If that just came from UK NSC, we would struggle to enable things to happen in the pathway, I think. It is a very good enabler for us.

[94] **Janet Finch-Saunders:** Quite recently, we held workshops on cancer treatment and care. I had a table of ladies and not one of them had been diagnosed easily, shall I say? One lady in particular had to go back 13 times and another lady had to go back seven times. I was quite alarmed to find, in taking evidence here, that, as Leighton referred to earlier, a GP was saying that, quite often—and this is even recommended on some occasions—it is picked up more at A&E, the approach being that you will get a quicker diagnosis if you go to A&E. That is what we were given to understand last week. Do you have any data on how many people are presenting at A&E with quite advanced cancer?

[95] **Dr Huws:** As I said earlier, Chair, yes, we would. I think that there is a lot of work in each project to look at this. We looked at colorectal cancer and lung cancer as an experiment, because there are technological and methodological issues. We have not come to breast cancer yet, and we are going to follow through with lung cancer, so it could be possible but we do not publish that on a routine basis.

[96] **Janet Finch-Saunders:** I had people within my little group who had only been diagnosed through finding themselves in A&E, so it is happening. It follows on from Leighton's point in terms of colonoscopy as to whether it is urgent or non-urgent. Even those cases that were urgent, as far as the GPs were concerned, were not seen fast enough. Therefore, there was an attitude of, 'You might be better if you present to A&E'. That is not a message that I am comfortable with.

[97] **Dr Huws:** You are absolutely right and I agree entirely. I mentioned earlier the possibility of linking our register to primary care data. I have an apprentice public health consultant looking at the feasibility of doing that right now. These are the kinds of things we will be able to look at in more detail to see to what extent this is happening in the population—and it is happening, you are quite right—

[98] **Janet Finch-Saunders:** Definitely; it sounds like it—

[99] **Dr Huws:**—and where in the pathway it is happening. It is our route to diagnosis project—

[100] **David Rees:** So, at this point in time, you are unable to identify whether a person who presents at A&E has been presenting at their GP practice with similar symptoms before that.

[101] **Dr Huws:** It would be possible as part of these ongoing projects, so we are continuously working to improve the efficiency of our registration process.

[102] **David Rees:** It would be possible, but the information is not available at this point in time.

[103] **Dr Huws:** Of course, then you have to analyse all that, make sense of it and interpret it. We are doing that for lung cancer this year and hopefully next year. Once we have done that as a prototype—and it is important that it is done for lung cancer anyway—we can move on and do these things more routinely in future.

[104] **Janet Finch-Saunders:** If I may, Chairman, the concern I have is that we all had to speak and, for every table, a common thread running through was that, with regard to diagnosis, GPs need to sit up and realise—. Even though people were describing their conditions, they were being sent away on numerous occasions, and it was almost like they had to swim through to get through that very fine—. A lot of my ladies felt that, by the time they were diagnosed, they knew it anyway but, by then, in some cases, it was pretty advanced. So, what are you doing to ensure that people are able to get through more easily by going to their GP and making it less—. I mean, 13 times—

[105] **David Rees:** You cannot answer that. I think that the question is: what work are you doing with GP practices and primary care to look at that, because we had concerns that people spent a long time going to their GP before they were referred on sometimes?

[106] **Janet Finch-Saunders:** There is also a recommendation in our papers that a cancer specialist nurse within a GP practice might be able to—. We certainly need a remedy for this because it is unacceptable if people are really struggling when they go to their GP.

10:30

[107] More than one person said to me, ‘I was diagnosed with anxiety and depression, when in actual fact I had cancer’, but it took for them to dare to almost fight to get through, and then someone picked it up through their going through the A&E for something completely different.

[108] **Dr Huws:** Obviously, that is not our remit—and that is not fobbing off; it is not our remit. I think that our remit—and our statutory duty allows us to look at it—is to help others to quantify this clear problem. We know that it is happening, but to what extent, and where? And, actually, is it the GP having trouble getting that referral and getting the diagnostic test? Is it the patients coming in? We are beginning to colour that in. So, as I said, the primary care data are one part of getting better knowledge about the extent and details of that.

[109] The other bit of the project, Chair, if I may—and primary care is essential here, and, as I said, if there is a change in the strategic approach, primary care needs to be there—is that we are working through the primary care public health team with Public Health Wales and our Public Health Wales Observatory colleagues to begin to look at all the different parameters of cancer, such as the aspect that you included, at the GP cluster level. Local health boards now are thinking about general practice and GP clusters, are they not? I think that it would be more informative to them if we took our analyses down so that they can use them, because we want to be useful to the NHS out there. You now have these new GP clusters, and they can begin to do things about what you say if we can feed them, you know, 80% of whatever cancer cases are turning up at A&E, and if they did not know that before, I would wager that that would be really useful information for them.

[110] **David Rees:** Rebecca has a short question on this. I am conscious of the time.

[111] **Rebecca Evans:** Well, it is on a different topic, but it is short. You have talked about the differences in the ways in which health boards are performing in meeting standards, but we have also heard evidence that there is a great deal of variation in the quality and content of the health boards’ cancer delivery plans. I was wondering whether you have a view on that

and, if so, are there improvements that you would like to see.

[112] **Dr Huws:** I think that that is beyond our territory, to be honest.

