



Cynulliad
Cenedlaethol
Cymru

National
Assembly for
Wales

Cofnod y Trafodion The Record of Proceedings

[Y Pwyllgor Deisebau](#)

[The Petitions Committee](#)

11/07/2017

[Agenda'r Cyfarfod](#)

[Meeting Agenda](#)

[Trawsgrifiadau'r Pwyllgor](#)

[Committee Transcripts](#)

Cynnwys Contents

- 4 Cyflwyniad, Ymddiheuriadau, Dirprwyon a Datganiadau o Fuddiant
Introduction, Apologies, Substitutions and Declarations of Interest
- 4 Deisebau Newydd
New Petitions
- 20 Sesiwn Dystiolaeth: P-04-682 Sgrinio Rheolaidd ar gyfer Diabetes
Math 1 mewn Plant a Phobl Ifanc
Evidence Session: P-04-682 Routine Screening for Type 1 Diabetes in
Children and Young People
- 34 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

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

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

Aelodau'r pwyllgor yn bresennol
Committee members in attendance

Janet Finch–Saunders Bywgraffiad Biography	Ceidwadwyr Cymreig Welsh Conservatives
Mike Hedges Bywgraffiad Biography	Llafur Labour
Neil McEvoy Bywgraffiad Biography	Plaid Cymru The Party of Wales
David J. Rowlands Bywgraffiad Biography	UKIP Cymru (Cadeirydd y Pwyllgor) UKIP Wales (Committee Chair)

Eraill yn bresennol
Others in attendance

Beth Baldwin	Deisebydd Petitioner
Libby Dowling	Diabetes UK
Sara Moran	Diabetes UK Cymru

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

Kayleigh Imperato	Dirprwy Glerc Deputy Clerk
Sam Mason	Cynghorydd Cyfreithiol Legal Adviser
Kath Thomas	Clerc Clerk

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

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

[1] **David J. Rowlands:** Good morning. Bore da. We'll now start the formal meeting of the Petitions Committee. Welcome, everybody, to the committee meeting. I will make note that participants are welcome to speak in Welsh or English. Headsets are available for translation of Welsh to English, and there is no need to turn off mobile phones, but any devices should be left in silent mode. There are no apologies or substitutions this morning.

Deisebau Newydd New Petitions

[2] **David J. Rowlands:** So, I think we shall proceed with the first of the new petitions. This petition is to 'Introduce updated stroke advice—B.E.F.A.S.T.—and help save lives and livelihoods'. The petition was submitted by Phillip Easton, having collected 105 signatures. The idea is to change the stroke advice that's available and to include 'balance' and 'eyes' in the FAST directions, which are currently being made available. The first-consideration letter was sent to the Cabinet Secretary for Health, Well-being and Sport on 22 May and we received a reply on 7 July. It was forwarded to the petitioner for information only, and accepting that there was insufficient time for him to provide a response before the papers were published. The Act FAST campaign has been running in England and Wales since 2009 and we should note here that the stroke implementation group cannot endorse the use of BEFAST in Wales at this time as evidence in support would appear to be limited. Possible actions on this are to give the petitioner the opportunity to comment on the Cabinet Secretary's response before considering the petition again as soon as possible in the autumn term. In the meantime, the committee could also write to the Stroke Association to seek their views on the petition and ask for the petitioner's views on both responses at the same time. Do the committee have any comments on that?

[3] **Mike Hedges:** I'll go first. Yes, I would urge us to follow our normal practice, and write to the Stoke Association, when we get their reply and we've got the Welsh Government's reply, send it to the petitioner, and let the petitioner have an opportunity to respond.

[4] **David J. Rowlands:** Are the rest of the committee in agreement with that?

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

[6] **Janet Finch–Saunders:** Yes.

[7] **David J. Rowlands:** Fine. Okay. The action that we'd like to go forward is to give the petitioner the opportunity to comment on the Cabinet Secretary's response before considering the petition again as soon as possible in the autumn term, and in the meantime the committee should also write to the Stroke Association to seek their views on the petition and ask for the petitioner's views on both responses at the same time.

[8] The next petition is to 'Make a Vegan Option Compulsory in Public Canteens'. The petition was submitted by Rachel Turnbull, having collected 118 signatures. A first-consideration letter was sent to the Cabinet Secretary for Health, Well-being and Sport on 6 June. At the time papers were published, no response had been received from the Cabinet Secretary. The possible actions with regard to this is to note that a response has not yet been received from the Cabinet Secretary and, once received, give the petitioner the opportunity to comment on it before considering the petition again as soon as possible in the autumn term. Are we all content?

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

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

[11] **David J. Rowlands:** Fine, so that's the action we will take: that we note that there is no response received from the Cabinet Secretary, and, once received, give the petitioner the opportunity to comment on it before considering the petition again as soon as possible in the autumn term.

[12] The next petition under consideration is 'Trunk Road Through Tre-Taliesin: Urgent Need for Effective Speed-Calming Measures'. This was submitted by Antony Foulkes, having collected 52 signatures. Now, I think we note that the Cabinet Secretary was sent a letter on 6 June, and a response was received on 23 June. The Welsh Government has advised the local community that they will be investigating the possible safety measures for the A487. The petitioners have offered to meet the officials at the point at which they undertake their assessment, but the offer has not been accepted. The possible actions here are to write to the Cabinet Secretary for Economy and Infrastructure to discuss further details about the timing of the review

and if he will inform the committee of the outcome in due course, and to ask if his officials will meet with the action group.

[13] **Mike Hedges:** Seems reasonable.

[14] **David J. Rowlands:** Are we content that that should be the procedure?

[15] **Mike Hedges:** Yes

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

[17] **David J. Rowlands:** Fine, so we will write to the Cabinet Secretary and request further details about the timing of the review, and if he would inform the committee of the outcome in due course, and to ask if his officials will meet with the action group.

[18] The next petition is 'A call for the return of 24 hour Consultant led Obstetrics, Paediatrics and SCBU (Special Care Baby Unit) to Withybush DGH.' The petition was submitted by SWAT—Save Withybush Action Team—having collected 3,532 signatures: 759 on line, and 2,773 on paper. I think we ought to note here that this is the second petition with regard to this matter, the first having been received, I think, in 2014. Now, the petitioners now claim that there is new evidence to show—I think, very recently—that there are figures to show that it has impacted on the local community, in particular with regard to disabled and young mothers, and therefore they have brought this petition again before the Assembly.

[19] I think the possible action, then, with regard to this, is that we note that a response was received from the Cabinet Secretary just before the papers were due to be published, and to give the petitioner the opportunity to comment on it before considering the petition again as soon as possible in the autumn term. The committee could also consider writing to Hywel Dda university health board at this stage, to ask what assessment they have made of the impact of the changes on obstetrics, paediatrics and SCBU services in the area since they were centralised at Glangwili, and for further information on how the recent perinatal mortality rates compares to those under the previous arrangements. Is the committee content with that? Are there any additions that one might make to those recommendations?

[20] **Janet Finch–Saunders:** May I just ask: where's the nearest consultant-led obstetric unit? Because I know we've had a big fight in north Wales on

that, and we are actually—you know, to be fair, the Welsh Government are doing something about it. I just was curious, really, as to how far consultant-led obstetric units are away from this hospital.

