Cynulliad Cenedlaethol Cymru
The National Assembly for Wales

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

Dydd Iau, 6 Mawrth 2014
Thursday, 6 March 2014

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.

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

Aelodau'r pwyllgor yn bresennol
Committee members in attendance

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

Eraill yn bresennol
Others in attendance

Clare Bath	Swyddog Materion Cyhoeddus Cymru, Ymchwil Canser y DU Public Affairs Officer for Wales, Cancer Research UK
Buddug Cope	Cyfarwyddwr Datblygu Cynghrair Geneteg y DU Director of Development for Genetic Alliance UK
Dr Tom Crosby	Cyfarwyddwr Clinigol Canolfan Ganser Felindre a Chyfarwyddwr Meddygol Rhwydwaith Canser De Cymru Medical Clinical Director of Velindre Cancer Centre, and the Medical Director of the South Wales Cancer Network
Deborah Evans	Rheolwr Gyfarwyddwr, Rhwydwaith Gwyddoniaeth Iechyd Academaidd Gorllewin Lloegr Managing Director, West of England Academic Health Science Network
Emma Greenwood	Pennaeth Datblygu Polisi, Ymchwil Canser y DU Head of Policy Development, Cancer Research UK
Yr Athro/Professor Carl Heneghan	Canolfan Meddygaeth Seiliedig ar Dystiolaeth, Prifysgol Rhydychen Centre for Evidence-Based Medicine, Oxford University
Emma Hughes	Swyddog Datblygu Cynghrair Geneteg y DU Development Officer for Genetic Alliance UK
Bernadette McCarthy	Rheolwr Radiotherapi, Canolfan Ganser Felindre Radiotherapy Manager, Velindre Cancer Centre
Hayley Norris	Cynrychiolydd Cleifion Patient representative
Dr Corinne Squire	Rheolwr, Partneriaeth Gwyddoniaeth Iechyd Academaidd De-ddwyrain Cymru Manager, South East Wales Academic Health Science Partnership

Yr Athro/Professor Lars Sundstrom	Cyfarwyddwr Menter a Chyfieithu, Rhwydwaith Gwyddoniaeth Iechyd Academaidd Gorllewin Lloegr Director of Enterprise and Translation, West of England Academic Health Science Network
Gwyn Tudor	Rheolwr y Fforwm, MediWales Forum Manager, MediWales

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

Llinos Madeley	Clerc Clerk
Sarah Sargent	Dirprwy Glerc Deputy Clerk
Philippa Watkins	Y Gwasanaeth Ymchwil Research Service

Dechreuodd y cyfarfod am 09:17.
The meeting began at 09:17.

Cyflwyniad, Ymddiheuriadau a Dirprwyon
Introductions, Apologies and Substitutions

[1] **David Rees:** Good morning and welcome to this morning's session of the Health and Social Care Committee in which we are continuing our inquiry into access to medical technologies. I remind Members that the meeting is bilingual and that headphones can be used for simultaneous translation on channel 1 or amplification on channel 0. I also remind Members to switch off their mobile phones and other electronic equipment that may interfere with broadcasting. In the event of a fire alarm, as there is no scheduled test this morning, please follow the directions of the ushers. We have received apologies from Darren Millar, Kirsty Williams and Gwyn R. Price this morning, and there are no substitutes.

Ymchwiliad i Fynediad at Dechnolegau Meddygol yng Nghymru: Sesiwn Dystiolaeth 8
Inquiry into Access to Medical Technologies in Wales: Evidence Session 8

[2] **David Rees:** I welcome our witnesses, Clare Bath, from Cancer Research UK, Dr Tom Crosby, medical director of Velindre cancer unit—is it is a trust, is it not, actually?

[3] **Dr Crosby:** It is, yes.

[4] **David Rees:** I also welcome Bernadette McCarthy, radiotherapy manager at the trust, and Emma Greenwood, head of policy development, Cancer Research UK. Thank you, first of all, for your written evidence to the committee.

[5] I remind Members that we are looking at the current arrangements and the impact on access to effective new treatments—clearly, there are different sizes in your area, because some of the equipment and technologies we are talking about are quite large capital investments—but also any specific examples of systems that work well. If you have any experience or knowledge of that, that would be helpful for us, as would, perhaps, the way in which patients' experiences and outcomes have an impact and perhaps patient involvement in some of the processes.

[6] In light of that, I will start off the questioning. In terms of the current process that we follow, clearly, there is no set process as there is for medicines in Wales at the moment, but how do you view the current processes for the introduction of new technologies and the impact that it has in terms of patients actually accessing effective treatments? So, I suppose, what are your criticisms or, perhaps, your praise of the system to introduce new technologies? Who would like to go first? Would you, Tom?

[7] **Dr Crosby:** I knew that you would look at me. [*Laughter.*] While there are similarities between the use of chemotherapy drugs, the pharma industry et cetera, access to medical treatments, and access to technologies, there are differences as well. I think that that is across the piece. There are some similarities. What I think is lacking is some horizon scanning, planning and the strategic planning of services looking forward. Then, I think that there is a problem with the robust and rapid appraisal of technologies and treatments. I think that we have relatively weak commissioning and performance monitoring of the services. So, across that, there is a lack of strategic planning in service delivery. As for how that applies to technologies, and particularly the patient experience, patients do not always have access to the latest treatments, which means that they sometimes have to travel to England for treatment that is not available in Wales. The most recent example of that is probably access to stereotactic radiotherapy. I know that some people may think of that as being the same as access to CyberKnife treatment, but it is different. CyberKnife is just one platform for the delivery of stereotactic treatment, but until recently patients had no access to that in Wales and they had to travel to England for that treatment. We are in the middle of that process of wrestling through the processes of evaluating that technology to see how effective it is, and commissioning it to run as a service. However, in the meantime, patients have experienced the inequity of access to that treatment. I think that we could look back a few years at the treatment—. We are becoming a little bit biased towards radiotherapy—

[8] **David Rees:** That is understandable.

[9] **Dr Crosby:** [*Continues.*]—intensity-modulated radiation therapy. We can look at how that process worked. However, for patients, for instance, there is still inequitable access to IMRT. What does that mean? Well, they are not having the latest treatment that we know is available. IMRT is a way of highly targeting radiotherapy to give better disease control, but also to spare very serious consequences of radiotherapy treatment. So, it can reduce by half the need for tube-feeding for the rest of people's lives. So, already, there is a delay and an inequity of access to that treatment. There is a plan now. We went through a rather chaotic system of getting the commissioning of IMRT, and it is happening at different speeds throughout Wales, but probably still slightly behind other countries in the UK. It was not a clear system that we had to go through to get that treatment.

[10] **David Rees:** Before colleagues start to ask you some questions, do you wish to make any comments, Bernadette?

[11] **Ms McCarthy:** I think that it is fair to say that, with regard to IMRT as an example, the department, the cancer centre and the individuals who work there were capable of delivering it some 10 years ago. The equipment was there. So, it was all about getting from that stage to getting it to the patient, as Tom described, which was quite chaotic. We were not able to understand the clear process from what we wanted to deliver to delivery. We are getting there now and our plan is working, and we are very happy with the progress that we are making with regard to IMRT numbers. However, it is an example of what seemed like an incredibly long time.

[12] **David Rees:** Can I ask a question? You say that it was a long time; is that as a consequence of the approval aspect of the technology or the commissioning aspect?

[13] **Dr Crosby:** I think that it was a little bit of both. Nearly all developments in the technology, particularly around radiotherapy, have really been driven through by clinical teams in spite of the processes. Usually, they ultimately go to the Welsh Government to get capital funding, which then put some pressure on commissioning to just get on and deliver the service, but all of that has been in a chaotic pathway of being told to take our opinions and professional views to different organisations. There is no clear process, as I am sure that you have been told already, for rapidly appraising technologies and making robust decisions as there is for medicines. Even when that decision has been made, there is weak commissioning of it and very poor performance monitoring of that service. So, across the piece, there are problems with each of those stages. There was never a clear appraisal process of IMRT. In terms of commissioning, we have three different systems for commissioning radiotherapy services. We were told that we would have to take things, initially, through an advisory group, which I chair, where there was a professional statement and advice to the Welsh Government—accepted. We were then told to take the business case to the Welsh Health Specialised Services Committee. Ultimately, after about 18 months, WHSSC said, 'No, this is a treatment that should be available to all and it should go back to the health boards to commission', so all of that was three years. The health boards have got a lot of things to focus on, and to ask them to focus on a highly technical form of radiotherapy was perhaps unrealistic, and so it has been slow. I think that, in the meantime, we have got on and we are catching up. As Bernadette says, the centres are able to deliver this treatment.

[14] **David Rees:** Emma, do you want to comment on this?

[15] **Ms Greenwood:** To touch on your question about patients and the impact on patients and the patient experience, this is an area unlike access to drugs, for example, where patients are perhaps not as aware of what they are missing out on, almost. The general public awareness and patient awareness of radiotherapy as a treatment option are quite low anyway. We are trying to do a lot of work as Cancer Research UK with the resources that we put on our websites, for example, to try to bring people a bit more up to speed with what to expect if they are having radiotherapy as a treatment option. However, it does mean that awareness of what they are missing out on and a real push to get access to new technologies do not necessarily happen in the same way as they would perhaps with access to certain drugs, cancer drugs.

[16] Having said that, we know that when we go out and seek to engage with cancer patients on these issues, they are actually really keen to get involved in the processes, understand how the decisions are made and understand what more can be done to get better access to some of the more innovative techniques. So, we did some work in England a couple of years back, and we had 37,000 people sign a petition for better access to radiotherapy techniques. Last year, we ran a series of roadshows going around the country, again in England, telling people about all of the changes that were under way and how those would impact on how services are going to be commissioned. You know, patients did want to hear about that. They were really keen to understand what the impact would be on them as patients and how the situation could be improved. So, just because we do not necessarily have a very vocal patient voice and patient lobby in this area does not mean to say that it is something that patients do not want to engage in or get better access to.

[17] The most striking thing, normally, when you talk to patients about this is when you tell them the figure that radiotherapy can be responsible for about 40% of cures in cancer, whereas drugs are more about 10%. They suddenly get that, if they could have access to this technology, it would be really valuable.

[18] **David Rees:** Claire, do you want to add anything?

[19] **Ms Bath:** I just want to echo the benefits of some of the new radiotherapy

technologies. IMRT in particular reduces side effects by up to 50%. It is a massive benefit to patients and it can save money in the long run, so any system that could be put in place to help quicker access to those technologies is going to massively benefit patients.

[20] **David Rees:** Rebecca and then Lynne have questions specifically on this, and then Lindsay wants to continue with questions on patient issues.

[21] **Rebecca Evans:** What do you think the value is of involving patients in the development and assessment of medical technologies? To what extent is that happening at the moment? Who wants to go first?

[22] **Ms McCarthy:** I think that it is fair to say that it is not happening enough. It is valuable because, as Emma has said, there is a desire out there to understand what we do and why we do it. I think that that is definitely something that we can work on and improve. It is difficult because our subject matter is not straightforward to understand, but that is not to exclude people from helping us to make the decisions, absolutely.

[23] **Ms Bath:** I am not aware that it happens in Wales at the moment, but it definitely needs to.

09:30

[24] **Ms Greenwood:** My reflection would be that it is not something—. Unlike drugs, where there is a very well-established process for looking at the evidence from clinical trials and it is relatively clear how that happens and at what stage to get involved, we simply just do not have that system in place for the assessment of these sorts of technologies. So, it is difficult to comment on whether that is happening at the moment, because there is no systematic approach anyway. However, if you think about how patients are keen to get engaged in decisions around what research to fund, for example, you will know that they are really keen to know what applications funding committees are getting in and about assessments between funding a radiotherapy trial versus a surgery trial; it is absolutely something that they want to play a part in. So, I think that if we had a more systematic approach, there would definitely be opportunities that patients would want to engage in.

[25] **Rebecca Evans:** Are there particular aspects of the development and assessment of technologies that patients would have a particularly important perspective on? We have heard something in our inquiry so far on the usability of technologies. That might be something that patients would have a good input into. Are there other aspects as well as usability?

[26] **Ms McCarthy:** I think there is what we have discussed already about the improved side effects. So, a patient's experience of having a treatment or access to technology that has not been as advanced as what we are appraising or offering would be quite strong evidence to say that a treatment was going to improve those things. Patient stories, with regard to their experience of radiotherapy, what it takes to go through that and what it is like to have feeding tubes and those kinds of experiences would be very strong and emotive evidence to show that what we want to do impacts directly on individuals. So, I think that a systematic approach to patients' involvement would be very welcome. We have a local approach to getting patients involved, but a wider approach, like a national one, would be very welcome.

[27] **Dr Crosby:** I think that that is absolutely key. We have seen that patient support groups and lobby groups are extremely powerful within the medicines industry. However, we need to understand that this crosses all of the aspects of this and we must understand the differences again between the medicines. There is a big pharmaceutical industry that will support a lot of the cancer charities for access to drug treatments. There is a relatively capital-rich but revenue-poor area at the high technology end that does not support those patient

groups, so, as Emma has said, patient awareness of this type of treatment is much lower than it is around access to drug treatment. However, supporting patients through and making appraisals around treatments that are balanced against cost-invested patient input is vital and it is very sporadic at the moment.

[28] **Lynne Neagle:** I want to go back to Tom's point about IMRT, please. You said that there were inequities in access to that. With the individual patient funding requests process with drugs, we have seen big variations between patients in different health board areas being able to access drugs. Is that how it is working with things like access to IMRT? Is it as pronounced?

[29] **Dr Crosby:** It certainly was. We knew that we were delivering a treatment that has twice the risk of leading to a patient requiring lifelong feeding. For example, because of the effect of radiotherapy on the salivary glands and patients having dry mouths and not being able to swallow normally, we knew that by the use of IMRT we would reduce the dependency on long-term feeding by 50% but we had to continue to use old-style technology to treat patients. It has been a drawn out process and we have moved on. I would say that, in some parts of Wales, we are close to the average now in England in terms of access to that. However, inevitably, things do not evolve at the same speed across Wales. In some areas of Wales, the access to that treatment even now is slower. We do have an implementation plan across Wales in all three cancer centres for that treatment. I suspect that that will happen over the next 12 months and nothing we can do will speed that up now; there are implementation plans. However, the decision ultimately was made that this was not a specialised treatment and that it should, therefore, go back to the health boards and work through the cancer networks, and, ultimately, that led to inequity of access to that treatment.

[30] **Lynne Neagle:** Are there any lessons that could be learnt from the way that that process has been handled that we could look to recommend being put in place for any future technologies?

[31] **Dr Crosby:** Very much so. I would say that there needs to be a cancer planning and delivery group that looks at horizon scanning and emerging technologies. There needs be effective, robust and rapid appraisal of that technology and there needs to be robust commissioning of that service and performance monitoring. What we seek, as clinicians within the departments, is clarity about what this process is. Each time that we have approached this, we have had to use a scattergun approach with every opportunity to try to drive the technology forward.

[32] **David Rees:** In your field, for example, or across Wales—we have heard evidence before about this being clinician led and clinician driven, depending on which clinicians are in which institutions—would you be looking for a more consistent approach across Wales?

[33] **Dr Crosby:** Yes. Wales has 3 million people and three cancer centres and the oncologists work very closely together. Clinical leadership is key—I would say that, but it is really important—and it should be in an advisory and supportive role. It should not be left to clinical leads to try to drive through the barriers to development. Their role should be to give clear advice when asked to do so and to point out areas that need to be looked at. However, there needs to be a robust appraisal process, as is the case with the highly respected All Wales Medicines Strategy Group around drug treatments. I know that you know already that that does not exist for technologies and some sort of process like that needs to occur.

[34] **Lindsay Whittle:** Good morning. Thank you for sparing your valuable time to come to inform us of what I thought was some alarming news from Dr Crosby. If I was a patient suffering from cancer, I would not be at all interested in commissioning health boards, WHSSC or where I would be having my treatment: I would just want the treatment. You

mentioned that it sometimes takes years, but you will know far better than me that some of these patients do not have years. Therefore, are people are dying while waiting for this treatment?

