Cynulliad Cenedlaethol Cymru
National Assembly for Wales

Cofnod y Trafodion
The Record of Proceedings

Y Pwyllgor Deisebau

The Petitions Committee

27/09/2016

Agenda'r Cyfarfod
Meeting Agenda

Trawsgrifiadau'r Pwyllgor
Committee Transcripts

Cynnwys
Contents

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

The proceedings are reported in the language in which they were spoken in the committee. In addition, a transcription of the simultaneous interpretation is included. Where contributors have supplied corrections to their evidence, these are noted in the transcript.

Aelodau'r pwyllgor yn bresennol
Committee members in attendance

Gareth Bennett Bywgraffiad|Biography	UKIP Cymru UKIP Wales
Suzy Davies Bywgraffiad|Biography	Ceidwadwyr Cymreig (yn dirprwyo ar ran Janet Finch-Saunders) Welsh Conservatives (substitute for Janet Finch-Saunders)
Mike Hedges Bywgraffiad|Biography	Llafur (Cadeirydd y Pwyllgor) Labour (Committee Chair)
Neil McEvoy Bywgraffiad|Biography	Plaid Cymru The Party of Wales

Eraill yn bresennol
Others in attendance

Rebecca Evans	Gweinidog Iechyd y Cyhoedd a Gwasanaethau Cymdeithasol Minister for Social Services and Public Health
Dr Rosemary Fox	Cyfarwyddwr yr Is-adran Sgrinio, Iechyd Cyhoeddus Cymru Director of Screening Division, Public Health Wales
Irfon Rees	Dirprwy Gyfarwyddwr, Iechyd y Cyhoedd, Llywodraeth Cymru Deputy Director, Public Health, Welsh Government

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

Jessica England	Dirprwy Glerc Deputy Clerk
Graeme Francis	Clerc Clerk

Kath Thomas	Dirprwy Glerc Deputy Clerk
Katie Wyatt	Cynghorydd Cyfreithiol Legal Adviser

Dechreuodd y cyfarfod am 09:01.
The meeting began at 09:01.

Cyflwyniad, Ymddiheuriadau, Dirprwyon a Datganiadau o Fuddiant
Introduction, Apologies, Substitutions and Declarations of Interest

[1] **Mike Hedges:** Can I welcome everyone to the meeting?

[2] Croeso i'r cyfarfod. Welcome to the meeting.

[3] Participants are welcome to speak in Welsh or English. Headsets are available for translation of Welsh to English. There is no need to turn off mobile phones or other electronic devices, but please ensure that any devices are on silent mode, if only because of the massive embarrassment that you have when you start fiddling around searching for it when it starts going off. Apologies: no apologies have been received—and that's still no apologies received.

09:02

Deisebau Newydd
New Petitions

[4] **Mike Hedges:** We've had some new petitions. I'll just mention that the number of new petitions, because we met a fortnight ago, have now reduced quite dramatically from the number we dealt with last time. The first one is to encourage planning committees to ensure that planning decisions take due regard of the impact on or closure of local community groups and voluntary organisations. A letter was sent to the Cabinet Secretary for Environment and Rural Affairs on 4 August. A response has been received and is in the papers. A research briefing on the petition and the related issues has been prepared for Members' information. The petitioner was informed that the petition would be considered by the committee, but had not responded when papers to the committee were finalised. Any comments?

Are we happy with the response that we've had from the Minister? It says, really—?

[5] **Neil McEvoy**: Where is the response, Mike?

[6] **Mike Hedges**: The response from the Cabinet Secretary said that the impact on local community groups and local communities should always be taken account as a material consideration by planning authorities.

[7] **Neil McEvoy**: Right. Because, really, I suppose, you've got to look at the merits of taking into account because it doesn't make any difference, does it, really? That's the problem.

[8] **Mike Hedges**: As you've probably had even more problems with planning committees than I have over time, there are difficulties with dealing with planning and planning officers' interpretation of views.

[9] **Neil McEvoy**: It's just that in Cardiff we've had the local development plan opposed by thousands of people in local referenda, and it hasn't made a jot of difference. I think that's the frustration from the public, really. I don't see much movement.

[10] **Mike Hedges**: Would it be helpful if we wrote back to the Cabinet Secretary asking, where it says that impact on community groups and local communities should already be taken into account as a material consideration, for clarification on that?

[11] **Neil McEvoy**: Yes, I think it would be. And the weight it carries, because our experience in Cardiff is that it carries no weight whatsoever.

[12] **Mike Hedges**: So, I think clarification on what it actually means, and the weight it carries when discussing a planning application.

[13] **Neil McEvoy**: Yes. Thanks.

[14] **Mike Hedges**: Is everybody happy with that? Yes. The next one is a ban on the manufacture, sale and use of snares in Wales. We've had the petition and we've had a letter from people opposed to the petition. [*Interruption*.] Oh, Suzy.