[21] **David J. Rowlands:** I think they're now centralised at Glangwili, aren't they? That's my understanding of it.

[22] **Janet Finch-Saunders:** How far is that? Does anyone know?

[23] **Mike Hedges:** I think, Carmarthen. Glangwili's just on the Carmarthen road going out towards—

[24] **Janet Finch-Saunders:** Easily accessible for anyone who might need those particular services.

[25] **Mike Hedges:** Nowhere is easily accessible in west Wales because the roads are not—. Easily accessible: you need motorways and dual carriageways. There's a limited amount of good roads around there. So, that's where some of the difficulties are. The other thing is that they've got a shortage of skilled staff to cover it. That's one of the weaknesses of the health board structure because the health board is responsible for recruitment and placing people. If hospitals were responsible for doing it themselves and they were run as stand-alone hospitals, then we'd either have or not have the service, depending on the hospital's ability to recruit staff. If the health board recruits staff and makes decisions where to put people, then that creates a feeling of 'we are left out'.

[26] **Janet Finch-Saunders:** Okay.

[27] **David J. Rowlands:** Right, fine. Would it be appropriate for us to ask if there are any data available on the timing from the previous hospital's accessibility to that now at Glangwili?

[28] **Janet Finch-Saunders:** Yes. It's just that having been involved in north Wales and a huge campaign—we had thousands signing a petition, and that is going forward now. I suppose I couldn't really sit here and not want the same for another part of Wales as we are now, sort of, able to have in north Wales.

[29] **David J. Rowlands:** Yes. So, do you understand that we're going to ask for data? If the data are available with regard to the transfer times to

Glangwili as opposed to the transfer times to other hospitals [*Inaudible.*]

[30] **Mr Thomas:** [*Inaudible.*] Yes.

[31] **David J. Rowlands:** That's fine, okay. So they're the recommendations in addition to the possible actions that I noted earlier. Okay, thank you.

[32] The next petition refers to making Senedd TV accessible to deaf people. The petition was submitted by Mervyn Jones and first considered on 21 January 2014, having collected 25 signatures. The decision on 9 May, when the committee last considered this petition, was to write to the Llywydd to request an update on any steps taken to make coverage of Assembly proceedings more accessible to deaf people since the previous correspondence. We would advise the petitioner that the issues relating to accessibility at the cross-party group on deaf issues cannot be addressed by the committee and should be raised with the group itself. So, the possible actions are—I'm sorry. The points for discussion are that the Llywydd outlined a number of improvements, including to the accuracy of the interpretation of First Minister's questions in BSL, and our possible actions, therefore, are to await the views of the petitioner before deciding what action to take, or to close the petition on the basis that there is little more that the committee can do to take the issue forward.

[33] **Janet Finch-Saunders:** I'm going to be controversial now. I'm disappointed that we've had to have a petition come forward. We are an evolving Government and legislature and, you know, we all talk about transparency in democratic proceedings, and we also say that equality is the main thread that runs through all the services that we provide. I think that the Commission—. You know, we spend on nice entrances and we've just had all the first floor revamped, but, for me, it's really key that anyone who wants to participate in the democratic proceedings here with any sight impairment or hearing loss is able to do so.

09:15

[34] So, I think that, as a committee, we should all be lobbying to have those facilities available and it would be really good if we, as a committee, actually wrote to the Commission, I think. I don't know what it's going to cost, but, in the scheme of things of what is spent here, I cannot see why that barrier should still exist today, in 2017. We're 19 years old in terms of devolution and I think that we should be accessible to all, really, so that they

can participate in our democratic proceedings.

[35] **David J. Rowlands:** Neil, did you want to make any comment?

[36] **Neil McEvoy:** Yes, I totally agree. Maybe we should write back to the Llywydd because we currently show signed and subtitled FMQs—great—on the YouTube channel, so then everything else isn't shown. It isn't good enough, really. I don't think the response is strong enough. I agree with Janet. I think we should maybe write back and just ask them what they are doing to make everything available with subtitles. It isn't rocket science. It's just a job—one person's job.

[37] **David. J Rowlands:** Do you have anything to add on that?

[38] **Mike Hedges:** I sort of half agree with Neil. I think that what we need is a programme to say: they've got First Minister's questions; then they should be looking at how they're going to do other questions and so—. I don't expect them to put everything on overnight into sign, but, certainly, they've got the First Minister—let's have the other Ministers' questions and a programme then so that the whole of the proceedings are in sign. Let's have a programme of how—. It might take five or six years to do it, but let's build up to it, but they should be looking to that. Perhaps we could write to Elin and ask them if they could look at producing a programme of improvement, starting perhaps with other ministerial questions.

[39] **David J. Rowlands:** Yes, fine. Okay. So, the suggestion by the committee is that we'll write again to the Llywydd and ask, 'Can a programme be put in place in order to introduce BSL to as much of the proceedings in the Senedd as is possible, and could you give us a timeline that might be appropriate with regard to that?' We will also, I feel, write to the petitioner to tell him the decision that we've made with regard to that so that he knows exactly what's going on.

[40] **Janet Finch-Saunders:** Can I just ask, Chairman, on the letter going in, if we could just sort of bring to their attention that this did come in in 2014, so there have been three years there in which changes could have been made, little by little.

[41] **David J. Rowlands:** Fine, yes. Could we include in that letter, then, the fact that this petition has been—? Fine. Thank you.

[42] **Janet Finch–Saunders:** Thank you, Chair.

[43] **David J. Rowlands:** The next petition under scrutiny is ‘Child and Adolescent Eating Disorder Service’. It was submitted by Helen Missen back on 17 July 2012, having collected 246 signatures. I think what the Welsh Government is saying with this is that there are measures in place with regard to eating and the provision of eating in all public places. It comes under the papers for the Cabinet Secretary for health well-being. The committee last considered this petition on 23 May, and we agreed to write to the Cabinet Secretary for Health, Well-being and Sport to share the comments made by the petitioner and to ask for an update on how the additional funding for eating disorder services in 2017–18 will be used. The Cabinet Secretary’s response was received on 22 June. The petitioner had been informed that the petition was considered but had not responded at the time the papers were finalised. So, our possible actions are to await the views of the petitioner before deciding what action to take—whether we take it any further.

[44] **Janet Finch–Saunders:** I think Bethan Jenkins had been a champion and an advocate, really. Just to highlight just how poorly off we are in Wales for services for children with eating disorders, I ended up with one of my constituents there—their child was in Stafford. Again, we talk about the devolution process, and 19 years down the line we still do not have a facility or a treatment centre and it’s really, really difficult to access services.

[45] **David J. Rowlands:** We note again that this petition came in on 17 July 2012. So, I think it may be best if we wait to see whether the petitioner is going to wish to take this action any further. Should we do that?

[46] **Janet Finch–Saunders:** I think we should support this petition and the petitioner because it’s not as if they’ve brought a petition here that we don’t know. We’ve spoken about it in Plenary, we’ve asked ministerial questions, we’ve attended cross-party groups. I’ve been here six years and I haven’t seen any real improvements to the provision in Wales. We’re so far behind England and children are suffering—boys and girls.

[47] **David J. Rowlands:** So, what action do you advocate that we actually take with regard to this?