[35] **Dr Crosby:** Broadly, the concerns that we have talked about relate to access to curative treatments, where there is a greater chance of cure with fewer side effects. However, I think that you are right: if there is a two-year delay, anybody diagnosed and treated in that two years may receive a suboptimal treatment, when better treatment was available elsewhere. Nothing can happen all at the same time, from day zero, but there is an unacceptable delay, and it is unacceptable because it is partly an organisational issue. A decision has to be made at some stage, but it should just be made earlier and at a prompt time.

[36] **Lindsay Whittle:** The Chair will ask you at the very end about the one thing that would end this—I am forewarning you of his question. [*Laughter.*] I also wanted to ask you about the involvement of patients. I appreciate that cancer comes in many different forms, and that some people have an excellent chance of survival—we should concentrate on the more positive—but others, sadly, do not. I lost a very dear friend to cancer only last week. How do you involve patients? In the Chamber yesterday, we heard about people in hospital who are, quite frankly, afraid and would, therefore, clutch at any straw. I know that I would—I would be the first to admit it. How do you involve those patients? For some, I am sure that the advice is, 'We may be able to help you,' and 'There is an excellent chance,' while for others the news is not so good. How would you involve those patients and their families? Some of us were discussing this before you came into the room—some family members may not be fully able to grasp the seriousness of the situation, or perhaps an older person would not be able to do so, and would be having the treatment before their close family even knew about it.

[37] **Dr Crosby:** Absolutely. It is a key area. Health services generally have not paid enough attention to the patient experience and patient feedback. When I say 'patients', you are absolutely right that it is about patients, carers, families and next of kin. There is not always a strong correlation between where there is investment and where money is spent and what patients feel, in terms of the benefit from the treatment that they are receiving.

[38] In terms of how we have tried to move that forward in cancer, we have regular patient and carer surveys. We hold them on a monthly basis and they are reported back through our cancer centre and, ultimately, up to the trust board. You may be aware that there has recently been a national cancer patient experience survey, run through Welsh Government and Macmillan Cancer Support, and that has given us vital information about what patients feel about the service, and also about variations in what patients experience and the support that they receive. I think that what that has told us is that, despite all the problems that we always, inevitably, focus on, broadly, patients have a good experience of cancer care in Wales. However, there are variations. Where we get it right, we have seen that the patient experience is probably better than in any centre in the UK. So, where we get it right, even where patients have to travel a little bit further for specialised treatment, we know that the patient experience is excellent. However, there are variations, and I think that it is now up to us as clinical leads, Welsh Government and partners in NHS Wales to focus on where those gaps and inequities are. Certainly, that is what I would say that we need to do more of.

[39] **Ms Bath:** May I add to that? It is a bit outside what the committee is trying to do, but the roll-out of a key worker for every patient in Wales would really help with some of those issues as well. However, I know that that is separate from what you are looking at here.

[40] **Lindsay Whittle:** Yes, I understand.

[41] **Ms McCarthy:** I think that it is fair to say that, all along the patient pathway, from diagnosis and discussion at the multidisciplinary team through to their treatment and their

follow-up, we are getting better all the time at structuring services around the patient need, so that if a patient does not understand their treatment, they have time with the clinicians, the clinical nurse specialists and the individual subject matter experts. That is available, and not just on one occasion—if you do not get it the first time, you are not left wondering what is going on. All the way through the pathway, these people are available to come back to re-explain and to make sure that the patient is completely involved in the decision making. I think that we are getting better at that all the time.

[42] **Ms Greenwood:** Just as a final thought, I think that it really highlights the importance of patient experience surveys and the regular capturing of data as patients travel throughout the entire cancer journey. We are talking about inequalities, perhaps, between different cancer types, but also, more generally, socioeconomic inequalities, and unless we are capturing the richness of data around this, it is really challenging to know at what point we need to be making changes or how we could better involve patients across those things. So, I think that it is relevant for this committee to consider how much more we could be doing in those areas or maintaining things like the patient experience surveys, which have been very valuable, and considering whether there are additional questions that we could and should be asking of patients about their experience in relation to radiotherapy, for example.

[43] **Ms McCarthy:** I was just thinking, going back to technology, that it would be really interesting for us to explore how we are going to use information technology, going forward, to better support patients, whether it be telemedicine follow-ups or access to information in anything from the language that they choose to the font that they choose,. It is about making sure that we can support the pathway all the way along with information technology as well. It will be really interesting to see how we are going to be able to do that in the future.

[44] **Dr Crosby:** Just to close the loop, from what I was saying earlier, I completely support listening to the patient experience, with the caveat, though, that patients are not as aware of the technologies that we are delivering in radiotherapy as they are, sometimes, with drug treatments. Obviously, sometimes, patients do not know what they do not know, so they do not know about the treatments that are available, and I think that, with patients and the public of Wales, sometimes, we need to drive them to demand that the system works better for them a little bit more. I cannot remember the last point.

[45] **Lindsay Whittle:** Well, I think that that point, Dr Crosby, was extremely interesting. I am old enough to remember a programme in the—I am not going to say when. It was called *Your Life In Their Hands*. We go to people like you in the hope of finding cures and that you will make us well again, and perhaps we do not ask enough questions. It is perhaps due to computers, in which I am a total Luddite. People are now beginning to get far more educated in this sort of field, but sometimes a little knowledge is dangerous, is it not? We have to rely on your good selves. Thank you for all the work that you do.

09:45

[46] **David Rees:** You mentioned at an earlier stage that AWMSG focuses on medicines, and we have heard a lot of evidence that, perhaps, there should be a similar body or a sub-group of AWMSG to look at technologies. Is that a view that you also hold?

[47] **Dr Crosby:** Yes, ultimately, there needs to be some sort of system, whether it is AWMSG or a group within WHSSC or a separate body again. There clearly needs to be a robust system for highlighting areas that need to be appraised for a very robust and rigorous appraisal process, and for that to feed into commissioning. What I would say is that, with the All Wales Medicines Strategy Group, as I said, the support and the input into that is different. If clinicians did nothing, the pharmaceutical industry would ensure that its drugs were reviewed in a timely way, and that it had partnerships with appraisers to have patient access

schemes. We do not always have that in the technology industry. There would need to be differences. Clearly, that body is geared around medicines, and there would need to be access to expertise in technologies, but that is relatively easy to establish. So, 'yes' is probably the obvious answer.

[48] **David Rees:** Would Cancer Research UK have the same view?

[49] **Ms Greenwood:** Yes, I think that we would agree with that. Just picking up on some of the points that Tom made, the assessment that you undertake to determine whether an innovation is clinically and cost-effective to introduce into the health system is very different if you are looking at a drug versus a technology. In radiotherapy, specifically, the manufacturers come up with these new whizzy bits of kit and check that they are safe for use, and that is where the process stops, pretty much, for them. Whereas with drugs you have four phases of clinical trials, then marketing authorisation, then they get a licence in one indication, and then they might take it through that process again for a different cancer type, we just do not have that for radiotherapy techniques. So, we would have to acknowledge upfront that it is a very different sort of assessment, and a different type of evidence base that this committee would need to be looking at. Therefore, it would require a very different type of expertise and input, and perhaps would need to identify different methods to also gather additional evidence to help make the decision. It comes back to the point about needing strategic oversight and planning to be set over this process, so that we are really clear about the end point, which is that we would like to get some of these things commissioned. If the assessment group does not have access to the right sort of evidence to make those decisions, there needs to be somebody responsible for steering in the direction needed in order to gather that evidence through other mechanisms, if clinical trials are not appropriate.

[50] **David Rees:** I have a question from Lynne, and then Janet Finch-Saunders.

[51] **Lynne Neagle:** It is on a different point.

[52] **David Rees:** Then I will go to Janet, because Janet is asking on this one.

[53] **Janet Finch-Saunders:** Having decided that there is a need for a multidisciplinary approach to the assessment and commissioning of new medical technologies, how could this be achieved? Do you have any examples of good practice in this?

[54] **David Rees:** If you want to find some examples and write to us about them, that is fine.

[55] **Dr Crosby:** I think that there are plenty of examples of good practice and service, but I have to say, it is a real struggle to find one that has gone through the process of appraisal and commissioning in a robust and efficient way. In terms of services, we probably now will have a centre of excellence equivalent to anything in the UK or Europe in terms of delivery of stereotactic radiotherapy. As I say, how we have got to where we are has not been straightforward, and there is still lack of clarity about how that service would be commissioned in the future, in terms of revenue support. On other things that are working very well, on the ground, there is stratified medicine, personalised medicine and personalised oncology. In terms of molecular testing, it selects out-patients who would benefit from a certain treatment, or who would not benefit from the toxicities of the treatment. We have a centre of excellence in Cardiff, but that is a service of excellence that is struggling to have its infrastructure reviewed and commissioned on a robust and sustainable platform, which is disappointing. It is a struggle to say, when one service or technology that we currently use has gone through in a streamlined way, 'Why don't we do it like that all the time?'

[56] **Janet Finch-Saunders:** Do you feel that the lack of a commissioning group is now

inhibiting Wales and that there are certain technologies being used in other parts of the UK that we could be using in Wales now?

[57] **Dr Crosby:** Yes, very much so. There is not a complete lack of commissioning; there are commissioning groups between the Welsh Health Specialised Services Committee, the health boards and, sometimes, Public Health Wales. However, it is weak. An example of that is access to proton beam treatment. People may be aware of the proposal to develop two centres in England. Until now, we have had the same access as anybody in the UK, through what is called the proton panel. However, the commissioning of that service has fallen under WHSSC's remit. There has been an initial review, and the extended indication outside of just children being treated with proton beams is that we will do something different in Wales and we will go down an individual-patient funding route. That may work, but I suspect that it will lead to variability and inequity of access, compared with other parts of the UK.

[58] **Janet Finch-Saunders:** Finally, on that, how do you see the patient's voice being represented on any such commissioning group?

[59] **Dr Crosby:** It is vital that it is and that we have patient representatives. We have seen, in a local centre, where we want to achieve something, that having the patient sitting around the table—sometimes challenging commissioners, management and the authority, but also challenging us not to put up with the poor delivery, commissioning and management, to say that this is not acceptable, as we sometimes become almost apologists for the system, and patients telling us, 'No; that is not right'—is vital.

[60] **David Rees:** Emma, do you want to comment on that last point?

[61] **Ms Greenwood:** No, I do not think that I have anything to add. Looking to other systems or processes, the one thing I would highlight, which I found to be quite positive, was some work that Cancer Research UK undertook with NHS England to set a vision for what radiotherapy should look like in the next 10 years. Cancer Research UK was keen that that was not nation-specific. So, the idea was that it was very forward-looking. We invited manufacturers to come to present to us in a confidential manner, to tell us what their new technologies were going to be, so that we could then set out what we thought patients should have access to in the next 10 years. It comes back to horizon scanning, strategy and having a plan in place. We found that to be a really useful process, hearing from the manufacturers, because, once again, that is where it differs slightly to drugs, because we already have great relationships with drug companies and they are always telling us what their new and exciting thing is, but we just do not replicate that. So, I wonder whether that is somewhere where we could be doing more in terms of horizon scanning and working out what we will need to look at in the next five to 10 years.

[62] **David Rees:** Would it be possible, perhaps, for you to send us more details on the work that you have been doing?

[63] **Ms Greenwood:** I can send you a copy. The way that it is written means that it should be a vision that could be taken up and applied across all four nations. Although it was done in collaboration with NHS England, from our perspective, it was deliberately written so that it was broad enough for anybody to take a look and see if they could apply it.

[64] **David Rees:** Rebecca, do you want to come in on this specific point, and then I will call Lynne?

[65] **Rebecca Evans:** Yes. If we were to recommend that a new technologies group was established within AWMSG, do you have a view on whether that should be limited to a certain kind of technology? The things that you have been talking about are the big-ticket

items, whereas other witnesses have talked to us about things like asthma inhalers and even surgical gloves. So, do you have a view on that?

[66] **Dr Crosby:** No, and we apologised earlier for being radiotherapy specific—

[67] **David Rees:** You do not have to apologise for that.

[68] **Dr Crosby:** In terms of commissioning, there just needs to be clarity regarding who appraises and commissions what. Appraisal should be on an all-Wales basis for whatever technology it is and wherever it is being used to ensure that health boards have access to that appraisal evidence that they can use to commission for their population. So, I would say that the appraisal process should be national. As to commissioning, anything that extends across a health board boundary should come into a specialist commissioning group. Health boards are fantastic organisations at looking at their own populations, but talking to a neighbour about collaboration and providing a service together is very weak. At the moment, we have WHSSC, which specialises in relatively ad hoc services, and certainly nothing on a regional basis. So, anything that should be provided on a health board basis should be commissioned by that health board. Anything beyond those boundaries should be commissioned by a specialist group for that service, and not just radiotherapy, but any technology.

[69] **Ms McCarthy:** If we have a good robust process, we should not limit it in any way, and any technology or new way of doing things should be appraised in a similar way, as long as it remains effective. So, we would not want to see the process get bogged down or slowed down by the amount of appraisals required. It is about reviewing the process, whichever process we choose or suggest. I think it is about ensuring that it remains fit-for-purpose going forward, but it would be a real shame to find a process that works and then limit it to expensive equipment.

[70] **Lynne Neagle:** I have two separate points. Things like appraisals are time-consuming and costly. Do you think that there is enough collaboration with other parts of the UK on these things, or is there more that we could be doing to reduce duplication in working with other parts of the UK?

[71] **Dr Crosby:** We have the advantage here of listening to colleagues in England and working together, and, where necessary, adopting a partnership approach and not reinventing wheels for Wales. Sometimes, we will take that evidence and do something different in Wales, and it is quite right that we do that. I think that that is one of the advantages of the All Wales Medicines Strategy Group, which has built up a good alliance with National Institute for Health and Care Excellence, and they would not cross review areas. That partnership is very strong. It does not exist in areas such as WHSSC, which insists on reinventing reviews and appraisals, which take time and, as you say, are costly and lead to delays. So, there is no reason why the technology that will be appraised and the evidence base, which is pretty scarce anyway, will be any different in England than in Wales.

[72] **Lynne Neagle:** So, you think that there is perhaps scope for WHSSC to collaborate more on these issues.

[73] **Dr Crosby:** Certainly, yes.

[74] **Lynne Neagle:** Going on to research, Cancer Research UK has raised concerns about the role of research and, in particular, that radiotherapy research is underfunded. Are you able to expand on how you see the role of research in driving the advanced medical technologies in Wales?

[75] **Ms Greenwood:** From Cancer Research UK’s perspective, it is an area about which

we feel that the UK as a whole has delivered less research than it perhaps could have. I think that that is for a number of reasons. There is a role that we have to play as a research funder as well. It comes back to the difference between trials that involve drugs and trials that involve radiotherapy techniques. There is definitely a lot that we can do differently as a funder, and there are several new initiatives in place to have a look at what is happening across the UK and to seek opportunities for better collaboration. Often, it comes down to patient numbers because, in order to have a robust trial, you have to get the right number of patients involved, which usually means a multi-site approach. So, we have to find mechanisms to be quicker and more efficient at getting all of the red tape sorted so that the whole of the UK can have the chance to participate in these sorts of trials.

[76] I do not know whether there is something that Tom would want to add.

[77] **Dr Crosby:** To support that, it is about research and development and, quite often, it is more about the 'D'—the development—in access to new technologies that is important. There needs to be strategic alignment to make research in using high technologies work, and a collaborative approach between the third sector, higher education institutions, which do not have a major interest in radiotherapy research in Wales at the moment, and the National Institute for Social Care and Health Research. It is about using all of those alliances. Part of the problem that we have is that the service is stretched. We have underprovision broadly of capital equipment, and to have dedicated time for research and development on those machines is a huge struggle when we are trying to maintain waiting times to be effective for our service. So, there needs to be protected and dedicated time for radiotherapy research.

10:00

[78] **Lynne Neagle:** So, that is something that you think the Welsh Government could put in place.

[79] **Dr Crosby:** Absolutely.