[15] **Suzy Davies**: Hello. I'm substituting for Janet.

[16] **Mike Hedges**: Croeso. [*Interruption*.] You can now be 'person with no name'. [*Laughter.*] Okay. Right, no problem. We're on the second one on the manufacture, sale and use of snares in Wales. I just said we've had a 1,405-signature petition. We've had a lot of correspondence from other bodies as well. We've written to the Cabinet Secretary, we've received a response from the Cabinet Secretary, we've had a research paper, we've had lots of correspondence from Countryside Alliance, and we've had further correspondence from the petitioner. I think that the word 'contentious' probably does sum up this petition.

[17] **Gareth Bennett**: The countryside people were kicking up a fuss over what they alleged were factual inaccuracies in the petition, but I don't know how we're supposed to deal with that as a Petitions Committee.

[18] **Mike Hedges**: There's nothing we can do about it because I think the factual inaccuracies are a matter of opinion, or the interpretation of numbers. We're not meant to act as jury on people's petitions. They've got a right to submit if they meet the criteria, and the Presiding Officer's staff have not said we can't do it.

[19] **Suzy Davies**: Can I just make an observation? It's occurred to me, all the parties put out manifestos very recently, and those were prepared after lobbying on this issue. I don't make a statement on views either way on this, but, having never served on this committee before, how do you treat petitions that are on areas of public interest that have already been dealt with fairly recently?

[20] **Mike Hedges**: We treat all petitions exactly the same. We get the petition in, we write to the Cabinet Secretary/Minister asking for their observations on it, and if they say, 'This is now being dealt with', we come to the conclusion whether we want to reopen it or whether we wish to just acknowledge that it's been done. With this petition, the Cabinet Secretary has already indicated that a meeting between officials and interested parties should take place imminently to coincide with the first anniversary of the code of practice.

[21] **Suzy Davies**: That's right, because there's a relatively new code on this, isn't there?

[22] **Mike Hedges**: The Government is also giving careful consideration to

the Law Commission's recommendations that the operation and inspection of snares may benefit from additional regulations. As such, the committee could forward the correspondence received to date to the Cabinet Secretary and request to be kept informed about the outcomes of these discussions before deciding whether to take further action at a later date, which is what I would recommend. If people can come to an amicable agreement, then we don't really want to interfere with that. So, can we do that? Yes. Two nods. Yes. Three nods. Okay.

[23] That takes us on to a success now, 'The Ghost Train', which confused me as well when I first read it. It's from the residents of the Ardudwy coast. A separate online petition has also collected over 300 signatures. I think we've got a note from Arriva Trains, which I saw earlier, which says:

[24] 'In response to requests from the public, local stakeholders, from Monday 12 September 2016, the Arriva Trains Wales 19:00 Machynlleth to Pwllheli service will now stop all stations upon request.'

[25] So, I think we can mark that down as a success.

[26] **Suzy Davies:** Yes.

[27] **Mike Hedges:** Shall we write to the petitioner to congratulate them on the successful outcome of their petition?

[28] **Suzy Davies:** Well, yes, it's encouraging for other petitioners, then.

[29] **Mike Hedges:** Yes. 'Welsh Assembly to Build a International Mother languages Monuments at Cardiff Bay'—this was submitted some time ago by Mohammed Sarul Islam and has 16 signatures. What do you want to do with it? I would have thought it was a matter for—I look to Neil who knows more about this than I do—but I would've thought this was a matter for Cardiff council rather than the National Assembly.

[30] **Neil McEvoy:** He's not responded, has he?

[31] **Mike Hedges:** No.

[32] **Neil McEvoy:** So, you know—

[33] **Mike Hedges:** Shall we just note it?

[34] **Neil McEvoy:** We should maybe just wait to see if he responds and then maybe close it next time.

[35] **Mike Hedges:** Give him another fortnight to respond?

[36] **Neil McEvoy:** Yes.

[37] **Mike Hedges:** Yes, give him another fortnight to respond.

09:10

Y Wybodaeth Ddiweddaraf am Ddeisebau Blaenorol
Updates to Previous Petitions

[38] **Mike Hedges:** We've got updates to previous petitions. We've got two petitions that are virtually identical, one on slaughterhouse practices and one on CCTV in slaughterhouses, which we looked at last time and which were so similar that we decided to treat them together. It was considered on 20 October 2015. The Welsh Government business unit provided an update that states that, back in November 2015, an industry group was to investigate issues surrounding the welfare of animals at the time of slaughter, including the role of CCTV. This group was to report their findings to the Cabinet Secretary for Environment and Rural Affairs this summer, which is summer 2016. The report has been delayed while they await publication of the Food Standards Agency's latest slaughterhouse survey results. So, we're expecting it to go to the Cabinet Secretary in the next few weeks. Should we wait until we find the results of the Cabinet Secretary's—?