[48] **Janet Finch–Saunders:** I think we should write back to the Cabinet Secretary and ask what, in terms of their own strategic planning—. You

know, do they have any plan? I'd heard that there was one—again in north Wales—coming forward, but we haven't heard any—. You hear these things. It would be nice to see where the Cabinet Secretary sees some priority for actually putting in—I'm not going to say 'all singing, all dancing'; that's politically incorrect, because this is a really serious disease and can actually stop all future development of the child as they're growing. It's one of the worst illnesses a child can experience when they're not taking in nutrition and, in some cases, hydration. We need to really be flag-bearers. The numbers that suffer are significant.

[49] **David J. Rowlands:** Okay. So, are we agreed that we'll write to the Cabinet Secretary—

[50] **Janet Finch-Saunders:** Yes, and we want a strategic plan.

[51] **David J. Rowlands:** —and ask for some strategic plan with regard to what they hope to be doing with regard to the eating disorder services?

[52] **Neil McEvoy:** I'd like more detail as well, because it's a very bland response. You know, four extra teams. What is the capacity of that? What does that money buy? I'd like to know how many people they're actually helping. It mentions CAMHS and anyone that's worked in education or any sector like that knows—

[53] **Janet Finch-Saunders:** Nightmare.

[54] **Neil McEvoy:** —that it's absolutely impossible to get appointments, almost, within a reasonable period.

[55] **Janet Finch-Saunders:** I feel that this petitioner has been fobbed off over the years, and I think we're a fairly new committee and I think we want to take these matters seriously.

[56] **David J. Rowlands:** Okay. Fine. So, we will do that, but we will also, I think—. I think, as Janet has mentioned, that this petitioner has probably lost interest in it because of the inaction previously. So, I think that it would be advisable that we, again, go back to the petitioner and tell her that we take this matter very seriously and that we're taking it up with the Cabinet Secretary.

[57] **Janet Finch-Saunders:** Can I just ask—? Has there been an inquiry ever

from this committee into eating disorders in adolescence?

[58] **Ms Thomas:** It was before my time, but Helen Missen, the petitioner, did come in to give evidence to the committee at one point—and the Minister did—but no report was ever produced. So, the petition was brought back to this committee for further consideration and, in doing that, we asked for an update, and that's where we're at now.

[59] **Janet Finch–Saunders:** Okay. Do you know when she came in to give evidence?

[60] **Ms Thomas:** Probably 2013 or 2014.

[61] **Janet Finch–Saunders:** So, it's a while. Can we not actually reopen this? Neil, what do you think—and Mike—about maybe having more evidence, more facts and figures on the table so we know where we're going and we know what we're talking about?

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

[63] **Mike Hedges:** Let's get the response first. We're writing to get a response. Let's get the response and then decide where we go next. Let's do it in stages.

[64] **Janet Finch–Saunders:** Okay. As long as we don't waste another five years, not actually getting anywhere.

[65] **David J. Rowlands:** No, let's wait for the response. I think Mike is right in that. Then, as you say, given whatever the text of that response is, we'll make a decision then as to how we take the matter forward. But we won't leave this wither on the vine, as such.

[66] **Janet Finch–Saunders:** Fantastic. If we can have it at the back of our minds that this might be going to an inquiry—

[67] **Mike Hedges:** Well, depending on what we want to do, without prejudging it, we might ask for a debate in the Assembly on it, but we need to go through the stages first. What I would say is that when I sat in your seat, David, I was very keen on doing one or two things—you either do something with the petition or you close it. Leaving it to sit there for years and years and years is of no good to anybody.

[68] **David J. Rowlands:** No, no, absolutely. We know that, and we certainly won't allow that to happen.

[69] **Janet Finch–Saunders:** Thank you, Chair.

[70] **David J. Rowlands:** Are you happy and content with that? Fine.

[71] We'll move on now to 'Reinstate Corwen's Mobile Dental Service'. Now, I think that if you read the information with regard to this, it appears that Betsi Cadwaladr university health board are going to put a replacement unit in place, and the only questions would be that we could ask Betsi Cadwaladr for a likely timescale for the unit, or we could, in fact, on the evidence that the petitioners seemed to be satisfied with the outcome of their petition, close the petition.

[72] **Mike Hedges:** I'd suggest we close the petition if the petitioners are happy.

[73] **David J. Rowlands:** Yes. So, the decision is that we should close that petition. Thank you.

[74] The next one is 'Restoration of Inpatient Beds, Minor Injuries Cover and X-Ray Unit to the Ffestiniog Memorial Hospital'. This was submitted by Geraint Vaughan Jones and was first considered on 17 June 2014, having collected a very large sum of 2,754 signatures. Now, the decision was made—. The committee last considered the petition on 9 May, and agreed to write to Besti Cadwaladr UHB. We asked for a number of points to be taken into account. A response was received from the chief executive of Betsi Cadwaladr on 30 May, and we also had a response from the Chair of the Health, Social Care and Sport Committee on 6 July. Further comments from the petitioner have been made available to the committee. The committee will consider the approach it wishes to take once the findings of the final report of the parliamentary review of health and social care in Wales are published at the end of this year. The health board has provided a detailed response setting out the provision for the area. It's their view that this demonstrates the board's commitment and progress to date in meeting the recommendations set out in 'Healthcare in North Wales is Changing'. So, our possible actions are, given the amount of detailed correspondence received from all parties over the last 3 years, to prepare a summary of the committee's consideration of the petition, to include its reflections and

conclusions and share it with the Welsh Government and Betsi Cadwaladr UHB early in the Autumn term.

[75] **Mike Hedges:** Can I suggest we share it with the petitioners as well?

[76] **David J. Rowlands:** Yes.

[77] **Mike Hedges:** I'm happy with that, but if we could share it with the petitioners so nothing is happening without them knowing.

[78] **David J. Rowlands:** Fine. Thank you.

[79] The next petition is 'Close the Gap for Deaf Pupils in Wales'. This petition was submitted by the National Deaf Children's Society and was first considered by the committee in May 2013.

[80] 'The National Deaf Children's Society Cymru presents this petition today as it is both Deaf Awareness Week'—

[81] and this was some years ago, obviously—

[82] 'and two years since 55 AMs pledged to take action to close the gap for deaf pupils. Still, Welsh Government statistics demonstrate significant attainment gaps between deaf pupils and their peers.'

[83] Would you like to make any comments on that?

[84] **Janet Finch-Saunders:** This is another one I think we should be driving through.

[85] **Mike Hedges:** I think that they'd like—the National Deaf Children's Society—to meet with the Minister and with ministerial officials to take it forward. Perhaps we can write to the Minister asking if the Minister will do that. If the Minister does that, then we can close the petition. If the Minister doesn't, then we have to come back and decide what we want to do.

[86] **David J. Rowlands:** Yes. It's true to say the Minister's offered to meet NDCS to discuss the issues raised by the petition, and NDCS have indicated that they would like to take up this offer. So, the possible actions at the moment are suggest that the NDCS contact the Minister's diary secretary directly to arrange a meeting and ask them to report back to the committee

following that. Are we all content? Yes.