[80] **David Rees:** Okay. Elin is next.

[81] **Elin Jones:** May I just take you back to the answers to Rebecca Evans's questions on commissioning? I was concerned when you commented earlier, in the context of IMRT, on the equality of roll-out and take-up between local health boards in Wales. So, I just want to understand a bit better your answer to Rebecca, when you said that commissioning should happen not on local health board level but on a specialist level. Are you saying that it should be based on the three cancer networks in Wales, or in what way would you see that working more effectively so that you do not have, possibly even within one cancer network, two health boards having two different views on take-up—Hywel Dda and Abertawe Bro Morgannwg University Local Health Board, for example, in my part of the world?

[82] **Dr Crosby:** Absolutely. What I think is that anything that is provided within a health board should be commissioned by that health board. For anything that is provided by more than one health board, there needs to be a robust commissioning body that oversees that. So—

[83] **Elin Jones:** So, in the context of my experience of Singleton Hospital serving as the cancer lead for Hywel Dda LHB as well, that would be a two-health-board commissioning process for some cancer services—

[84] **Dr Crosby:** I would say that there needs to be a process for Wales. I think that the delivery model may vary from place to place, and south-east Wales will have a centre for three health boards; south-west Wales would have a centre for two health boards; and then one in north Wales—they are sort of coterminous. I think that that is the delivery model. The

commissioning should be on an all-Wales basis for anything that spreads beyond a health board boundary. I am the medical director of a cancer network, and it is a movable feast. We have one in south Wales now, but the delivery models between south-west Wales and south-east Wales are different. We probably should have one network, but that is a different thing. However, I think that that is different to commissioning. That is a delivery model, which will vary. It is unlikely, but we may decide to have a satellite centre somewhere else in Wales, but, broadly, there are going to be three specialist centres in Wales, going forward. So, the delivery model is clear. The commissioning of that service will vary across Wales. However, I come back to the point that I think that anything that crosses a health board boundary should be nationally commissioned.

[85] **Elin Jones:** Okay, good.

[86] **David Rees:** We are coming to the end of the time we have. I have my traditional question, but, before I ask that, you mentioned horizon scanning as a big issue. At the moment, in your area, is horizon scanning undertaken by clinicians effectively?

[87] **Dr Crosby:** Not in a structured and—. I think that we are blessed with clinical leadership in Wales, and we participate in UK-based groups. So, we have access to what is coming around the corner. However, I do not think that we have an organisational structure that then receives that advice in a structured way. So, I am not aware of anybody coming to me and asking, 'What is around the corner for radiotherapy technology?' I would commend the report from CRUK, which focuses a lot on that. The third sector quite often comes in to provide things when the NHS is not doing so well. It speaks volumes that the third sector has come in and said, 'Look, we need to horizon scan for radiotherapy technologies, looking forward'. I do not think there is any formal horizon scanning and strategic planning.

[88] **David Rees:** Okay, thank you for that. I have two quick points. The health technology fund has been talked about. Again, with radiotherapy, clearly, we are seeing some investment in treatment, but I suppose that we understand the revenue cost associated with the capital costs. Is there a way to improve the system for assessing how we can use the health technology fund more effectively and use the technologies coming along?

[89] **Dr Crosby:** Emma, do you want to talk a little bit about commissioning through evaluation and the partnership you are developing?

[90] **Ms Greenwood:** Yes. I suppose that what we are finding at the moment in England is that we have done this work on horizon scanning and it is kind of like, 'Well, what next?' We are starting to have a think about commissioning through evaluation as a potential model. If we had a pot of money and the clinicians were telling us that we really should be thinking about rolling out SABRE, for example, but for different cancer indications to what we currently have policies in place for, and there is no clinical trial running so we need another way of capturing the evidence, that is a process where that pot of money could really be used effectively to determine what is next and what are the next big things that we should be commissioning. So, it is where you already have the technology in place, I suppose. We have a situation where we can deliver SABRE, but we are just trying to work out exactly where we should be commissioning it. Commissioning through evaluation is a potential route, where you have a pot of money similar to the health technology fund and you use that to collect evidence on the effectiveness of a particular technique or technology.

[91] **Dr Crosby:** Just to follow on from that, on the radiotherapy innovation fund in England, as you are probably aware, there are similarities but also differences to the health technology fund in Wales. It appeared to be quite a joined-up process between having a pot of money available for capital investment to bring on use of health technologies and then clinical advice and expertise about where to use that best. I am very grateful for the health technology

fund; we have benefited from it in terms of the development of stereotactic radiotherapy. There is a slight disconnect with the revenue to go with it and we are trying to work that through now with WHSSC, but we are very grateful for that money being available. It certainly enabled service developments to happen that would not have otherwise. However, a joined-up use of that technology funding to best be used across Wales to develop a strategic service and not to duplicate, but to use it most effectively, might have been more worthwhile.

[92] **David Rees:** Thank you for that. Time has come upon us, so I will ask my final question. You have given us a lot of information, but if I can just take one answer from the representatives of Velindre and one from Cancer Research UK, if there was one key recommendation that you felt that we should be looking at as a committee, what would it be?

[93] **Dr Crosby:** In some ways, you are hopefully going to recommend that there needs to be an improvement in the appraisal process. If I may, I will just say two things: there needs to be strategic planning and delivery and that needs to be a co-ordinated approach. The one thing that we take away is that we cannot always use research evidence as we can with medicines, and this approach of commissioning through evaluation, where you commission a service on the basis that you collect very thorough information on the outcomes from the use of that technology, is something that we must have access to. That is now moving ahead in England. Whether we shadow that approach or have our own commissioning through evaluation, others can decide, but it seems a very sensible approach for use of capital-intense technologies. So, for selective radiotherapy, that is now being commissioned through evaluation in four or five centres in England and, at the moment, we do not have access to that approach in Wales. If there was one thing, it would be to consider that as an approach to commissioning for technologies.

[94] **Ms Greenwood:** My take on it would be to absolutely welcome the focus on whether there is a different approach in terms of that very specific issue around the assessment and appraisal of new technologies. However, I would caution against looking at that in isolation because I do not think that will actually solve the wider access problems. You can have a really great assessment evaluation process in place, but if it is not underpinned by a strategic vision of where you want to get to, and then a subsequent commissioning process that is at the specialist level and would therefore apply across the whole of Wales, inevitably you will just have these assessments that are not ultimately really able to be effectively rolled out to patients. So, it needs to be a joined-up process.

[95] **Ms Bath:** I think some other witnesses have alluded to this, but I would like to add that whatever system is put in place, I think that it needs to be stipulated where the molecular tests that accompany some of the new emerging drugs sit and how they are going to be commissioned. Is the All Wales Medicines Strategy Group going to take that on because the tests relate to drugs, or is it going to be this new body that will take on technology appraisals? I think it is really important for these new molecular tests to be commissioned because some drugs are being appraised but are just sitting there because the tests are not available to figure out if that drug is going to be appropriate for your cancer.

[96] **David Rees:** Thank you very much for your evidence this morning. You will receive a copy of the transcript to check for factual inaccuracy or accuracy. So, once again, thank you.

[97] Our next session will be with Genetic Alliance UK. We will have a patient representative present today as well; I just wish to make Members aware of that. You have received a piece of paper tabled by Genetic Alliance UK with figures in it, which may be used in some responses to questions—I do not know.

10:11

Ymchwiliad i Fynediad at Dechnolegau Meddygol yng Nghymru: Sesiwn Dystiolaeth 9
Inquiry into Access to Medical Technologies in Wales: Evidence Session 9

[98] **David Rees:** Good morning. I will just remind witnesses that we are a bilingual institution and if you wish to have simultaneous translation, it will be on channel 1, and amplification is on channel 0. You do not need to touch the microphones—they will automatically come on. I welcome you to this second session this morning. We have Buddug Cope, director of development at Genetic Alliance UK.

[99] **Ms Cope:** Yes, that is right.

[100] **David Rees:** We also have Emma Hughes, development officer at Genetic Alliance UK, and Hayley Norris, who is a patient.

[101] **Ms Norris:** I am not a patient, but my son is.

[102] **David Rees:** Okay; you are a patient representative. I thank Genetic Alliance UK for its written evidence to the committee. May we move on to questioning, if that is okay?

[103] **Ms Cope:** That is absolutely fine.

[104] **David Rees:** I will start the questioning. How do you see the current processes that exist for new technologies' assessment and appraisal impacting on patients today? Perhaps a very simple question is: what can we do to improve them? Who wants to start? Buddug, do you want to?

[105] **Ms Cope:** Yes, I will start with that. Thank you very much, Chair, for the invitation to speak today. Genetic Alliance UK is a national charity for everyone with all sorts of genetic conditions. Typically, four out of 100 children born in the UK, including Wales, are affected by a genetic condition. We are talking about 175,000 people living in Wales with a rare disease. Many of those—about 80% of them—are genetic. We are speaking very much today from a diagnostic perspective and we are looking at medical technologies from a diagnostic perspective. We would very much like to share our views as a patient group—with Hayley here as part of our team speaking from an undiagnosed genetic condition perspective, from our syndromes without a name network—to talk about the need for families in Wales to benefit from better diagnostics.

[106] We see that the current situation in Wales is that families are behind, really, in terms of receiving access to diagnostic tests and medical technologies. When we compare that to the situation across the UK, we see Wales as being behind on that. We see that, looking into some of the reasons for that—the investment in the medical technologies, both in terms of capital and ensuring that those technologies and tests can be run safely and efficiently to the standard that we would expect to see, which is quite standard practice elsewhere across the UK—Welsh families are not getting as equitable a service at the best level. Emma, do you want to add to that?

[107] **Ms Hughes:** As an example, because I know that Hayley has some experience in this, micro-array comparative genomic hybridization is a diagnostic test that is a bit newer and it was introduced in England in 2009-10, but we only got access to it last year in Wales. So, you can tell that we are very far behind. In terms of the technologies coming through, in terms of next generation sequencing technologies, we think that patients need to have the benefits of these, moving forward. Without the investment in these technologies and without proper

policies and access to them, in terms of commissioning models and a way to assess them properly, patients will be left behind compared to those in other countries in the UK. I do not know whether Hayley wants to add anything to that.

10:15

[108] **Ms Norris:** Yes, I do. With regard to testing for my son, Jonah, we had the CGH array done, but it took over a year to get results for that because, obviously, it was not available in Wales at the time when Jonah had it done. So, a year in our lives, with a child who was undiagnosed, was a long, long time. It is a long time when someone says that you are going to have to wait for a year for results, especially when, after that year, they say, 'Actually, we didn't find anything'. From that point of view, the time is a big frustration as a mum of a patient. It is a long time to have to wait.

[109] **Ms Cope:** Diagnosis is a really important thing in terms of helping families to understand prognosis and what the future will hold for them, and in terms of helping us to make sure that the patient can get the correct management, where therapy or treatment is available or where they can get involved in research. So, it is really a critical step to make sure that patients have access to timely diagnosis. I do not know if you agree with that, Hayley.

[110] **Ms Norris:** Absolutely. Another big thing relating to the fact that Jonah is undiagnosed is having to make decisions on other children. I have a younger daughter, but because Jonah is undiagnosed and because it takes so long for results to come back, you kind of make the decision very blindly. There is a one in four chance of the next child having the same condition—whatever it is—that Jonah has. So, with more timely testing that is not going to take as long, you kind of hope that you will get to the right diagnosis. It just prolongs that process, which is almost tortuous. It is quite frustrating to be having that waiting time.

[111] **Ms Cope:** I will make a final point to conclude, in answering your question, Chair. Using array CGH as an example, which Jonah has had the benefit of access to now, with credit to the genetics service here in Wales, it has reconfigured its service to make sure that it is now able to offer that technology, but that has probably been to the detriment of other diagnostic services that might have been available to other patients and that the service may have been able to offer. So, there has been a pinch and a real squeeze there. Elsewhere in the UK, other families that Hayley has been in touch with, and that we are in touch with, through the SWAN network are receiving access to this technology. It is not a bells and whistles technology now; it is standard clinical practice and standard testing practice everywhere else in the UK in the NHS. We would just like to make sure that, through this inquiry, the introduction of reviewing and the introduction and implementation of diagnostic medical technologies can be taken forward and introduced properly, so that patients can access and benefit from diagnostics.

[112] **David Rees:** That is why we have undertaken the inquiry: to see whether a system needs to be put into place for that. Rebecca is next.

[113] **Rebecca Evans:** You referred to the assessment process—or the lack of an assessment process, I suppose—as one of the barriers to people accessing medical technologies. We have had suggestions that there should be a new technologies group within AWMSG. Do you think that that is the answer, or are there other suggestions as to how we could deal with this?

[114] **Ms Hughes:** Do you mean in terms of appraising the technologies though AWMSG?

[115] **Rebecca Evans:** Yes.

[116] **Ms Hughes:** At the moment, there is a review of AWMSG in terms of how it appraises orphan and ultra-orphan medicines. In terms of medical technologies, I would say that that needs to be a more clinically led system. So, clinicians would bring the technology and have a prioritisation system where they could see the need for the patient, rather than a manufacturer-focused process, which is AWMSG's current process for bringing medicines forward.

[117] **Ms Cope:** We would be really interested to explore the thinking around the involvement of patients within such an evaluation or appraisal framework. We would definitely like to see a clinician-led process, but with a patient-led perspective or patient involvement in that process as well. We think that that would be very important.

[118] **Rebecca Evans:** To what extent are patients involved at the moment? You suggested that the situation is better in other parts of the UK than it is in Wales at the moment. To what extent are patients involved there, and are there models that we should look at?

[119] **Ms Cope:** Can you comment on the situation in Wales?

[120] **Ms Hughes:** In Wales, in terms of what I know about AWMSG, patients have written evidence that they send in. However, in terms of diagnostic tests, I think that they are commissioned through the UK genetic testing network, and then WHSSC needs to have a commissioning model in place to make them available. However, that is not there at the moment, so tests are not being made available because there has been no uplift in the amount of money available for testing. You have some data on the table provided today showing how the number of tests has increased since 2002, and the amount of money available since then has not increased, even though the number of tests available for patients with rare conditions has gone up. So, in Wales, we have not had access to any more funding to make more tests available.

[121] **Ms Cope:** Wales takes part, from a genetic diagnostic and a genetic testing service perspective, in what is called the UK genetic testing network, UKGTN, and that is a clinician and scientist-led committee board that reviews new genetic tests and diagnostic technologies that become available. There is a good patient perspective and input at that level, and through those evaluation criteria, the tests become available on the UKGTN portfolio or menu. Elsewhere in the UK, that test is then commissioned and made available. However, our understanding is that that is not necessarily the case in Wales, again because of the financial constraints. There has been no uplift for 12 years, which is a long time.

[122] **David Rees:** You have talked about the UKGTN, what association does that have with NICE's health technologies programme?

[123] **Ms Cope:** I believe that they are separate, although I would need to check that, if that is okay. However, the NHS genetics community from across the UK, with good representation from Wales, works very well and effectively. It is about enabling the best clinical and practice decisions to be made together and for service providers to have that autonomy within their services to deliver those approved tests.

[124] **David Rees:** You say 'approved tests', but by whom are they approved, because NICE is—[*Inaudible.*]

[125] **Ms Cope:** They are approved by the UK genetic testing network, and that is a UK-level committee.

[126] **David Rees:** If you could find out whether there is an association with the NICE's

health technologies programme, that would be helpful for us.

[127] **Ms Cope:** Yes, of course.

[128] **David Rees:** Janet, would you like to ask a question on research?

[129] **Janet Finch-Saunders:** I have a question on this, actually. As regards financial constraints and NHS Wales organisational structures, to what extent do you feel that these are acting as a barrier to technology adoption? How can we address that?

[130] **Ms Cope:** Our understanding is that they are a barrier. The table that we have shared with you shows that we are unable to take up these tests and new technologies.

[131] **Janet Finch-Saunders:** What about the organisational structures that exist?