[39] **Suzy Davies:** I think you have to, don't you?

[40] **Mike Hedges:** Yes.

[41] 'Unconventional Oil and Gas Planning Applications'—this goes back to 2013. It was last considered on 2 February 2016 and an update from the Cabinet Secretary for rural affairs was received on 13 September and is in the papers for this meeting. The petitioner was informed that the petition would be considered by the committee, but had not responded when the papers for the committee were being finalised. Give them another fortnight to respond?

[42] **Neil McEvoy:** Yes.

[43] **Mike Hedges:** Yes, okay. Give them another fortnight to respond.

[44] 'Cilmeri Community Council Appeal for The Prince Llywelyn Monument'—this goes back to May 2014. It was last considered on 12 July when we considered correspondence from the then Minister for Economy, Science and Transport and agreed to write to the Cabinet Secretary for Economy and infrastructure to ask for an update. The correspondence from the Cabinet Secretary for Economy and Infrastructure received on 28 August is in the papers for the meeting and the petitioner was informed that the petition would be considered by the committee and a further response is included in the papers. Shall we forward the petitioner's comments to the Cabinet Secretary and ask him to provide the committee with a further update when a decision has been reached?

[45] **Neil McEvoy:** Yes.

[46] **Mike Hedges:** Yes. On to another one of our successes, 'Food in Welsh Hospitals'. This was submitted in January 2016. The Public Accounts Committee is looking at food in hospitals and, as a member of the Public Accounts Committee, I can say that the auditor general is looking at it again and the variation between not just different hospitals, but different wards in hospitals and different practices between different wards, including adjacent wards in the same hospital. The auditor general is looking at this and the Public Accounts Committee have considered it in private, so I'd better not say any more, but the Public Accounts Committee have had the petitioner's views, which have also been given to the auditor general. So, shall we wait for the Public Accounts Committee and the auditor general to report back? But I think the petitioner should be pleased to know that this is a matter that is being taken very seriously by both the Public Accounts Committee and the auditor general and by some community health councils—I say 'some', it might be all the community health councils, but I know that some of them are taking it very seriously and are doing work on it. So, if the answer's 'all community health councils', apologies, but I only know of two and they both are.

[47] **Suzy Davies:** Well, I'd rather hope that all CHCs will take this up now.

[48] **Mike Hedges:** Is it worth us just letting CHCs know about it? Is that a problem?

09:15

[49] **Mr Francis:** About the—?

[50] **Mike Hedges:** The concern about—. Shall we write to them and let them all know of our concerns?

[51] **Suzy Davies:** Do you want to wait for the PAC response, or—? I think the auditor general's letter is good enough for us all, to be honest.

[52] **Mike Hedges:** Yes, fine. We'll leave that until we've seen the response from the auditor general. Rather than bring it up at every meeting, can we agree that any comments on hospital food that come in, the clerk forwards them on to the Public Accounts Committee and the auditor general, rather than reporting to us, because they are the ones doing the work?

[53] Can we have a break until 09:45? Can I thank you—have I missed something?

[54] **Mr Francis:** Yes, the Minister's coming in at 09:45.

[55] **Mike Hedges:** The Minister's coming in at 09:45 to follow on from last week's report. I'll see everybody in half an hour.

Gohiriwyd y cyfarfod rhwng 09:16 a 09:47.
The meeting adjourned between 09:16 and 09:47.

Sesiwn Dystiolaeth
Evidence Session

[56] **Mike Hedges:** Can I welcome you to the meeting, and would you like, Cabinet Secretary, to introduce your two colleagues? We're waiting for Suzy Davies, who's due very shortly.

[57] **The Minister for Social Services and Public Health (Rebecca Evans):** Right, okay. I'll ask my officials to introduce themselves.

[58] **Mr Rees:** Irfon Rees, deputy director for public health in Welsh Government.

[59] **Dr Fox:** I'm Dr Rosemary Fox. I'm the director of screening division in

Public Health Wales. I was a member of the United Kingdom National Screening Committee from 2010 to 2015 and I'm now an observer on that committee.

[60] **Mike Hedges:** Thank you. Do you want to introduce yourself for the record?

[61] **Rebecca Evans:** Yes, Rebecca Evans, Minister for Social Services and Public Health.

[62] **Mike Hedges:** Thank you very much. Just a quick introduction, which I think you should know, is that we had Margaret Hutcheson in last week. She produced a petition that was first considered in 2016 and she had 104 signatures. She gave oral evidence last week, and we're now seeking evidence from the Minister for Social Services and Public Health and, obviously, your technical advisers. We've written to you in advance telling you what was raised by the speaker last time and an opportunity for you to answer some of those comments.