09:30

[87] The next petition is 'Asbestos in Schools'. This petition was submitted by Cenric Clement-Evans and was first considered in December 2013, having collected 448 signatures. The committee last considered the petition on 23 May and, given the time that has passed since evidence was taken by the previous Petitions Committee, agreed to write to the Cabinet Secretary for Education to seek the Government's current position on the issues raised by the petitioner. A response was received on 16 June. The petitioner contacted the clerking team to express his gratitude to the Cabinet Secretary for her considered response and broadly welcomed what was outlined. However, given the short amount of time for him to respond to such a detailed letter, he would prefer to prepare a considered response over the summer.

[88] So, the possible action is to await further comments from the petitioner and consider the petition again early in the autumn term. Are we all agreed on that?

[89] **Janet Finch-Saunders:** I do have a concern, though, on the letter back from the Minister. It says here,

[90] 'Accessing Asbestos Information Online. As I explained to Mr Clement-Evans when I met him on 6 October 2016, I do not intend to require local authorities to make information about asbestos management available online, as this information is already available on request.'

[91] I have tried accessing information as to the buildings in my own constituency. I can tell you, if I'm finding—. I'm pretty adept at finding information out, and putting freedom of information requests in, but it is very, very difficult. I think parents, teachers, parents of pupils—they have a right to know.

[92] I sadly lost one of my constituents who was a teacher, and the coroner's report was quite categorical that the exposure to asbestos—. We have a duty as elected politicians here to ensure that—. You know, there's mention here of all this money that's going to be spent on the twenty-first century schools, and it's wonderful for those schools that are a new build and everything, but we have hundreds of schools and public buildings—public toilets, even. But as regards this, I think that somebody in this

Government needs to be fairly robust in their approach on this. We can't afford for people to be unknowingly or unwittingly teaching in a school—. If my children were still in school and I thought for a minute there was asbestos in the school, I would want to know. I have a right to know. So, we do need to turn the volume up on this one.

[93] **David J. Rowlands:** Right, okay. So, shall we await further comments from the petitioner in the first instance?

[94] **Janet Finch–Saunders:** Yes.

[95] **David J. Rowlands:** But we will note that we will be taking this matter further, having had those comments.

[96] **Janet Finch–Saunders:** Thank you.

[97] **David J. Rowlands:** The next petition for us to review is 'Protect Special Educational Needs'. This petition was submitted by Nicola Butterfield and was first considered on 13 December 2016, having collected 553 signatures. It was calling on the Welsh Government to provide for special educational needs, and that the funding for that should be ring-fenced. I think the Cabinet Secretary has said that—. The petitioner was informed that the petition would be considered by the committee, but had not responded when the papers were finalised, nor has she responded to the previous request for comments. The chief executive of Port Talbot stated that he can see no basis for the petitioner's observations that the system is open to abuse and not fit for purpose. He also reiterated his offer to meet with the petitioner to discuss her concerns.

[98] **Mike Hedges:** Shall we write to the petitioner telling the petitioner that—that the chief executive is prepared to meet with them?

[99] **David J. Rowlands:** I think what we've said here is that the possible action is to write to the petitioner to ask whether she would like to take up the chief executive's offer to meet his officials locally, and we could also write to the Minister for Lifelong Learning and Welsh Language to ask for further details about the western bay regional partnership board, and how the petitioner could access the service if appropriate. Given the Minister's previously stated position that core Welsh Government funding provided through the local government settlement is unhypothecated, it is unlikely that the petitioner's aim of ring-fencing funding will be achieved. So, the

possibility is that we could close the petition. I think that we ought, in this case, to write and ask for the petitioner to meet with the chief executive.

[100] **Mike Hedges:** Like a lot of things, getting people to meet to discuss these things—really our major role is to try and get the meeting of minds between those who have got a petition and those who can solve their problems.

[101] **David J. Rowlands:** Yes. Fine. Are we all content with that?

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

[103] **David J. Rowlands:** Fine, thank you. The next petition is 'Trees in Towns'. This petition was submitted by Coed Cadw Woodland Trust and was first considered on 8 March 2016, having collected 2,258 signatures. The petitioner was concerned with regard to the tree canopy in suburbs and in conurbations in particular. The committee last considered the petition on 23 May and we agreed at that time to write to the Cabinet Secretary for Environment and Rural Affairs to ask what increase in tree cover in urban areas has been achieved in the last five years, and whether other plant species are also used for a similar purpose, and we would seek views from the petitioners on the response received. A response was received from the Cabinet Secretary on 22 June. We had further comments that have also been received from the petitioner.

[104] I think the Cabinet Secretary and Natural Resources Wales have accepted that there's been an overall trend of a decrease in the percentage of tree canopy in urban areas in Wales. The Cabinet Secretary considers increasing tree canopy coverage in Wales's towns and cities a priority for the area statement process that will be contributed to by Natural Resources Wales.

[105] So, the possible actions is that we write to the Welsh Government to ask if they will consider increasing canopy coverage in Wales's towns and cities as a priority for the area statement process that will be contributed to by Natural Resources Wales.

[106] **Mike Hedges:** Can you also send a copy of that petition on to the climate change committee?

[107] **David J. Rowlands:** Yes, fine.

[108] **Mike Hedges:** We're looking at trees at the moment, so at the very least, they can add it as an appendix to their report.

[109] **David J. Rowlands:** Fine. Yes. Are we all in agreement on that?

[110] **Janet Finch-Saunders:** Yes.

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

[112] **David J. Rowlands:** Fine, thank you. The next petition refers to the testing of cattle for TB. The petition was submitted by Nigel Bowyer and was first considered on 21 March 2017, having collected 309 signatures. What he wanted was the Welsh Government not to have routine testing of cattle every six months. It currently is at 12 months. He has received information from the Cabinet Secretary that there will be no routine testing of cattle every six months but that the testing would remain and will only be coming into effect where herds are at the highest risk of becoming infected. The petitioner has welcomed the announcement. So, the invitation is that we close the petition, given that it appears to have achieved its aim.

[113] **David J. Rowlands:** Do we all agree with that? Yes. Fine. Good. So, we will close that petition.

[114] The next petition is 'Strengthening the Legislative and Regulatory Framework Surrounding Waste Wood Processing Facilities'. The petition was submitted by Alexander Williams, having collected 232 signatures and was first considered on 23 May 2017. I think this petition was probably instigated by an incident of a fire at South Wales Wood Recycling Ltd. The committee last considered the petition on 23 May and agreed to write to the Cabinet Secretary for Environment and Rural Affairs to share the comments made by the petitioner and ask for a further response to these. The Cabinet Secretary's response was received on 22 June. The petitioner has submitted further comments, which are available in the public papers. So, the Cabinet Secretary has provided a detailed response to each of the points raised by the petitioner, and it seems that one of the comments by the petitioner was that, where they did not comply with existing rules, they seemed to be raising the tonnage from 25,000 tonnes to 125,000 tonnes, exceeding the original permit. So, the possibilities for us, I think, and possible actions, are to write to the Cabinet Secretary, seeking her views on the petitioner's latest comments, before deciding how to take the petition forward.

[115] **Janet Finch–Saunders:** Yes.