[132] **Ms Hughes:** At the moment, one of the difficulties is that there needs to be some sort of a commissioning model, and that is not in place in Wales. So, WHSSC, as the commissioner for health services, would be the one that would commission the test to be made available. At the moment, that is not done. So, one of the big issues for us is the lack of a model to make these tests available to patients.

[133] **Ms Cope:** That includes the capital investment in that big and fuzzy machine in the corner of the lab but also the ongoing sustainability to ensure that the scientists are trained up adequately and properly so that we can make sure that patients can receive tests that are high quality and safe. It is about that ongoing investment and cost as well.

[134] **Janet Finch-Saunders:** What role would there be for the health technologies fund that is in place under an improved system for the assessment and introduction of new technologies?

[135] **Ms Hughes:** Could you repeat that, please?

[136] **Janet Finch-Saunders:** What are the benefits and limitations of the health technologies fund currently? However, more importantly, what role would there be for the health technologies fund under an improved system for the assessment and introduction of new technologies?

[137] **Ms Hughes:** I think that maybe WHSSC would have to take on that role, because, as the body making the funds available for those tests, it would perhaps have to tap into that funding. I am not aware of what the criteria are for the funding, so I am not quite sure whether it would be able to do that. Do you want to add to that?

[138] **Ms Cope:** I am not aware either, I am afraid.

[139] **David Rees:** Are the tests that you have talked about in the paper tests that have been approved by the UKGTN?

[140] **Ms Cope:** Yes, they have had rigorous, scientific clinical screening and have been subject to a rigorous evaluation process.

[141] **Lindsay Whittle:** Good morning. I hope that you got my apology for not attending your event last week; I had to speak at the funeral of a very close friend of mine.

[142] I am extremely interested in patient involvement because, as I see it, there are two different aspects. I would be interested to learn about the experience of adults who suddenly

develop or contract a rare illness or disease, because I am sure that that happens. Hayley, your experience with Jonah almost breaks my heart. I have enormous sympathy for you. I said to the previous witnesses that if I developed a serious illness at my age—I am not going to tell you what that is—I, quite frankly, could not care less where I had the treatment. It could be anywhere in Britain or the world. However, when you have a young child, it is not so easy to uproot, because you will want to remain where you can have the support of your family—you mentioned that you have other children as well. I guess that you are torn because you want the best treatment for Jonah, as we all do, I can assure you. What are your experiences? How do you think that we can help? I would be really interested in that aspect. The previous witnesses told us about frustrations with WHSSC and commissioning and health boards, with meetings taking two or three years to resolve issues. Some people do not have two or three years, with respect. That would be very frustrating for everybody. I am interested to hear your views on that aspect.

[143] **Ms Cope:** Maybe this is a bit simplistic and maybe we could all come up with this response, but we would hope to get a recommendation that WHSSC and the specialised services commissioner should have adequate and robust commissioning policies in place, as Emma has alluded to previously. It is about addressing the gaps between it being the responsibility of the health boards or WHSSC and making sure that the evaluation or appraisal process is thorough, robust and adequate, with clear patient representation and input, as well as clinician input, in terms of those criteria and those prioritisations. It should take into account the need for medical technologies—you may have to invest in capital, as well as ongoing investment afterwards and looking to renew that technology within x number of years. Those sorts of things should be in place to make sure that the commissioning structures can keep up with that and recognise that. We also hear anecdotally about decisions being made at the WHSSC level about how long it might take for that payment to be processed from local health boards—you know, that signing off. Where is that paperwork lost—on whose desk in which office within which board? These are real gaps or cracks in the system that cost many months. For lots of people who we care for who have rare conditions—whether they are undiagnosed genetic conditions or whether they have a name for them and have been successfully diagnosed—we see that they are losing time and are not able to access those interventions. I suppose that that also includes medicines, but I appreciate that we are not talking about medicines today. So, those are the recommendations that we would like to see. We would like to see clear policies and we would like to see them being implemented adequately and that we can measure the success of those policies and see how we are doing in a year or two's time with those to see whether they are working.

10:30

[144] **Lindsay Whittle:** Is it the same issue for diagnosis and for treatment, once the illness has been diagnosed?

[145] **Ms Cope:** Essentially, I would say that it is, yes. What would you say, Emma?

[146] **Ms Hughes:** Yes. I think that they are definitely similar issues. However, it is really important to recognise the benefits of the new technologies coming through, because these can often save a lot of time. When you get a diagnosis there are obviously better treatment options, because you know the name of the condition and you can treat that appropriately. Also, there is future planning for patients and a prognosis. So, really, investment in the new technologies will save money and time further down the line because the patient can receive treatment more quickly.

[147] **Ms Cope:** It is also about getting the right treatment—

[148] **Ms Hughes:** Exactly.

[149] **Ms Cope:** —as opposed to rattling around the system, being seen by medics when they do not need to be seen, and being offered interventions, tests or therapies that they might not need—so that the money being spent on the patient is for the right care.

[150] **Lindsay Whittle:** Thank you. That is interesting.

[151] **David Rees:** Obviously, you have talked about the UKGTN and, as I said, I think that it is important to assess how we in Wales can benefit from the approach that it takes. You said that, in England, that seems to be accepted. Have the appraisals been accepted by the NHS in England, or is it the local health boards or trusts that accept them?

[152] **Ms Cope:** Sorry; it is by the rest of the NHS across the UK, really—we are not just talking about England, but Scotland and Northern Ireland as well. It is a specialised service, so, in England, it would be done by NHS England, which is the specialised commissioner. Then comes a commissioning policy, which is then commissioned within those services in England. That is the case with the National Services Division in Scotland.

[153] **David Rees:** So, it is very much a commissioning issue.

[154] **Ms Cope:** Yes, very much so.

[155] **David Rees:** Thank you for that clarification. Do any other Members have questions? No. You are all very quiet. Normally, we give you the opportunity to give us one recommendation. I think that you have already given us some of your recommendations, but if I were to pin you down to a single point—and you have talked about the commissioning side of issues—should we be looking at a commissioning-strengthening issue or should we be looking at an assessment by a separate group? I know that there is the AWMSG and other organisations, but I am thinking of something along the lines of the NICE health technologies programme.

[156] **Ms Hughes:** Given that these tests are appraised at the UKGTN level, once they have been done, there does not need to be another assessment process. They probably just need to be commissioned locally, because they have been proven to be safe and effective. In that sense, a commissioning model really needs to be in place to make them available to patients in Wales.

[157] **Ms Cope:** Yes, so that patients in Wales are not disadvantaged, essentially, by the red tape in the commissioning system.

[158] **David Rees:** I want to ask Hayley a question on this. Elin has a question, but I will ask mine before she comes in. When you said that you were waiting for a long period of time, was that because there was nothing being offered by the services in Wales, or was it actually referring you to an English centre at that time?

[159] **Ms Norris:** I am not sure where the testing was done. I know that some of it was not done within Wales and within Cardiff. I guess that the frustration for us, from a monetary point of view—. As a parent you obviously investigate. I was like the Google queen when I found out that Jonah was disabled. I must have been the one person who hit Google constantly. You are looking for answers. So, it would often be a case of us going in to see the geneticists and saying, 'Actually, could we test for this because Jonah seems to fit quite well with these children?', and it would be a case of them saying, 'Well, no. You have had this, this and this done, therefore we don't think it's worth investing money in you having another test done', which is quite frustrating. If you are looking at it and thinking, 'What if he has that condition? They're not doing anything, and it's all down to money', you will see that that is a

huge frustration as a mother. My son is very profoundly disabled; he does not talk, walk and he will probably be in a wheelchair for life. He is tube-fed because he will not eat. It is incredibly frustrating, as a parent, to know that the reason why, perhaps, you are not having certain tests done is because of money restraints. This has happened fairly recently with my geneticist. There was a test that I wanted done. He said, 'If I held the purse strings, I would do it for you, but I just can't'. So that is why we have now been enrolled on the deciphering developmental disorders, DDD, study. He said that it would all be done through that but, again, that is a very, very long process. You are talking about years and, in the meantime, like you say, he is having treatment and we are second-guessing things because he will do something and you will think, 'Oh, right, okay, why is that? Why is he doing that?' when, if you have a more specific diagnosis, you can treat that syndrome or whatever in a more effective way. So, I think that a lot of it is down to money and that is quite frustrating for us because, obviously, we are on the receiving end of that.

[160] **David Rees:** Thank you, Hayley. Elin, do you have a question?

[161] **Elin Jones:** Yes. I just want to understand a little better what you mean when you talk about the commissioning of specialist diagnostic testing available in Wales. You do not necessarily mean that the kit and the laboratory and the staff around that have to be in Wales. The commissioning could be done from part of the NHS in England or in Scotland, even, but it is the availability of the test that you are referring to rather than the physical part and the staff part having to be in Wales, is it?

[162] **Ms Cope:** No, it is the other way round for the commissioning of it, the buying of it, really—whether that is done in the Cardiff laboratory or whether it is a send-away to anywhere else either in the UK or internationally, wherever the right lab for the right test is. It is the funding that is not available—

[163] **Elin Jones:** For the test?

[164] **Ms Cope:** For the test, even though the test has been approved through the UK Genetic Testing Network, had a great deal of scrutiny, meets all the clinical utility criteria, and is to the standard required, et cetera. There just are not the resources available for the clinical geneticist—the geneticist who Hayley and her family see—to say, 'Right, let's buy that test', essentially, regardless of which laboratory that takes place in. That is the difference we are seeing for families like Hayley's who live in Cardiff compared to, say, families in Dundee. That is what we have found through her talks with the SWAN network for undiagnosed genetic conditions and for lots of other rare conditions as well. Taking those together—175,000 people in Wales—it is not a tiny number, you know, it is significant.

[165] **David Rees:** Lynne, do you want to ask a question?

[166] **Lynne Neagle:** Yes. Hayley, you said that there was a test that you wanted to have for Jonah but that your clinician said, 'No, I am sorry, we haven't got the money for that'. Is there no process in place, as there would be for a drug, say, where a special application can be made? Is there anything like that in place for genetic testing?

[167] **Ms Cope:** I believe that individual patient funding requests are—

[168] **Lynne Neagle:** You could use that, could you?

[169] **Ms Cope:** —for technologies, so they are for interventions and tests as well. That is quite a long process, really, is it not—

[170] **Lynne Neagle:** Oh, I know all about the IPFR process. I have the scars on my back—

[171] **Ms Cope:** —particularly when the test in question has already been assessed at UK level with Welsh buy-in and Welsh support and knowledge from the scientists here as well as those across the UK. It has been put on the menu, if you like, of approved tests. So, there is a big thumbs-up, a big rubber stamp, on the test.

[172] **Lynne Neagle:** Okay. I also want to ask something else because you mentioned Dundee. What are they doing differently in Scotland, then? Obviously, it is another devolved nation. What are they doing that is different? Are you saying that they have access to all these things in Scotland? Is there better collaboration with England?

[173] **Ms Cope:** It is not necessarily about better collaboration with other countries across the UK. Our understanding is that, once these tests are approved, the commissioning policies are in place to enable them to take up those tests, to offer those tests to those patients.

[174] **David Rees:** Just to clarify that, it is your understanding, therefore, that, once the tests are approved by the UKGTN, for example, the commissioning body in Scotland then says, 'Okay, we are now going to commission those tests'?

[175] **Ms Cope:** That is our understanding, yes. I will go back and double-check that and, if I am wrong, I will certainly let you know.

[176] **David Rees:** If you could let us know that would be wonderful. Are there no further questions from Members? There are none. In that case, thank you very much for your evidence. You will be given a copy of the transcript to check for accuracy. Thank you once again for your written evidence as well.

[177] I suggest that we now go to a break. The next session will commence at 11 a.m., when the next witnesses are due.

Gohiriwyd y cyfarfod rhwng 10:40 ac 11:02.
The meeting adjourned between 10:40 and 11:02.

Ymchwiliad i Fynediad at Dechnolegau Meddygol yng Nghymru: Sesiwn Dystiolaeth 10
Inquiry into Access to Medical Technologies in Wales: Evidence Session 10

[178] **David Rees:** I welcome Members back to this morning's session. The third evidence session that we have this morning is with MediWales and I welcome Gwyn Tudor, who is the forum manager. Thank you for your written evidence and also for the written evidence from the Association of British Healthcare Industries, if you could pass on our thanks to it as well, please. Clearly, we have some questions. I remind Members that we are trying to focus upon the impacts of the development and uptake of new technologies and the way in which industry engages with the Welsh NHS, which is a critical element. So, perhaps I can start off by asking about the extent to which you believe that Wales is open for business in relation to industry and the access to new technologies.

[179] **Mr Tudor:** In 2010, we conducted a bit of research and produced a report that was submitted to the Welsh Government on that particular issue, identifying where industry, academic and clinical expertise need to engage for the good of patient outcomes, but also of economic development in Wales. We identified a number of key areas, one of which was early-stage identification of technological needs that could then be taken up and used as a cue to develop a specific technology. Another was clinical trials, so that is the development of data to support the hypothesis that the piece of technology actually delivers what it is

supposed to deliver and does so safely and economically. We then looked at the adoption of new innovations, so if the Welsh NHS is engaged with industrial or if academia is engaged with industry to develop a new technology, that is not going to be particularly valuable to the Welsh NHS unless there is some kind of adoption or at least evaluation and consideration as to whether or not that technology should be adopted. We then looked at what you might call standard procurement practices, tendering, et cetera, and at what would be most advantageous to the adoption of new innovation.

[180] To answer your question about the phrase 'open for business', we could tick three out of those four areas, and I think that Wales is doing exceptionally well. The National Institute for Social Care and Health Research—NISCHR—is, essentially, the access point. NISCHR has established its academic health science collaboration with Health Research Wales, both of which have a role to play in engaging partners in research and development, which can result in new innovation and new technologies, either to improve patient care or to reduce cost. At the other end, in procurement, I think we have seen major leaps forward in terms of shared services and the individual health boards being receptive to buying technologies in order to improve, mostly driven in that case by better economies, but they are very definitely receptive. The area where we feel there is a gap—and it is a gap that is affecting the issues concerning this committee—is whether or not Wales, and specifically the Welsh NHS, is looking out for new technologies, identifying them, evaluating them, and adopting the ones that are most appropriate. From a procurement point of view, procurement people buy what they are told to buy, so it has to be a known technology in order for it to be bought. From an R&D point of view, there is a lot of help to support the development of the product, but then no obligation to see that through to adoption, so we do feel, as we pointed out in the paper that we submitted, that there is a gap there that needs to be addressed.

[181] **David Rees:** So that is the horizon-scanning aspect.

[182] **Mr Tudor:** It is horizon scanning, it is engagement, it is a systemic, formal way that, if an organisation has a new technology that it believes can improve patient care or reduce costs to the NHS, it can be submitted and evaluated independently on a level playing field, and, if it is appropriate and does provide those benefits, can then be carried through to adoption. I think most companies feel that they have to identify key clinicians, and they have to identify key decision makers, pretty much on a one-by-one basis. One of our members refers to it as guerrilla marketing. They have to try to identify people who can then create a pull through the system, whereas one might assume that it would be more appropriate for the NHS to be considering all technologies on an equal footing.

[183] **David Rees:** Lindsay, do you have your question?

[184] **Lindsay Whittle:** Good morning—if it is still morning; we do not see the daylight much here, so we are never sure what time it is. [*Laughter.*] I am really interested in the views of all stakeholders, and I have asked all the witnesses here about the views of patients and how you take those on board. Clearly, you would also be interested in the views of manufacturers of this technology. We heard from some witnesses—people who suffer from rare diseases and illnesses—that they are very much on Google all the time trying to find answers to their very real, serious concerns. I appreciate that, but sometimes a little knowledge can be dangerous, can it not?

[185] **Mr Tudor:** Yes.

[186] **Lindsay Whittle:** There is always that danger. How do the stakeholders work with the health providers, then? What is the best way of making sure we have the right technology and are addressing the right issues involved?