[63] **Rebecca Evans:** Okay. I took the opportunity to review the evidence that you received at the last meeting and it was very much about the affordability of the screening programme. I think we have to start by taking a step back from that, because whether or not we introduce a screening programme in the first place is very much dependent on the best evidence available as to the efficacy and affordability of such a screening programme.

[64] Screening programmes should only be offered when there is robust, high-quality evidence that screening will actually do more good than harm and also be cost-effective within the Welsh NHS budget. We take our advice from the UK National Screening Committee and they provide independent expert advice on population-based screening to all UK Ministers. It's a world leader in its field and the screening programmes in the UK, I think, are amongst the most respected internationally. The screening committee does not currently recommend population screening for ovarian cancer. Rosemary sits as an observer on that committee and she might be able to tell us a little bit more about the kinds of conditions and criteria that are set in order to determine whether a population-screening initiative should be introduced.

[65] **Dr Fox:** Thank you. The first premise of screening programmes is that they must be shown to do more good than harm. That's really important because you invite populations for screening. So, most of the people that

you're inviting for any screening test or to enter any screening programme haven't got the condition that's concerned. So, if you do even a small amount of harm to a number of those people who haven't got the condition concerned, that can easily outweigh any good that's done to the people who do have the condition.

[66] I think it's important to state at the outset that I don't think anybody would argue that ovarian cancer isn't a very significant disease and a terrible disease to have. But, we need to have the evidence that actually detecting ovarian cancer early by means of a screening programme will improve the outcome—and by 'outcome', we're talking about people dying from ovarian cancer—in the group of people that have been screened. At the moment, the United Kingdom collaborative trial of ovarian cancer screening, which reported last year, hasn't provided that evidence.

[67] And, I must say, on a personal basis, as somebody who's worked in screening for the last 10 years, that was quite a surprise. I think everybody had been expecting that the trial would show that there was a benefit from screening. The fact that it hasn't shown that means that we need to be very careful not to allow enthusiasm to do good to overcome looking at the actual evidence to see whether we will do more good than harm.

[68] **Rebecca Evans**: Could I add to that, in terms of what the study Rosemary referred to found? It found that, for every ovarian cancer case detected by the screening, two additional women in the multimodal group and 10 in the ultrasound group had unnecessary surgery, where the ovaries had benign legions or were normal, and around 3 per cent of the women who had the unnecessary surgery had a major complication with that as well. So, this is very much what must be considered when we're balancing doing more good than harm.

[69] **Mike Hedges**: I think Suzy indicated first.

[70] **Neil McEvoy**: Just a quick question. Do we have the report? Have you provided it to committee members?

[71] **Mr Rees**: The link has been provided in previous correspondence in relation to this, but can be provided again.

[72] **Neil McEvoy**: What the Minister's reading from, because I've not seen the report.

[73] **Mr Rees:** There was a *The Lancet* article summarising the results from that study that we can share—absolutely.

[74] **Rebecca Evans:** The committee has had the report previously.

[75] **Neil McEvoy:** As a new committee member, it would have been helpful to have seen it before today, really.

[76] **Mike Hedges:** Suzy, you wanted—.

[77] **Suzy Davies:** Yes, I just want you to talk a little bit more about the screening that shows up conditions that aren't actually ovarian cancer, because the CA 125 test doesn't detect cancer, it detects growth irregularities on the ovaries. Of course, ovarian cancer isn't the only condition that affects women's ovaries. It is a particularly effective tool for identifying endometrial cysts, for example, which may not actually in themselves be dangerous, but can cause women a great deal of unnecessary aggravation and pain. Don't you think the widespread screening should take into account the value for non-ovarian-cancer conditions that are discovered as a result of the initial CA 125 coming up with a positive test? It doesn't necessarily lead to surgery, but it does lead to the identification of other conditions.

[78] **Dr Fox:** The use of the CA 125 as a screening test for ovarian cancer has really just looked at mortality from ovarian cancer. I think women who've got ovarian cysts that are not causing them any symptoms are probably just as well not knowing about them, and if they are causing them symptoms, then obviously they need to know and that should be recognised and treatment should be offered appropriately. So, screening for things that aren't actually going to cause any harm, just to find out if they're there or to know if they're there, is actually sometimes what we refer to as a 'harm' of a screening programme, because you're turning people who otherwise would be well into patients.

[79] That's been quite well rehearsed recently in the case of breast cancer screening, where some women are being diagnosed with conditions, non-invasive breast cancers, that probably wouldn't have gone on to become breast cancers in their lifetime, but we can't tell which ones will and which ones won't. So, there's been quite a lot of criticism of breast screening for that at the moment. I think it's really important that we don't, with the best

of intentions, go down a route that ends up with a lot of women being told they've got conditions that they never otherwise would have known about if they hadn't gone for screening.