[116] **David J. Rowlands:** Fine. The next petition is to reopen the Cwmcarn forest drive in Easter 2018. I must declare a slight interest in this, in that I attended a meeting of the petitioners a little while ago, and I was supportive of their attempts to get that drive open. The petition was first submitted by the Friends of Cwmcarn Forest Drive, and was first considered on 13 June 2017, having collected 1,450 signatures. The committee considered the petition for the first time on 13 June, and agreed to write to the Cabinet Secretary for Environment and Rural Affairs to ask if the Welsh Government has considered providing funding to NRW to support the reopening of the forest drive to vehicles, and to highlight the petitioner's concerns about the timescales for the proposed study. The Cabinet Secretary's response was received on 28 June. I think the committee has had time to review her response. It says that forest drive will be considered once the study into commercial viability has been completed, but that no commitment in respect of funding support will be given until then. The petitioner is disappointed that the Welsh Government will give no commitment to funding for the reopening of the drive at this time.

[117] So, the possible actions that are open to us are to write to the NRW, to ask for more details of the time frame for the feasibility study, and seek their views on the petitioners' comments, relating to funding for other facilities for mountain bike users. Are we happy to do that? We're happy to go with the possible actions for that.

[118] The next petition is 'Unconventional Oil and Gas Planning Applications'. The petition was submitted by Arfon Jones, and was first considered on 22 September 2015, having collected 1,254 online signatures and 293 paper signatures. The petitioner made the point that the current direction does not apply to underground coal gasification. The committee last considered the petition on 13 June, and agreed to write to the Cabinet Secretary for Environment and Rural Affairs, and the Cabinet Secretary's response was received on 28 June. The petitioner was given a very short timescale in which to comment, but had not responded when the papers were being finalised. The Cabinet Secretary and her officials are currently assessing the implications of the transfer of the oil and gas licensing system to Wales. So, our possible actions are to await further comments from the petitioner and/or write to the Cabinet Secretary asking her to update the committee when she has determined how the Welsh Government will

approach the handling of existing licences and future policy.

09:45

[119] **Mike Hedges:** 'Yes' to both.

[120] **David J. Rowlands:** So, I think we should do both of those possible points of discussion.

[121] Right, given the time factor now, what I think we shall do is we shall defer these further petitions until after the next session. Are you in agreement with that? Yes.

09:47

**Sesiwn Dystiolaeth: P-04-682 Sgrinio Rheolaidd ar gyfer Diabetes
Math 1 mewn Plant a Phobl Ifanc
Evidence Session: P-04-682 Routine Screening for Type 1 Diabetes in
Children and Young People**

[122] **David J. Rowlands:** Good morning. Bore da. Welcome to the evidence session with regard to the routine screening for type 1 diabetes in children and young people. This is when the committee agreed to take evidence from the petitioners: Diabetes UK, Diabetes UK Cymru and the Welsh Government on this petition, as well as the petitioner, Beth Baldwin.

[123] So, I welcome the guests to the committee this meeting. We have Libby Dowling from Diabetes UK; Sara Moran from Diabetes UK Cymru; and, obviously, we have Beth Baldwin, who is the petitioner in this matter. Can I say that the committee offers their sincere condolences to you, Beth, on the loss of your son, Peter, in such tragic circumstances? Can we commend you on your courage in bringing this petition forward?

[124] **Ms Baldwin:** Thank you.

[125] **David J. Rowlands:** And Beth—. Can I refer to each of you by your Christian names? Are you happy with that? So, Beth, you indicated to us that you would like to make some comments with regard to this, so please do so.

[126] **Ms Baldwin:** My son, Peter, turned 13 on 10 December 2014. He loved life, school and his friends. He was a fit and healthy teenager who had the

world at his feet. He'd just been to Germany with the school and had come back with a winter cold. On New Year's Eve, he was very unwell, so we visited our general practitioner. The GP diagnosed a chest infection and gave us antibiotics. No type 1 test was offered or considered. I explained that Peter was sleeping lots and drinking lots, which we now know are two of the signs of the 4Ts. Twenty-four hours later at 16.30 on New Year's Day, we called the out-of-hours service and explained that we were very concerned about Peter, who was deteriorating fast—laboured breathing and delirium. Insisting that this was very urgent, we were transferred to 999, which was engaged for a short time. I asked for an ambulance, which I had to be very direct about. The operator kept asking if this was deemed necessary. Thank goodness I insisted and stuck to my guns. Many at this point would have given up. The rapid-response paramedic arrived shortly, and the first thing he did after giving Peter oxygen was to prick his finger. He diagnosed Peter on the spot with type 1 diabetes, and it took less than 30 seconds. The paramedic called an ambulance and, within 15 minutes, we were in the resus department at the Heath hospital, Peter was being given the right care. He fought for six days, but his poor body couldn't cope and he never recovered. Diabetic ketoacidosis can be fatal.

[127] I would like to say that staff at the University Hospital of Wales were absolutely amazing and did all that they could. Had the GP pricked Peter's finger we'd have had a 24-hour head start and he would have had a chance to recover from this DKA. This was preventable. We have the technology. It's not expensive. There are finger-prick monitors in all GP practices—why aren't they being used more? Why is type 1 diabetes not on the radar when unwell children visit GPs? We call upon you, the National Assembly for Wales, to urge Welsh Government to introduce the four Ts as a routine question for primary care when children are presented ill to prevent another family going through this tragedy. You can introduce protocol for type 1 testing and raise the profile to check for type 1 diabetes for anyone presented with illness.

[128] Over the past two years, we have learned about policies and pathways that are in place. We've learned about guidelines. We've learned that guidelines can be interpreted in many different ways. The system is set up to give little accountability or responsibility when guidelines are not followed. This petition has immediate, short- and long-term aims: sharing Peter's story and introducing type 1 testing as part of protocol, refreshing GP and primary care awareness, annual e-learning for the dangers of undetected type 1 diabetes, working in partnership with organisations to create awareness campaigns. This petition is to prevent the 25 per cent of children

who are diagnosed at a critical state with type 1 diabetes. Vigilance and testing can save lives.

[129] Changes have already been made, and we're really pleased. Training took place at out-of-hours after my call was listened to. They audit calls to ensure handlers do not act as gatekeepers and waste critical time. With each new type 1 diagnosis in Cardiff and the Vale an investigation is carried out to check the pathway and timescales to this diagnosis, and this information proves really, really helpful. There is an EDDY study campaign, which is looking for round 2 funding into awareness campaigns. Our Know Type 1 video has been viewed thousands of times and has been included on the training agenda for trainee GPs in Wales very recently—over 400 trainee GPs.

[130] We as a family, with the support of the type 1 army, ambassadors of a community—thank you so much—with Diabetes UK Cymru, we continue to do—

[131] **David J. Rowlands:** Beth, if you'd like to pause at any time and take a drink, by all means do that.

[132] **Ms Baldwin:** Thank you. We've done as much as we could do, and we will continue to do everything we can do. You, as Welsh Government, have the power to enforce changes, to govern, to legislate. You can help us to save lives. You can do research. You can monitor. You can evaluate. You can ask the questions and you can make others ask questions. You have power and influence and are in a position to help us to prevent late diagnosis for this one in four children, and give those a fighting chance who are diagnosed in the future.