[187] **Mr Tudor:** As I have mentioned, we have done quite well in a number of ways, but I think manufacturers have to be very careful how they engage with patients. As you say, a little knowledge can be dangerous. Manufacturers have to show a level of responsibility, especially these days, when so much information is available on the internet. Manufacturers have to be careful that they are not selling direct to patients. That being said, there is no such thing as a purchase driven by poorer patient outcomes, so the manufacturers have to be acutely aware of patient needs and clinicians' needs in order to meet those needs in order to market their product. Increasingly across the NHS, and across health procurement throughout the world, there is a view, an increasingly sophisticated view, of looking at medical technologies with a view to improving patient quality of life. So, the companies are aware. They engage, often, through formal patient groups, but in respect of marketing their products, it would usually be done with the healthcare provider, rather than directly to the patients.

[188] **Lindsay Whittle:** I am sorry; I was not suggesting that you contact the patient directly.

[189] **Mr Tudor:** Some do, but they do it through formal arrangements.

[190] **Lindsay Whittle:** Right, I see. With regard to technology working with medicines, what is the mix there? Could you enlighten me, as I have no idea, if I am being honest?

[191] **Mr Tudor:** Obviously, both are required, in a lot of areas. However, the academic disciplines and the clinical disciplines required to expertly evaluate both are very different. Medicines have a very formal process, through clinical trials and then, in Wales, we have the All Wales Medicines Strategy Group that can evaluate new medicines as they come out. However, those steps, as I understand it, lead to the chief pharmaceutical officer, whose responsibility it is to provide an overview, guidance and leadership in terms of medicines procurement. Medical devices, and other health technologies—assistive technologies, wheelchairs, beds et cetera—tend to come under a different procurement path. So, it is not appropriate to, maybe, seek to influence the same people or seek to have horizon scanning and evaluation from the same people, because they are not directly related to the procurement of those devices and objects.

[192] **Lindsay Whittle:** One small question: is there any experience or evidence that those companies developing medical technology concentrate on the more common cancers and, perhaps, ignore the less common?

[193] **Mr Tudor:** I understand the issue that you are raising, and it is probably less of a concern in the majority of medical technologies, because, for example, if you have a company that is manufacturing disposable surgical instruments, they may well be selling them in procedure packs for specific activities and, obviously, those activities that have the highest volume demand will be their larger lines. However, essentially, it is the same surgical equipment, regardless of what procedure is being undertaken. So, it is less of an issue. Given that pharmaceuticals are directed at very specific therapeutic areas, there is a concern about that in pharmaceuticals, but in medical technology, the products are more general.

[194] **David Rees:** Elin, is your question on this subject, because Rebecca has a question on this subject?

[195] **Elin Jones:** Well, yes, sort of.

[196] **David Rees:** Okay, go on.

[197] **Elin Jones:** Thank you for the evidence. It is really interesting, because it brings a different perspective to the work that we have been doing on this, especially the two case

studies here of two companies in Wales developing their products, and their inability even to have their products assessed and recognised by the NHS in Wales, or in England, for that matter. Of course, when we compare that to the work of large pharmaceutical companies, with the assessment processes, they are very well integrated into the assessment processes, but because a number of these companies, and there will be others in England and in Wales, are quite small, they do not interact in the same way, or there are so many more of them—rather than the fact that they are small—the process is not as structured for them as it is for the large pharmaceutical companies. Some of the evidence that you have put in here is quite startling, really, when you talk about Invacare in Bridgend, which talks about the resistance to adopting innovation and the fact that incumbent interests have blocked the adoption of this innovation. It is very concerning to read that. How can these barriers be broken down?

11:15

[198] **Mr Tudor:** When I talk to our companies, and when I identify case studies, all of our companies, and we represent about 140 organisations in Wales, and the Association of British Healthcare Industries represents the larger med-tech companies, all of them would like to have a moan about products that they have not managed to sell. What I have tried to do in identifying these case studies is to look for systemic reasons why those products have not been adopted, rather than look at competitive issues. Invacare can support, with various folders of evidence gathered over the years, the various reasons why its product has not been adopted. It goes through the whole gamut of reasons, such as that its product does not meet the tender requirement, because the tender requirement is for oxygen cylinder supply, so a machine that produces oxygen at someone's home does not meet the same specification—it achieves the same outcome, and arguably better, but it is not the same technical specification. Invacare has had experiences where a single tender has been given to one big company, and the incumbent company—this is the point that I was alluding to—has been given the responsibility of evaluating the new technology. Where this technology may be disruptive to its supply lines, there are reasons why you can assume that that would not be an independent evaluation. Whether that is the case or not I leave to Invacare to decide, but what I am trying to point out to you is that the possibility of that situation is obviously there.

[199] So, it is giving lots of reasons, but it would be better is to ask, as you did, 'What is the solution?' I think that the solution is to be able to approach a specific organisation or department representing the whole of NHS Wales to say, 'Here's the technology, here's the evidence that it improves patient outcomes and patient care, quality of life or costs', and let the NHS decide which would be the better product to purchase.

[200] **Elin Jones:** So, it is getting the ability to be appraised by the NHS in Wales in some form, first of all, to get that right, to get on to a list of appraised products and then go through the appraisal process.

[201] **Mr Tudor:** I think that it is in two directions. One is for any company to say, 'We've got this product and we've got this level of evidence, will you please consider it?' The other is for, arguably, that same organisation to be spending some time horizon scanning, talking to manufacturers, going to conferences and going to trade shows so that we have an organisation, a department or at least a few people in Wales who are totally up to date with the cutting edge of new health technology. I do not think that it is fair to leave that to the clinicians.

[202] **Elin Jones:** We are very familiar as Assembly Members with instances where pharmaceutical companies will have talked to patient groups, lobby groups or patient interest groups, and will then lobby for drugs to be approved and commissioned. However, there does not seem to be the same lobbying process. I am not saying that none of that should have to happen. For example, EKF Diagnostics with its HbA1c analyser testing, in which I can see

real value straight away just from reading what I read there, Diabetes UK and other interested groups around diabetes could well be very active in lobbying for new technology to be appraised. They do it with pharmaceutical companies—not only Diabetes UK, but everyone—so why is that dynamic not happening?

[203] **Mr Tudor:** The examples that I have given involve very large companies, but they are dwarfed by large pharmaceutical companies. Their marketing budgets and public relations budgets are dwarfed by pharmaceutical company budgets. The Association of British Healthcare Industries—which I spoke to before this committee and it was happy for me to represent both of our points of view, because they were overlapping—is a very similar organisations to the Association of the British Pharmaceutical Industry in many ways; it would regard itself as a London based, Westminster lobbying organisation on behalf of the health technology sector.

[204] However, it does not have the budget to be as ever-present in all areas as the pharmaceutical industry, and I do not think that it has the same objectives. The development of a medical device is more collaborative and more needs based. We have many good biotechnology companies developing new drugs and new diagnostics in Wales that go forward then to be considered by pharmaceutical companies. We work with them, but the same is not really true for medical device companies. It is a more complicated pipeline. It might start with a clinician saying, 'What I really need is a thing that can get me in here or can do this,' and then a company will come up with a product that will satisfy that need and then collaborate with the clinician again to test it, to trial it and to improve it. It is more of a back and forth process than the very well-established pipeline for pharmaceuticals.

[205] **Lynne Neagle:** The Invacare example is very striking and I can see huge benefits for patients in not having to lug around big canisters; it could possibly transform their lives. So, why has it been possible to get this product taken up in England and not in Wales?

[206] **Mr Tudor:** I think that it is individual procurement processes. It comes down to individual people. If you can find a key opinion leader who understands and recognises the benefit, and you do not have an incumbent supplier that has an influence in other areas, you can then create a market that is self-sustaining because the patients see the benefits. That is maybe not the way it should be, because, again, that is about individual companies influencing individual people. I think that there is a general feeling that there should be a more systematic approach to evaluation.

[207] **David Rees:** Leighton, did you have a question on this point specifically?

[208] **Leighton Andrews:** It was a slightly more general point.

[209] **David Rees:** We will go to Rebecca first and then Leighton.

[210] **Rebecca Evans:** My original point has been covered, but I would like to ask about piloting. ABHI said in its evidence that we need to minimise the pilot culture. Is that a view that you share, and could you expand on what the problems are?

[211] **Mr Tudor:** From ABHI's evidence, that is probably not one of the points that I have focused on; I would have to say that. I assume that what it is alluding to is an effort for getting something for nothing from manufacturing companies. Is that—

[212] **Rebecca Evans:** I think that its concern is that the current system of piloting new technologies leads to small-scale uptake, as you were talking about, which is interest driven. Does it ever lead to a more widespread uptake? What are the problems and what can we do?

[213] **Mr Tudor:** Understood, yes. There is dissemination of good practice, which is working very well in some areas of the Welsh NHS and, often, NICE guidance is adopted across the board. So, I would not say that there is an issue with piloting per se, which is why I was a little confused by your question. However, ABHI has identified that this needs to be disseminated and adopted more widely, because you can then create a demand for better practice. I have seen examples of this in Welsh health boards, where even within the same board, two different hospitals have adopted a different procedure and, if you evaluate those procedures, one is better than the other. So, the difference between the outcomes of those two procedures is clearly a concern. Maybe dissemination of good products, good practice and good techniques might be part of this solution, as well—not just horizon scanning and adoption, but telling the rest of the NHS about it.

[214] **Rebecca Evans:** Would that then be done on an all-Wales basis rather than on a locally driven basis, as happens at the moment?

[215] **Mr Tudor:** I think that the manufacturers have expressed to me quite often that the opportunity to speak to the Welsh NHS as a whole—an opportunity that was created in terms of clinical trials through the development of Health Research Wales just last year—has a significant advantage, because you then have one contract, you can go through permissions once and you can eliminate an awful lot of bureaucracy on both sides of the table to everybody's benefit. As I say, if you have two boards doing different things and one of them is better, then the other one should be doing the same thing, arguably.

[216] **Leighton Andrews:** MediWales was established in the time of the Welsh Development Agency, so you have clearly been going for a while. To what extent do you feel that your experience has been drawn on by the Welsh Government over that period?

[217] **Mr Tudor:** I would say that we have a uniquely collaborative approach in Wales. We have been supported by the Welsh Government and we have had close dialogue with the Welsh Government, academia and clinical organisations—health boards or individual centres—over that period. So, MediWales is not a traditional—I did not call us a trade association for those reasons. We are more of a forum of health technology organisations, whether they are public or private. Our make-up is around 70% private sector and 30% academic, clinical and Government organisations. I think that we are uniquely collaborative, and I think that that has created a number of opportunities, one of which—our greatest success, I believe—is the creation of Health Research Wales and the fact that there was a close dialogue between the National Institute for Social Care and Health Research academic health science collaboration and MediWales during that process to everybody's benefit, I believe. So, 'more collaborative than adversarial' is the answer to that, I think.

[218] **Leighton Andrews:** Are there good examples, then, as a result of that collaborative relationship, of the introduction of technologies in Wales in advance of other places?

[219] **Mr Tudor:** Yes. There are examples of companies that have come to us and said, 'We would like to engage with Welsh academia or the Welsh NHS in a number of capacities, whether it is to conduct research or for companies to engage with leading clinical experts'. We have been able to approach those experts or organisations to identify the appropriate individuals in those organisations and provide a matchmaking of companies and individuals that has resulted in successes.

[220] **Leighton Andrews:** Has that resulted in the use of new technologies in the Welsh NHS before they have been used in other health services?

[221] **Mr Tudor:** I cannot tell you that they have been adopted before other health services, but I can tell you that there have been situations where the NHS has been made aware—not

usually at the procurement stage, but at the research and development stage—of new technologies being developed in Wales or existing technologies that have been applied differently that have then gone on to be adopted. Whether they are being used elsewhere in the world as well is a difficult one for me to answer.

[222] Every year, we run national awards. We award people for growth and innovation, and we award start-ups, but we also provide one award for partnership with the NHS. Every year, we have a list of applications of companies that have gone into partnership with organisations in the NHS resulting in a successful outcome for patients.

[223] **David Rees:** You have obviously highlighted that there are successful processes on some points in relation to this. What do you feel could be improved in that process, so that this becomes a more natural and common mechanism for approving technologies?

11:30

[224] **Mr Tudor:** Your phrase ‘open for business’ is one that I have endorsed, and I have said that I think that the Welsh NHS is open for business. However, what I do not think that we have in this particular area is a front door. I do not think that there is a place—an organisation or department—where industry can engage with the Welsh NHS in an appropriate fashion and say, ‘We are doing this already. We are doing it overseas and we are doing it in England, but we cannot seem to get someone to evaluate it in Wales’, or, ‘We have a new technology, and will you please just look at it?’ That would create a level playing field, and it would improve things dramatically.

[225] **David Rees:** The evaluation obviously depends on clinical testing, which is a major issue. How can we strengthen that aspect of it as well?

[226] **Mr Tudor:** Quite often, the companies tell me that they have done their clinical trials, and quite often they have been done to the highest standards. So, evaluation requires two things: a study of the clinical data and a recognition and view of those clinical data. However, it requires an independent evaluation—or rather, it is not independent; it is from the NHS’s interest—to see whether those outcomes are appropriate to the needs of the Welsh NHS. We are not really concerned with the production of clinical data and collaboration in clinical trials. We feel that these are being undertaken appropriately. It is about the review and assessment of those data once they have been produced.

[227] **David Rees:** You feel that the Welsh companies are okay in undertaking that element, and that it is the next stage that is the issue that needs to be addressed.

[228] **Mr Tudor:** Yes.

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

[230] **Janet Finch-Saunders:** Yes. Thank you, Chair.

[231] Mr Tudor, you have highlighted the negative impact of silo budgeting. Could you just expand on that in some greater detail, please?

[232] **Mr Tudor:** Yes. Essentially, I am conveying the words of our members, who are saying that if a procurement process is based entirely on the cheapest product, or on quality and price but for a specific device, then that might not be the most cost-effective way of delivering the appropriate patient outcome. If you take a different approach to delivering the same outcome, you may increase costs in one department but reduce them in another. Therefore, your net benefit may be reduced cost and improved patient care, but somebody’s

budget might have to sustain an increase. That is where the problems lie.

[233] **Janet Finch-Saunders:** Are you experiencing, in a negative way, organisational silo working, which can often lead to duplication and confusion?

[234] **Mr Tudor:** Yes. It might not be to do with silo budgeting, but organisational silos might be there.

[235] **Janet Finch-Saunders:** Is that a barrier?

[236] **Mr Tudor:** Yes. We have seen it in areas such as permissions and ethics, where individual organisations are not prepared to share each other's permissions and ethics outcomes. This is not my area of expertise, but maybe they are concerned about legal issues down the line, so they want to undertake their own permissions and ethics procedures, understandably. That does create duplication.

[237] **Janet Finch-Saunders:** Is that holding things back?

[238] **Mr Tudor:** In some ways, yes. In terms of companies being able to supply to the NHS in Wales as a whole, going to see each board individually definitely increases the cost and the price because you have to invest more in sales and marketing. Alternatively, if a good decision is being made in one area, maybe sharing it would be more cost-effective for everybody. On the other hand, it means that companies have individual opportunities to sell their products. So, if everything was an all-Wales procurement process, that would reduce the opportunities. Once the tender was placed with the company, other companies would not be able to go to other boards in order to try to sell their products. So, there are issues on both sides for the companies there, but, on the whole, for the good of the NHS and the patients, I think that shared information and shared bureaucracy is probably a good idea.

[239] **David Rees:** You have mentioned the issue of medical technologies, and we tend to think an awful lot of medical technologies in the secondary care sector, but one of the examples that you give in your case study is clearly focused on the primary care sector. Do you believe that the community and primary care sectors are represented sufficiently in any evaluation processes that go on in Wales?

[240] **Mr Tudor:** If you look at where the potential cost savings are to be gained, primary care and social care have a huge role to play. So, characterising medical technology procurement as being something for hospitals would be wrong, because a lot of our members are involved in remote or home diagnostics and assisted living. The two case studies I have given are applicable to the home, so, it is an issue that extends not only to primary care, but to social care, definitely.