[80] **Suzy Davies:** But you are talking about asymptomatic—sorry, this is the last bit of this question—

[81] **Mike Hedges:** Keep going.

[82] **Suzy Davies:** You are talking about asymptomatic conditions. There will be women who think there's something wrong, but it doesn't occur to them that it's to do with their ovaries. Quite a lot of endometriosis, for example, presents in other ways. It feels as if it's happening to you in a different part of your body, so you wouldn't necessarily think, 'Oh, I must go and get screened for ovarian cancer'. Wouldn't the general screening pick up that?

[83] **Dr Fox:** I don't think it would. I'm not familiar with the fine detail, but, I think, when we're screening for ovarian cancer, we tend to be screening women who are post-menopausal, or over 50. Whereas women with endometriosis are pre-menopausal, and endometriosis ceases to be such a problem after the menopause. So, I think it would be an age thing, in that particular incidence of endometriosis.

[84] **Suzy Davies:** Okay, thank you.

[85] **Mike Hedges:** Neil.

[86] **Neil McEvoy:** Just listening to your opening remarks, so do you therefore dispute the figures presented by Cancer Research UK that the survival rate is 46 per cent, but if diagnosed at the earlier stage, up to 90 per cent of women with ovarian cancer would survive five years or more? Is there a dispute on those figures?

[87] **Dr Fox:** I don't think there's any dispute on Cancer Research UK's figures. I think the dispute is about to what extent screening prevents mortality. And, at the moment, Cancer Research UK doesn't support screening for ovarian cancer; it doesn't believe that the evidence is strong enough.

[88] **Neil McEvoy:** Okay. Can I carry on, Mike, because I've got a few, or

shall I let the others come in?

[89] **Mike Hedges**: Can you come in after this, because I've got a question that immediately follows this?

[90] **Neil McEvoy**: Of course, yes.

[91] **Mike Hedges**: We know, or we've been told, that survival rates are higher elsewhere in Europe. Why do you think that is then—that other parts of Europe are having better survival rates?

[92] **Rebecca Evans**: I think there's certainly more that we can learn in terms of international practice for survival rates. I think part of this is in terms of how we collect and analyse our data, and perhaps Irfon might be able to say a little bit more about that. We do participate in some key international partnerships studies, such as the International Cancer Benchmarking Partnership, which is enabling us to scrutinise what we do. The studies do point us in the direction of some of the answers to the question that you asked, and, so far, they've indicated that we've got some issues with data completeness, but also that some women are less likely here to recognise their symptoms and to seek help, and that GPs may be less willing here than in other countries to refer patients for testing, or certainly that has been the case in the past.

[93] **Mike Hedges**: Isn't that an argument for screening?

[94] **Rebecca Evans**: Well, screening can only be introduced if it's demonstrated to be effective and efficient in terms of better outcomes for people. It's an argument, certainly, for greater awareness raising amongst women and it's an argument for greater awareness raising and training amongst GPs, but I don't think that that in itself is an argument for a universal, or a population screening programme.

[95] **Mike Hedges**: Do other countries in Europe screen?

[96] **Dr Fox**: No. And the UK has been a leader in the research into screening, so the UK trial that I referred to, that's what everybody's been waiting for, to see the result of that, before deciding whether or not the screening programme should be established.

[97] **Mike Hedges**: Sorry, Neil, I interrupted you.

[98] **Neil McEvoy:** No, that was the question I was going to ask, actually.

[99] **Mike Hedges:** Sorry.

[100] **Neil McEvoy:** No—thanks. I was just wondering what the difference was between what happens in Wales and what happens in the rest of Europe. But we seem to be saying that, actually, it's not worse in Wales, it's just the way we collect our data. Is that correct?

[101] **Mr Rees:** There are data issues, but, as the Minister said, there are a number of factors where we are wanting to do better. Some of those factors, as the Minister said, are patient behaviour and some of those are doctor behaviours and doctors' capacity to identify, perhaps, what is a very rare condition when we think of the day-to-day activities of a GP and the numbers of ovarian cancer cases in Wales. Therefore, it's those areas that we are focusing on improving, both through awareness campaigns, but significant work with primary care, to improve earlier diagnosis. To give an example of that, this has been identified as a priority area in the GP contract, and GPs are now asked to review, as part of that, every case of ovarian cancer in 2015, to understand whether there are any lessons that could be learned in terms of practice around diagnosis and referral.

[102] **Rebecca Evans:** And that also applies to lung cancer and gastrointestinal cancer as well.

[103] **Neil McEvoy:** Okay. On page 64, it says that false positive tests are common. I just wondered what percentage were not reliable.

[104] **Dr Fox:** I'm sorry, I don't have the answer to that.

[105] **Rebecca Evans:** Perhaps we can write to you—

[106] **Mike Hedges:** You say that false positive tests are occurring. What Neil was asking is, why, and what can be done to stop them.