[133] In the last 10 days, I've had two e-mails thanking us for our campaign, which has led to the swift diagnosis of an 11-year-old boy and a 16-year-old girl locally. We had, and still have, great support from the fourth Assembly Petitions Committee. We have support from the current healthcare committee and the children's committee, and many more AMs. We are currently awaiting a date with the health Minister.

[134] Our community supports us in all we do. Many are here today—thank you. We asked the committee to ensure no other family suffers like we do, because it is unnecessary. My son Peter could have been saved. He should have been given a chance. Four questions that lead to a finger-prick test would have saved him. You have the power to make this happen. We have the

equipment. Guidance doesn't go far enough. Thank you.

[135] **David J. Rowlands:** Thank you, Beth, for that. It's obvious to all of us the distress this causes you. Again, can we thank you for the courage that you've shown in coming here today?

[136] **Ms Baldwin:** Thank you.

[137] **David J. Rowlands:** Now, do either Diabetes UK or Diabetes Cymru want to make any comments at this particular time with regard to that?

[138] **Ms Moran:** Yes, thank you, Chair. I think I'd just like to provide an overview of numbers, stats and figures for Wales, if I may, just to give the Petitions Committee an idea of the scope of the issue. So, there are approximately 1,400 children and young people with type 1 in Wales. We hear frequently from families that the diagnosis process was particularly traumatic. The stat is usually one in five of those children or young people are diagnosed at the critical stage of DKA. We know that a report is coming out in two days' time, and that has increased to one in four. So, we're looking at a quarter of these children and young people being diagnosed in a very late stage, which is life-threatening. That's coming out on Thursday.

[139] There are ways that this can improve. We've spoken to several clinicians over the years and they are optimistic that things can improve. It's challenging, but we believe we can make progress in Wales. I'd just like to defer to my colleague, Libby, just to give an overview of the condition. Libby is a paediatric nurse, so she'll be able to answer any clinical questions that you might have.

[140] **Ms Dowling:** Thank you. I'm not sure how familiar you are with type 1 diabetes, but it's when there's a complete absence of insulin in your body. Insulin is the hormone that we need to convert glucose from the food we eat into energy for our bodies to use. So, if you don't have any insulin, you digest the food, the glucose goes into your bloodstream, but you need insulin to get it from your bloodstream into your body cells so you have the energy to function. Obviously, without insulin, the sugar stays in the blood, the blood sugar rises, and you get the symptoms that Beth has described—going to the toilet a lot to pass urine, feeling incredibly thirsty, obviously being very, very tired, because you're not getting any energy, and losing weight. So, these we term the four Ts—toilet, thirsty, tired, thinner—and it's crucial that people, parents, carers are aware of those, but also that GPs are

aware that these are signs of type 1 diabetes. Because if we don't pick it up at those early stages when you're showing those early signs, we get to the situation that, unfortunately, Peter was in, where you're extremely unwell and your body starts to fail. Frankly, if you can pick up type 1 diabetes early, you can stop that happening.

[141] **David J. Rowlands:** Fine, thank you. Now, in order to further our consideration, obviously, of this petition, we would like to ask some questions of you. Some of those you might have touched on in your presentations now, but are you content that we should ask you questions on this matter? Fine. So, first of all, could you tell us why early diagnosis of type 1 diabetes is so critical with regard to this disease?

[142] **Ms Dowling:** That's because, if you can pick it up early, a child doesn't become very unwell. If the diagnosis is delayed, you get a child who is extremely unwell, with breathing difficulties, possibly even in a coma. This is called diabetic ketoacidosis, when basically your blood sugar levels have gone so high your body has become acidotic. You certainly need hospital admission for that, and sometimes you need intensive care admission as well.

[143] So, not only is that life-threatening, but, even if the life is saved, it's an incredibly traumatic experience for a child and their family to be hooked up to drips, sometimes even ventilated. We're talking really intensive medical care here that might be necessary. It's not only incredibly traumatic for the child and family, but also incredibly expensive for the health service. Whereas, if you pick it up early, with a finger prick early on, then you can start a child on insulin injections quickly, you stop all that happening and you support them to manage their diabetes before they get very sick.

[144] **David J. Rowlands:** Fine. Thank you for that. Janet.

[145] **Janet Finch-Saunders:** Thank you. Good morning. Twenty per cent of children with type 1 diabetes are not diagnosed until they are in diabetic ketoacidosis, DKA. What are the barriers to early detection of type 1 diabetes, particularly in the primary care setting?

10:00

[146] **Ms Moran:** Well, we know there are barriers around awareness, access to equipment and awareness of what action to take. So, if I just summarise

the three of those, in terms of awareness, we do hear a lot from families who advise us that the primary care staff weren't very aware. It was only when they got to secondary care that any action was taken—well, not 'any action', but life-saving action in some cases. But also, there's low awareness amongst the public. People aren't aware of the symptoms. They're not presenting to their GP, asking for these tests to be carried out. There are also issues around access to equipment, as Beth touched on in her statement, that every GP should have a blood glucose monitor. Certainly, there should be one in each surgery. We don't think that's the case, although we can't be sure. No equipment audit has been undertaken in Wales. So, yes, the access to that equipment, and not just that, but, once they've got the equipment, the confidence in being able to use it, in interpreting the results, and in what action to take, depending on those results. We hear a lot from healthcare professionals in secondary care that incorrect action was taken. The wrong blood test was carried out, or even a blood test scheduled for the following week, or being told to come back in a week's time, deferring it to a more junior colleague, who might not be available on that day. So, there's a wealth of issues around those, and each of those present as a barrier.

[147] We do know more about services in secondary care, especially the answers that the committee has received from each health board, and those have been particularly insightful and they've been collated for the first time in Wales, which has been very, very enlightening for us. But the fact remains that most people present to their primary care services first, and that is where the grey area is, if you like, and the lack of standardisation and the approaches. So, those are the key barriers, really: awareness, equipment, and then what action, what pathway, to take.

[148] **Janet Finch-Saunders:** Just two points I'd like to pick up on—one is the fact that there's a lack of awareness of how many, say, of our GP surgeries have the ability to be able to test. I'd have thought that was just standard practice.

[149] **Ms Moran:** Yes, I agree.

[150] **Janet Finch-Saunders:** And then it's how can we—is it through the schools—build that awareness in parents and children themselves, because I know that, from an early age, now, children quite often will take themselves off to the GP. How do we build that awareness up?

[151] **Ms Moran:** Well, Diabetes UK have just launched a campaign in June,

called the Know Type 1 campaign, which really does push the four T's out there. Diabetes UK launched the four T's campaign several years ago, which Libby was involved in, and we know that awareness in the public went up from 9 per cent to 14 per cent at that time. So, it is doable. It is achievable. And I think Diabetes UK's more recent campaign, which is funded by the Baldwin family, will go a long way in Wales into doing that, and we are evaluating it as well. But it is the two-ply, really, of having the public awareness as well as healthcare professional awareness, and that's what we need to do.

[152] **Janet Finch-Saunders:** May I ask, is there an app? Is it used at all? Because I know a lot of campaigns now and charities, health charities—leading health charities—are using social media to get it out there more. Is there a way so then it brings it to the awareness of the health professionals and indeed to the public?