[241] **Elin Jones:** My question is related to that, because we had clinical leaders from Velindre give evidence earlier this morning, and it strikes me that, with very specialist medical technology, there could well be clinical champions within the system, because there are very few of them. So, clinical leads in Velindre or Singleton could champion particular technologies through the system. Whereas with the two case studies that you have given, and with other issues, such as insulin pumps, they are very much related to the primary care element. The benefits would be found primarily by GPs and in running primary care, and that is a very dispersed community and is less likely to have individuals who are clinical champions. So, how do you work with the kind of GP community, the primary care community, to try to make them into clinical champions for some of these technologies?

[242] **Mr Tudor:** To understand working with the clinical community, there is a very easy answer, but to extend that out to GPs is slightly more challenging, by definition, because they

are in general practice. Our members, who work in specific therapeutic areas, understand and engage with the research that is going on in those areas. Wales has a number of globally recognised leaders in certain clinical areas, including diabetes, neurology and wound care. So, there are already, by default, identified champions who, if you were seeking to introduce a new device or process into the Welsh NHS, would be key opinion leaders who you would already have identified. Those people would need to be engaged if there was a centralised function for evaluation and horizon scanning, and it would obviously have to bring in those experts, on a case-by-case basis, otherwise there would be some resistance to some kind of centralised body casting out dictates, when the expertise is, as you say, more dispersed than that.

[243] **Elin Jones:** It is just that when you think about the HbA1c test, the benefits to that would be found in the GP surgery. They would have less people like us coming to have their tests and then have them sent off to the labs. It may not be of particular interest to whoever might be the clinical lead on diabetes in Wales, because it is not specialist enough. The test is the same test, but it is done in a different way. So, it is about the application and the ease of the testing for the patient and the GP. I am not sure whether the fact that it is such a practical bit of work, rather than being interesting in terms of the progress of diabetes science, is reflected in how these technologies are respected in the medical community.

[244] **Mr Tudor:** I understand what you are saying, and there would probably need to be primary care champions who are able to evaluate a technology within that environment. I think that the various diabetes opinion leaders in Wales are interested in this particular case study because they have a role to play in the improvement of diabetes management, which is conducted at the GP level but it is part of their area of expertise.

[245] **David Rees:** You mentioned that there is a difference between secondary care, primary care and so on—and we highlighted that—and I think that you mentioned social care. Do you have an idea of what balance of members you have between social care and health care? That is just to give us an idea of the areas in which we will see developments.

[246] **Mr Tudor:** That is a really challenging question because a wheelchair is a wheelchair, whether it is used in a hospital or an old people's home. I would say that we have a very vibrant assistive technology sector in Wales, which is sometimes not at the cutting edge of clinical research, but the company Invacare produces this oxygen production method but it also manufactures a large number of wheelchairs, hospital beds and mattresses. We also have Huntleigh Healthcare and other companies that are also involved in assistive technology, whether it is in a social care, primary care or secondary care setting.

[247] **David Rees:** I have other questions and I see that other Members have. NICE has a health technology programme and you mentioned that one of your case studies failed to get involved with that. How do you find that that programme is working? Obviously, in that case it did not. How do you find the issues around that programme?

[248] **Mr Tudor:** It is just not big enough or specific enough to accommodate Welsh needs. It is essentially a bottleneck in the process. If you have a company, wherever it is in the world or the UK, that needs to get a NICE evaluation in order to sell to the NHS in Wales, it will be waiting for NICE to choose to evaluate that product group and to choose its product as one of the products that is going to be evaluated. If that was the only route to market, it would not be economically viable for an awful lot of companies to take that route. If NICE was much bigger or if there was a Welsh NICE that accommodated the specific needs of Wales, then that is what we might be talking about here. We have Cedar in Cardiff Medicentre, which is a NICE evaluation centre that is very well regarded for what it does within the UK clinical community. However, there is no access point to Cedar in a Welsh context; it is tasked through NICE. We are seeing it deliver an excellent service in device evaluation, but you

cannot go to it directly.

[249] **David Rees:** A theme that has come through from many of our witnesses is that AWMSG should perhaps have a technology section or sub-group. Would that be your front-door approach?

[250] **Mr Tudor:** No. MediWales sat on AWMSG for a short period of time a number of years ago. In its present structure, because it is chaired and led by the chief pharmaceutical officer, it does not lead evaluation or decision making in the right direction at all for medical devices and medical technology. The post that I filled was referred to as allied sectors and after a period of time sitting on that board—

[251] **David Rees:** What about a sister organisation?

[252] **Mr Tudor:** A similar organisation looking at medical devices would go a long way towards resolving some of the issues. To my knowledge, that is just a board rather than an operational team, which would limit its success in this area, but it would move us in the right direction.

11:45

[253] **David Rees:** Do any other Members have questions? I see that they do not. In that case, I will give you the opportunity that I have given to everyone else. You have given us four recommendations in your paper. Which one would you highlight as one that you want us to consider? Or is there something different?

[254] **Mr Tudor:** Since submitting that evidence, I have talked it through with a few people, and one of the things, given the opportunity to make a final comment to this committee, that I have felt I wanted to say is that it could be that, if you look at the various organisations and evaluation centres and NISCHR activity, you may find activities, projects or organisations that might tick the box in this area, or you may go away and say, 'Oh, MediWales said this didn't exist, but here we go: we've found it, and it does exist'. I am not alluding to any specific organisations here, but I would suggest that if that function has been designated to some organisation or body and industry is not aware of it, or if it has not been marketed or identified appropriately so that the companies that have explained these issues to me do not see it as a solution, then that might be as much of a problem as the lack of such an organisation in the first place.

[255] **David Rees:** I understand that. Thank you very much for that, and for your evidence, and the written evidence. You will receive a copy of the transcript for correction if there are any inaccuracies. Once again, thank you very much.

[256] **Mr Tudor:** I appreciate it. Thank you very much. Thanks for the opportunity.

[257] **David Rees:** We have finished about 10 minutes early, so if everyone is happy, we can move to item 6 now, just so that we do not have to do it this afternoon.

11:46

Papurau i'w Nodi
Papers to Note

[258] **David Rees:** We have the minutes of 13 and 19 February. Are Members happy to note those minutes? I see that you are. Also, there is the letter from the Chief Nursing Officer for Wales in relation to some points that arose following the meeting on 30 January. Are

people happy to note that? Thank you very much for that. In that case, we will now break for lunch and we are scheduled to be back at 1 p.m..

[259] **Leighton Andrews:** [*Inaudible*.]

[260] **David Rees:** Yes, okay. Let us do it now in public. We will do it in public. I was going to do it in private, but I do not see that it needs to be done in private. I think that we will do it in public now. Is that okay?

[261] [*Inaudible*.]

[262] **David Rees:** Should we go public? I do not think it is—

[263] **Ms Madeley:** The papers are not available.

[264] **David Rees:** Right. The papers are not available. Let us go private.

11:48

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

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

the committee resolves to exclude the public for item 8 in accordance with Standing Order 17.42.

[266] I see that the committee is in agreement.

Derbyniwyd y cynnig.
Motion agreed.

Daeth rhan gyhoeddus y cyfarfod i ben am 11:48.
The public part of the meeting ended at 11:48.

Ailymgynullodd y pwyllgor yn gyhoeddus am 13:06
The committee reconvened in public at 13:06

Ymchwiliad i Fynediad at Dechnolegau Meddygol yng Nghymru: Sesiwn Dystiolaeth 11
Inquiry into Access to Medical Technologies in Wales: Evidence Session 11

[267] **David Rees:** I welcome Members back to this afternoon's session of the Health and Social Care Committee, continuing our inquiry into access to medical technologies. At this afternoon's session we have Dr Corinne Squire from the south-east Wales academic health science partnership.

[268] **Dr Squire:** That is right.

[269] **David Rees:** We then have Professor Carl Heneghan, from the Centre for Evidence-Based Medicine at Oxford University.

[270] **Professor Heneghan:** Good afternoon.

[271] **David Rees:** We also have Deborah Evans from the south-west academic partnership and Lars Sundstrom is—

[272] **Ms Evans:** It is the west of England—

[273] **David Rees:** I am sorry; south-west England, yes. Lars Sundstrom is similarly from the south-west England academic health partnership. I welcome you this afternoon. First, I thank you all for the written evidence that you have submitted to the committee. Obviously, we now hope to follow on with some questioning on the information. I remind Members that, in a sense, this session is about how academia engages with the NHS and with industry, and the impacts on the development of uptake of new technologies as a consequence. Perhaps we can start by describing the relationship and the role that the academic health science partnerships have within that picture of development of new technologies. I know that you are from different backgrounds, but I will start from my right and we will go across. Is that okay? Therefore, I will turn to Dr Corinne Squire first.

[274] **Dr Squire:** Okay. The academic health science partnership in south-east Wales is a partnership of the three universities in Cardiff—that is, Cardiff University, Cardiff Metropolitan University and the University of South Wales—the three local health boards, namely Cwm Taf Local Health Board, Aneurin Bevan Local Health Board and Cardiff and Vale University Local Health Board, and the NHS trusts of Velindre NHS Trust, the Welsh Ambulance Services NHS Trust and Public Health Wales. So, that is our constituency, if you like.

[275] I have started in this role and, in fact, most of my colleagues began their roles towards the end of last year. So, in terms of what we have been doing, it is still in the sort of fledgling stages. Before I started in the role that I am in now, I had initiated some programmes with south-east Wales academic health science partnership—one of them being the health technology challenge that I put in my written submission. There are a number of other work streams that are part of what we do. So, we have a knowledge transfer work stream that is quite relevant to what this committee is talking about, because it is about sharing best practice, how we disseminate what different hospitals are doing, new developments within academia between academic institutions and between the health boards and trusts within south-east Wales. Actually, it has become a Wales-wide scoping study that is now being carried out.

[276] We also have a workforce in education programme, which is looking at a number of things, but also things like professional dilemmas and how you would introduce training for medical students to cope with the dilemmas that they will come across in professional life. There will be some things like introducing computer modelling of bed occupancy, and all sorts of issues within the NHS to work out how they should best deal with issues that have arisen that can be modelled. I am trying to think what else—

[277] **David Rees:** That is okay. Are you the only one in Wales?

[278] **Dr Squire:** No. There are three academic health science partnerships. We are for the south-east. There is also one for west Wales and one for north Wales. The north Wales one covers everywhere from Powys upwards, but it is based in Bangor. The one for west Wales is based in Swansea but covers the whole of west Wales.

[279] **David Rees:** Professor Heneghan, I hope I do not mix it up this time. It is—[*Inaudible*.]—and south-west England. Is it a similar role you play in south-west England, because you are one of 15, are you not?

[280] **Ms Evans:** Yes, that is right. Thank you. We are one of 15 academic health science networks. We have been set up by NHS England as part of a five-year programme. We are just at the end of the first year. We have a licence agreement with it about the areas that we will work in. There are a lot of similarities. The first area is areas where we are trying to make improvement for individual patient or population benefit. We have two programmes in the west of England under that banner. One is about patient safety, and we have a patient safety programme. The second is called 'connecting data for patient benefit', and it is about connecting individual patient data across all the organisations involved in an individual's care. So, that will be local authorities, social care, mental health, GP systems and acute hospitals. So, we have a programme that is about encouraging the spread of that across the west of England. So, that comes under patient and population benefit.

[281] Then we have programmes under the heading of 'evidence into practice and commissioning evidence-based care'. So, this is looking at already established research evidence that has not been put into practice consistently across the NHS. I am sorry to say that there is quite a lot of that. On the programmes that we are looking at for next year, one is about preventing cerebral palsy in pre-term babies; one is about better outcomes in hip replacement; and one is about taking up NICE guidance on anticoagulants for stroke prevention. So, we have those programmes. Then, our third area of work is about what we call enterprise and translation. My colleague Professor Sundstrom can describe to you what that is about.

[282] **David Rees:** The microphone comes on automatically.

[283] **Professor Sundstrom:** I turned it off, sorry. So, what we are trying to do here is get better engagement with business and the NHS and the academic community to try to bring these people together to co-create solutions. The NHS has a long history of working with industry but it has been more a vendor/supplier relationship. So, we are trying to build partnerships. In the west of England academic health sciences network, where we are, we focus very much on the small and medium-sized community and trying to make sure that we get traction for businesses. Most SMEs find working with the NHS in particular very challenging because they do not really understand how to enter into the value systems, and the procurement systems are not used to dealing with small companies with recent track records and these kinds of things. So, we are putting in place measures to make that easier for people to do. We are also helping these companies to try to adapt their products so that they are fit for purpose and can assist us in achieving patient benefit in that way. In a previous role, I spent a lot of time trying to work between academia and industry, and I can talk about that too, if that is of interest to this committee.

[284] **David Rees:** We heard this morning that, for example, opening the front door to businesses is a crucial element—

[285] **Professor Sundstrom:** That is correct.

[286] **David Rees:** Do you see yourselves as a way of opening the front door to the NHS for businesses?

[287] **Professor Sundstrom:** I think that we can do that. One of the things that we are very conscious of is that we have to focus. In other words, the demand far exceeds our capability to deal with it. We are trying to make connections with as many companies as we can, but we are focusing on the ones that are linked to our thematic priorities, as Deborah said. So, those companies that can help us to achieve benefits are the ones that we are focusing particularly on supporting at the moment.

[288] **David Rees:** Do you do the same?

[289] **Dr Squire:** We are looking at companies in two ways. We have been making some connections with local companies to see what their interests are and where we can engage, but we have also been looking for companies that we have an interest in working with on a particular area, similar to the thematic priorities, but we have a programme of engaging with local companies as well. However, we are also particularly trying to make contact with companies that are interested in clinical trials and trying to make those links.

13:15

[290] **David Rees:** Just for clarity, the thematic priorities are as a consequence of the funding programmes that you have. Are the thematic priorities that you are following as a consequence of the funded programmes that you are operating?

[291] **Ms Evans:** Yes, the funding comes from NHS England and, because, like the Welsh partnership, we are a partnership of member organisations, we have seven clinical commissioning groups, so they are the people who have the budgets to commission healthcare, and, as you know, that is GP-led, we have the three universities, which are Bristol, Bath and the University of the West of England, and then we have a mixture of acute trusts, community trusts and mental health trusts. So, our priorities were debated among our member organisations and, of course, they have to relate to the main NHS issues and challenges. However, patient safety was chosen in particular because our patient and public stakeholder group said, 'We think you should take that as your flagship priority'. It was a programme that we had inherited, so it had a good track record and a lot of work was already done, and the group said, 'That's the most important priority from the patient perspective for the NHS'.

[292] The one about connecting data for patient benefit, and I know that you have something around this area that is very similar, was partly because, at national level, they want to see the benefits, but also because it underpins better urgent care and it underpins integration between the local authorities and the health service, and we are looking at how to strengthen and broaden primary care. So, the reason that we chose that programme was because it is a big enabler of all of that.

[293] **David Rees:** Before I bring Lindsay in, Professor Heneghan, in your paper, you also highlighted that the academic health science networks are one of the innovative initiatives being put forward. How do you see them progressing?

[294] **Professor Heneghan:** It is interesting, is it not? I think that the first thing that I would like to say is that I do not like the idea of access to medical technology. They should be thinking about effective and affordable medical technologies, and I think that you should really think about that, because that is the key question here. What everybody is doing is trying to take effective, affordable technologies to the healthcare market and grow businesses. On average, most technologies will have no benefit; that is how it works. The key is that you start with small or medium-sized enterprises and you try to understand how to take them forward. Most small or medium-sized enterprises do not have the skills to develop the evidence, they do not have the academic ability or the cost basis to bring that academic infrastructure, to say what studies they should do and what they should look like. So, what you are really trying to do is combine two things: academic credibility and evidence bases with companies trying to build effective technologies, and so the whole pipeline of National Institute for Health Research is designed to try to do that. It is actually quite a complex structure, where you start from biomedical research centres at the front end, right through to the back end, which is the academic health sciences network. Its job is to try to start to help companies to understand the evidence base, what type of studies they will do and how they then take them through into the marketplace, where you can say, 'This is affordable and this

will change healthcare'.

[295] **David Rees:** Lindsay is next.