10:00

[107] **Dr Fox:** False positive tests are inevitable in a screening programme. A screening programme is only ever going to sift out the people who are likely to have the condition and those who are not likely. So, both false positive

and, very importantly, false negative tests are inevitable in a screening programme. You will always have some people who do have the condition and are missed by the screening programme. So, the blood test itself is a fairly blunt instrument, if you like. And, as we've heard, it can pick up other conditions, such as cysts or endometriosis. Then you go on to have a vaginal ultrasound to have a look at the ovaries. Ultimately, the final diagnostic test is to have a biopsy taken of the ovaries, and that's done under general anaesthetic as a surgical procedure. So, I'm sorry, I don't know the figures for false positive tests in the trial, but we could find that out, I suspect.

[108] **Mike Hedges:** That would be very helpful. Suzy, you wanted—.

[109] **Suzy Davies:** Yes. How much does a CA 125 test cost?

[110] **Rebecca Evans:** Well, we wouldn't be in a position to provide you with the cost. As I referred to in my letter to the Chair of earlier this week, an economic evaluation would only be undertaken if there was evidence that the population screening would be beneficial to patients.

[111] **Suzy Davies:** I'm just curious because, obviously, the tests are being done now after a clinical decision to take them is conducted. You must have an idea how much they cost. Not on a population level, but for a health board.

[112] **Mr Rees:** Well, if I could just rehearse what would be involved in having a test and having the follow-up necessary for a test. I'm afraid that I can't give you a figure for actually administrating the blood test, but it's far more than actually just taking blood from a patient. The costs would then involve the costs of a specialist being able to read and interpret that test. It would then go on to—. If there were issues for further diagnosis, as Dr Fox has referred to, there would be the costs for further diagnostic tests, ultrasounds and so on, before we get into the treatment costs. There would then be, if we were to be—

[113] **Suzy Davies:** Sorry. Can I interrupt? I appreciate what you're saying about the sort of, 'Oh, there's a problem here; we need to do something about it', but that actual phlebotomy moment, where the blood is taken out of you, and the test that's run to show whether it's a high reading or a low reading, to that point, is that a particularly expensive process? I genuinely don't know.

[114] **Mr Rees**: The cost for an individual to have a single test is not hugely expensive.

[115] **Suzy Davies**: Okay.

[116] **Neil McEvoy**: We were told at the last meeting that it was £25 or £20.

[117] **Suzy Davies**: Oh, right. Okay. Apologies; I wasn't here then.

[118] **Mike Hedges**: That was what people were charging for it, not necessarily the marginal cost of doing it.

[119] **Neil McEvoy**: Yes. So, there's a profit in that.

[120] **Mike Hedges**: Yes.

[121] **Neil McEvoy**: So, it's less than £20.

[122] **Suzy Davies**: Okay. It was just to give me an idea, really.

[123] **Rebecca Evans**: It's worth recognising as well that the major charities involved in this area of work have recommended against seeking private tests and so on, because they recognise the issues that we've outlined earlier on.

[124] **Neil McEvoy**: Are they UK charities or Welsh charities? Because I think there's a differentiation between both. Funding is tied up, isn't it, with Welsh charities from the Welsh Government, so, there's an issue there.

[125] **Mr Rees**: They're UK charities with a Welsh—

[126] **Neil McEvoy**: So, UK, yes?

[127] **Mr Rees**: Yes. So, they're UK charities. Cancer Research UK is an example that has gone on the record, but others have too. But, yes, we have relationships with those charities at a Welsh level and, for instance, are working with Macmillan on some of the improvements in primary care that I referred to, and they will be in the same position.

[128] **Neil McEvoy**: Yes. So, just to go back to the overall figure then, if there's a profit in £20, could we have a figure—as Suzy said—about the blunt

cost of a test? Not now, but after this committee at some point. I think that that would be—

[129] **Rebecca Evans**: I'm not sure that—. We can provide the cost, I suppose, of a blood test, but I'm not sure that that would be helpful to the committee in terms of your deliberations as to whether or not, actually, population screening is effective and desirable. This needs to be an evidence-based decision, not a cost-based decision. We look at cost after we've got the evidence as to whether it's desirable or not, and whether or not the good outweighs the harm that is potentially done.

[130] **Neil McEvoy**: It's a question now, so, it would be good to have the figure.

[131] **Mike Hedges**: Don't you have the figures from the trial?

[132] **Rebecca Evans**: It's not a Welsh Government trial, but information should be provided. We did provide the committee with a link to the trials. So, I'm sure the information would be available in there. I assume it might be.

[133] **Mike Hedges**: Any more questions? Can I just end with one final question and then I will thank you for coming along? But I've got a final question and Neil's got a final question. Neil will go first and then I'll come in.