[113] **Dr Riordan:** Certainly, that is not something that, since my time in Public Health Wales, I have been exposed to, in terms of monitoring the quality of delivery plans. My understanding is that it is the remit of Welsh Government to monitor the quality of those plans. Nevertheless, in looking at the overall quality of care, it is certainly something that Public Health Wales could look at, in terms of the various indicators that we could develop to monitor quality. It is work that we could potentially anticipate, but in terms of our statutory duty as Public Health Wales, it is not our remit to monitor the quality of the delivery plans.

[114] **David Rees:** Thank you for that. Now, if you do not mind, I have two questions that I want to get in quickly—I have the Chair's privilege of asking those two questions, and you can give me short answers. We have been presented with evidence about bowel scope screening, and I just wanted your view on whether you would consider that to be something that should be included in bowel screening.

[115] **Dr Hillier:** Bowel scope is something for which the evidence is there, and it is being rolled out in England. We in Wales have looked at this in lots of different ways as to how we can implement it, and it is the capacity of that at the minute, and the resources. So, if we were to put in bowel scope screening in Wales, it would be over 90 lists with 10 people on them per week. It is a very, very large number, and we just do not have the endoscopy capacity for that currently in Wales. That is where we are. So, there is evidence that it is effective, and we have looked in different ways at how we could possibly feasibly run that in Wales, maybe under a different model from the one they are using in England, but it really is the endoscopy capacity that is the limiting factor for implementation in Wales—it is not a small capacity issue; it is a large issue, really.

[116] **David Rees:** Thank you for that point. The final question that I am going to ask is this: we have not talked much about the information to patients, in one sense. I know that, in your paper, you did have some comments on that, and the cancer survey highlighted some of those points as well. Is there a lot of work still to be done to provide sufficient information to patients, particularly on how they can self-manage, in one sense, as a consequence? Is that something that you get involved in at that point?

[117] **Dr Hillier:** I can answer, once again, from a screening point of view. It is the same focus; it is a matter of informed choice, with regard to the screening programme. It is not mandatory, but a person's informed choice. There has been a lot of work done on breast cancer screening to make sure that women can make an informed choice. A leaflet has been produced following a lot of consultation in England about that choice, explaining the risks and benefits as much as they can do. It is a very complicated message to get over to women, because there is a risk of a diagnosis of cancer and that cancer increasing your mortality, but there is a risk of over-diagnosis. You are told that you have a cancer and you have treatment, but that decision of treatment will not have made a difference to your mortality. There is no way of knowing which women that will affect. So, it is a matter of explaining to women at the start so that they are aware of the pathway that they could go along following the screening. That informed choice leaflet will shortly be sent out. It is available on our website now, but it will be sent out in the very near future, because it has to be bilingual and it is taking some time because it is now quite a weighty piece of information. That seems to be the way ahead for the screening programmes: ensuring that people have the right information on which to base their decision. We are reviewing that with our colleagues.

[118] **Dr Huws:** She is not here, Chair, but I know that there is a Macmillan Cancer Support-funded post within Public Health Wales to look at the evidence base of what works,

and that is developing the field that you have just talked about. I was new to the post last year, but we are trying to reach the public better with our information. That arms the public with regard to knowing what is happening with cancer in Wales, and it is a tool that they can then use for advocacy, perhaps to come to you or whatever.

[119] There is an issue around health service quality and operational level data, and this is something that I get frustrated about in the strategic area, or the area, perhaps, that needs to be more strategic in terms of the oversight of the cancer policy world in that we get continuously drawn in to do what the LHBs and the trusts are meant to be doing—and it says that in the cancer delivery plan—that is not related to our statutory duty, which is the population-level register and all of that work that I have talked about, which involves people who go across the border, wherever they are, but our population. There does not seem to be central co-ordination.

[120] We can provide expert advice and facilitation for the collection and analysis of operational level data, such as the audits that LHBs are charged to do and factors such as 30-day mortality after chemotherapy or whatever. Of course, we have an interest that the data around that improve for our own register. However, if we get sucked in to doing that for people, as has been happening, and the pressure is on us to do that, then we lose the focus on our role and expertise, and it takes away the incentive for the clinical services to improve their own data—and, as I said, we have an interest in that happening—but also doing something about those services from the information. It is true in life that, if something is done for you, you never learn how to do it yourself, and there is no chance of improving because it is all done on your behalf somewhere else. So, that is something that, hopefully, perhaps within changes in the strategic world of cancer, can be clearly acknowledged and sorted out. It is happening in clinical services, and we are quite happy to provide expert advice there, but if we get drawn in to doing it at a very nitty-gritty operational level, then you can forget everything that I have told you, because we will not be able to fulfil our statutory functions.

[121] **David Rees:** Thank you for that, and thank you for the extra 10 minutes that we have taken of your time. You will receive a copy of the transcript to correct any factual inaccuracies that may appear. Once again, thank you for your evidence this morning.

10:39

Papurau i'w Nodi Papers to Note

[122] **David Rees:** We have one paper to note, namely the minutes of our meeting of 12 June 2014. Are Members happy to note those minutes? I see that you are. Thank you for that. Before I move back to item 3, we have received apologies from Kirsty who has a family crisis, unfortunately. She has sent her apologies this morning. I want to put that on the record.

10:40

Cynnig o dan Reol Sefydlog 17.42 i Benderfynu Gwahardd y Cyhoedd o'r Cyfarfod Motion under Standing Order 17.42 to Resolve to Exclude the Public from the Meeting

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

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

[124] Are all Members content? I see that you are. Thank you.

*Derbyniwyd y cynnig.
Motion agreed.*

*Daeth y cyfarfod i ben am 10:40.
The meeting ended at 10:40.*