[153] **Ms Moran:** Yes, absolutely. We've got a number of measures that we'll be carrying out to contact healthcare professionals. We've already seen some of our supportive healthcare professionals going out to GPs to present the campaign video, which I think you've all seen, as well as the infographics, et cetera. So, there's a lot happening, but it does tend to rely on individual clinicians, very much so, as well as the third sector. I think we've all got our part to play—

[154] **Janet Finch-Saunders:** Of course, yes.

[155] **Ms Moran:** Of course, and, when you look and speak to individual clinicians' activities, it is very much them driving it. It's not systematic. It's very much them taking their own initiative, perhaps even doing it as part of their QI, their personal development within their role, and it's very much up to that individual to take the lead. As Beth has mentioned to me several times, if that person leaves that post, quite often you'll see that drop off, won't you, so—

[156] **Janet Finch-Saunders:** No consistency.

[157] **Ms Moran:** Exactly. So, it's not in systems. It's not—. For example, type 1 diabetes, it's not in baby packs in Wales. It's not in the red book that new mothers get. That's only done very locally by our campaigners at grass-roots level speaking to their GP surgery and asking for the four Ts poster to be put in the pack. It's really not driven centrally at all, unfortunately. Other

conditions like meningitis: we all are aware of the symptoms. It's never received that attention.

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

[159] **David J. Rowlands:** Mike.

[160] **Mike Hedges:** Yes, I think that—. I know we've talked about the four Ts. From my experience, two Ts are very easy to identify: tiredness and thirst. They're very easy to pick up. I used to teach in a college and I had a student who was continually tired and was drinking water almost continually, who I convinced to make his way to the doctor, who really started off treating him as a 'worried well' rather than actually dealing with it. We can do what we like; Welsh Government can have whatever policies they like and health boards can have it; until we get GPs to actually start treating it—. Once you have those two easy-to-identify symptoms—. Because you don't notice people getting thinner over a period of time, or, hopefully, people don't notice me getting fatter over a period of time. But you don't notice that, do you, if people are losing small amounts of weight over a period of time? But thirst and tiredness are something you notice because it's something that becomes apparent. I mean, what do we need to do to get GPs to just take those two easily identifiable items and actually just do a test following those?

[161] **Ms Baldwin:** Can I just say I think all GPs need a monitor, and we know that pharmaceutical companies often give the monitors away for free because it's the test strips that cost money and even they are pennies? We're not talking about MRI scanners or anything here. This is a monitor that they give away for free—basic. If every single GP had one on the desk with the stethoscope and the temperature gauge and their normal equipment, it would be in their mindset, on the radar—check, check. It's as simple as that. It needs to be there: four Ts, sign, on the monitor—check.

[162] **David J. Rowlands:** Neil.

[163] **Neil McEvoy:** Just listening to you, really, I suppose I'd like to thank you as a parent, really, for enlightening us and everyone. Is there any good reason why this isn't already being done? It just seems common sense, really. Is there some impediment to driving this out as a centralised policy?

[164] **Ms Moran:** Not that we're aware of. It's in the diabetes delivery plan, but some of the actions are attributed to the third sector in that so it's not—.

You can't point to something and say, 'Right. That's where it is and that's where it should be done.' It is covered by NICE guidelines, but as Mike touched on, really, policies and procedures can only go so far. What we really want to see happen as part of this is that GPs are asking the questions that they see the symptoms, see one or more of the symptoms, and carry out the finger-prick test. All four symptoms don't have to be present. It can be one or more, and we really want to see GPs being proactive in asking and probing—asking these questions that will draw out the answers from parents who might not be aware of the symptoms themselves.

[165] **Neil McEvoy:** You said the awareness-raising campaign has put it up to 14 per cent.

[166] **Ms Moran:** The original wave. I think it was in—.

[167] **Ms Dowling:** In 2012, we launched the four Ts campaign, and it was following that that awareness went up, and we also have reports where similar things have been done in other countries. When you do these types of campaigns, they work.

[168] **Neil McEvoy:** Yes. Do you think there's—? What scope is there to promote this further? Has it been relaunched, in June?

[169] **Ms Moran:** That's right, yes. So, we'll be promoting that amongst healthcare professionals. We've also got an e-learning module available. It's not mandatory, unfortunately, but that is available as well to healthcare professionals, and Diabetes UK have a suite of materials that are available to healthcare professionals that they are able to use in cluster training, and they can also watch the campaign video, which is really succinct in highlighting the symptoms. So, there are a number of activities being carried out by Diabetes UK to that end. Where the gaps are, really, is in further investigating primary care in terms of, you know—. We could easily, I think, look at how many tests are being carried out. We don't have that information. A few of the health boards carry out a serious case review or a DATIX report when a child is diagnosed and it hasn't gone as smoothly as it could have, or even when it's gone well, they have that dialogue between secondary and primary care and that sort of thing can be monitored. But that's where the gaps in our knowledge are at the moment.

[170] **Neil McEvoy:** Right, okay. When did the scheme start in North Carolina?

[171] **Ms Moran:** I think it was two or three years ago. And, again, that's health visitors going in to meet with families and to promote the four Ts there, so that's another nice example of what can be done.

[172] **Neil McEvoy:** Yes. Because I think it'll be worth, maybe, getting those data as a committee and maybe pushing that forward.

[173] **David J. Rowlands:** Yes. Thank you, Neil. Okay, Mike.

[174] **Mike Hedges:** You've seen the Welsh Government and local health boards' responses. Are you happy with those, or do you have any criticism of them?

[175] **Ms Baldwin:** Secondary care, in our experience with Peter, the Heath hospital were amazing and I've got no complaint with them. Sara has a synopsis, I suppose, of the responses from secondary care. As great as that is and will be for the charity, and it's the first time in Wales this information has been gathered, our main focus is on the diagnosis, which in 99 per cent of cases is on primary care, so we would really like to see a similar thing done with primary care and find out how many children present ill to the GP each week; how many of those do they consider testing; and, how many they actually test. You know, these things can be—.

[176] **Mike Hedges:** I think it really comes down to a matter that I talk about a lot in lots of different cases: we have Government policy, we have health support policy, and then we have the person who is at the sharp end who is there doing something. You can have all the policies in the world, and everybody can say how good these policies are, but if the person at the end of it doesn't implement them, they are not worth the paper they're written on. But—I'm not putting words in your mouth—would you like a position where the actions are being reported—I think it's something you said earlier just to take it on to the next stage—that GPs do an annual report of how many tests they've done and how many were positive, so that you can indicate which GPs are doing it, and more importantly, it'll concentrate their minds? Nothing concentrates people's minds like an annual report. I'm sure that works for you inside your organisation; it certainly used to work for me in education, and I think it works for most people in most employment. Having to produce an annual report and having to put numbers in there concentrates your mind during the year to work towards it. Would you see something like that being of benefit?

[177] **Ms Moran:** It certainly would fill a gap in knowledge. I'm not sure whether that would be the easiest or most obtainable format, but certainly any reporting would assist at this stage. I do take your point about procedures, Mike, but I do think it's important that there is a clear policy and procedure at central level to show that commitment to helping it as well, and that would filter down. But, I do think, in terms of the Welsh Government's response to the committee, I know that it was very distressing for the family to read that the Cabinet Secretary was unable to meet with them, for example, and I think—

[178] **Janet Finch–Saunders:** I'm coming onto that point right now.