[134] **Neil McEvoy**: In terms of awareness raising, you've outlined one or two things. Is there a budget from the Welsh Government to raise awareness amongst the general population about ovarian cancer?

[135] **Rebecca Evans**: There was an awareness-raising campaign that took place in March of this year and that was delivered through Velindre. So, an awareness—

[136] **Neil McEvoy**: Is there a Welsh Government budget for that, though, or was that done by Velindre? Is there a specific budget from your department for it?

[137] **Mr Rees**: There isn't a specific budget assigned to an individual campaign necessarily within Welsh Government, partly because some of the awareness raising forms part of day-to-day interaction between practitioners

and the population. There will be a figure for how much that awareness-raising campaign, run by Velindre, costs, but I'm afraid I don't have it with me, but we can provide it.

[138] **Neil McEvoy**: I just wonder whether it would be helpful or useful in future to maybe set aside a budget for this, because some of the things that we were made aware of in the last meeting, I was really shocked by and totally unaware of. I think it would be helpful for people to be more aware of this issue, really, and the illness. Do you not agree?

[139] **Rebecca Evans**: Absolutely. Awareness raising for this and all other types of cancer is very important because of the reasons that the committee has discussed about the desirability of an early diagnosis, which can lead to better outcomes. This cancer—perhaps you'd prefer a medical view on this, but certainly the symptoms for ovarian cancer do tend to be at quite a low level and can be confused for other things as well, which is one of the issues and one of the challenges in diagnosing this.

[140] **Neil McEvoy**: Just finally, Chair, I want to touch on Avastin, which it says here is available in England, but not to women living in Wales. I just wonder whether that is the case and whether or not you think that women in Wales are disadvantaged in that sense, geographically, by being cared for by the Welsh NHS.

[141] **Rebecca Evans**: All new medicines—medicines such as Avastin and so on—which are deemed clinically cost-effective by NICE and the AWMSG in Wales are available to patients here in the NHS, but Avastin has not been deemed to be cost-effective and efficient. What would be the most appropriate way to describe it?

[142] **Mr Rees**: The manufacturer was unable to demonstrate the benefits to patients when balanced against the costs, and therefore it was deemed by NICE to be not cost-effective

[143] **Neil McEvoy**: In Wales, or—? So, it's not available in England.

[144] **Rebecca Evans**: It was available in England through the cancer drugs fund, but that came to a close on 31 March. So, patients in England who started their treatment before 31 March will be able to continue it, but my understanding is that that fund is now closed, so patients wouldn't be able to access it through that.

[145] **Neil McEvoy**: So, it's more of a cost decision, really, than how somebody would benefit, then, we could say.

[146] **Mr Rees**: NICE take into account a range of factors and, on the balance of that range of factors, were unable to recommend its use in England and Wales.

[147] **Neil McEvoy**: Mainly on the basis of—?

[148] **Mr Rees**: A range of factors, including cost.

[149] **Neil McEvoy**: Such as—? I'm just trying to get a handle on the range of factors.

[150] **Mr Rees**: Clinical effectiveness, cost effectiveness, availability to bring it to market—there'll be a range of issues.

[151] **Neil McEvoy**: So, to reiterate, Avastin, then, is not a very effective drug in that sense of prolonging life or benefitting patients. Is that what we're saying?

[152] **Mr Rees**: Avastin, on the balance of measures, including affordability within the system, was not recommended for use.

[153] **Neil McEvoy**: We seem to be hung up on the issue of cost. So, it's more about cost than effectiveness. So, it could help, but we can't really afford it. Is that the situation?

[154] **Rebecca Evans**: Perhaps it would be an idea for the committee to write to NICE or explore this with the AWMSG in order to understand the criteria by which they recommend drugs to be available in the NHS.

[155] **Neil McEvoy**: For example, with the compact with Plaid Cymru and the Labour Party, or the Labour Government, we were looking at the drugs fund. Do you think that this would be available as part of that compact in future?

[156] **Rebecca Evans**: This is something that I would suggest that you explored with the Cabinet Secretary, but I know that the Cabinet Secretary is currently considering the options for implementing the fund, so I think it would be far too early for me to make any kind of comment on that.

[157] **Mike Hedges:** Suzy, you wanted to come in.

[158] **Suzy Davies:** Yes. You may not be able to answer this question, in all fairness, but why do you think survival rates are lower in Wales than elsewhere in the UK and Europe, and what can we do to balance that out?

[159] **Rebecca Evans:** Survival rates are improving, which is positive, but, obviously, there's certainly more that we can do. Again, it's about early diagnosis, and I hope the work that we're doing in terms of asking GPs to really focus in on specific cancers as part of their contract will help do that. We've got our referral-to-treatment times, which apply to this cancer as well. So I would hope, again, that that would help people access treatment in the most timely way possible.

[160] **Suzy Davies:** So, timing has a lot—. I appreciate in diagnosis it obviously does, but timing of treatment has been an issue in the past as well, then.