[296] **Lindsay Whittle:** Good afternoon. Thank you, first, for sparing your valuable time to come to give evidence to us today. May I say that the evidence that you give will probably baffle me entirely, so please forgive my questions? You certainly have the longest titles that I have ever come across in my political career. [*Laughter.*] I am interested in the experience of the network partnership in bringing together industry, academia and the NHS as an early stage. I only caught fragments on Radio Wales this morning of the new, innovative idea of taking young students in their first year to work with more senior health people. Apparently, it is quite exciting. How will young students become involved with the industry here in Wales in particular? I accept everything that Professor Heneghan has said about how not all industries can take on young people like that, but it is about capturing these young, imaginative minds at an early stage, I would have thought, and, maybe—who knows—learning from them as well, because they can often come up with fantastically bright ideas. I would be interested to know that.

[297] My second question is this: what is the role of the patient voice in any initiatives you have? I also welcome information regarding the experience of our colleagues in the south-west of England.

[298] **Professor Heneghan:** You raise an interesting point. If you look at the No. 1 university in the world, it is California Institute of Technology. All it does is technology development, and it does exactly what you said: it has a whole technology infrastructure. I have been quite surprised that we have not gone down that route a bit more with our universities, and asked, 'Where is the Cardiff institute of technology that has 1,000 students who are just dedicated to technology', because, out of that, you want the 10 or 20 ideas that are worth taking forward. We should now change ourselves to think about technology, because, for the last 10 or 15 years, we have not put that to the fore. A very good example with which to compare that is southern Ireland, which is the No. 2 in the European Union for medical technologies, behind Germany. It has a university system that is not only geared up at an undergraduate level, but for postgraduate education as well. You really do have to think about educating the people in the workforce as well. So, somebody who grasps that will take it forward. We are only at the beginning of this idea, because these initiatives are new, to start thinking about the technology development among our undergraduates and PhD students and how we expand that base. The flip side is that you then want to start thinking about how businesses are putting money back in to get that early intellectual property development and combining. It is a sensible move, but we just have not thought about it until now.

[299] **Professor Sundstrom:** May I add to that? I also happen to have a chair of translational medicine at the University of Bristol. One of the issues that you touched upon that is absolutely correct is that the idea of periods of immersion for students, either with enterprises or, for that matter, clinical practitioners is an extremely important and valuable thing to try to encourage, particularly encouraging people at that formative time, because they will be your future entrepreneurs. So, there are a number of initiatives that are quite remarkable and have been successful quite recently in this regard. For example, placements of students—once again, many of them coming from the United States—of periods of deep clinical immersion, where graduates in engineering, business, or other sectors can follow what a practitioner does and try to identify the key missing ingredients and the things that should be done, and then bring that back and work with the academic sector to build that up and to do research projects. That is an extremely valuable way to do it. There are good examples of this sort of thing with industry as well. In both cases, it is challenging, because clinicians are busy people on the front line, and companies are very pressed for time to find the place to do that. I have also worked in SMEs for many years, and finding time and supervision for these

people within a company environment is extremely difficult. So, if those schemes were supported centrally by some mechanism, that would encourage that greatly, and you would do two things: first, you would bring real innovation from the front line into the education system, but, secondly, you would also infect, as I would say, a lot of young people with really good ideas who would probably go forth and do some things in the future.

[300] **Dr Squire:** I have two things that I was going to say about the students. We have a programme at Cardiff, as part of the introduction of the new medical curriculum, to introduce more enterprise into the curriculum, both for undergraduates and for Master's students. This involves things like teaching them the background of how intellectual property is developed and protected and how you go about starting a company. We have programmes to support students across the university, not just in the medical school, to start their own companies if they have ideas. We have a student enterprise department that takes care of that.

[301] In terms of getting people to work with the companies and back, we are trying to encourage more people within the medical school to take up knowledge-transfer partnership placements, which is a Technology Strategy Board-funded scheme in which academics go to work in a company, or vice versa. Cardiff has been quite successful at getting people on to that scheme. That is something that we are trying to push within the medical school, because so far it has been much more the engineering and business school areas that have taken that up. So, that is a programme that we are really trying to encourage at the moment.

[302] **Professor Heneghan:** I guess that we could also come in on a point that we made. Within the same sector, one of the places ought to have been very successful in its innovation and spin-outs initiatives, which started with Oxford Instruments many years ago, so it was before much of this. So, the innovation and spin-outs from a university and how that is managed and supported is also an important part of the initiative, so that some of the good ideas are retained with the intellectual property, but then given the infrastructure and support to take the idea forward. That is an important area for universities to grow.

[303] **Ms Evans:** May I pick up on the issue about the public voice that Lindsay asked about?

[304] **David Rees:** Yes. The patient voice.

[305] **Ms Evans:** Our academic health science network is, and, I think, all academic health science networks are, working to make sure that, whether we are working on evidence into practice and how we spread best practice across the NHS, or working on the enterprise and translation work, we are building in service user, carer and public voice. There are lots of well-established ways that people use to do that, which are perhaps not all that innovative. However, one of the ones that I wanted to mention to you that I have seen in operation around the Bristol area is in relation to teams that they have called 'health integration teams'. These teams are teams of researchers working with people who commission services and the providers of services. So, the idea of them working together is that you get more relevant research, because it is informed by perspectives about service provision, and you get research that will help change services in ways that commissioners think is important.

[306] To illustrate that with an example, all of those groups that are supported have a criterion that they must have patient and public involvement at the heart of the group. So, it is not just informed by the researchers and the service providers; the whole thing is informed by the service-user perspective. They also have local authority involvement, so that you bridge into the social care and wider aspects. That is a really powerful model, which we are seeing lots of benefits from. A particular example for you to consider is that there is a musculoskeletal team there called a 'health integration team', and it has a joint director between a professor of rheumatology and a person who has severe arthritis, so they are co-

directors of that group.

[307] The example that they like to give is that, over many years, the research team would ask the service users, 'What do you think our priorities should be?' The service users used to say, 'Well, one thing about our condition is that we are exhausted all the time', to which the doctors all would say, 'We're exhausted too', which is slightly missing the point. [*Laughter*.] However, over time, they realised that it is really important to understand fatigue in arthritis. Now we have got to the point where every substantial international study of arthritis across the world has fatigue in it. It is a great example of how, if you put the service-user perspective at the heart of what you do, you can change the research questions, but not only that—you change how you do the research and therefore the outcomes that you get. So, that is just a pen portrait.

[308] **Lindsay Whittle:** If I may just quickly follow that up, Chair, a main issue, I guess, is finance. Has there been any work done on shared budgets, for example? Would that be possible? I have been a politician for close on 40 years, and everyone that I have spoken to always wants more money; we all want more money, but we know in these austere times that that is probably not going to happen. However, sometimes just sharing a budget can move us forward just a tad.

[309] **Ms Evans:** Are you thinking in particular of sharing between health and local authority budgets for the provision of care?

[310] **Lindsay Whittle:** Health, local authority, some of the research projects, some of the private businesses that you deal with and some of the charities involved, even.

[311] **Professor Heneghan:** I fail to understand, though, in the current—. We have a very strong patient voice, and in Oxford we have health experience groups, and, over 15 years, there have been 3,000 interviews, leading lots of that research. However, if I add into that the clinical, commissioning voice, right now, there is a pressure to save £25 million in Oxfordshire and the idea that it will share its budget with someone else is not worked through. Many budgets are siloed, but, actually, the pressure to come up with what its priorities are right now and to meet and work with them is far greater than reorganising the budget. If you are talking about budgets that sit outside of that commissioning, then maybe it is different.

13:30

[312] **Ms Evans:** The very big initiative that is going on in England is the better care fund, which is all about promoting and stimulating integration between health and social care. That has been done, in effect, by taking a top slice from the health budget and transferring it to social care control, but the parties agree jointly what the priorities are. So, it is very much moving in the direction that you are thinking about. As you can imagine, in financially constrained times, it causes some tension, but that is why we are also interested in the whole issue of joining data for patient benefit.

[313] We have that system live now in Bristol and the surrounding area, and we were able to show Sir Bruce Keogh, who is the medical director for NHS England, how it works. In an accident and emergency department last week, we had a consultant, a GP and a community team. They were able to show him that, by being able to see all of the data about a patient—they could see that a patient in A&E had seen an occupational therapist the day before and they could see what their local authority care package was—and seeing the whole picture, you can take a different decision about the risk of whether to admit or not. So, you begin to get in—. That joint working promotes the benefits of seeing things in a much more integrated way. These are very early days for this scheme, but, interestingly enough, the big users of the scheme in these early days are accident and emergency departments—you can see how it

would help them—but also social care teams are using it just as much. It is helping them to take decisions for their clients in the light of all of the health context. They say that, just as it saves the A&E department money, because it might not have to admit people, it is saving social care money, because they are changing packages around in the light of circumstances.

[314] **Professor Sundstrom:** May I also comment? Another way that you can work under severe budgetary pressure is to involve partnership with the private sector. I think that that is key. I think it benefits both the private sector and the healthcare community to do that. Honestly, quite often, I see equations that show that more technology equals more cost; actually, it is the reverse. Most of what we find is that smarter care allows you to do a lot of self-monitoring and not to access healthcare services as much as you would do otherwise. That is a major benefit. It is also an opportunity for businesses to get involved. I think that the concept of co-creation with businesses is something new that we really have to try to push, because it is a win-win situation. We are also moving towards increasing consumer choice for patients. Whenever I am a patient myself, I want to be able to have choice over how this is done. At the moment, I do not have that. I see the private sector as offering a benefit to me in that as well.

[315] As Deborah mentioned, using connecting care across—. As you can imagine, this is a huge benefit to anybody developing health IT solutions, for example. It also allows for the whole concept of remote monitoring, sensing in the home, telemedicine. In fact, in Wales, you are very good at this. So, it is something that I think that we should encourage, because it boosts enterprise and reduces healthcare costs, and we can always sell our products abroad and, hopefully, bring some investment back in that way. So, as long as we use that as a virtuous circle, I think that it is a very powerful argument for supporting industries' involvement in this.

[316] **David Rees:** I want to move on now. Leighton is next.

[317] **Leighton Andrews:** I want to go back to the higher education and industry relationship. In fact, although Welsh universities only account for 5% of UK higher education, they do account for 10% of graduate start-ups by number and more than 10% by turn over. So, I think that we are doing a reasonably good job in that area. However, I was very interested in what you had to say about the Republic of Ireland and its higher education sector. I wonder whether I could draw you a bit more on that, in the sense of whether you attribute that to the organisation and the higher education system in the Republic of Ireland or to the investment environment for business.

[318] **Professor Heneghan:** Yes, I think it starts with the lower corporation tax rate at 12.5%, which is an incentive to locate—

[319] **Leighton Andrews:** So, it is a race to the bottom, then?

[320] **Professor Heneghan:** Yes, so it is self-serving. From there, you have the location, then you have the incentives, and then you need the workforce and you have to train them to a very high level. To be honest with you, it is in the postgraduate arena now. Undergraduate education is a very broad base, but we will move more and more to specialist Master of science degrees in software engineering and areas like that. What we tend to do now is focus around the continuing education agenda, trying to get that skilled workforce up. The race to the bottom is difficult in the European Union because it is not a level playing field—

[321] **Leighton Andrews:** Well, not if you have corporation tax rates of 12.5%. You clearly have a race to the bottom there.

[322] **Professor Heneghan:** I guess that the argument is that 12.5% of something is better

than 23% of nothing. So, we have to work hard then on what the research and development incentives are. Then, as you grow that base, how do you—. The issue is that your SMEs will always be bought up by larger companies if they have successful technologies. That is what they do. The problem you then have is where those larger companies locate and where they take that technology and workforce. That is part of the problem for us with SMEs. In addition to that, I have people working on where good technologies are actually buried by some larger companies. That is another problem.

[323] **Leighton Andrews:** I accept that; that is an interesting point as well. In Wales, we have a life sciences fund of £100 million. That was created in the last couple of years. So, there has been significant investment in this area. However, as you will appreciate, the capacity to lose money in medical technologies is enormous, is it not, in terms of early-stage investments?

[324] **Professor Heneghan:** I am going to come on and question everybody around here that, on the whole, medical technologies are always more affordable. I am in a place, in a home, of evidence-based practice with Archie Cochrane and people like Julian Tudor Hart. I work with the World Health Organization on non-communicable diseases, looking at low-resource settings, thinking about how technologies help us. Generally, on the whole, they increase costs. In some areas, they increase costs dramatically with no added benefit. For example, with self-monitoring of blood glucose, the evidence base is that it does not benefit patients. However, there are areas where we have technologies that work but the cost is very high, and we do not use our budgets to negotiate prices that make them affordable and make companies—. NHS purchasing has a greater power to say, 'We can purchase this on a greater basis', when it is effective. If we did that, we would move forward. However, all the tele-monitoring—and a classic example is a whole-system demonstrator—. In fact, the technology is now defunct. It does not even exist any more, because it has been usurped by iPhones and iPads as they have come down in price. So, much of what we have invested in is already—. It is very difficult with technologies to move as fast as the pace of the technology to catch up with the evidence base.

[325] **Professor Sundstrom:** If I may comment, I hear this argument about increased costs quite a lot. I think what we have to do is take a fairly balanced view—

[326] **Leighton Andrews:** I accept the argument. I am not suggesting that technology necessarily results in increased costs. What I am talking about is the fact that there are certain areas of investment, particularly in biotechnology, arguably, where it is quite possible to sink a huge amount of venture capital and lose it. Therefore, the Government, it seems to me, has to be very circumspect about the areas in which it is prepared to invest. Would you accept that?

[327] **Professor Heneghan:** Yes. We spend an awful lot of time at the very early stage. We run a horizon-scanning service. We sit around in a group like this with lots of expertise trying to understand that exact issue. Where is this technology going? What does it meet in terms of the problem? What is it going to solve in the pathway? We often find that some of the technologies are missing bits. For example, they may do a chlamydia test, but we say, 'What about the other tests? Can you do those at the same time?' So, they go back to the drawing board because we need both tests. Yes, you can sink lots of money. However, the company is always trying to develop that technology and support to get to that next level. It is a difficult problem, but you are right.

[328] **Professor Sundstrom:** I think that we are looking at this in a bit of a linear fashion here. It would be hard to argue that investment and technology had not benefited southern California, which is where I was born. The issue there is a bit broader than this because one of the things we try to do quite often in the UK is emulate these models that have worked. It is a

question of scale, also. Just as many companies fail in the US as in Europe; there are just more of them, and you need more of them to be successful. That is why the venture capital industry works much better there; it is an issue of critical mass. That is something that is very important to Wales in relation to your life sciences fund. I think that you could probably look to the Irish model as being quite a good one, where, essentially, the sector specialism is regionally divided. In other words, the government support is different in different regions. If you want to do pharmaceuticals, you would tend to move to Dublin. If you want to med-tech, you end up in Galway. What that does is create clusters of companies that feed upon themselves. There is something about the entrepreneurial issue as well. If you have lived and worked in California, you realise that many of these people have started many businesses before they were successful, and there is a sort of virtuous circle to that, which you need to take into account. The critical mass and the regional support structures that come with that are very important.

[329] **Dr Squire:** I would like to echo that because, at the moment, I am looking at the NISCHR reorganisation, and it wants to change all its policies to all-Wales policies. We are arguing very strongly that there should be a more regional focus.

[330] **David Rees:** That is an interesting point, because we have had a lot of discussions about whether there should be an all-Wales focus, which is the reverse of that.

[331] **Elin Jones:** I wanted to ask you whether you think it is doable, or a good thing, to replicate the established process on appraising and commissioning for pharmaceuticals for medical technologies. Is it possible to do that given the nature of the businesses involved in medical technologies? They are SMEs, they are less involved in the NHS than the pharmaceutical companies are, and their budgets are much lower for championing their products. The question really is: is it a good thing to try to move towards replicating that process, and those processes in the pharmaceutical industries, or is it that we need to look far more flexibly at medical technologies and just try to do it a bit better than it is happening at the moment?