[179] **Ms Moran:** And I think having that commitment at the start does go a long way.

[180] **Janet Finch–Saunders:** Thank you. During your introduction you said we are still waiting for the Minister—of course, now we call them Cabinet Secretaries—but I also note in our research paper it said:

[181] 'In February 2017, the Petitions Committee agreed to write to the Cabinet Secretary for Health, Well-being and Sport to ask if he would be willing to meet with the petitioners to discuss the issues raised in their petition in more detail.'

[182] And I am really disappointed to have to read this out.

[183] 'The Cabinet Secretary's response stated: "Unfortunately, I am unable to meet with the petitioners at this time. (...). I would draw the petitioners' attention to our recently refreshed diabetes delivery plan, which sets out the Welsh Government's Vision for services in Wales and action by health boards to improve the detection of diabetes."'

10:15

[184] Well, I can tell you, if I was the Cabinet Secretary and you, and these good people here, had asked to see me, I'm afraid I would be wanting to meet with you, and you would not be getting a response like that from me. Chairman, I think we should write to the Cabinet Secretary now and insist that he has the courtesy, the manners and some goodwill towards the valuable work that they are doing. As you've rightly said, this won't bring your son back, sadly. But you are sat there, hoping that lessons will be

learned, and no other family goes through what you're doing. I'm very, very annoyed that the Cabinet Secretary has refused to meet with you, and I will certainly do my best, if it's through this committee or if it's through standing up in the Senedd, to ask the Cabinet Secretary to spare some time to spend with you to discuss this in more detail.

[185] **David J. Rowlands:** I think that Janet echoes the concerns of this committee in general that there has not been a direct response to you as petitioners. We will be making this matter known to the Cabinet Secretary in future. Janet, there was one other question that you might want to ask, which is on the progress.

[186] **Janet Finch-Saunders:** Do you know, I've forgotten the number of it. Seven, wasn't it? Right. How should progress in improving early diagnosis be monitored and reported? I shall certainly be asking more questions generally of the Cabinet Secretary, and of the health boards, because I think we all have to work together. It's just a pity that you have to be sat here, but I'm glad you are, and as I say, we will all do our best to support you in your aims.

[187] But anyway, the question was: how should progress in improving early diagnosis be monitored and reported?

[188] **Ms Moran:** There are a number of audits already that we use—established audits that we have a lot of data from, mainly the national paediatric diabetes audit, the NPDA. That's the report that's coming out on Thursday. Certainly, we could benefit from, as I said, point of care testing in terms of reporting that. Monitoring referrals to secondary care could be done, and also the case reviews—so, any serious incident, in terms of reviewing that. We know of some excellent work in Cardiff and Vale health board being carried out by Dr Ambika Shetty, who's a consultant paediatrician, to review that snippet of the pathway between primary and secondary care, and to really look at that under the microscope, and, as I said, go back for learning where it hasn't gone to plan, and also praise it when it has gone right as well. So, there are a number of things that can be done that aren't being done at the moment that would be of absolute benefit to this area.

[189] **Janet Finch-Saunders:** I just find it astounding, really, that you're talking about 25 per cent being very advanced before it's picked up in children. It just beggars belief.

[190] **Ms Baldwin:** And often they've been to the GP on numerous occasions. When we submitted this petition we had hundreds, and I mean hundreds, of people sharing, heart and soul, their stories of how many times they'd been to the GP and how many times they'd been fobbed off.

[191] **Janet Finch–Saunders:** And there's a waste of resources there that could be put to better use and potentially save lives.

[192] **Ms Baldwin:** Absolutely.

[193] **Ms Moran:** It is very rare for a GP, I have to say, to diagnose a child. It could be once in their careers, it's thought, and every few years they may see a child with type 1, because the vast majority of their patients will have type 2. But it's absolutely critical that those questions are asked and that the probing is done when a child has these symptoms. They're really common symptoms, but if they're in extremis, and if they're present, as I said, one or more, just ask those questions that would trigger the rest of the four Ts, and then carry out the finger prick test. As you said, Janet, it's remarkable, really, that it's not done as par for the course. But, yes, it's doable. It's asking those questions. It's not just saying, 'Oh, it's an infection', 'It's viral.' It's making sure that you cover the four Ts in conversations.

[194] **Janet Finch–Saunders:** Well, thank you again for everything that you're doing, for making us aware. Hopefully, we can certainly take some responsibility and challenge and hold the Government to account on your behalf.

[195] **Ms Baldwin:** Thank you.

[196] **David J. Rowlands:** Neil, do you want to make—?

[197] **Neil McEvoy:** I just want to echo Janet's view about the Cabinet Secretary or Minister not taking time to meet you. It's not acceptable.

[198] **Janet Finch–Saunders:** Shocking.

[199] **Neil McEvoy:** What I'd like to do is—I think this is an issue that should go to a full debate in the Plenary. I think I'd really like to do that.

[200] **David J. Rowlands:** I think that will almost certainly happen with regard to that response, which we think is completely unacceptable. Can I say, to

wind up, really, that it appears to us that this is very much an intervention that could happen at the primary care stage? You pointed out, Beth, to us that this sort of test costs absolute peanuts. We're not talking about high technology with regard to this, and it seems to me that it really lies in the hands of GPs. It seems incomprehensible to me that it isn't incorporated in the normal routine that they would go through with a patient with regard to taking temperature or blood pressure. This small, tiny little intervention that could happen at that stage could be so critical in diagnosing this, as you know, Beth, potentially devastating disease. So, I think we as a committee will do all that we can to raise awareness of this situation, particularly with regard to the Cabinet Secretary, making it an absolute priority that doctors are very, very much aware of this simple intervention, as I say, that can be taken forward.

[201] So, all we have to do now is just ask if you have any other recommendations that you would like to make to the committee at this point.

[202] **Ms Moran:** No. I think we've covered everything, thank you, Chair.

[203] **Ms Baldwin:** I would just like to say thank you to you, the Petitions Committee, the previous committee, and all the AMs who support us. This is not a party political issue. This is an everybody issue. And to our amazing community. Thank you. Thanks very much.

[204] **David J. Rowlands:** Thank you. I'd like to say thank you very much again, particularly you, Beth, for coming in front of us. There will be a transcript available of this whole meeting that will be made available to you, and if you want to come back to us on anything that you see in that transcript that you'd like to talk to us about, or there may be something that you feel should or should not be in that transcript, you may come back to us and talk to us about that. But, in the meantime, thank you very much; I can assure you this will not be allowed to wither on the vine.

[205] **Mike Hedges:** Also, Chair, if there's anything you want to add to the evidence that you gave this morning, you can put it in writing and it will be added then into the information we've got.

[206] **David J. Rowlands:** Thank you for that, Mike. Thank you very much.

10:23

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

Cynnig:

Motion:

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

*accordance with Standing Order
17.42(ix).*

Cynigiwyd y cynnig.

Motion moved.

[207] **David J. Rowlands:** Could I now propose a motion under Standing Order 17.42 to resolve to exclude the public from the remainder of the meeting?

Derbyniwyd y cynnig.

Motion agreed.

Daeth rhan gyhoeddus y cyfarfod i ben am 10:24.

The public part of the meeting ended at 10:24.