[161] **Rebecca Evans:** The latest figures do show that things are improving. For example, 70 per cent of women living in Wales who are diagnosed with ovarian cancer survive at least one year, and almost 38 per cent survive five years. And those figures have actually improved by 4.3 per cent and 0.2 per cent respectively since 2004. So, there is an improvement, albeit slow, and obviously we want to seek to continue to move in this direction.

[162] **Suzy Davies:** Is it easier to pinpoint where that improvement's come from? Is it better awareness amongst women, better awareness amongst GPs, or better diagnostic tools?

[163] **Mr Rees:** I think you've hit a number of the factors. I think it's a range of those factors. It won't be a single one. I think, as we mentioned earlier, there are a range of factors behind the reasons we want earlier diagnosis, and that's better awareness amongst the population, better referral, GPs better equipped to recognise, and better links between primary care and secondary care. And, finally, better access and speedier access to further diagnostics and treatment.

[164] **Suzy Davies:** Again, I don't want to take you back round in a circle here, but obviously, stage 1 is when this disease is pretty asymptomatic—how on earth is a GP going to know you've got it; how are you going to know

you've got it? I'll just leave that there, because I think this is quite a difficult question to answer.

[165] **Rebecca Evans:** It is. NICE has introduced new referral guidelines for suspected cancer. That lowers the threshold of suspicion, and hopefully that will encourage more referrals to come forward in a more timely fashion as well.

[166] **Suzy Davies:** Because, to be honest, these sorts of symptoms that could be caused by a host of other reasons—actually, that, to me, is a reason to go and have the test, even if it does show that there's nothing wrong. Thank you.

[167] **Mike Hedges:** The last question I've got is: we're all agreed now that early diagnosis is the most important thing. You do not believe—you've got evidence to say that screening is not going to be the solution. What is the solution to try and get greater early diagnosis, and what's going to be done to improve the survival rates in Wales to a level comparable with the rest of Europe?

[168] **Rebecca Evans:** It is about, as you say, increasing awareness, both amongst the women concerned, and also amongst the GPs, and allowing some of the new methods of working to work through, such as the new reduced threshold for referrals from NICE and so on. No-one's suggesting this is an easy topic at all; it's extremely difficult. The symptoms are very hard to distinguish from other conditions. We need to consider what's worked well, though, in other awareness-raising campaigns. We do see when we have awareness-raising campaigns that, actually, there is a small increase of people seeking diagnosis when an awareness-raising campaign is ongoing. But, then, we do see that falling off over time as people become less engaged with those—or looking for those symptoms.

[169] But, one example where it has worked well, I think, is the work that's been done on breast cancer, and awareness-raising in that sphere. So, we should be looking, really, and taking guidance and advice from the experts as to how we can use learning from that kind of campaign to inform awareness-raising on this agenda. But, obviously, Chair, we'll keep a close eye on the evidence, and, if and when the evidence changes, and the screening committee is convinced of the benefit, or the good outweighing the harm of the screening programme, then, obviously, we will take advice from the screening committee in future. I think we understand that the end

of this particular research project is probably three or four years off at the moment.

[170] **Dr Fox:** Yes, it is. So, the work isn't finished. The UK national screening committee has asked that the evaluation of that trial continues over the next three to five years. So, those women—if there's a survival benefit, you might expect it to increase as time goes by. So, that work will be coming back to the UK national screening committee for further review.

[171] **Rebecca Evans:** It's kept constantly under review, as other screening issues are as well.

[172] **Mike Hedges:** Can I thank the Minister and her officials, Irfon Rees and Dr Rosemary Fox, for attending the committee today? Can I thank my colleagues? We've actually finished exactly on time. So, thank you very much.

[173] **Rebecca Evans:** Thank you.

10:15

Cynnig o dan Reol Sefydlog 17.42 i Benderfynu Eithrio'r Cyhoedd o'r Cyfarfod ar gyfer y Busnes a Ganlyn: Eitem 6
Motion under Standing Order 17.42 to Resolve to Exclude the Public from the Meeting for the Following Business: Item 6

Cynnig:	*Motion:*
bod y pwyllgor yn penderfynu gwahardd y cyhoedd o weddill y cyfarfod yn unol â Rheol Sefydlog 17.42(ix).	*that the committee resolves to exclude the public from the remainder of the meeting in accordance with Standing Order 17.42(ix).*

Cynigiwyd y cynnig.
Motion moved.

[174] **Mike Hedges:** Can I now move that we move into private session? Can I move a motion under Standing Order 17.42 to resolve to exclude the public from the meeting for the following business?

Derbyniwyd y cynnig.
Motion agreed.

Daeth rhan gyhoeddus y cyfarfod i ben am 10:15.
The public part of the meeting ended at 10:15.