[332] **Dr Squire:** I think it is a good thing to have an organised approach. I have looked at the all-Wales medicines group, and I think the way that it does things is very good, but I do not know whether you need that involvement from all pharmaceutical companies, where they promote their products, essentially. I do not think that you would get the same thing if you had a technology group within that, because, as you say, the nature of the companies is very different. However, you could still take that organised approach of having specialists, patients—a stakeholder group that analyses things much in the way that the medicines group does. Probably, the industry involvement would not be such a strong voice within that, but I am sure that there are industries that would like to be involved in that and that would have a strong voice.

[333] **Professor Heneghan:** In a simple word, ‘no’; you cannot do that, but it is important to understand the two differences, and there are interesting comparisons. The first is that you have a drug that you want intellectual property protection on, and you have to go to the FDA or the European Medicines Agency with two clinical trials of effectiveness. They will get the licence authorisation, but that still does not mean that that drug will be taken up, because then you have NICE, which will ask, ‘Is it cost-effective? Does it apply to our population?’ In technologies, you have CE marking, which basically means that when you go into John Lewis and it says it is a teddy, is it a teddy bear; so, when it says it is a hip, or a mesh, it is a mesh. It has no relationship or bearing on its effectiveness. What it allows you to do is use it in the marketplace. What the idea should be is that, given the groups that are starting to come together, with NICE med-tech and NICE diagnostic board, we need a second, which they have in America, called Medicaid, which looks at devices and says, ‘Okay, you have had access, but have you built the clinical evidence base for us to be able to judge that this is cost-

effective?' The problem where it has gone wrong is that we have not had that step until now. It is starting to emerge, but we need that second step. So, we have had a number of big problems like metal hips; vaginal mesh is another one, as are breast implants—there is whole host of them. What you cannot do is put that step in such a way as you say, 'You cannot have access to the markets, start to use it in trials, or x, y and z' with devices, because there are just so many of them. Does that make sense?

[334] **Elin Jones:** We had evidence this morning from a Velindre cancer clinician who said that there should be far more ability to commission and evaluate medical technologies. So, because you are not doing the two clinical trials, you commission, but you evaluate properly over the first three years of use. I do not know whether you think that that is a model that could work in this context.

13:45

[335] **Professor Heneghan:** You have to take it from the high-risk devices, do you not? You are really talking about implantable devices, because if it goes badly wrong, what do you do? It is not like a drug, where you can stop it. You end up with the cohort patient in trouble. So, yes, there should be a system, and we should be using our data and our NHS systems to be able to say, 'If you put this device in, we'll be able to follow you up for this period, and start to test that'. We are doing that now in some areas, such as with the joint registries, but we are not doing it in all of them. I still think that it is odd that we decided to do it in some parts and that we do not have it in the whole system. By having that in play, you want to do as you said—you want to have more innovations, but you are quicker to pull those that will not work and you invest in those that will go forward. If you can offer that to business, you want the networks in place to run the studies so that you can say, 'If you come here, you can learn more quickly whether your technology is better or is ineffective'. The companies get this. I have worked with some companies, and a very good example of that was laparoscopic hernia. They sold only four in the UK, because when NICE looked at it, it said 'This is not cost-effective; it's much easier to give you a little nick, it's much safer and, actually, we don't need a laparoscopic appendecectomy and to do that, because it is too costly and causes too much harm'. The companies said, 'We couldn't understand that; we had invested hundreds of millions in this technology and nobody wanted to buy it'. So, it makes sense to develop our infrastructure to support that development of evidence at the same time.

[336] **Rebecca Evans:** Can you give us an idea of the incidence of device recall? You mentioned the PIP implants, for example; how often is damage being done to patients by devices that have not gone through robust trials to get the evidence base?

[337] **Professor Heneghan:** That is a very interesting question, is it not? I do not believe that you can fully answer that; you can answer only about the big ones. The current system relies on a regulatory system where it is almost voluntary. Either the manufacturers or someone in healthcare submits to the Medicines and Healthcare Products Regulatory Agency and field safety notices come out. From there, there are either device recalls or different things go on. The big area where that has happened is that of metal hips, which have been a worldwide disaster, and vaginal mesh is looking to be going down that route. The PIP implant is a big disaster. PIP implants are a very good example—these are slight regulatory issues in the European Union. If you want to change the component in America, you have to inform the Food and Drug Administration and put a new submission in, even if it is through the light route—what is called 510(k)—you still have to tell it, whereas in the EU, you can do that without any regulatory approval. That is why they did not have the PIP implant problem in the US. So, there are many bits where the regulation could be better to serve effective innovations.

[338] **Rebecca Evans:** You referred to the US and the EU in your paper. Are there

regulatory systems outside the EU and the US that we could look to as models?

[339] **Professor Heneghan:** No, not really. The Japanese and the Australians have their independent regulation systems. However, interestingly, the US is probably the one to look to. What the US is doing is to say that there are two different issues here. In implantable devices, we need a much more rigorous pre-market approval, which requires a clinical trial, as opposed to the 510(k) application, which is much shorter and uses equivalence. 'Equivalence' in relation to devices means that you can get access to the market because you say, 'My device is similar to this device over here, and that has been on the market, so could I please have access?' Your CE marking will generally be given as will the 510(k) access. That is generally where problems have occurred: in those innovations for which nobody has asked in the very high-risk areas for a new clinical trial or some new evidence of safety. At some point, something changes to the point where it could be beneficial or harmful, but it starts from equipoise.

[340] **Rebecca Evans:** In terms of post-adoption monitoring and evaluation, to what extent does that take place at the moment and to what extent is it necessary?

[341] **Professor Heneghan:** In some areas, it takes place very well, because we have instituted our own areas, like the hip joints and the renal registry. We have very well-functioning registries that come from associations, whether the Royal College of Surgeons or the British Orthopaedic Association, which tend to lead that process. They are probably the best people to lead those processes. Having them strongly in place is very helpful. I will give you a good idea of where this works very well: blood pressure machines. It seems obvious. There are hundreds of blood pressure machines and, if you go into Boots, you can buy one over the counter, but the British Hypertension Society worked out that they have to be accurate. So, there is a British Hypertension Society kitemark that says that it is approved by it. So, it has the CE mark, it has been on the market, but if does not have the BHS stamp, nobody in practice will use it and they should not be using it. The purpose behind that, if you have an inaccurate machine, is the cost in misdiagnosed blood pressure—we are going to escalate costs and treat all the wrong people. It is really important that blood pressure machines are accurate. We look at things sold over the counter and ask, 'Do Boots or Lloyds sell the ones that are accurate or not, because it is important?' There are areas where it is done really well. Societies are formed that help the innovators and lead the way. In other areas, it is completely void.

[342] **David Rees:** May I just follow up on your point? You therefore have the colleges or other organisations within the UK approving devices. Is there any regulation or monitoring of those to ensure that there is consistency across the sector?

[343] **Professor Heneghan:** No, not that I am aware of.

[344] **David Rees:** Okay. Leighton is next.

[345] **Leighton Andrews:** I wanted to see whether you thought that there was any evidence as to the level—whether it is at nation state level or devolved level—at which decisions should be taken. What makes the most sense, either in a regulatory sense or a commissioning sense, or potentially on a cost basis of evaluation of technology?

[346] **Professor Heneghan:** I think that the idea of access to the European market is a very sensible strategy. There are problems with that because, at the moment, you use private organisations called 'notified bodies'. You go to one to get access to the whole European market and that has been shown to have problems. I think that the notified body should be a public entity, which means that it has to be transparent and open to scrutiny. So, I think that notified bodies should become public entities and there should be one located in Wales and

England—in all of the member states—to show that we are functioning. Beyond that, I think that there is a real role to combine health technology development with a good evidence base and good regulation that allows what we have said, which is that it is not a race to the bottom—it is a sort of McLaren; we want to see McLaren here, do we not? We do not want to see the bottom end; we want to be involved with the Formula 1 products.

[347] We are—and Wales is—a leader in knowledge and information. We are really good at developing the knowledge and information to support the evidence-based decisions. We have half of the Cochrane groups in the world within the UK. When we talk about what we are really good at, we are really good at saying, 'Let's take these, and take them from the point of developing the evidence to make them useable'. That is what we should be selling to businesses around the world right now.

[348] **Professor Sundstrom:** That is very true, but the other thing that you have to do is to anchor that to your local economy in such a way that you end up buying products from here rather than abroad all the time. That is also quite an important factor. You mentioned commissioning development and commissioning evidence. Those two things are important, and we have introduced a new system in England, which is open to Welsh companies, and we actually assist Welsh companies in accessing English funds in that way. It is called the small business research initiative and is a method of commissioning research and development through the healthcare system around unmet clinical need. What that also does is to tie good relationships between your companies and the clinical practitioners. I think that is an important initiative that I would urge you to look at it as a mechanism to drive that better translation between the private sector and the practitioners.

[349] **Leighton Andrews:** Would it be possible for us to get a note with more detail on that from someone?

[350] **Dr Squire:** It is Technology Strategy Board-funded, is it not?

[351] **Professor Sundstrom:** It is a TSB scheme. The current scheme in healthcare is funded by NHS England and operated with the Technology Strategy Board.

[352] **Professor Heneghan:** There are two distinct issues, I think. One issue is around supporting SMEs to develop technologies and bring them to the forefront. The second issue is to develop technologies to be fit for purpose in a healthcare setting. They are very distinct. Often, you are looking at something and saying, 'It is still too early; it needs more work, more input and more clinician and patient input to get it where it wants to be'. The second point is support for the bigger firms, so that we are able to say, 'How do we develop the correct evidence base and help you to do that?'

[353] **David Rees:** May I ask a question? Based upon those points, how good are we at actually using the technologies that are effective and affordable? That is one of the questions that we really want to know the answer to.

[354] **Professor Sundstrom:** Of course, and that is one of the reasons why the academic science health networks were set up, to look at the adoption and spread of existing solutions. It is not a perfect world in that sense; we know that there are good things and good practices that are not being adopted and spread currently across the NHS in the way that it should be done. We have some way to go. We are looking at ways of trying to address these issues. I do not know whether you want to pick that up, Deborah.

[355] **Ms Evans:** Just to go back to some simple examples, you talked, Lars, about the small business research initiative. I do not know whether it is helpful, but I find examples help me to understand how things work. What we did this year with the small business

research initiative was to take our patient safety theme and work with clinicians up and down the south-west of England. We asked, 'If you were going to develop a brief for companies about a clinical issue in patient safety, what would it be?' Over the course of three days, they had intensive discussion among themselves, and they said, 'It's about spotting and treating the deteriorating patient; that's where we think there could be a bit of a gap, and we're interested in new innovations, not only outside the acute sector, but also in hospitals'.

[356] So, the state that we have got to now, which Lars has led, is that we have used those clinicians and put out a very broad brief to companies, to which we received 60 responses. We used the clinicians to shortlist the more promising ones, and we are working with three of them; I think that four got through. They have proposals that are in the early stage and they need more clinical dialogue to understand how their things might work. They are about ways in which you can very easily read vital signs for people, such as reading their electrocardiogram by them touching something, using a sticking plaster that will do their temperature, their blood pressure and everything else all in one go, and transmit it via the wireless somewhere. It is those sorts of things.

[357] That is the potential of the small business research initiative, and you can see how it fits in with this dialogue that my colleagues have been having about the need for that interaction between the small company and the clinicians to develop things that are relevant.

[358] In terms of whether we are using the technologies appropriately and whether we are spreading them, the evidence-into-practice schemes that I talked about give some good examples. One is about joint replacements, where the joint registry work shows us that cemented hip replacements generally lead to better outcomes than un-cemented hip replacements. However, persuading orthopaedic surgeons that they want to change their practice requires some attention, shall we say. That is one of the things that we are working on. There is strong evidence-based research on it, but we need to work on how we get it into practice.

[359] Another example, which comes from a Cochrane review—a systematic review of all the evidence—suggests that if you give magnesium sulphate to women who go into labour early, it can be protective against cerebral palsy. Again, it is very well established and based on rock-solid evidence, but it has not spread across England—it will be Wales as well—in the way that it should have done. So, they are good examples of how the evidence is there, and we are not necessarily promoting the best practice, getting the spread and embedding those innovations in the way that we should.

[360] **Professor Heneghan:** There is an idea that, somehow, you can develop a technology, innovate and change healthcare tomorrow. It generally takes about 15 years to go from the start of a technology to having something that is ready to change healthcare, and that is drugs as well, not just medical technology. There is an idea that we have all these technologies and if we just adopt them, we will be better off.

[361] In my other job, I am an out-of-hours primary care physician. The only technology that I have had in the last 10 years that is probably different is an electronic blood pressure machine. For us to sit here and say 'We're going to bring all these new technologies for telemonitoring', there is no robust evidence that it saves money or reduces any ineffectiveness. We are still in the development phase. We can cure about 80% of cardiovascular disease with what we already know. We use technologies to help us to do what we should do and what we already know. I come to Wales and I read that you have 300 to 400 people on the waiting list for heart bypass surgery. We have 150 people in our area. We knew this 20 years ago, and we still have not solved this. I still sit with people with ideas around emergency admissions and, 15 years in, we still have the same problem, because people do not understand that it takes a lot of effort and a lot of smart people to develop technologies

and interventions that change practice in healthcare.

14:00

[362] You can create a lot of business and a lot of wealth really easily. The easiest way to do that is to break up the NHS, because, if you make it a private organisation, you will double the cost, create a lot more effort, and you double the diagnosis for no additional healthcare benefits. That is why, in September, we ran a conference around over-diagnosis and too much medicine. The Americans are really into it now, because they have to save money. We are in the fastest growing business in the world right now—in most countries it is up to 20%—and there is a lot of money being spent. However, there is not a lot of smart money being spent on allowing us to sit back, take our time, work with businesses, and try to go for where we want to be. I hear this a lot. There are many great companies, but I do not see the technologies coming through.

[363] We need to start to work much more with clinicians, asking 'What do you want?' We started doing it the other way round. Instead of them all building what they want, we are asking, 'What is it that you want that will support you? How will new technology support you to keep this patient in the home setting? What is it that you want?' No-one is actually asking those simple questions. What does a GP want to keep a patient at home? How is this new technology going to help, and how do we do that the other way round? I think that that is coming to some. We have done the first ever needs assessment survey of at what point care diagnostics might help you. We are just about doing that now. We are trying to turn it the other way round—the whole idea. So, I do think, 'Yes; lots of businesses and technologies', but what is the evidence base? The magnesium sulphate is a very good example, because the first trial was in approximately 1989 or 1990, which is 25 years ago.

[364] **Dr Squire:** I was going to say that this point of asking the clinicians what they want is exactly what we have been trying to do in south Wales and in the west of England with challenge-led innovation, which is asking clinicians what they want. It is a very good route in, because asking clinicians what they want and then getting them involved in the development means that it will then have end users already in place and ready to use it, and it will be designed for their specific needs. So, it is a great way in. Obviously, on spreading that, you are back to the issue of how you then spread best practice, which is a knowledge transfer issue. There is also the use of new technologies that require training. We have not really addressed that in this forum yet. How do you disseminate that training if it is something that is quite specialised and requires people to be able to know how to use it, particularly for primary care settings or for nurse-led clinics? It requires a training programme to be put in place with the technology. That is obviously often not thought of.

[365] **Professor Sundstrom:** I would like to make one very quick point. The life care and health sector industries do exist and they make a major contribution to healthcare. I completely agree with you. We are trying to get them to make better products that people actually need and use, which should solve a real problem. However, to come back to the point that I made right at the beginning, given the public pressures, we need to work with the private sector to do that. We are not going to solve this on our own. We will not be able to address it just by putting into practice things that already exist.

[366] **David Rees:** Time has caught up with us. I thank you very much for your evidence this afternoon. It has been very interesting—a different perspective totally to what we have had before. That was quite enlightening. You will receive a copy of the transcript to check for any factual inaccuracies that you wish to correct.

[367] I thank Members for their attendance today. The next meeting will be our outreach visit to Cwmbran on Wednesday. So, I call the meeting to a halt.

Daeth y cyfarfod i ben am 14:04.
The meeting ended at 14:04.